University of the Witwatersrand

Anomaly: An Anthropology of Atypical Children

PhD Thesis

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ABSTRACT

This thesis explores the lived experience of children defined as atypical. The ethnographic focus of the study spans an initial cohort of nine children from private schools in Johannesburg diagnosed variously with learning disabilities, ADHD, developmental delays, speech disabilities, sensory challenges, anxiety, and autism. In-depth observational work was also conducted with autistic children at a boxing programme based in the inner city, from more diverse socio-economic backgrounds. A final level of insight was gained from 'deep hanging out' amongst atypical adults in online 'bio' social media groups spanning autism, ADHD, learning disabilities and Ehlers Danlos Syndrome. Using the philosophy and methodology of phenomenology, I developed a model that illustrates a cycle of atypical embodied engagement with the world, spanning stages or phenomena of *Presence, Perception, Control, Participation, Flow, Communication* and *Adaptability*. While there is much contestation over the homogenisation of 'neurodiverse' brains (Ortega 2009), the lived experience of atypical children that I observed during my research had a high degree of consistency.

Using a range of creative interactive methodologies, I collaboratively explored what is understood and misunderstood around each of these stages or phenomena from the perspective of those defined as atypical. Much of the dominant academic and popular discourse surrounding atypicality focusses on either a medical or social model of disability. By mapping medical diagnoses to a social model of engagement, a new holistic perspective was revealed. This traversed the physical, intellectual, emotional, and social motivations, behaviour and agency of the children illustrating their unique and different ways of being in the world. New enabling characteristics were identified in behaviours previously defined and diagnosed as disabilities.

This exploration brings to light the meaning that atypical children derive from their various stages of engagement with their world. A new kind of spectrum emerged that moved beyond disabling biomedical labels to one of enablement. The vectors of this spectrum could travel in either direction, without implying dysfunction or defectiveness. My research revealed a multitude of cultural and social creativity and invention, which the children continue to expand in the 'biosocial borderland' that they occupy.

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This research has been an incredibly emotional journey, given my personal experience of growing up under the label of disability. I am deeply grateful to my ‘superheroes’, their parents, siblings, and members of their support groups that so generously gave of their time to make this research possible. I would like to thank especially the mothers for their ongoing support, guidance, and friendship throughout my research process; you are my tribe. To the team at Fight with Insight, and the various coaches, teachers, occupational therapists, psychologists and psychiatrists who supported my second round of research, thank you for inviting me into your work spaces and letting me be part of your teams; it was an honour. Finally, to my online social media community and the participants who made the online discussion so rich with insight and advice: I was not able to thank each of you individually, however, I hope this dissertation goes some way to representing the incredible role you play in helping atypical people engage positively in this often confounding neurotypical world.

To my supervisors, Professor Nolwazi Mkhwanazi and Professor Lenore Manderson, thank you for your support and guidance throughout my research process. Your expertise in disability studies and medical anthropology is astounding and the fact that you have given so generously of your time has made this study possible.

To my family, I thank my sister Nicky, my steadfast friend even during my rebellious teenage years, my mother Jill, and my father Paul, who never gave up on me and always had my back. You supported me through my various challenges, often finding innovative approaches to health, education and social support that were way before their time, I feel profoundly lucky to have you as my family. To my children, Isabeau and Alexander, your imaginative ways of seeing the world, have helped me to embrace the genius of living life authentically atypical: the world will forever be a more joyful place with both of you in it. Finally, to my husband William, my rock and creative inspiration, without you, none of this would have happened. The idea of pursuing a doctorate in philosophy only became possible after I met you at university some 29 years ago. You have never wavered in your support of my different ideas and ways of being in the world, your love and support is infinite and for that I will always be grateful.

ABBREVIATIONS

AAC	Augmented and Alternative Communication
ABA	Applied Behaviour Analysis
ADHD	Attention-Deficit/Hyperactivity Disorder
ASD	Autism Spectrum Disease
Aspies	Children diagnosed with Asperger's Syndrome (also ASD)
CDG	Care and Dependency Grant
CFS	Chronic Fatigue Syndrome
cPTSD	Complex Post Traumatic Stress Disorder
DD	Developmental Delays or Disorder
DSM-5	The Diagnostic and Statistical Manual 5th Edition
EDS	Ehlers-Danlos Syndrome
FBA	Functional Behaviour Assessment
HFA	High Functioning Autism
LD or SLD	Learning Disability or Specific Learning Disability
MCAS	Mast Cell Activation Syndrome
OCD	Obsessive Compulsive Disorder
ODD	Oppositional Defiance Disorder
PANDAS	Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections
PANS	Paediatric Acute-onset Neuropsychiatric Syndrome
PAR	Participatory Action Research
PDA	Pathological Demand Avoidance
POTS	Postural Orthostatic Tachycardia Syndrome
RAD	Reactive Attachment Disorder
RDI	Relationship Development Intervention
RPM	Rapid Prompting Method
S2C	Spell to Communicate
SM	Selective Mutism
SPD	Sensory Processing Disorder
Stim or Stimming	Stereotypic Movement (Disorder) or Stereotypy
ToM	Theory of Mind

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CHAPTER 1

I NOW PRONOUNCE YOU DISABLED

‘Disability’, in the form of neurodevelopmental disorders,[1] has been part of my life for many years. I was born at around 36 weeks gestation[2] and displayed some cognitive and developmental delays in auditory processing in my early years. I was diagnosed with ‘dyslexia’, now referred to as a ‘specific learning disability’ (SLD), and ‘concentration difficulties’ (Attention Deficit Hyperactivity Disorder - ADHD), at the age of nine and had to repeat grade three. What followed were many years of remedial therapy to assist with ‘frequent visual discrimination errors’, ‘a weak analysis and synthesis of words’ and the fact that my reading and spelling accuracy and rate were well below chronological age.[3] In grade ten, I completed a test which indicated that my reading and comprehension rate was only 120 words per minute; however, to pass grade twelve, I would need to read in excess of 350 words.[4] Today, this would be diagnosed as slow cognitive processing, and my difficulties with schoolwork, which prompted the test, as executive functioning challenges. I reluctantly returned to remedial therapy, which I had stopped at the end of junior school, hoping that I was ‘better’. In the first therapy session, I was horrified to be given a speed and comprehension tests that I recalled from grade three, implying that I was of the same scholastic level as a nine-year-old child. I recall the abject humiliation, but more devastating was the fear that I may never achieve my goal of going to university. I was eventually granted the highest level of additional time accommodation (fifteen minutes per hour) in my final school exams which, coupled with extensive remedial support, enabled a university pass and attendance.

As a child, I struggled with upper respiratory tract infections and chronic allergies leading to the removal of my tonsils and adenoids aged six, and my nickname ‘Sleepy’. This was testament to my ability to fall into a deep sleep absolutely anywhere, which I did

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[1] Neurodevelopmental disorders span intellectual disability, communication disorders, autism spectrum disorder, attention-deficit/hyperactivity disorder, specific learning disorders and motor disorders (DSM-5 2013).

[2] Late preterm births (34–36 weeks) have increased mortality and in-hospital morbidity including respiratory difficulties and long-term cognitive, school performance, behaviour and psychiatric problems (Cheong 2012).

[3] Remedial assessment and diagnoses conducted age 9 by educational psychologist, Dr Elizabeth Wheeler.

[4] Reading and comprehension test conducted age 16 by Educent, remedial education and training centre.

frequently, especially at school during tests and exams. In grade nine, aged 14, I contracted Epstein-Barr virus, which led to a debilitating bout of chronic fatigue syndrome (CFS) and more than half a year of bed rest, unable to do anything other than watch TV and sleep. I suffered relapses of CFS every year until the age of 20. In addition to my learning difficulties and health challenges, being repeatedly referred to as ‘slow’ and ‘lazy’ by teachers, I became extremely rebellious and was frequently sanctioned for oppositional defiant behaviour. I obsessively sought out older children as friends to prove my social maturity, which resulted in risky behaviour and experiences throughout my adolescent life. In later years I have been diagnosed with anxiety and depression, with which I believe I struggled throughout my childhood, but was undiagnosed and therefore untreated.

This story of physical and emotional disability does not, however, represent the vibrant, creative life I recall leading as a child and my experience of adulthood. Although still suffering from sensory sensitivity, my acute awareness of my environment and atypical way of seeing the world has led to a successful career in marketing and communication. My specialist focus of ‘human behaviour’, which led to my commercial career in market research and academic career in anthropology, was driven by my inability to understand why people do the things they do, and an intense desire to remedy this. ‘Participant observation’ is not just a skill I developed as a social scientist, but rather a survival strategy that I have employed since childhood, to find ways to fit in and cope in a social environment that I often found confusing and overwhelming. Endless hours in front of TV and watching movies to understand history, geography, biology, literature and popular culture, due to my challenges with reading, provided me with a rich source of data which I still recall in fine detail. This contrasts with the facts and figures I was taught at school, which barely made it into my working memory, a typical challenge for people with ADHD. My need to find alternative ways to learn, led to ongoing engagement with strategic thinking tools and approaches that I have used in my career as a business and brand consultant. And finally, my ability to imitate appropriate behaviour by mimicking TV or film characters and scenarios, often to mask insecurities, led to invaluable skills in workshop facilitation and presentation. It has been far from a disabled life.

Paralympic medallist and disability activist, Elizabeth Wright, explains how her disability as a person born with limb difference (without an arm and leg) is different to that of someone who has lost a limb through disease or accident, and has endured amputation, as she notes:

> We look the same because we are missing limbs, but we have very different disabilities and very different experiences of these disabilities. It is important that you understand why, so that you don't make assumptions about disability when you meet disabled people. (Medium, 24 February 2020)

Lenore Manderson notes how following the loss of bodily function or mobility, "a person needs to establish a new sense of embodiment, cognitively, neurologically and physically reorganising the body schema" (2011:96). For those born with disability, however, there is no need for reorganisation, their lived experience of difference is all they have ever known. Disabilities impact on all our lives, whether we are born with them, acquire them, or are part of a disabled person's family, support system or broader community. The differences are sometimes visible, but as occurs with many neurodevelopmental challenges, they are frequently invisible but no less impactful. As each person is different, so too is their experience of disability. For some it is disabling, for others it can be enabling; for all whether they either embrace or reject it, it is a core part of their identity, and key to their lived experience.

Childhood vulnerability and disability in South Africa

Whilst recovering from postpartum depression after several miscarriages, I saw a picture on the front page of a newspaper of a new-born baby girl who had been abandoned and died on a rubbish heap in Soweto.[5] This led to a new career over the past decade in the South African 'child protection community'[6] around the practices of child abandonment and adoption. Child abandonment is an ongoing challenge in South Africa, with an estimated 3500 children being abandoned annually (Blackie 2014). These children usually have an extremely traumatic start to their lives. They are often born premature, the result of a third trimester illegal abortion (NACSA 2017). They are usually left in unsafe spaces due to the illegality of abandonment, and they often spend most of their childhood growing up in institutions or in temporary care due to cultural concerns over the practice of adoption (Blackie 2014). In addition, their mothers have often experienced high levels of anxiety and

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[5] SOWETO, derived from South Western Township, is a large township/suburb situated to the South of Johannesburg's central business district.

[6] Child Protection refers to the need to protect the child from any physical or psychological harm that may be caused by (i) subjecting the child to maltreatment, abuse, neglect, exploitation or degradation or exposing the child to violence or exploitation or other harmful behaviour; or (ii) exposing the child to maltreatment, abuse, degradation, ill-treatment, violence or harmful behaviour towards another person (Children's Act 27 of 2005).

depression, due to the ‘crisis’ nature of their pregnancy, which ultimately leads to their choice to abandon their child (*ibid.*). The combination of an anxious mother, premature birth, trauma, and institutionalisation has a significant impact on the wellbeing of abandoned children.

In her presentation on the best interests and needs of a child in the first thousand days (from conception to two years of age), physician-anthropologist Michelle Pentecost (2016), emphasised that early childhood adversity has a marked impact on a child’s long-term wellbeing. This adversity can include the lack of a primary caregiver, exposure to violent and unsafe spaces, and poor nutrition (Lock 2013). Children in these environments consistently experience high levels of cortisol and form insecure attachments which can result in ongoing social, educational, and behavioural challenges (Brown & Ward 2013). What is also evident is the interplay of biological and social processes, and their combined influences on a child’s behaviour, adaption, and development over time (Grotevant & McDermott 2014). In the context of anthropology, Margaret Lock notes that “we must recognise the entanglement of nature/nurture that exists throughout every human life”, to understand how social environments and lived experiences are “literally embodied in individual biology” (2013:381). Abandoned, abused, and neglected children are extremely vulnerable and often struggle with learning difficulties, developmental delays, behavioural issues, poor self-regulation, and anti-social behaviour (Blackie 2015). My work in child protection deals primarily with organising and conducting community engagement workshops with adults and children in underprivileged communities. I have facilitated a number of workshops in children’s homes and centres, focussed on personal and community empowerment. Many children in these spaces have been abandoned, and many have been diagnosed with neurodevelopmental disorders or have social and behavioural difficulties. Most do not receive any form of therapeutic intervention or assistance.

A study conducted by UNICEF on children with disabilities in South Africa from 2001 to 2011, identified that nearly thirty percent of children in registered child and youth care facilities are reported to have at least one type of disability and most facilities are not equipped to cater for them (DSD, DWCPD & UNICEF 2012). The report identified several challenges in how disability is dealt with. Of the nearly 2.1 million children classified as disabled (11.2 percent of the total child population), poverty was found to have a profoundly negative impact on children with disabilities. Disabled children have less access to schools in general, and although special needs schools have increased, there are still far too few to deal with the children defined as disabled and in need of high levels of support. A study conducted on schools in the Western Cape found that only 0.1 percent of children are diagnosed on the autism spectrum, however, the worldwide prevalence of autism is at least 10 times higher, at 1 to 2 percent (Spectrum News, 8th September 2017). Professor Petrus de Vries, head of Child and Adolescent Psychiatry at the University of Cape Town, believes that these numbers are artificially low due to a lack of diagnosis and that many of these children are not in school (*ibid.*). The UNICEF study also found that children with disabilities were more likely to suffer from illness and poor health, are more prone to abuse and neglect, and had less access to the criminal justice system. In rural areas, the majority of disabled children do not receive rehabilitation services or the assistive devices that they require for their disability. As noted by Watermeyer and colleagues, “the primary story of disability in South Africa is one of social oppression” (2016:1).

A clear and consistently applied definition of disability, and “the components that make up the experience of disability”, is required in South Africa (Watermeyer *et al.* 2016:17). At the Africa Regional International Meeting for Autism Research in 2017, multiple teams reported that common diagnostic tests for autism do not translate well to African cultures due to the diversity of cultural contexts, although some efforts were being made amongst isiZulu speaking children (Chambers *et al.* 2017). The research team found that a number of words, phrases and cultural practices lack relevance to children in South Africa, identifying the need for translated tools and an open source project to address screening, diagnosis and therapy (Spectrum News, 11 September 2017). UNICEF recommended improvements in the Care Dependency Grant (CDG), assistive devices, rehabilitation services, early childhood development services, inclusive education, and access to health facilities, but each of these areas experience problems in service delivery. Central to lack of delivery is a non-alignment between government departments, including the departments of education, health, and social development, and between state and civil society organisations around funds provision.

In addition to the lack of service delivery and support around disability in South Africa, a major underlying challenge identified in the UNICEF report was societal attitudes towards disability. Although there has been a shift in government policy from a medical and welfare model to one based on the social model, where human rights are considered, most adults and children experience discrimination for their disability in their communities:

> Children who participated in the focus group discussions that formed part of the study reported that people's negative attitude towards them was one of the most difficult things for them to deal with. Their greatest dislikes were being laughed at, being called derogatory names, and being teased about their disabilities. (DSD *et al.* 2012:17)

There has been some policy development, including a White Paper (6) on inclusive education and the Children's Act (2005) implemented in 2010. However, there is an absence of a concrete plan for the implementation of these services. This leaves children with disabilities, and especially those growing up in an institutional environment, in a precarious and vulnerable position in their communities and society as a whole.

A combination of my subjectivity, together with an appreciation of the lived experienced of disabled children in our many child and youth care centres or homes, prompted my desire to conduct an in-depth exploration of how children experience neurodevelopmental challenges. Due to the structural inequalities in South Africa, many disabled children remain undiagnosed and have little access to therapeutic support. My research focussed initially on children from middle-class backgrounds, many of whom had access to special needs support. A primary point of inclusion was that the children had some form of neurodevelopmental diagnosis, and understanding of this diagnosis, and were thus able to assent to taking part in my study. I did gain a more varied perspective in my second round of fieldwork which was conducted at an institution for autistic and special needs children in Johannesburg's inner city. However, the issue of access to and support of special needs children from disadvantaged backgrounds, remains a major concern in disability studies in South Africa.

Reframing neurodevelopmental disabilities

The World Health Organization defines disability as an umbrella term covering "impairments, activity limitations, and participation restrictions"[7] on its website. It describes disability as not just a health problem, but rather "a complex phenomenon, reflecting the interaction between features of a person's body and features of society in which he or she lives", acknowledging the role that context plays in its definition and experience (*ibid.*). It also points out that overcoming a disability requires interventions to remove both environmental and societal barriers. From an anthropological perspective, this definition

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[7] http://www.who.int/topics/disabilities/en/ Accessed 20/05/2015

supports the social model of disability that emerged in 1980s, where disability was not defined as a medical condition, but rather as the disabling by society of people who are deemed different or atypical (Ablon 1981; Oliver 1992; Shakespeare 1996; Kasnitz & Shuttleworth 2001; Ginsburg & Rapp 2013).

Despite this shift of focus, medical diagnosis still plays an important role in understanding, treatment, and support of disabilities. My own experience of diagnosis was both liberating and disempowering; it helped me understand my challenges and provided me with accommodations to deal with them, but living with a label of 'disability' and difference can impact negatively on one's identity and self-esteem. The most frequently cited diagnostic manual amongst practitioners and disability commentators in South Africa is the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5 2013), published by the American Psychiatric Association. The fifth edition of the manual, for the first time, indicates possible comorbid conditions. As noted above, although I was only diagnosed with dyslexia as a child, my later diagnoses of ADHD, difficulty with behaviour regulation, anxiety, depression, and sensory sensitivity are typical comorbid impairments amongst children diagnosed with neurodevelopmental disorders.

A detailed analysis of the more than 200 possible neurodevelopmental and behavioural disorders in DSM-5 reveals that most children have a range of challenges that they experience to a greater or lesser degree. Their experience can also depend on context and how they are feeling or coping on a particular day. Much of the popular discourse and diagnoses are described using the analogy of a 'spectrum'. The spectrum language is used to describe many disorders including neurodevelopmental, psychotic, bipolar, depressive, anxiety, obsessive-compulsive, trauma, stress, dissociative, somatic, and more. What constitutes this spectrum is not always defined in detail, but there is often reference to variation in functioning and support needs, especially in the diagnosis of autism spectrum disorder. Although many autistic adults contest the concept of being 'low' or 'high' functioning, most do ascribe to the spectrum analogy. To them, however, this is not seen as a linear spectrum, but rather a kaleidoscope of attributes that could impact on a person's level of difficulties in different areas. This is beautifully illustrated in Rebecca Burges simple cartoon on the subject titled 'Understanding the Spectrum', which she launched for Autism Acceptance Week in 2016 (The Art of Autism, 5th March 2019). The cartoon has been widely praised by the autistic community as reflecting how they experience their world. It illustrates the multitude of 'traits', and how their brains process information, rather than a linear model which defines an individual as either "very autistic," "a little autistic," or somewhere in between. Burges explains that these different traits can be broadly divided into categories such as language, motor skills, perception, executive function, and sensory filters, as illustrated in Figure 1 below:

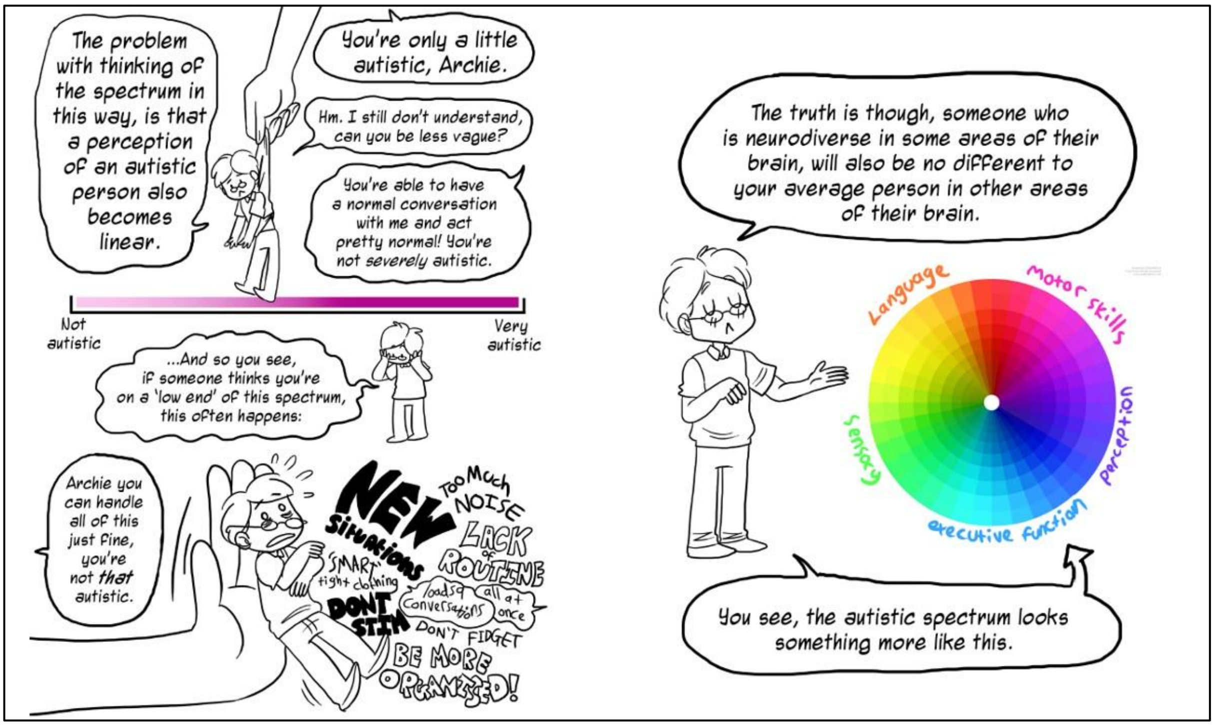

Figure 1.

Although I have not been diagnosed on the autism spectrum, this illustration most aptly depicts my experience of living with a range of disabilities. It also best represents my experience and understanding of engaging with children and adults who have been diagnosed with learning disabilities and neurodevelopmental disorders.

Burge's spectrum shows the comorbidity of neurodevelopmental challenges that can span intellectual, communication, autism, attention-deficit/hyperactivity, learning and motor disorders (DSM-5 2013). Whilst these differences are often challenging, they can provide unique and different ways of perceiving and engaging with the world. The neurodiversity movement, conceived by sociologist Judy Singer in 1998, rejects the pathologising of these differences, positioning them rather as natural expressions of human diversity (Bagatell 2007; Grinker 2007; Lawson 2008; Savarese 2013; Singer 2016). The movement, popularised by Steve Silberman's cult classic *Neurotribes* (2015), has becomes a rallying cry for many autistic adults and advocates. However, some parents of autistic children and researchers believe it fosters division amongst autistic and non-autistic communities. Neurotypical individuals and the medical research community are positioned as the oppressors in the social disabling of atypical individuals (Aeon, 12th September 2019). In the field of Critical Autism Studies, scholars argue that the neurodiversity movement can be viewed as a form of identity politics, that "dichotomises would be allies" by not representing all interested atypical parties (Russell 2016:288). Conversely, the movement is also believed to undermine the severity of challenges that many autistic individuals with severe mental retardation and substantial intellectual delays experience in their daily lives (Cortical Chauvinism, 5th January 2015). Francisco Ortega (2009) argues that the neurodiversity movement reframes atypical children and adults as "cerebral subjects" in the tradition of medicalisation and is in danger of becoming both a 'solipsistic' and 'reductionist' ideology. For all its criticisms, however, the neurodiversity movement is still aiming for a non-pathologizing form of identity for individuals identified as atypical or different (Russell 2016).

Whilst the neurodiversity movement helps us to understand the complexity of the atypical experience, it still appears constrained by biomedical categories. Research tends to focus on specific areas or challenges, rather than a holistic lived experience. Exploration also tends to focus on the behaviours that show up, rather than delving into the motivation or meaning of these behaviours from the perspective of the diagnosed child or adult. Although Burges' illustration goes some way to explaining the spectrum of an atypical lived experience, it still focusses primarily on medical categories of disablement. It does not explore how some atypical differences can be experienced as enabling or enhancing. Many atypical children and adults identify with their differences, as they enable unique and sometimes exceptional ways of perceiving and engaging with the world. This is not to diminish the often debilitating physical, emotional, and social challenges that they encounter in their day-to-day lived experience, but rather to explore the possible benefits to atypical ways of being. Ralf Savarese (2013) refers to this as 'Neurocosmopolitanism', a form of global atypical citizenship, with a shared value set that stands up to the pathologizing of differences. His greatest concern, however, is that 'neurotypicals' are often not prepared to meet this community half way, and "apprentice themselves to an autistic neurology", instead expecting the neurodiverse community to do all the work in this "cross-cultural and cross-sensorial exchange" (Savarese 2013: 192; 193).

Thesis map

As our understanding of neurodevelopmental difference increases, so too does our acknowledgement that it is a clustering of characteristics rather than individual biomedical diagnoses requiring specific treatment protocols. In contrast to modern trends of specialist focus and interrogation, the appreciation of the lived experience of ‘atypicalness’ comes from expanding our inquiry to all possible inputs at a physical, intellectual, emotional and social level. The assemblage of differences in the context of social and political influence captures the true lived experience of someone defined as atypical. Beyond understanding the difficulties and possibilities encountered by the atypical body, an appreciation of how this impacts on personal and social identity in the context of an ever-changing world provides a far more accurate appreciation of the experience. It also reveals a new world of biosociality of atypical culture, as illustrated amongst growing autism, ADHD, and differently abled learning communities.

In this thesis, informed by anthropological, biomedical, and social theory, I explore new ways of conceiving the atypical child. As with understanding lived experience, the key to problematising atypicality lies not in discounting the medical model for a social model of disability, developmental models for neurodiversity, or precariousness for biosocial empowerment, but rather in understanding how they relate to each other. In the chapter on creating a phenomenology of atypical children, I define what Peter Willis (2011) describes as ‘the thing themselves’, the phenomena that I wished to explore. Robert Merton (1987) notes how in the study of phenomenology, it is important to establish what the phenomenon is, and that it does indeed exist. One then needs to examine ‘specified ignorance’ around the phenomena, or what is known or unknown about it. Finally, he supports the creation of ‘strategic research materials’, or ways of positioning or presenting the phenomena that enables “fruitful investigation of previously stubborn problems, and the discovery of new problems for further inquiry” (1987:1). To this end, I developed a model that explores stages of engagement or sociality, where atypical behaviours, difficulties or differences are most acutely experienced or observed. These stages include *presence*, *perception*, *control*, *participation*, *flow*, *communication*, and *adaptability*. I explore each of these stages in the chapters that follow.

The chapter on presence examines how atypical children ‘show up’ in their world, and how they define their personal and social identity. I start with Puck, one of my atypical subjects, and examine his account of his life to date. I then explore the different worlds that atypical children inhabit and how these influence their identity and sense of self. I also examine their embodied experience of their world, when they are feeling strong and healthy, and when they are feeling vulnerable and unwell. As many of their challenges are related to neurological development, I spend some time understanding their perceptions of their brains and of learning. I conclude by exploring what the children dream for themselves in the form of their personal vision and beliefs, illustrating the many ‘anomalies’ they are contending with in exercising their agency as atypical children in a neurotypical world.

The chapter on perception, control and participation explores how atypical children experience their world. I start with a detailed account of the children’s difficulties in accessing or interpreting internal and external sensory inputs. Beyond sensory and emotional processing challenges, I examine the difficulties they have in perceiving their world, through common comorbid barriers of pain, allergies, and a disconcerting lack of bodily boundaries. From a social perspective I explore common atypical challenges of prosopagnosia or face-blindness, sensory sensitivity, and difficulty in making eye contact. Ultimately, I examine how ‘permeable’ atypical children feel to the world around them. On the one hand this invites new and interesting insights into the world, but on the other, it calls for increased levels of self-protection in the form of physical, emotional, and social boundaries.

The chapter on flow, communication and adaptability explores how atypical children respond to a changing world. I examine the high levels of trauma and complex post-traumatic stress disorder (cPTSD) in atypical children, due to their extreme sensory sensitivity, uncompromising remedial and behavioural therapies, and the relentless bullying they often experience on a day-to-day basis. The constant assault on their vulnerable bodies also appears to lead to an increased susceptibility to a broad range of illnesses, syndromes, and auto-immune diseases. This is believed to be due to exhausted autonomic nervous systems and a seemingly constant sympathetic stress responses to living in a world that is perceived as dangerous and alienating. Their tendency to ‘disrupt the flow of their lives’ is examined at physical, intellectual, emotional, and social levels. This includes the children’s range of eating, digestion and elimination challenges, the disruption to their flow of learning due to concentration difficulties, emotional dysregulation and social awkwardness. In the section on communication I explore how nonverbal atypical children find new ways to express themselves using their bodies and alternative communication devices. I question current theory of mind and empathy models that appear out of touch with atypical experiences and argue for a new understanding of empathy that moves beyond cognition between human beings. Finally, I examine how atypical children can overcome great obstacles and adapt to an everchanging environment if they have developed a personal vision or purpose.

I conclude the dissertation by proposing a new model or spectrum to understand atypical behaviour, and the meaning of those behaviours, that considers first and foremost the perspective of the atypical child.

CHAPTER 2

THE EMERGENCE OF ATYPICAL

In my child protection community work, I usually start discussions with a simple question: “Why do we have children, and what is their purpose in our lives?” The response is often a shocked silence, followed by nervous giggles, and finally a litany of reasons as to why children play an important role in families and society. From being a tangible expression of a couples’ love for each other, to the passing on of genes, and ultimately the hope of a better future, a range of reasons are presented to me. Sometimes the reasons are less positive: “they are often a mistake”, “because my culture expects it of me”, “they are a great source of labour” and “they are a good retirement plan”. I use this exercise to get my participants to think about the role of children in society, and to explain that just as an organisation with a clear purpose is often far more stable and focussed on building a positive future, so too are children. If a child’s role has been articulated to them in their family, their community and in society at large, they are able to fulfil that role.

The most interesting responses, however, come from the children themselves. When I ask them, “why do you think you are here?” and “what do you think your purpose as a child is?” again, there is much laughter and hilarity, but their responses are telling, and often different to that of their parents or caregivers. They speak of their role as catalysts of new ways of being in the world, creating a more loving, caring and connected world where they are safe and can be who they want to be, without judgement or the need to fulfil other’s expectations of them. They are the ‘authors’ rather than the ‘subjects’ of their lives, as noted by Manderson and colleagues (2016):

> Children are the subjects of patterns of socialization, formal and informal learning, and ritual occasions that ‘make’ them human, but they are rarely represented as social actors who might contribute to our knowledge of social processes, structures and institutions or to our imagination of social life (2016:48).

Children and their perspectives have been neglected by anthropologists, as they are perceived as products of societal structure who are still ‘becoming’, rather than fully realised human beings, with their own thoughts, feelings and agency (Piaget 1936; Geertz 1960). This, however, is changing as more ethnographies are shared that illustrate the plurality of childhood and how children are not just passive recipients of adult culture, but rather active participants in the complex relationships and social interactions that make up their world. As noted by Sean Jones in *Assaulting Childhood*, his exploration of children's experiences of migrancy and hostel life in South Africa in the late 1980s, we need an anthropology which "acknowledges and accounts for both childhood in culture and culture in childhood" (1993:6).

This 'anthropology of childhood' should question 'normative behaviour', as demonstrated in Margaret Mead's pioneering work *Coming of Age in Samoa* (1928). Although contested by Freeman (1983), Mead illustrated stark differences in attitudes towards puberty and sexuality amongst young women in Samoa and conservative America at the time. We need to question how we conceptualise and construct children, childhoods, and child participation in different social environments (Reynolds 1989; Le Vine 2007; Lockhart 2008). We also need to move beyond positioning children in the context of protectionism and vulnerability (Burman & Reynolds 1986; Scheper-Hughes & Sargent 1998). Despite the United Nations 'Declaration on the Rights and Needs of Children' in 1989, the application and implementation of these rights differ in cultural contexts around the world (De Sousa Santos 2008). Rather than protecting children, the strict implementation of children's rights is seen as an attempt to discipline countries believed to be politically and/or ethically questionable (Kleinman *et al.* 1997). However, children often do need to be protected in our increasingly 'adults centred society', as Nancy Scheper-Hughes and Carolyn Sargent argue: "traditional cultural and moral relativism may no longer be adequate for the complex transnational world in which we live" (1998:9). They call for a new ethical standard that invites "radically different cultural and philosophical sensibilities" in the creation of a child centred anthropology (1998:15).

Childhood and medicalisation

Childhood has been increasingly medicalised through global health initiatives such as breastfeeding, growth monitoring, immunisation, and oral rehydration therapy (Scheper-Hughes & Sargent 1998; Manderson *et al.* 2016). The focus has been on global solutions that are low cost, require little technology, and that focus primarily on the individual child or mother-child dyad. In her research for the First Thousand Days of Life,[8] Michelle Pentecost illustrates how "new biosocial concepts of life arrive in policy and public spheres" (2018:29). The first thousand days, the period from conception to a child's second birthday, is seen as a critical time in shaping a child's ability to develop and grow. In her study of epigenetics in

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[8] http://www.thousanddays.uct.ac.za/ Accessed 28th March 2019.

everyday life, Pentecost notes that nutrition is perceived and used as a medical tool to decrease transgenerational risk of non-communicable diseases and improve "future human capital" (2018:4).

The study of epigenetics, or how the experiences of previous generations can affect who we are, highlights the interconnectedness of the biological and the social as objects of study. This is illustrated in social neuroscience research which explores how brain structure, function and even ongoing neuron production are partly produced through environmental and social relations (Meloni *et al.* 2018). Concepts such as neuroplasticity illustrate how the brain can change and develop as a person grows older, influenced by factors such as nutrition, socio-economic status, stress, toxins in the environment, and the influence of previous generation's lifestyles. As noted by Richelle Mychasiuk (2015), in her study of the epigenetics of brain plasticity and behaviour, "the mammalian brain is unique in this respect as it develops intimately with the environment, both prenatally and postnatally in the context of all experiences" (2015:848). From the moment of conception our brains continue to develop, evolve, and adapt to a range of stimulus in a continuous and dynamic relationship between the epigenome, the environment, and behavioural outcomes. Recent research conducted at Columbia University into the impact of childhood trauma on gut bacteria indicates that adversity early in life is associated with increased gastrointestinal symptoms in children and may impact on their brain and behaviour as they grow to maturity (NNR, 1st April 2019). There is much epidemiological research into the impact of diet, famine and maternal stress on prenatal children and their increased likelihood of long-term neurodevelopmental disorders (Mychasiuk 2015). Weary of somatic reductionism from 'molecular level' epigenetic research, Margaret Lock (2013) highlights the importance of concepts such as 'local biologies' and 'embedded bodies' that contextualise epigenetic findings in specific lived experiences complete with historical, social, political and environmental influences. As noted by Nancy Krieger (2005) in her work on embodiment in epidemiological research, our bodies are actively engaged entities that incorporate the world we live in, into our biologies.

> This world is comprised of animate populations and inanimate ecosystems that have evolved over time, with the living beings actively shaping and not simply passively responding to their environs. (Krieger 2005:351)

Krieger (2005) argues that our bodies are able to tell stories about how we exist, which don't always match our stated accounts of this existence, and sometimes, how these stories are able to speak for us, when we are unable to.

The interaction between the biological and social is keenly observed by disability scholars, where dominant theoretical perspectives include medical and social models of disability. Tom Shakespeare (1996) notes how disability can be viewed as both an active verb, as in the process of uncovering disabled people, and in the reflexive sense, where individuals identify themselves as part of larger groups or collectives. He outlines five alternatives to identifying disabilities beyond biological determinism of impairment through physical difference: the social model; as a minority group; as social policy, in the tradition of Weber and Foucault; as definitions derived from social research or surveys; and, as a cultural category (1996:96-97). These alternatives illustrate how disability is socially constructed, and how people are 'made up' by the state, schools and other agencies that exert power over them and label them accordingly (Hacking 1986). Identity can be constructed both medically, around the impairment and perceived loss, or socially, as a result of negative social relations. In popular culture, disability identity is increasingly being represented as 'superpowers:' Percy Jackson's dyslexia, allows him to decipher ancient texts and clues in Percy Jackson and the Olympians series (Riordan 2005-2009); ADHD gives Spiderman the ability to assimilate complex physical activities simultaneously in Tom Holland's recent depiction of the character for Marvel Studios (2017); and autism gives Newt Scamander his sensitivity and ability to manage unusual animals in the recent Fantastic Beasts Series developed by J. K. Rowling (Warner Brothers Studios 2017, 2018). However, it is often far more complex than this, as impairments create daily struggles that need to be overcome physically, intellectually, emotionally, and socially.

'Medicalisation' describes a process by which nonmedical experiences become defined and treated as medical problems, usually as an illness or disorder. Key characteristics include universal representations of the 'normal body' versus that of the 'sick', 'disabled' or 'deviant body'. Lock and Nguyen (2010) note that this is supported by: the systematisation of pathological science; the routinisation of physical examinations; population health monitoring and control; and finally, "dividing practices", where the sick are divided from the healthy, illness from crime and madness from sanity (2010:69). Medicalisation is usually reflected by the creation or construction of a medical category. This category could be the expropriation of a common life process such as childbirth, menopause or anxiety, or what is perceived to be deviant from what is considered normal, such as mental disorders, alcoholism, learning disabilities and autism spectrum disorder (Kitanaka 2012; Scheper-Hughes 1988; Ong 1988; Ha *et al.* 2014). Support is then gleaned from individuals, organisations, and the state for this new 'medical category'. It is promoted and expanded, often with the support of the pharmaceutical industry, endorsed by health authorities, and finally what was a new jurisdiction is now a fully-fledged medical industry. This is particularly true in the world of disability where perceived disorders are routinely institutionalised and reified. People with disabilities are repositioned as consumers, and the market for rehabilitation continues to grow into a flourishing enterprise (Ingstad & Whyte 1995:10).

In the context of neurodevelopmental disorders such as autism, Ian Hacking (1986) argues that new categories of people are created and new ways of being identified. Once the distinction is made, new social realities of personhood become possible. However, these newly defined categories also create a power relation that can marginalise and prevent their inclusion and participation in mainstream society. The term autism, derived from the Greek word for self (autos), was first used by Eugon Bleuler in 1912 to describe the social withdrawal he observed in schizophrenic adults (Fletcher-Watson & Happé 2019). In 1943, Leo Kanner published his article titled, 'Autistic Disturbances of Affective Contact', describing his clinical experience with eleven children who displayed many characteristics that we associate with autism today. These characteristics included a 'desire for aloneness', 'insistence on sameness', 'stereotypy' and 'echolalia' (1943:248). Although only widely discovered in the late 1990s, Hans Asperger (1991) published his work on 'Autistic Psychopathy' in 1944. Unlike Kanner, his definition allowed for a far broader inclusion of atypical children into the diagnosis of autism, including those able to socialise and communicate. Following Kanner's hypothesis that autism may be related to a lack of emotional bonding between the children and their highly educated and often working mothers, Bruno Bettelheim published his now discredited "refrigerator mother" theory in 1967. This theory shifted autism from a purely medical to a socially derived disability, foreshadowing later diagnoses of 'reactive attachment disorder' of autistic children due to cultural sensitivities in countries around the world (Ha *et al.* 2014). The late 1970s saw the introduction of autism as a genetically based disorder following research conducted by Susan Folstein and Michael Rutter (1977). The concept of an 'autistic continuum' was introduced by Lorna Wing and Judith Gould in 1979, which formed the basis for how we understand autism today as a spectrum disorder. From its naming, to diagnostic criteria and its expansion as a disability category, autism has evolved as a medically and socially constructed phenomenon. Autistic individuals are now merging into cohesive minority cultural groupings with their own distinctive identity, complete with writing, art, and music (Strauss 2013). Ben Belek (2020), in his study of autism as heredity and heritage, notes how autistic individuals conceive themselves as part of an autistic lineage, where personal diagnoses reveal new insights into family members from previous generations, and the possibility of producing autistic children themselves. He notes: “Autism can thus be understood as the temporal axis along which one imagines not only one’s own life, but also one’s familial origins, on the one hand, and familial horizons on the other” (2020:Para 23).

In contrast to views of kinship and familial heritage, medicalisation focusses on the individual (Watermeyer *et al.* 2016). As an individualised experience, the structural and cultural contexts are not challenged, and differences are fetishised or overlooked in what Tom Shakespeare refers to as a “medical tragedy” (1996:99). In the classic tradition of Foucault’s biopower of the late 1970s, individuals who do not fit into the norm are perceived as costly to society, and in need of efficient remediation back to an appropriate normative band. Practices such as rehabilitation, accommodation and special education are exercised as power over those who do not ‘fit in’. These regulatory mechanisms are used to remediate affected individuals to an acceptable standard, or to find an appropriate way to exclude them from mainstream society, often through institutions (Foucault 1982), as Vu Song Ha notes of Hanoi, Vietnam:

> A pervasive attitude expressed towards individuals with ASD is that they are worthless and burdensome for their family and society. Further, within the context of the recent government emphasis upon population quality within the family planning program and promotion of prenatal screening for foetal anomalies, parents of children with disabilities are viewed as irresponsible and failing as citizens to contribute to society through a quality child (2014:281).

Within the realm of neurodevelopmental disorders, there has been much contestation over the development, revision, and overuse of diagnostic categories (Stone 1984). As most of these challenges are diagnosed clinically, through a detailed psychological assessment rather than through biomedical tests, there is also debate as to what constitutes an accurate diagnosis. These can fluctuate from mental retardation, to learning disabilities, ADHD, and autism spectrum disorder over the period of a subject's life, calling into question the effectiveness and accuracy of the process (Rapp & Ginsburg 2012:176).

A disability diagnosis can have a marked impact on a family and a child. In the global West, a diagnosis 'entitles' you to a range of remedial alternatives and social support in an effort to realise notions of equality, rights, and participation. This support can be extensive and for some, it may be viewed as "political privilege" (Ingstad & Whyte 1995:9). However, the label of disability can also lead to social segregation and invisibility, as acceptance turns to fear and an inability to speak openly about the impairment. Much of this fear stems from the tacit belief that everyone is 'susceptible' to becoming disabled through birth, trauma, illness and age, and as Ginsburg and Rapp remark, this challenges assumptions of "stable identities" and "normativity" throughout one's life (2013:43). In South Africa, although remedial solutions are far less accessible than in the global North, there are still state funded remedial schools and tax benefits in the private sector, contingent on a diagnosis of 'mental impairment'.

A social model of disability

> Disability is a profoundly relational category, shaped by social conditions that exclude full participation in society. What counts as impairment in different sociocultural settings is highly variable. Recently, new approaches by disability scholars and activists show that disability is not simply lodged in the body but created by the social and material conditions that "dis-able" the full participation in society by those considered atypical. (Ginsberg & Rapp 2013:4.1/55)

This introduction by Faye Ginsburg and Rayna Rapp to their *Disability Worlds* clearly illustrates how the social model of disability is a critique of the medical model and the ways that it defines, individualises and categorises atypical subjects. In the social model, disability becomes associated with negative interactions between a person defined as impaired or disabled and their social environment. Devva Kasnitz and Russell Shuttleworth note that "disability only exists in reference to ability", illustrating its social and cultural construction (2001:2-17). Tom Shakespeare notes how questioning normality "assumes a certain standard from which disabled people deviate" (1996:95). The social model of disability explores how the social organisation of a person's daily life shapes their disability and impacts on their sense of personhood. It explores what is enabling and disabling for the person defined as atypical, and what unites them, rather than ‘essentialising’ their differences (Shakespeare 1996). Whilst the medical model assumes a negative self-identity as the outcome of a defined disability or impairment, the social model tries to understand how their disability influences who they are and their way of being in the world. By way of example, for people diagnosed on the autism spectrum there is much contestation over how their diagnosis is framed, and how this relates to their identity. “I am autistic” versus “I am a person with autism” have distinctly different connotations. The first positions autism as a fundamental part of the individual; the second implies that autism is something that is separate to the person, and possibly unwanted or in need of remediation and cure. In her article titled, ‘Autistic’ or ‘has autism’, Fiona Churchman, the mother of an autistic child, explains that “the right words can show respect and help grow understanding [of autism], the wrong ones can destroy it” (ABC Life, 19th February 2019). Chris Bonello, an autistic teacher, author, and speaker, asked subscribers to his website, ‘Autistic Not Weird’,[9] how they describe their diagnosis. Of more than 11,000 people who responded, the majority preferred ‘autistic person’ to ‘person with autism’.

There is a complex relationship between embodied limitations and social discrimination which is keenly observed in the language used to describe it. Ginsburg & Rapp (2013) note how we use the terms “disability” and “impairment” interchangeably in the definition and categorisation of normative subjects. This supports Shuttleworth & Kasnitz’ statement that the anthropology of impairment-disability “suffers from terminological confusion, theoretical oversimplification, and a radical relativist bias” (2004:153). In the context of autism, this oversimplification and bias is observed in the used of ‘functioning labels’. In the DSM-5, the diagnosis for autism is divided into three severity levels: Level 3, “requiring very substantial support”; Level 2, “requiring substantial support”; and Level 1, “requiring support” (2013:52). Despite this spectrum focussing on levels of support required, many people refer to functioning labels of ‘low’, ‘medium’ or ‘high’, or severity levels of ‘mild’, ‘moderate’ or ‘severe’, to differentiate between how they perceive autistic people’s levels of functional ability or independence in the world. ‘High Functioning Autism’ (HFA) is frequently referred to in literature on autism as Asperger’s Syndrome,[10] and is usually associated with the results of the Griffiths Mental Development Scales[11] and standardised IQ

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[9] http://autisticnotweird.com/ Accessed 30/03/2019

[10] Identified by Hans Asperger in 1938, this is now referred to as Level 1 Autism in the DSM-5.

[11] https://psychologicalassessmentinsouthafrica.com Accessed 05/04/2019.

tests. Murray (2009) notes that the concept of functionality is central to how neurotypical individuals understand autistic ways of being in the world, but that this results in the oversimplification of 'autistic presence' and intelligence. Chris Bonello explains how 'high functioning' implies the need for medium and low functioning, which is insulting and possibly biologically incorrect for most autistic individuals (Autistic Not Weird, 1st July 2015).

Judging an individual's worth based on their lack of physical or mental ability is not uncommon, as disabled anthropologist Robert Murphy notes: "The disabled are often vaguely blamed for their condition, or at least for not achieving maximum recover" (1990:152). Lenore Manderson explains how "unruly embodiment is often interpreted not as an artefact of a physical event, but as the corporeal symbol of a fundamental failure or decay in character" (2011:35). Autistic writer Jessica Flynn counters the 'morality of the good body', glorified in modern society, by stating: "I'm not embarrassed to admit I need support…It's not shameful to admit the world was not made for you" (The Mighty, 23rd July 2018). It is these perspectives that the social model of disability attempts to question, as noted by Tom Shakespeare: "Social approaches view negative self-identity as a result of the experience of oppressive social relations, and focus attention on the possibilities for changing society, empowering disabled people, and promoting a different self-understanding" (1996:97).

Beyond its framing, terminology and language, the contestation of disability labels extends to the validity of diagnoses itself (Arnold 2016; Milton 2016). Neil Greenspan (2018) argues that autism is a combination of a number of variations of many different traits: "referring to this variation as a 'spectrum', defined as a range of values along an axis, understates the extent of such variation and can foster incorrect inferences" (2018:213). Neurodiversity scholars argue that at some point, we will need to move beyond the simple pathologising of differences and acknowledge that these differences are a result of human diversity. Rather than diagnosing new or expanding categories of neurodevelopmental disorders, it is time to expand our definitions of what is perceived as normal and acceptable (Bagatell 2007; Grinker 2007; Lawson 2008; Savarese 2013; Singer 2016). Some of the concerns surrounding diagnoses reflect the often seemingly arbitrary use of the word 'spectrum'. Francisco Ortega (2009) argues that whilst concepts such as neuroplasticity help to explain the diversity of atypical brains, homogenising neurotypical and atypical individuals on a single spectrum is paradoxical. The 'spectrum' analogy also creates space for the appropriation of an autism diagnosis, where neurotypical individuals claim, “but aren’t we all on the autism spectrum?” This is found to be extremely offensive by the autism community, who argue that if you cannot match an autistic person’s life experience, you should not try to claim their identity. Bonello notes that “if everyone really were ‘a little autistic’, people would try to understand our social differences rather than trying to solve them” (Autistic Not Weird, 2nd October 2017). A linear spectrum view is therefore considered problematic, as it does not account for various combinations of traits. However, even with a kaleidoscopic or multi-trait view, there is still much debate around the constitution of this spectrum.

These conflicting views about autism, its diagnosis, and the epistemological integrity of how it is studied and understood, led to the creation of a new field in disability theory in the late 1990s, referred to as Critical Autism Studies (CAS). The formation of CAS focussed on three key platforms. The first was the exploration of the power relationships that construct autism. The second was to explore autistic narratives that challenge the dominant medical discourse. The third was concerned with creating theoretical and methodological approaches that are both emancipatory and respectful of the individual nature of autism and emerging autistic culture (Davidson & Orsini 2014; Woods *et al.* 2018). However, even CAS is contested, with the Re-Thinking Autism Network (RAN) questioning the scientific validity of an autism diagnosis and the meaning of this label, especially given the multitude of comorbid challenges often diagnosed alongside it (Woods *et al.* 2018). The questions of what constitutes an autism diagnosis and whose voice should be prioritised (autistic versus non-autistic but still atypical) are central to the conflicts that have arisen within this field of study, which includes both the autistic rights and the neurodiversity movements. The primary fear is that by including non-autistic voices, autistic voices will once again be marginalised. However, exclusion of the range of perspectives contained in the neurodiversity movement that fall outside of a traditional autism diagnosis fails to address the complexity of the lived experience of individuals who occupy the broader category of atypicality, as identified in this study. In their review of CAS, Woods *et al.* (2018) propose Mitzi Waltz’ definition, which prioritises inclusion rather than exclusion, as she notes:

> The ‘criticality’ comes from investigating power dynamics that operate in Discourses around autism, questioning deficit-based definitions of autism, and being willing to consider the ways in which biology and culture intersect to produce ‘disability’. (Waltz 2014:1337)

Of primary importance to CAS is the reclaiming of the autistic narrative by autistic persons as primary producers of autistic knowledge (Arnold 2013; Waltz, 2014; O'Dell *et al.* 2016).

Claiming disability rights

The disability rights movement emerged in the mid to late 20th century with the aim of improving the lives, social inclusion, and equality of those diagnosed as disabled or impaired. This social movement included attention to issues such as eugenics, citizenship, state policy and human rights (Ingstad & Whyte 2007). Its goal was, and remains, a desire to create a democratic society for those defined as disabled, supporting their rights to social access, education, employment and a supportive legislative framework within which to realise their best futures (Phillips 2011; Kohrman 2005; Watermeyer *et al.* 2006). One of the greatest challenges noted by the atypical community, is that their views are often not heard or even considered. This is a major criticism of Autism Speaks, the largest autism foundations globally. The organisations spends in excess of $14 million annually on research; however, most of this is dedicated to finding biological markers for autism, causation and prevention, including prenatal testing.[12] Its advertising campaigns, notably the "I am Autism" commercial, launched in 2009, positions autism as a terrifying presence that will "bankrupt you", "make your marriage fail", and "rob you of your children and your dreams". [13] The Autistic Self Advocacy Network, whose motto is 'nothing about us without us,' notes: "Autism Speaks uses its platform and advertising budget to portray autism and autistic people as mysterious and frightening, their fundraising tactics increase stigma and create barriers to the inclusion of autistic people in our communities" (Autistic Self Advocacy, April 2017).

The New York University Child Study Centre launched a poster and billboard campaign entitled "Ransom Notes" in 2017, with the aim of creating awareness of neurodevelopmental and psychiatric challenges including ADHD, autism, bulimia, and obsessive-compulsive disorder, as depicted in Figure 2 below. The posters imply that these various disorders 'kidnap' children, stating: "Don't let psychiatric disorders take your child". They go on to explain that they are dedicated to helping children "take back their childhood", by preventing, identifying, and treating these psychiatric and learning disorders. Anne McGuire (2016), in her book *War on Autism*, illustrates how advocacy groups often position autism outside of the child, medicalising it as a separate condition that parents can use as a

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[12] https://www.autismspeaks.org/about-us Accessed 01/04/2019

[13] https://www.youtube.com/watch?v=9UgLnWJFGHQ Accessed 01/04/2019

target for their frustration. This creates a conflict between the children and adults who identify with their diagnoses, and their parents, teachers and therapists who target their challenges for remediation and possible cure.

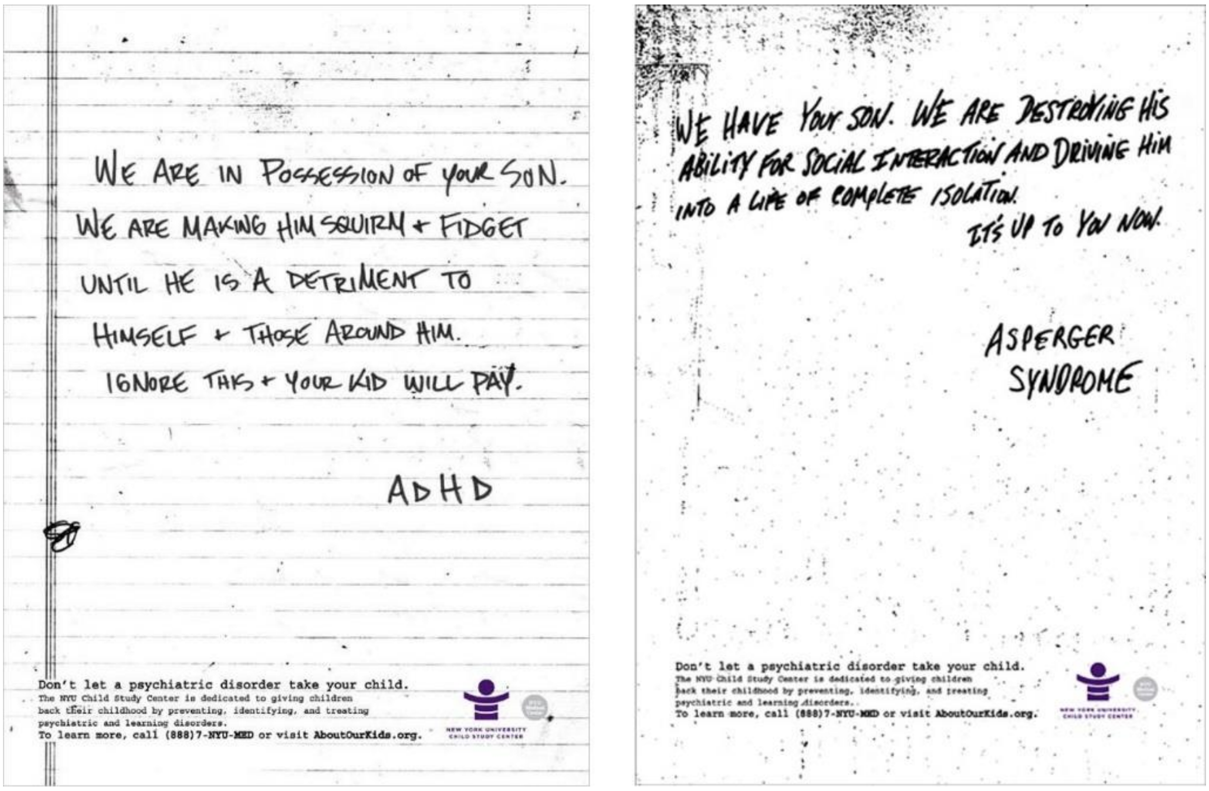

Figure 2.

Grinker (2014) observes how the positioning of autistic children as vulnerable and weak, allows them to become the object through which adult subjectivities can be imagined and performed, as illustrated by the anti-vaccination movement (Hussain, Ali & Hussain 2018). Following the publication of a now discredited study by British researcher and medical doctor, Andrew Wakefield, in *The Lancet* in 1998, many parents around the world choose not to vaccinate their children for incorrectly fearing that the measles, mumps and rubella (MMR) vaccine may cause autism in young children. Despite proving the fraudulent nature of the study, the withdrawal of the article from *The Lancet*, the stripping of Wakefield's licence to practice medicine, and extensive global research refuting the claim, the World Health Organization notes that the anti-vaccination movement is now a threat to global health (WHO 2019). From a social perspective, this movement positions children as completely vulnerable and subject to external forces that could damage or destroy them. The discourse implies that a diagnosis of autism is worse than contracting a vaccine-preventable disease which often results in the death of the child.

Autism Speaks, and other cure orientated advocacy groups, are also heavily criticised from a therapeutic perspective by the autistic community for its support of Applied Behaviour Analysis (ABA). This therapy is often referred to as abusive by autistic adults, despite being supported by many parents of autistic children. Part of the controversy is related to the fact that its original creator, O. Ivar Lovaas, used electric shock therapy to stop children from engaging in obsessive, repetitive behaviours commonly referred to as 'stimming' (discussed in later chapters). Milton and Lyte (2012) refer to this therapy as an attempt to 'normalise behaviour', which often results in the psycho-emotional disablement of autistic people. Modern ABA practices have largely but not entirely removed these painful inducements (ABC News, 2nd July 2018). Autistic author, C.L. Lynch, notes that although ABA has evolved substantially over the years, the underlying goals have not changed: "It is these goals that, like gay conversion therapy, do long-term damage to the human psyche" (Neuroclastic, 28th March 2019). The goals she is referring to include the remediation or eradication of autistic behaviours, such as stimming and lack of eye contact, rather than addressing the child's emotional needs, and seeing these practices as forms of communication and self-regulation (Baggs 2007, 2010). Lynch explains that the reason parents and therapists do not see ABA practices as abusive, is because they cannot observe the therapy from an autistic point of view.

Cultural relativity and the other

The concept of cultural relativity, where a person's beliefs, values and social practices are understood based on their cultural context, is a fundamental principle in the study of anthropology. Key to this principle is how different cultures perceive 'otherness'. The social model of disability explores how disabled people are 'othered' by the society within which they live. Disability, as a social construct, is about understanding a society's standards for normative bodies and how disabled bodies are believed to deviate from this (Armstrong & Maureen 1996; Holzer *et al.* 1999; Ingstad & Whyte 1995). It explores how different cultures conceive and understand disability in different ways (Holzer *et al.* 1999; Littlewood 2006; Whyte 1995). Much exploration of the social model supports Erving Goffman's (1963) foundational views on stigma and how people attempt to manage and/or conceal their atypical behaviours and appearance for fear of shame and being discredited socially. These studies span dwarfism, deformity, and genetic disorders (Ablon 1981, 1984, 1999), mental retardation (Edgerton 1967, 1984), epilepsy (Whyte 1995) and autism spectrum disorder (Ha *et al.* 2014).

Richard Grinker (2007), in his anthropological exploration of autism around the world, shares the story of a young isiZulu boy diagnosed with autism at the age of two, in South Africa. The child's father and mother viewed his 'problems' as a disability; however, his grandparents perceived it as a disease, bad luck or punishment meted out by their ancestors and possibly even spirit possession (2007:203). When the parents finally relented and took the child to an *inyanga*,[14] the diagnosis was deemed to be 'ancestral punishment'; however, this was qualified as "a white man's disease called autism" (2007:205). Grinker also found that in South Korea, psychiatrists often diagnose children on the autism spectrum with Reactive Attachment Disorder (RAD), a retardation of the brain caused by extensive neglect, as this is perceived to be more 'culturally acceptable' (2007:12). Anne Fadiman (1998) illustrates how a clash of cultural understanding and treatment of epilepsy led to devastating consequences for a Hmong child in California. The doctor's clinical professionalism was viewed as arrogant and indifferent by the child's parents, who perceived the illness as a 'loss of soul', rather than a neurological abnormality. In Vietnam, Ha and colleagues (2014) report similar challenges in the cultural interpretation of autism:

> ASD has been socially constructed as a disease and family problem rather than a life-long developmental disorder that needs support from government. Social attitudes in Vietnam towards people with ASD are based upon stereotypes of people with ASD as mentally ill and potentially dangerous and traditional beliefs in rebirth and karma which associate disability as a consequence of an ancestor's karmic demerit. This discredits the whole family, a finding reported in other Asian settings such as South Korea and China (2014:284).

The definition of what constitutes disability is often dependent on a society's belief system and its broader cultural codes for health and wellbeing. As noted by Grinker, "(a)utism, like all disorders, does not exist outside of culture, it is culture that sees something as abnormal or wrong, names it, and does something about it, and all cultures respond to illness differently" (2007:12). These dominant social codes have major implications for those who do not fit into accepted societal norms and illustrate how disability can be viewed as a model for the production and reproduction of social inequality.

Paraplegic anthropologist, Robert Murphy (1995), attributes much of the social exclusion and stigmatisation of disabled people to the psychological mechanisms of

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[14] The name for a traditional Zulu healer in South Africa.

‘projection’ and ‘identification’. He notes that “the disabled arouse in the able bodied the fear that impairment could happen to them,” and possibly even guilt that it has not (1995:143). He argues that the disabled become a symbol of ‘failure, frailty, and emasculation’, the counterpoint to normality, the quintessential ‘other’. ‘Othering’ evolves to invisibility, as people are taught to fear and avert their eyes from those who are different. This, however, creates a moral dilemma as people find themselves both wanting to help those in need, while rejecting their difference or finding them frightening. Murphy uses the framework of ‘liminality’ to explain these conflicting values, a concept that is widely associated with ‘rites of passage’ (1995:153). In his view, the three phases of rites of passage, ‘isolation and instruction of the initiate’, ‘ritual emergence’, and ‘reincorporation into society in the new role’, aptly describes the experience of a person diagnosed as disabled. The ‘social limbo’ that liminality represents also describes how atypical people are viewed outside of formal social systems and the change in their social status (Devlieger 1999; Murphy 1990; Murphy *et al.* 1988; Stiker 1999). This ambiguous state of liminality may remain throughout a person’s life, or they may reject this state and create their own disabled culture (Ingstad & Whyte 1995). For people with hearing impairments and people with sight impairments, this ‘social limbo’ has led to ‘created communities’, moving from strategies to survive to newly defined minority groups (Becker 1980; Groce 1988; Gwaltney 1970; Deshen 1992; Ha *et al.* 2014).

Disability in the context of the social is therefore not just related to difference and stigma but to personhood itself. Susan Reynolds Whyte and Benedict Ingstad, in their exploration of disability and culture, pose the question: “are people with impairments, impaired people, and are they valued differently than other members of society?” (1995:10). Today in Iceland more than 85 percent of pregnant women opt for prenatal testing for Downs Syndrome and termination if results are positive. This has reduced the incidence of this chromosomal condition almost completely. The national dialogue of ‘eradicating Downs Syndrome’ has prompted some to equate the drive with genocide, and the “deliberate and systematic attempt to erase a certain category of people” (The Washington Post, 15th March 2018). Nancy Scheper-Hughes (1992) explored a similar theme in her devastating ethnography on Catholic mothers in Brazil. Unable to access safe legal abortions, the mothers would neglect their sickly, wasted or congenitally deformed children to death. Cultural categories of humanness vary and reflect what is perceived to make people ‘valuable’ to a society. This could relate to individual accomplishment as we see in the global North or based on social relationships and a person's role in a community as observed in ethnographies in the Global South. In her research of physical disability in Barbados, Ann Goerdt (1984) explored how personhood is conceived through a balance of autonomy and connectedness (1984:88). Ido Nicolaison (1995) explored how personhood is associated with social relations and kinship amongst the Punam Bah of central Borneo, and how a disabled person who is productive and can contribute to the community is still seen as valuable. However, should a woman not be able to marry or have children due to her disability, her humanness is once again brought into question, as she is unable to fulfil kinship responsibilities. Parents of a child diagnosed with autism in Vietnam are often advised by health care providers to have another child, as their child with autism "could not become a person" (Ha *et al.* 2014:281). Rupert Isaacson (2014) noted of a San Bushman healer in Namibia, who he sought treatment from for his autistic son:

> Besa rarely spoke, and when he did, it tended to be in snatches of song, riddle, rhyme. Occasionally he would say something fully lucid, fully coherent, but usually not. Often, he would laugh, flap his hands, dance a few jigging steps as if to music in his own head…in his culture, a culture where no human resources could afford to be wasted, he was a valued shaman, with a wife, children, grandchildren, and a successful career. Was he autistic? It seemed so. Yet in his culture such a condition – one foot seemingly in the spirit world, one foot seemingly in our own – was regarded as a job qualification (2014:109).

These examples illustrate how a person defined as disabled or different, is valued or devalued, incorporated into a community, or dehumanised, allowed to thrive or denied their right to live, based on their cultural context. Disability is thus a complex negotiation of identity, especially if one is unable to procure the resources they need to support themselves due to poverty.

Across class, race, sexual orientation and gender, disability is an extremely contested subject. In her lecture on disability and race, Karen Nakamura (2018) argues that disability studies could be viewed as 'white disability studies', due to the lack of representation of people of colour in the field. She illustrates how in recent years disability and mental illness have been used as a tool to mask racism, and to rationalise killing black men in police homicides in the US. In this context, disability is equated with legal oppression. In Crip Theory, Robert McRuer (2006) examines what he refers to as the 'cultural signs' of queerness and disability, and the intersectionality of these often-invisible identities. Disability studies and queer theory are both concerned with how bodies, pleasures and identities are represented as normal versus atypical. Crip theory attempts to explore how these disciplines inform each other, creating new possibilities for identity and resistance.

From a gendered perspective, a range of historical literature cites the incidence of autism and ADHD in far more boys than girls. More recent research indicates that the reason for this gendered view is a lack of understanding as to how these defined disabilities show up in young girls and transgender children (Each Other, 4th April 2019). Carol Povey, Director of the National Autistic Society's Centre for Autism in the United Kingdom, notes:

> The problem is that professionals often don't understand the different ways autism can manifest in women and girls, with many going through their lives without a diagnosis and an understanding of why they feel 'different'. This is because past research has largely concentrated on males, which means the way we understand autism tends to be very much based on the experiences of men and boys with the condition (Each Other, 4th April 2019).

The representation of diverse individuals and the diversity of their experiences is currently inadequate in disability studies. This is partly due to a lack of awareness of disabilities such as ADHD and autism in women, often attributed to their ability to mask the many typical and understood signs of the defined disorders.

People diagnosed as disabled often go to great lengths to hide their disability to assimilate into society, and in many instances, this costs them dearly both physically and emotionally. Emily Martin (2007), in her research of bipolar disorder, explores how mania is idealised as a creative state in American corporate culture. However, when this slips into the opposite world of psychosis, she notes that we fail to critically examine this far less palatable mental illness. Martin explores how people use their diagnosis as a "cloak" to prevent further surveillance. She argues that the standardised categories of diagnostic manuals such as DSM-5 allow people to avoid sharing more intimate and divergent psychotic experiences. This is reminiscent of Robert Edgerton's (1993 [1931]) seminal American ethnography, of the everyday lives of people diagnosed with mental impairment in institutions and after their integration back into society. Edgerton explains how patients had to 'unlearn' their experience of institutional life, and in turn, to re/learn the new culture of the communities to which they were returning (1993:216). To avoid the stigma of their disability, many of his subjects felt the need to deny their cognitive challenges and tried to 'pass as normal', despite the emotional consequences of this. Dana Raphael, Mike Salovesh and Martha Laclave (2001), in their account of living with learning disabilities (LD), note that "brain different people need to become their own most intense listener, powerfully sensitive to what is happening inside their body and their brain" (2001:159). In their experience, most 'outsiders' deny or lack any form of understanding or empathy for what the LD sufferer is experiencing. Since it is an 'invisible condition', it is difficult to explain or gain support for, and people with LDs often become experts in accommodation and concealment. Povey notes that 'masking' "can lead to a great deal of stress, and many women and girls go on to develop secondary problems such as anxiety, eating disorders or depression" (Each Other, 4th April 2019).

Constructing disabled identities

Identity is a complex field. In anthropology, it relates to how individuals construct themselves and the people around them. It relates to the identification of individuals and groups of people in the realms of politics, culture, gender, and race, and it is often contested. Shakespeare recommends the use of storytelling as a useful tool to understand identity creation in the realm of identity politics: "Identity connects the social and the personal and involves the individual putting themselves in a collective context" (1996:99). Michael Angrosino (1998) captures the complexity of what it feels like to be mentally impaired and its impact on self-identity, through a range of short stories about the occupants of a home for the disabled, in *Opportunity House*. His creative life histories illustrated how disabled people do not fit into a linear 'culture of disability' (1998:30). Rather, he portrays them as complicated, vulnerable, and often humorous individuals who are trying to negotiate their way through a world that is widely intolerant of difference. Shakespeare notes how individuals can choose the negative identification of the medical model, or a more positive social model, however, they cannot make others accept their choice. Gilson and colleagues (1997) note that "understanding how disabled people perceive themselves and how they wish to be perceived is essential in defining the emerging identity of disabled people" (1997:88).

Key to identity development is an understanding of the atypical body and its impact on both identity creation and as a tool to experience the social world. Distortions of body perceptions, perceived functionality of various body parts, and how disorders are somaticised into various areas of the body, all influence how an individual perceives themself. Lenore Manderson (2011) proposes that all human experiences are incarnated and that we interact with our worlds through our bodies. She explores the experiences of dramatic loss of bodily function by various individuals, noting that healthy bodies go unnoticed, whilst bodies in pain, that have lost function, or are deemed disabled, become visible. These bodies require a great deal of identity construction as they are a primary source of how we represent ourselves to the world (2011:24). This has important implications for the disabled or rather differently abled body and mind, which are often seen as bad or unhealthy and in need of remediation. Maria Tapias (2006), in her work on emotions and embodiment of social suffering in rural Bolivia, argues: “Understanding of culture should begin with an examination of the lived-in body, because one knows, feels, and thinks about the social world through the body” (2006:403). For Tapias, embodiment involves an in-depth analysis of how people experience and live their day-to-day lives. How their bodies relate to other bodies in these social environments, including understanding how social suffering through poverty, violence, exclusion, or discrimination, can be internalised through the process of embodiment (Scheper-Hughes 1988; Farmer 1996; Tapias 2006). Krieger also calls for an “embodied study of human culture, cognition, behaviour, and emotion”, as each of these components have a powerful impact on how we “live in our bodies” (2005:352). She notes that such research should include our use of language, consumption of food, sexual practices, recreation, substance use or abuse, and experiences of violence, emotions, and various forms of trauma. She argues that each of these aspects are also impacted by social conventions, economic resources, and historical context (2005:352).

Alternative socialities is a growing field of study in autism, where different views on humanity and the social are explored in the context of neurodiversity and different kinds of minds (Solomon 2010; Hollin 2014). Many atypical activists are calling for neurodiversity to be seen as part of human diversity and normal variation in the human genome. It is a fundamentally different way of looking at conditions that were traditionally pathologised such as autism, ADHD and learning disabilities (Bagatell 2007, 2008; Grinker 2007; Lawson 2008; Savarese 2013). Although not universally accepted, Neurodiversity is increasingly being supported by science. Scholar and autistic author, John Elder Robison, notes: “Science suggests conditions like autism have a stable prevalence in human society as far back as we can measure, we are realising that autism, ADHD, and other conditions emerge through a combination of genetic predisposition and environmental interaction; they are not the result of disease or injury” (Psychology Today, 7th October 2013). This new approach focusses less on cure and remediation and more on support, accommodation, inclusivity and the possible strengths of cognitive variations and different ways of being in the world (Watermeyer *et al.*

2006). It reinforces the notion that human diversity is critical for human development and proposes that eliminating difference could even be harmful to humanity (Silberman 2015). In the context of autism, neurodiversity advocates argue that being ‘on the spectrum’, is an integral part of their way of being in the world. They identify as ‘Autistics’, ‘Auties’, ‘Aspies’ and ‘Aspergians’ (Lawson 2008; Milton & Lyte 2012), and references to prevention, cures, remedies, and recovery are deemed intolerant and oppressive (Belek 2019).

Biosociality and interdependency

In problematising and theorising disability, the concept of inclusivity needs to move beyond the tangible environment. Rather than pitting the medical model of disability against the social model, a biosocial model calls for us to explore the relationship between the two. Paul Rabinow (1996) foresaw the development of biosocial connections, where individuals with distinct biological diagnoses would come together to form new social or kinship groups in a process he called ‘biosociality’. Through the use of social media this concept has exploded in recent years, into a range of biologically based social networks and groups where people share experiences, offer advice, and provide general support and friendship to each other. Meloni and colleagues *(*2018) note that these ‘entanglements’ go beyond established social constructionist claims that “biological knowledge is shaped by meaning, power, and norms” (2018:6). They argue that biological matter, including genomes, brains, diseases, and viruses are social in both form and content.

In moving beyond a biomedical or social model, Bøttcher and Dammeyer (2016) explore Lev Vygotsky’s cultural-historical theory of the 1920s to understand development and learning in young children with disabilities. They argue that both the medical and social models have limitations, due to their binary approach to understanding the evolving consequences of disability. The medical model’s strength lies in its ability to explore how impairment impacts on an individual’s functional abilities; however, it fails to understand the wider context or social environment that impacts on a child’s behaviour. The social model, whilst focussing on removing barriers to participation, fails to appreciate the consequences of impairments, such as chronic pain or fatigue, on their lived experience. Bøttcher and Dammeyer illustrate how a child’s development is formed through a dialectical process between biological maturation and participation in cultural forms. For neurotypical children these processes support each other; however, for children diagnosed with disabilities ‘incongruencies’ appear between the two. Challenges also develop between the child’s motivations, and the social environment they find themselves within, such as the need for specialised support versus their desire to engage in a mainstream schooling. As many social expectations of children are based on chronological age, disabled children's social participation is often in conflict with this. We are only able to understand this conflict by exploring the relationship between the child's impairment and their specific conditions of social engagement.

In Nikolas Rose's (2001) view on biopolitics, human beings have become `somatic individuals'. Rose proposes that in a world where personhood is increasingly defined in terms of corporeality or the material and physical form of the body, direct relations become established between our biology and our conduct. This somatic and corporeal individuality opens new choices and responsibility to people in the form of experimentation and contestation, and thus a 'politics of life itself'. However, rather than the state monitoring, evaluating, and controlling our bodies, it has now become the responsibility of the individual to do this. As Rose notes, "every citizen must now become an active partner in the drive for health, accepting responsibility for securing their own well-being" (2001: 6). Risky individuals are identified and where possible preventative interventions are instituted, or managed in what Rose refers to as "biopolitical risk management" (2011:7):

> Life now appears to be open to shaping and reshaping at the molecular level: by precisely calculated interventions that prevent something from happening, alter the way something happens, make something new happen in the cellular process themselves. As the distinction between treatment and enhancement, between the natural and the prosthetic blurs, the management and maximization of life itself has become the life's work, not only of each individual, but of their doctors, together with the scientists, entrepreneurs and corporations who make the reworking of life the object of their knowledge, inventions and products (Rose 2011:17).

The combination of biopolitics and our somatic individuality is challenging existing ethics around life where vital and social norms collide. Normal bodies and minds are being questioned, personhood is being defined not just in terms of our limitations but also in terms of our choices and our possibilities.

In the context of neurodiversity, Rose and Abi-Rached (2014) note how the brain is becoming an object through which human beings are governed. We are no longer persons with brains, but rather persons as brains, the 'psychological complex' of the twentieth century is being replaced by a 'neurobiological complex' in the twenty first (2014:3). In a process of radical reductionism, we have moved from human beings who were part of a complex human sociality, to organs that are managed by psychopharmacology, brain imaging, plasticity, and genomics (2014:17). Yet even as we reduce ourselves to smaller and smaller units of understanding and management, we are constantly reminded of our interconnectedness, and reliance on each other:

> For humans are, after all, animals, albeit rather special ones, but nonetheless shaped crucially by their character as vital, living organisms in constant transaction with a *milieu* that they themselves constitute and transform" (Rose and Abi-Rached, 2014:18).

Judith Butler (2018) argues that we are all born into a condition of 'radical dependency'. This dependency follows us into adulthood in a range of different ways through our navigation of the built environment, accessing food systems and social support. However, in adulthood we imagine ourselves as self-sufficient, rather than dependent. As social beings we are all equally vulnerable, dependent, and dependable, a point clearly illustrated in the recent global COVID-19 pandemic. However, some individuals, or groups of individuals, as in the case of atypical children, are made to feel more vulnerable than others. The challenge is not their vulnerability, but how a neoliberal society positions them as dependent, inscribing vulnerability onto their identity (Butler 2020). Our very understanding of autism, ADHD and learning disabilities is based on functional ability and support requirements. Butler argues that to move towards a world of radical equality and democracy, we need to appreciate how interdependent we are not just as individuals, but as communities and societies. The world she proposes is one in which all lives are equally 'grievable', and where the loss of any life, including those defined as disabled or different, would be intolerable. To achieve this, we need to persist in building appreciation for the value of different ways of thinking and being in the world, and the importance of mutual vulnerability as a precursor to global interdependency. Rather than dismissing vulnerability as weak and in need of support, we need to celebrate it as a means through which we are able to experience our worlds freely through our bodies: "persistence in the condition of vulnerability proves to be its own kind of strength" (Butler 2020:201).

CHAPTER 3

CREATING AN EMPOWERING METHODOLOGY

In his commentary on ‘being autistic and social’, anthropologist and father to an autistic daughter, Richard Grinker noted:

> We need to focus attention on the anthropological study of a form of difference that has previously been conceived of as lying outside the realm of the social. The concept of "diversity", with all its positive connotations of acceptance and celebration of difference, need not only apply to gender, race, ethnicity, and religion. We can also begin to celebrate a diversity of minds (2010: 177-178).

To celebrate this diversity of minds, unsullied by other’s perspectives or interpretations of their behaviour, I committed to understanding first and foremost the lived experience of atypical children. To achieve this, I turned to the philosophy and methodology of phenomenology, which allowed me to explore the various structures of consciousness experienced by atypical children in a pre-reflexive state. As noted by one of the fathers of phenomenology, Maurice Merleau-Ponty: “The world is not what I think, but what I live through” (2005 [1945]: xvii).

As the name denotes, phenomenology is the study of ‘phenomena’, or how things appear in our experience of them, and the meaning we then attribute to these experiences. Phenomenologists argue that there is a structure to how we experience our worlds. Husserl, in *Logical Investigations* (1901), argued that this structure is dependent on our intentionality or consciousness towards what we experience, and the meaning we derive from these experiences. Phenomenology seeks to understand a layering of awareness, from the physical, to the emotional, to the social and finally to the intellectual. It also examines how supportive our environment or context is in ensuring that we realise our potential. Despite requiring some level of intentionality, both Husserl and Heidegger (1927) noted that our experiences can be conscious, semi-conscious and even unconscious, and that meaning can be derived from each.

Fundamental to phenomenology is the rejection of René Descartes’s Cartesian Legacy and mind-body dualism, that he first outlined in his *Méditations Métaphysiques* published in 1647. In *Méditations*, Descartes rejects ‘perception’ as unreliable, and outlines how the body is not capable of thinking or interpreting the world. In contrast, the body is central in Merleau-Ponty’s *Phenomenology of Perception* (1945). For Merleau-Ponty, our experience of our world is greatly influenced by our experience of our body and how it interacts with the world around us, they are in fact inseparable, as he notes:

> My body and the world are no longer objects co-ordinated together by the kind of functional relationships that physics establishes. The system of experience in which they intercommunicate is not spread out before me and ranged over by a constituting consciousness (1945:408).

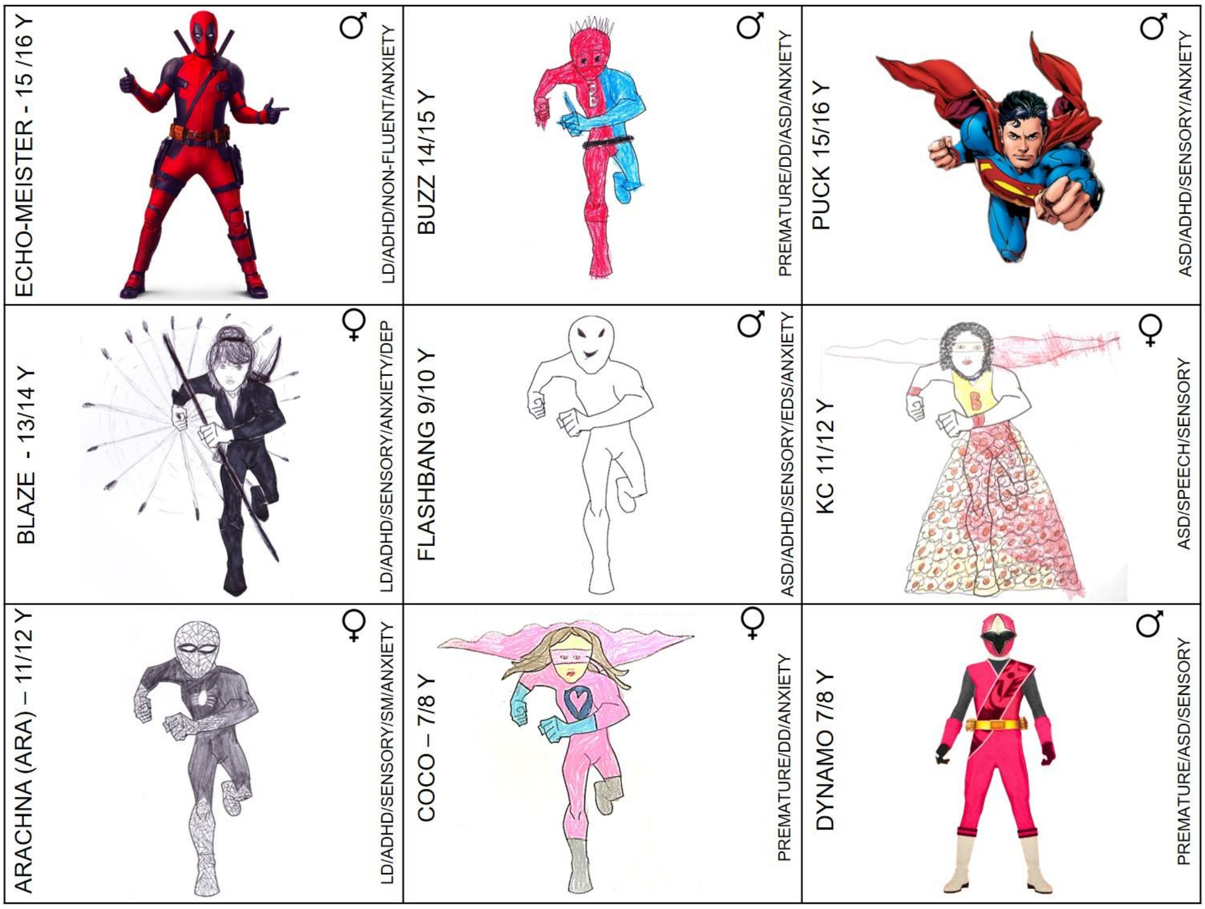
Body and mind are one, with a shared consciousness and a shared sense of subjectivity. The body becomes an important tool through which a person views and experiences the world around them, and ultimately makes meaning of this.

As a method, phenomenologists identity several levels of engagement and interpretation. The first is how we describe our experience of our world, or what Husserl and Merleau-Ponty referred to as the pure description of our lived experience. Secondly, how we interpret our experience in its context, Heidegger's (1927) hermeneutics, which refers to our openness as researchers to appreciating how the individual relates to the whole or context in which the experience takes place. Finally, how we analyse the experience and identify areas for further investigation. It is thus a process of detailed description, followed by detailed interpretation, and then further investigation. This interpretation should come from two different perspectives. The first is the researcher's own insight into the phenomena and how they have understood and made sense of the experience as explained to them by their participants. Second, through a process of reduction, the researcher is able to identify the true meaning or essence of the phenomena they are exploring through suspending their own preconceived ideas or subjectivity. Critical to my process of analysis was defining emic, that is, from the perspective of my participants, versus etic, that is, from my perspective as researcher. I identified positions on each phenomenon for exploration.

My time in the field and in writing this research followed this three-step approach. Firstly, my work involved a lengthy engagement over a period of two years with an initial cohort of nine children diagnosed as atypical. Although much of my research was conducted using participant observation, in the ethnographic tradition, I did use semi-structured interview guides which I developed in an effort to explore and answer my research question; these can be found in Appendix C. Following each interaction with the children, I spent several hours detailing not just what was discussed, from my interview recordings, but how they engaged physically and emotionally to each aspect of our discussion and interaction. It was at this point that I interrogated differences between how the children responded to a particular concept or creative exercise (their emic position) compared with my own views as informed by anthropological and social theory on what was being discussed, and my etic observations of them. Invariably, I was not always certain why they responded in a particular way and I would often seek clarity from them. As the children often struggled to articulate their thoughts and feelings, I did this by giving them alternative perspectives to select from. From a research perspective, providing children with a range of alternatives could appear leading and subjective. However, due to their honesty, or rather their inability to conceal their true thoughts and feelings, as I discuss in detail in Chapter 7 (see Li *et al.* 2011), the children were very single minded in selecting the perspective that resonated with them. They would respond with a simple “no” or “yes” to my exploratory questions, and it was apparent that they did not feel the need to support any perspective for my benefit.

Following my initial engagement with the 9 different children, I then spent several months interpreting my subjects’ experience of their world, which provided me with a range of phenomena that I wished to explore further. This further investigation was conducted through in-depth participant observation of a number of atypical children in the context of sporting activities and workshops over the period of a year. To understand the meaning of certain behaviours in more detail, I also engaged with a range of online atypical communities who identified as autistic or with challenges such as ADHD, learning disabilities and Ehlers-Danlos Syndrome. As these social media groups had been formed to share their lived experience with other atypical individuals and their parents or partners, they generously engaged on each phenomenon, often through rich debate, informed by their own experiences of their childhoods. The final level of interpretation came through sharing children’s stories back to them. This allowed for further clarification between emic and etic positions, as I was able to explore if my interpretation of how they experienced their world was an accurate reflection. This final sharing phase elicited further discussion and input from the children and helped me to crystalise the meaning that the children associated with each phenomenon that I had observed in their engagement with their world. Each stage of my research with my various interlocutors is discussed in detail below.

Meeting the superheroes



DIAGNOSIS KEY: LD = LEARNING DISABILITIES; SENSORY = SENSORY SEEKING OR SENSITIVE; SM = SELECTIVE MUTISM; DD = DEVELOPMENTAL DELAYS; ASD = AUTISM SPECTRUM DISORDER.

Figure 3.

Through a process of snowball recruitment, I identified nine English speaking children, ranging in age from 7 to 15 years in three broad atypical groups:

1) Specific learning disabilities and ADHD.
2) Non-specific developmental and behavioural challenges.
3) Autism spectrum.

The children I spent time with, in my initial research cohort, were from middle class white families, and thus represent a minority Western perspective in the context of South Africa. All the children had been diagnosed with a learning disability, ADHD, developmental delays or on the autism spectrum by a qualified doctor, psychologist, or psychiatrist. All were receiving extensive support for these defined challenges raging from medication to occupational therapy, physiotherapy, special education, remedial support, counselling, and specialised sports coaching. I was able to explore a more diverse range of children's experiences when I engaged with the Johannesburg inner city autism boxing classes, however, this was in the form of participant observation, rather than individual one-on-one sessions. I have spent some time running workshops with children who present as atypical from disadvantaged and predominantly black communities through my child protection work, especially in the context of children's homes, however, most of these children have not received a diagnosis that would define them as atypical. I was thus unable to include them in this study from an ethical perspective; however, this is an area of potential research.

In the South African middle-class private school environment, neurodevelopmental disorders are often identified in primary school, when children first start to engage in a broader social environment and learn to read, write, and understand mathematical concepts. Their challenges can have a profound impact on how they define their identity as they become teenagers. I therefore wanted to recruit children who ranged in age from 8 to 15 years to explore the atypical lived experience at this foundational stage of their lives. I met most of my participant's mothers at a remedial school close to where I live in the Northern suburbs of Johannesburg. This school offers regular talks and workshops for parents and practitioners in the field of neurodevelopmental disorders and associated challenges. One of the mothers invited me to attend a weekly support group for parents of children diagnosed on the autism spectrum. I introduced my research topic and approach to the group, and a few of the parents informed me that they would like to take part in my study. The parents were primarily interested in my methodological approach and the fact that I wanted to focus not on the disabling aspect of their children's diagnoses, but rather their unique ways of being in the world, which many spoke of passionately. Through this support group I was introduced to parents in another school that positioned their offering as 'private individualised education'. I once again presented my research proposal to interested parties, some of whom agreed to take part in my research. I met the mothers of most of my learning disabled and developmentally delayed participants at two workshops that I attended. The first, 'Sensory Intelligence in Education',[15] was for parents and teachers of children with sensory processing challenges, and the second, RAVE-O Training,[16] was for training in a literacy programme specially designed for children diagnosed with dyslexia. Once again, I shared my research proposal with these parents who then indicated that they would like to take part in my research. All the parents were particularly interested in my approach of understanding the impact of multiple comorbid challenges on their children's lived experience, as all had a

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[15] *Sensory Intelligence in Education,* facilitated by Annemarie Lombard, May 2014.

[16] *RAVE-O Training,* facilitated by Stephanie Gottwald, September 2012.

range of diagnoses that they were trying to help their children navigate. Once the parents indicated that they were interested in taking part in my research, I would follow this up with a separate meeting, where I took them through my research process, proposed methodology, and consent and asset procedures in detail. I then conducted a further meeting with the child children and their mothers, where we discussed my research, methodology and assent process. Only once all parties had consented and assented did I proceed with my research.

Of the nine children I recruited, five were boys and four were girls, and although each participant fitted broadly into my three separate diagnostic areas, further diagnoses were identified during our time together. Ultimately, five of the children were diagnosed on the autism spectrum and all had some form of learning disability. All had concentration challenges and some level of ADHD, although not all were being treated for this. All the children suffered from high levels of anxiety, and seven of them were on medication to assist with their attention or anxiety levels. All had sensory challenges with six being significantly sensory sensitive, and three displaying sensory seeking behaviour. Seven of the children were born prematurely and had challenging birth experiences including intensive care unit (ICU) stays. Coco and Dynamo are twins and were born at just twenty-nine weeks, spending two months in ICU. Dynamo was especially vulnerable at birth as he was diagnosed with necrotising enterocolitis in his intestinal tract; he struggles with gut challenges to this day. Buzz was born three weeks prematurely with a hole in his heart and had eight major surgeries in the first four months of his life. Four of the children were diagnosed with language challenges that included selective mutism at a younger age, non-fluency, and auditory processing disorders. Flashbang had a diagnosis of Ehlers Danlos Syndrome, a hyper flexibility and connective tissue disorder, but five of the children showed signs of hypermobility. Five of the children attended mainstream school but had a range of remedial support, and four of the children attended remedial schools designed to assist them. KC was adopted into her transracial[17] family at eight weeks of age from a baby home, after her biological mother formally consented to her adoption.

On meeting all the children, I assessed their ability, willingness, and informed assent to engage in my research process. This entailed meeting with me weekly, over several months, interspersed with a range of outings, usually on their own, to observe the children in different social environments. Our weekly meetings involved many creative exercises which

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[17] 'Transracial' is a term used by the adoption community in South Africa, when the race of the child being adopted is different from that of the family they are being adopted into.

we would complete together and then discuss in detail. On some occasions, we would just play games together, that the children devised. Play and engaging in various forms of creativity were my primary methodology throughout my research. Using the exercises outlined below, I created a personal biography or 'brand book' (photographed below in Figure 4) for each child, which I was then able to present back to them for their feedback and input. Only once I had completed most of my meetings with the children, did I engage with their parents, siblings, teachers, doctors, and therapists. This was to ensure that the narratives were primarily from the perspective of the children. Later interviews with family members, and other people in their broader support system, were used to clarify behaviours, assess their frequency, and determine how they differed in alternative social contexts or environments. Introductions to the broader family and members of the children's support circles were made by my primary family contact, in each case the children's mothers. The mothers decided which individuals I should speak to and introduced both me and my research to them. I provided further information about my research as part of my consent procedure.

Figure 4.

Developing empowering ethnographic tools

Although my methodological starting point was phenomenology, as most of my participants struggled with communication and concentration, I realised that I would need to develop an innovative approach to assist the children in sharing their lived experience and personal narratives. In her exploration of creative methodologies in the development of different ethnographies, Dara Culhane, argues that “ethnographic knowledge emerges not through detached observation but through conversations and exchanges of many kinds among people interacting in diverse zones of entanglement” (Elliot & Culhane 2017:3). Elliot and Culhane (2017) recommend the use of imaginative practices that allow for “collaborative and co-creative knowledge making” (2017:3). The National Institute for Disability and Rehabilitation Research, in creating a better understanding of the lived experience of disability, have called for ‘participatory action research’ (PAR) (Kasnitz & Shuttleworth, 2001). PAR is a form of applied anthropology, also referred to as engaged or action anthropology, and can encompass social support, education, social entrepreneurship, and collaborative research.

This approach empowers subjects to have a role in determining the outcome of the research process. Some concerns have been raised about the objectivity of this ‘engaged’ approach, however, as Paul Mullins (2011) argues:

> Problem-focussed collaborative research, is an exceptionally powerful mechanism for securing meaningful informed consent that dissects research methods and questions, articulates anticipated research outcomes, and outlines both researcher and community rights and obligations (237).

French-Gilson and colleagues (1997), in their work on ethnographic research in disability and identity argued that “disabled people are the most accurate and insightful source of who they are” (1990:88). Michael Agrosino (1997) illustrates the richness of personal life histories in understanding the impact of disability on everyday life in his collection of short stories about ‘Opportunity House’, a home for adults with intellectual disabilities. These ethnographies present a highly functional but marginalised community, that he wanted to represent as accurately as possible from their perspective, as he notes:

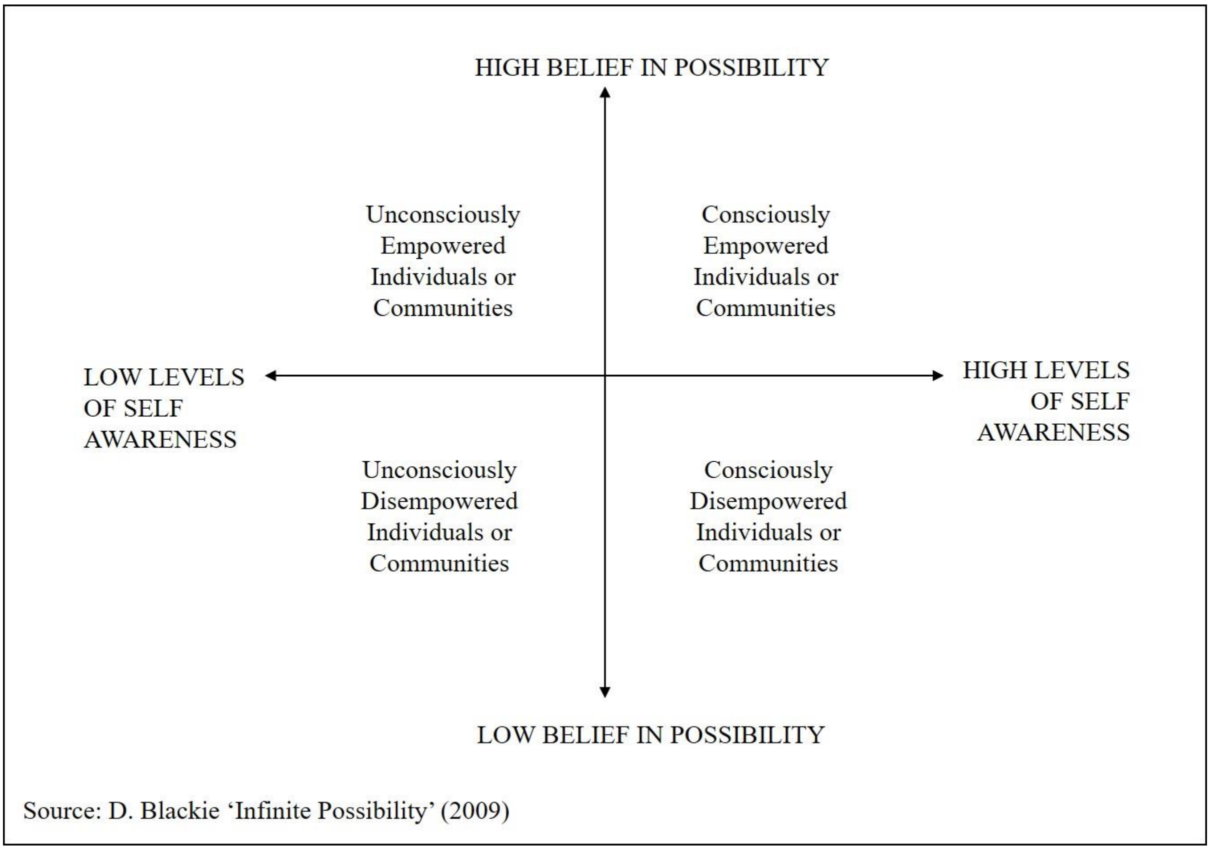
> I don’t think you can ever fully enter into the experiential nexus of another person – even someone from your own culture with whom you share many important formative

> experiences – but I think you can come close by sharing the experience of creating an account of that person's life (Agrosino, 1997:20).

This approach of collaboratively creating an account of each of the children's lives inspired me. It also called for me to constantly question, compare and then separate my personal or autoethnographic experience of disability from that of the children, not just at a holistic level, but after every single interaction.

As an initial framework, I turned to a methodology I developed during my work in corporate change management called 'Infinite Possibility' (Blackie 2009). Following extensive desk research on the subject of 'personal empowerment', spanning business, leadership, religion, spirituality, self-help, counselling, meditation, and mindfulness, I identified several themes that appeared to be repeated in each of these contexts. These seven themes included: 1) The definition of personal values or beliefs; 2) The identification of partners or collaborators; 3) The building of one's self esteem and self-worth; 4) The understanding of love, care and community; 5) The creation of a personal vision or purpose; 6) The building of knowledge and insight; and finally, 7) The development of a detailed personal action plan. I have used this methodology in a number of corporate workshops over the past decade, and this also formed the basis for my child protection community engagement work.

The central hypothesis for the methodology is that to be empowered, one must build both one's belief in possibility, and one's level of self-awareness and understanding, as illustrated in Figure 5 below. An individual with low levels of self-awareness and who does not believe in possibility, is defined as 'unconsciously disempowered'. If that individual were to increase their belief in possibility, and their level of self-awareness, they could become 'consciously empowered'. The move from a low to a high belief in possibility relates to defining one's vision or purpose, building personal knowledge and insight, and creating an action plan to achieve this. The move from low to high levels of self-awareness, relates to defining one's personal values or beliefs, identifying partners who will support you in your endeavours, and building one's personal self-esteem and self-worth. The difference between unconscious and conscious levels of empowerment lies in one's personal motivation. If one is focussed primarily on the self and personal empowerment to the exclusion of others, a form of radical individualism, then one is driven by the scarcity often found in neoliberal constructs. However, if one is driven by a desire to build abundant communities defined by an ethic of care and empathy, then radical equality, democracy, and conscious empowerment can be achieved. A form of social interdependency where all are enabled to live their best lives. Rather than naïve, the ‘unrealism’ of such imaginary is its strength. Judith Butler (2020) argues that the ability to ‘make fools of ourselves’ in imagining new possibilities, in this instance, the empowerment and celebration of atypical minds, moves us beyond conventional realism.



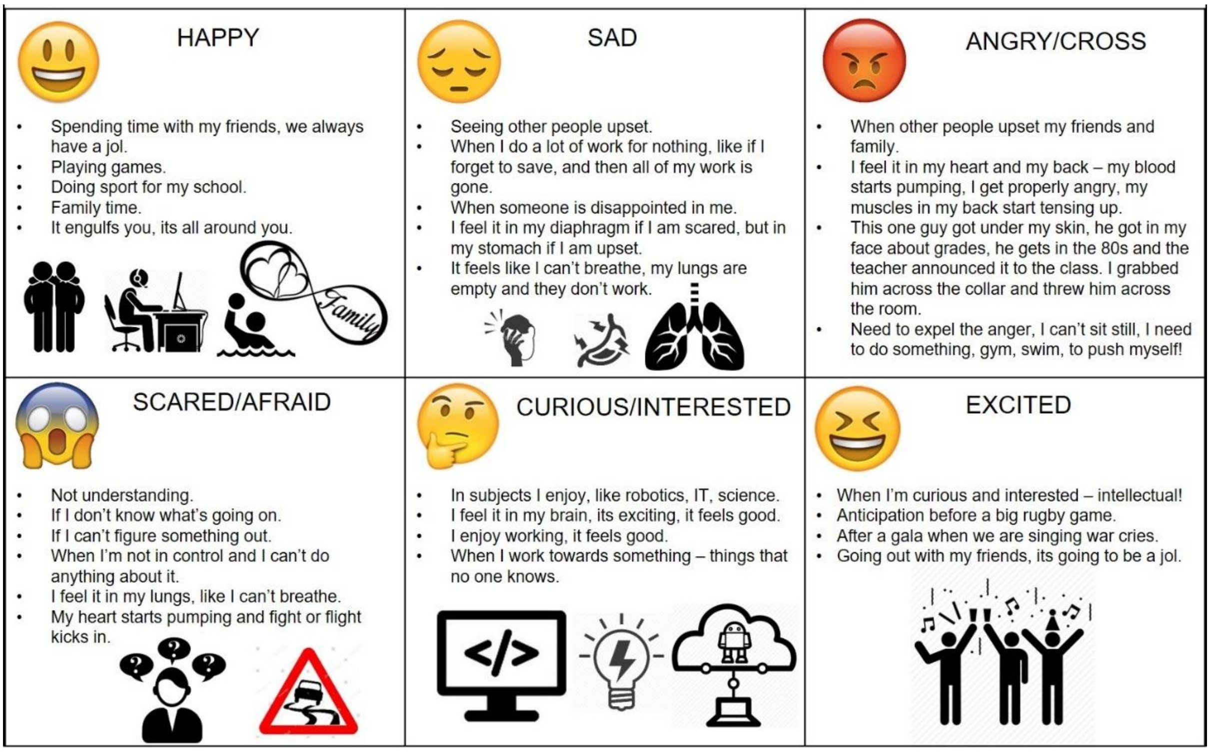
Source: D. Blackie ‘Infinite Possibility’ (2009)

Figure 5.

In the pursuit of developing an empowering approach to understanding the lived experience of atypical children, I developed several creative exercises that encompass all the ‘personal empowerment’ themes outlined above. In totality, the interactive exercises represented a ‘personal brand story’ for each child. These stories focussed not just on their current reality, but also on the future that they dreamt for themselves and are illustrated in detail below.

In the first session, the children completed the ‘Superhero exercise’, illustrated in Figure 3 above, where they drew themselves as Superheroes, complete with special skill or ‘powers’ they believed they had, and any tools or supports they used in their day-to-day lives. Despite all being aware of their various challenges, they identified as strong, strategic and sensorially powerful, but also atypical and unique. Most of them chose as their superhero sidekick a special animal with whom they often had a strong and meaningful relationship. As my research evolved, my observation of the children's relationships with animals became an important means of exploring their understanding of love, care, and empathy (see Malcolm, *et al.* 2018). Further insight into the children's lives was generated through developing a personal timeline from birth to their current age, detailing their high and low points. If the children struggled with this exercise, where possible, I conducted it as a sharing session of family photo albums. Beyond specific events, the children discussed what they viewed as their strengths and weaknesses. They also shared how they liked spending their time, in contrast to activities that they would rather not engage in. Using improvisation techniques, the children acted out their best and worst days. In some instances, these were actual days that they had experienced; in others, they created a composite day of best and worst activities. For each, they explained what had happened to them, the people they met who they liked or disliked, the foods they enjoyed eating and those they did not, and how they spent time relaxing or entertaining themselves.

To explore the children's understanding of, and engagement with, their various emotional states, I used emoji icons to assist them in creating a mind-map of personal emotions. A summary of some of Echo's (15) emotional states is detailed in Figure 6 below:



HAPPY

- Spending time with my friends, we always have a jol.
- Playing games.
- Doing sport for my school.
- Family time.
- It engulfs you, its all around you.

SAD

- Seeing other people upset.
- When I do a lot of work for nothing, like if I forget to save, and then all of my work is gone.
- When someone is disappointed in me.
- I feel it in my diaphragm if I am scared, but in my stomach if I am upset.
- It feels like I can't breathe, my lungs are empty and they don't work.

ANGRY/CROSS

- When other people upset my friends and family.
- I feel it in my heart and my back – my blood starts pumping, I get properly angry, my muscles in my back start tensing up.
- This one guy got under my skin, he got in my face about grades, he gets in the 80s and the teacher announced it to the class. I grabbed him across the collar and threw him across the room.
- Need to expel the anger, I can't sit still, I need to do something, gym, swim, to push myself!

SCARED/AFRAID

- Not understanding.
- If I don't know what's going on.
- If I can't figure something out.
- When I'm not in control and I can't do anything about it.
- I feel it in my lungs, like I can't breathe.
- My heart starts pumping and fight or flight kicks in.

CURIOUS/INTERESTED

- In subjects I enjoy, like robotics, IT, science.
- I feel it in my brain, its exciting, it feels good.
- I enjoy working, it feels good.
- When I work towards something – things that no one knows.

EXCITED

- When I'm curious and interested – intellectual!
- Anticipation before a big rugby game.
- After a gala when we are singing war cries.
- Going out with my friends, its going to be a jol.

Figure 6.

The maps explored when certain emotions occurred, why they occurred, what they felt like, and where and how they were experienced in their bodies. We then did a ranking exercise exploring which emotions they experienced most, and which they experienced the least.

Collaboratively, we conducted a detailed exploration of how the children experienced their world through their bodies, when they were happy and well, and when they were unhappy or unwell. Using the outline of a body as a starting point, the children illustrated these states using form and colour. Dynamo's (7) embodied comparison is illustrated in Figure 7 below.

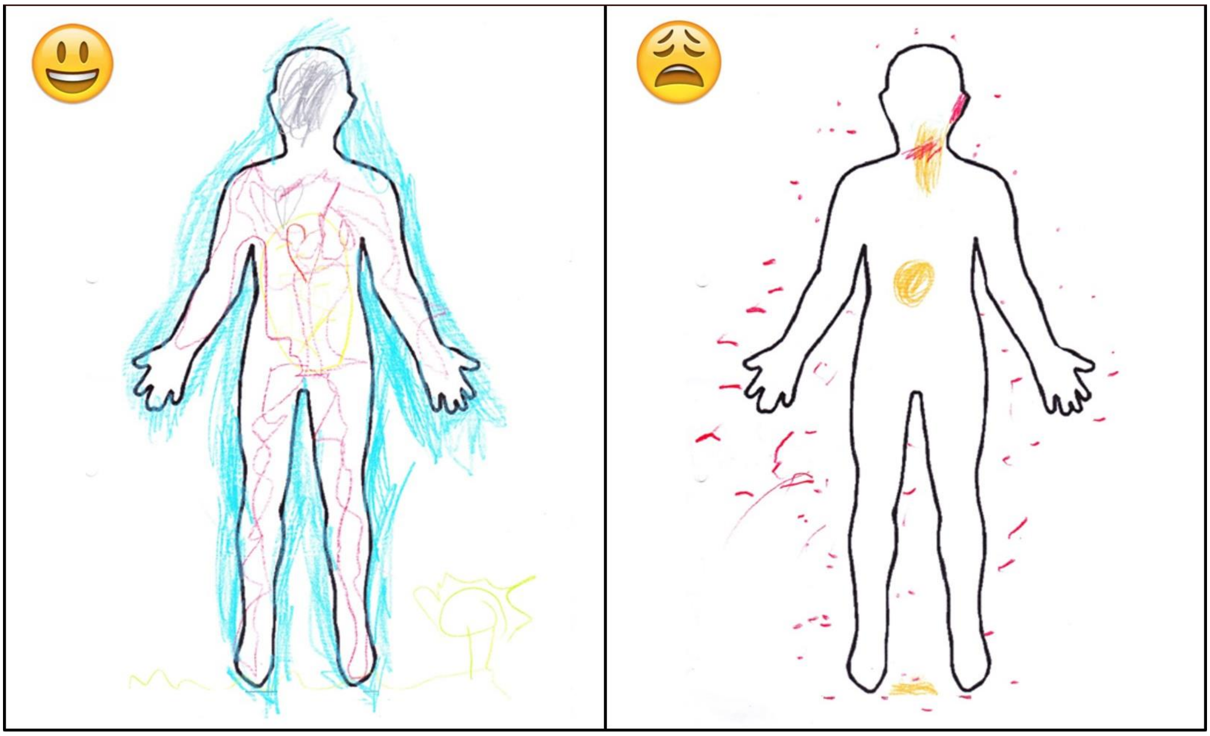


Figure 7.

Although the children did not situate their challenges or differences entirely within their brains, I felt it important to explore whether and how they experienced their mental processing in the context of neurodiversity. By not providing a template, as with the embodiment exercise, the children's perceptions of their brains moved beyond tangible material expression, to that of conceptual. Coco (7) and Buzz's (14) depictions of their neurological processes are illustrated in Figure 8 below. Coco's shows a partnership or conflict between soldiers and foxes, and Buzz (14), Rebels in conflict with Stormtroopers, from his favourite Star Wars franchise:

To understand the different people and partnerships in the children's lives, I used a range of toy animals that we mapped out together on large sheets of paper. The children selected animals for all the people in their lives, based on their perceptions of them. They then created a physical constellation of how they related to each person and their level of impact on their lives. We examined how each relationship worked, exploring the various attributes between the children and their circle of family, friends, teachers, therapists, and acquaintances, as illustrated in Figure 9 below:

Figure 9.

After an in-depth discussion of their existing learning environments, the children got to design their own school. They did this through creating a collage of pictures that represented all the attributes they felt an ideal school should have. Some children used a range of pictures and ideas, whilst others identified existing spaces that they had encountered on TV, in books, or in their direct experience, such as a waterpark or spaceship. The children also shared their 'toolkit for learning', which included strategies, implements, devices, toys and even medication, that they used to assist them in staying focused and on task in the classroom environment. Ara's (11) school design is illustrated in Figure 10:

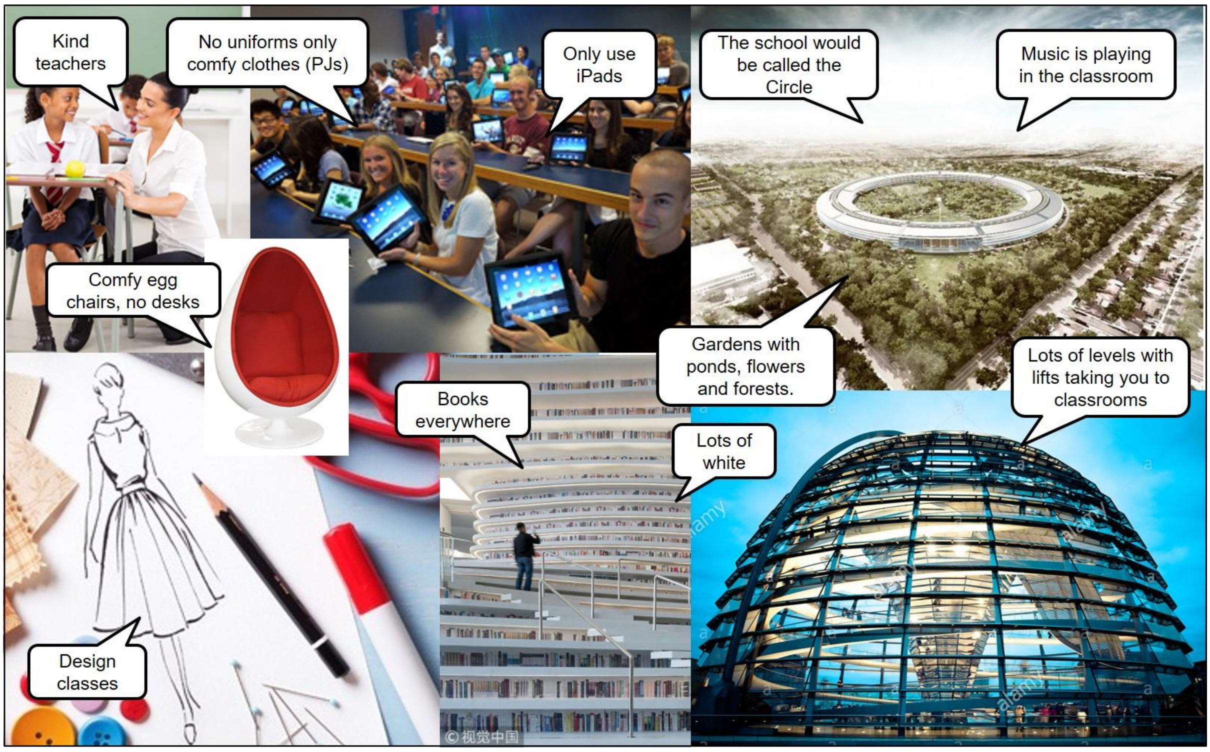
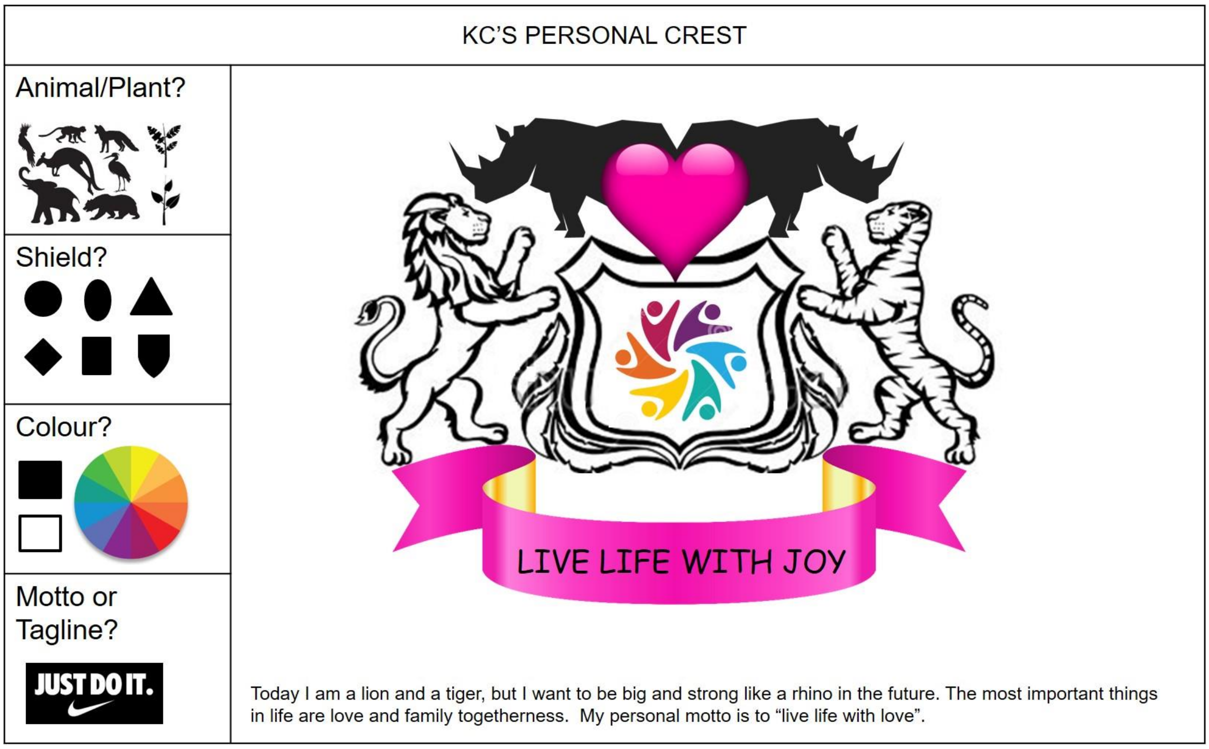


Figure 10.

The final exercises focused on assisting the children in developing their 'future dream world', or the world that they would like to live in when they were grown up. With my help, they developed a vision board using a collage of pictures and phrases. Puck's (15) vision board is illustrated below in Figure 11. In support of this vision board, the children identified their personal vision statement or purpose. We discussed their personal beliefs or the values that they felt would guide them in achieving their vision. As a final step, we identified the people and partnerships that they believed would help them along the way, to achieve their 'future dream world'. The children also created a personal self-esteem bowl in which they placed notes and tokens that represented what they thought made them special and unique.

Figure 11.

Using a kit of creative parts, the children summed up who they believed they were by developing a personal crest, complete with a motto. KC's (12) crest is illustrated in Figure 12 below.



Today I am a lion and a tiger, but I want to be big and strong like a rhino in the future. The most important things in life are love and family togetherness. My personal motto is to "live life with love".

Figure 12

In my final creative interactive session with each child, we discussed the various actions they should take to achieve this future dream world that they had defined for themselves. We then developed a personal pledge that they made to themselves to this effect. What was compelling was that more than half of the children in my cohort enacted these plans in the space between developing them and my presenting their ‘brand books’ back to them. Most did this on their own without their parents’ input or support, indicating a high level of self-motivation.

In-depth observation

Following my interaction with the initial group of children, I identified several ‘stages of engagement’ or phenomena, that I wished to explore further. Firstly, to assess if these phenomena were important to the atypical lived experience, and secondly to dive deeper into my understanding of their meaning in the children’s lives. To achieve this, I spent a year observing a range of boxing classes with children diagnosed on the autism spectrum and running workshops with their coaches and the occupational therapists that supported them.

Figure 13.

I also ran a few workshops with atypical children in remedial schools and community spaces as part of my community engagement work, which gave me an opportunity to observe their behaviour in group environments. In the boxing space, I was asked to form part of a team to explore the impact of boxing lessons on autistic children. The boxing programme is a partnership between Fight with Insight (FWI) and the Johannesburg Hospital School's Children Disability Centre, based in the inner city of Johannesburg, at the Children's Memorial Institute (CMI), photographed in figure 13.

The boxing classes are for learners aged 10 to 21 years, all of whom are diagnosed on the autism spectrum. The classes are small with six to twelve learners, grouped by age level and support needs (low, medium and high support required). The boxing programme aims to assist their autistic learners with sensory modulation, muscle tone, stamina, and general fitness. My role in the team was to observe and report on the embodied and social experience of the children in the classes: how they engaged with their coach, their occupational therapists, and each other, from an anthropological perspective. The value of this stage of fieldwork was that it allowed me to observe atypical children from a range of economic backgrounds in Johannesburg, as many of the children in the classes came from environments as diverse as the inner-city and townships such as Soweto and Alexandra.

Online atypical communities

As a final level of insight, and to assess the accuracy of my phenomenological assessment, I spent countless hours engaging with atypical online communities on social media over the full length of my fieldwork, approximately five years. As mainstream or neurotypical communication is often challenging for people diagnosed as atypical, the social media environment is a rich biosocial source of dialogue and exploration on the subject (Rabinow 1996). I started by accessing around twenty-five social media groups on Facebook which were defined variously as representatives of the autism, dyslexia, ADHD and Ehlers Danlos Syndrome communities. Although I continued to scan many broadly, I quickly reduced my day to day focus on five key groups, three focussed on Autism and related challenges, one focussed on learning disabilities, one focussed on ADHD and one focussed on Ehlers-Danlos Syndrome. A key selection criteria was that the dominant voice of the group was that of individuals diagnosed with one or a range of the challenges the group identified with, rather than their parents, partners or therapists working in these communities. The groups ranged in size from ten thousand followers to over one hundred and twenty thousand followers. The primary group I interacted with was South African based and although they had members from around the world, the dominant voices were those of the South African autistic community. As with my initial cohort, the participants in these biosocial groups held a predominantly Western perspective on the atypical lived experience. I conducted in-depth participant observation of thematic discussions in these groups and on occasion posed specific themes for interpretation in the context of my research. In doing this I was able to explore each of the phenomena that I had identified amongst the children with an adult atypical community, who often found it easier to explain or articulate what they were experiencing or feeling. Many shared insights from their own growing up experience, which they had since had time to reflect on. They were therefore able to offer a rich understanding of the meaning of each stage of atypical engagement that I had identified as key phenomena.

All research participants were allocated a pseudonym in my research notes, analysis and this final thesis. All physical and electronic notes were stored securely to ensure the confidentiality of my participants was not compromised. As far as possible, all my research findings were presented to my research participants which elicited further insights and discussions and confirmation of my interpretation of the data. This was conducted both in person to the children, their parents, and the team at Fight with Insight, or via social media posts with the online biosocial communities with whom I had engaged.

Professional development courses, conferences, and talks

To broaden my understanding of atypical challenges from a clinical and therapeutic perspective I attended several courses conducted by experts in the field of neurodevelopmental challenges. These included professional development courses on dyslexia, ADHD, autism spectrum disorder, childhood anxiety, sensory processing disorder and the use of sensory integration rooms. I also attended and presented a paper on child protection at the South African Association for Child and Adolescent Psychiatry and Allied Professions for 2019, which gave me access to a number of presentations and professionals involved in the biomedical treatment of neurodevelopmental challenges.

Ethical considerations

My primary concern was ensuring that I accurately represented the views and perceptions of my subjects, rather than those of their family, teachers, carers, or therapists. Oliver (1992) argues for a “critical enquiry praxis” and “a new emancipatory paradigm”, where researchers place their knowledge and skills at the disposal of their research subjects to enable them to tell their story (1992:111). Other researchers argue for a level of empathy that only comes from having experienced some form of disability themselves (Bury 2008:63). Having experienced a number of disability labels, I believe I was able to bring this level of empathy to my fieldwork; however, it was also important to employ a critical level of self-reflexivity, to ensure that my personal experience did not cloud my observations of my subjects' lived experience. I did this through daily journaling where I critically assessed my experiences in relation to my subjects.

Researching children, defined as disabled, brings several ethical considerations to bear, as their levels of vulnerability are considerable. First and foremost, I was guided by the specified institutional Codes of Ethics for Research on Human Subjects, as outlined by the University of the Witwatersrand. As an anthropologist, I ensured that I practiced the principles outlined by Anthropology Southern Africa's Code of Ethics (2005) and the Singapore Statement on Research Integrity[18] throughout fieldwork and analysis. There is a growing call for more children's voices and opinions to be heard at all levels of society, especially on issues that impact on their lives (Morrow & Richards 1996:91). The United Nations Convention on the Rights of the Child (1995) and the South African Children's Act (2005) both call for the participation of children in issues that concern them. Few social studies consider the everyday life experiences of children, from their perspective, and there is a need to address this (Alanen 1992; Qvortrup 1987). There has been an important shift in recent years in the social study of children, from focussing on their socialisation and development to one that seriously considers their perspective on their lived experiences (Morrow & Richards 1996:92).

Conducting research with children from their perspective is therefore important; however, two key precautions need to be considered from an ethical standpoint. The first is informed assent from the child and informed consent from the parents or caregivers, if they are above the age of seven years and considered 'competent'.[19] The second is the protection of the research respondents during the research process and beyond. I adhered to both principles, ensuring consent from the children's parents or guardians, and developing a picture-based assent form, to ensure understanding and engagement of the children, that was

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[18] Singapore Statement on Research Integrity (2010), developed at the 2nd World Conference on Research Integrity www.singaporestatement.org, accessed 22 July 2015.

[19] The legal distinction of 'competence', is referred to as 'Gillick-competence' and stipulates that a competent child is one who "achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed", and has "sufficient discretion to enable him or her to make a wise choice in his or her own interests" (Morrow & Richards 1996:94-95).

reiterated before each session (see Appendix A). I used pseudonyms for all my participants in my research notes, analysis of findings and final thesis, ensuring that any recognisable attributes of the children were removed or disguised. Recordings were kept on my computer password protected to ensure confidentiality. Where photographs are shared, I ensured that the children's faces were obscured through blurring and gained consent from the parents and guardians, and assent from the children in each instance. Many researchers suggest that involving a child in the decision-making process of participating in research is a positive and empowering move, as most children can assess whether they want to do something or not. Their involvement and consent gives them a sense of control over their own individuality, autonomy, and privacy (Weithron & Scherer 1994). I found this to be true throughout my research; the children wanted to share their perspective on how they experienced their world, to grow understanding amongst their community. Before conducting any research, I spent time with the family and the children, to assess their feelings towards the research and their ability to engage with it. I also used this opportunity to ascertain their level of understanding and comfort in discussing their various diagnoses, to ensure that the research process did not cause undue stress or anxiety.

As with research about children, research involving people with disabilities also provides an important opportunity to expand knowledge and provide evidence to policymakers and legislators of rights-based solutions for those affected. In line with the United Nation's Convention on the Rights of Persons with Disabilities (2006),[20] I ensured that my research was framed and conducted in such a way that it respected the human rights of the individuals concerned. Central to this was respect for each subject's inherent dignity, individual autonomy (including their right to make their own choices) and independence. Once again, participatory approaches are recommended to ensure full equality, respect for difference and accessibility. Wiles and colleagues (2004) recommend that researchers are mindful of the issues that can arise during the research process with disabled participants. This can relate to their needs during the engagement, ensuring ongoing assent or consent, managing the relationship throughout the research process, and being sensitive to unanticipated and distressing emotions or outbursts (Wiles *et al.* 2004). Having experienced some of the behavioural consequences of learning disabilities and neurodevelopmental

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[20] Articles 4 and 21 of the United Nation's Convention on the Rights of Persons with Disabilities adopted by the UN General Assembly in 2006 which was developed in extensive consultation with persons with disabilities and their representative organisations.

disorders at a personal and parental level, I ensured that I remained extremely sensitive to these challenges throughout my fieldwork. As many of my participants had difficulty with concentration, I endeavoured to keep any discussion to regular short informal conversations rather than long in-depth discussions. As most respondents also had challenges with communication, I ensured that our conversations revolved around creative workshop techniques which made discussions on the various issues far more interactive and engaging. All participation in my research was voluntary and given that many struggled with a range of challenges, attention was paid to any indications that they might be feeling uncomfortable. In these instances, observation or discussions were ended immediately.

As part of my research process, I created a distress protocol. This involved ensuring assent from the child participant at the beginning of each research session and reminding them that they could stop at any point. If the child felt uncomfortable at any stage, I stopped the interview immediately and sought out their parent or caregiver to ensure comfort levels. Together with the children's parents or caregivers, I then discussed if or when the best time would be to proceed, or whether the research should be terminated. I also identified a selection of experts who agreed to provide counselling support should the need have arisen for either the children or their families during the research process; this was not, however, needed. My research visits became akin to a 'playdate' with each child, who usually looked forward to seeing me. The creative exercises were extremely popular and were particularly appreciated when each child received his or her own brand book at the conclusion of the research process.

I had one or two occasions when the children I was working with felt tired or uncomfortable, and in each instance, I ended the research process immediately. I then met with their parents to discuss their lack of comfort, and in each instance, it was due to the child feeling tired or anxious about issues other than the research. On two occasions a child struggled to keep their emotions in check and lashed out at me, but in discussion with the parents, I established that this was not unusual for the child concerned. I discussed their apprehension in-depth with them in a safe and caring manner, and in both instances the children explained that they often struggled to manage their emotions. The method of participant observation, the assurance of confidentiality, and my own personal experience and sensitivity towards both learning disabilities and neurodevelopmental disorders, all appeared to support their and my belief that my research was low risk to the individuals involved. However, the findings will be extremely important in understanding and supporting children who have been diagnosed with neurodevelopmental challenges, especially in South Africa where research of this nature is limited.

As part of a broader team observing the Fight with Insight Autism Boxing Programme, I formed part of their ethics process. Informed consent was obtained from both the parents of the children who participated in the programme and the Johannesburg Hospital School's Children's Disability Centre. In addition to observing the children in the context of the programme, I participated in many of the sessions as a support coach, to ensure the comfort levels of the children. My observations were shared with all organisations and individuals involved in the research, in the form of a detailed report, which was positively received.

Part of my research involved 'deep hanging out' in social media spaces, spending meaningful time observing and engaging in social interactions. Social media, such as Facebook groups, are an incredibly rich source of insight into specific social groups, such as those defined or diagnosed as autistic, ADHD or struggling with a range of other neurodevelopmental challenges. Murthy (2008) notes that the online social space can increase access to these previously marginalised groups. Despite the digital environment appearing to be a neutral space, it is still fraught with power relations, and findings are influenced by the subjectivity of the researcher and access of participants to the technology. The most important question is one of ethics and interrogating the impact and implications of research in the social media space on the subjects being observed. Using a phenomenological method calls for the repeated interrogation of observations. My engagement with social media groups gave me an opportunity to explore some of the phenomena that I observed with the children and in the autism boxing space, with a broader digital audience. Where possible, I introduced myself to the online community and advised them of my research, which is common protocol among many of these social media groups. Many require some level of vetting by an administrative group which enabled a more detailed introduction to my research and its objectives. In some instances, I sent my research proposal to the administrative team, and received feedback on how to position certain terms, diagnoses and perspectives, as well as guidance on how to interact with the group. If I asked a particular question of any group, I ensured that I informed them of how this would be incorporated into my research, sharing updates on my findings and analysis where appropriate. In one instance, I was questioned about my research, and I sent a detailed response to the administrator to position its relevance in my study. Without exception, participants stated the importance of sharing their authentic experience of neurodiversity as widely as possible and contributed enthusiastically to all the debates and questions I proposed. As with all of my other fields of enquiry, I ensured strict confidentiality and assigned pseudonyms to all personal comments captured in my field notes and this final thesis, in line with the Social Media Ethics Framework outlined by Townsend and Wallace (2016). All groups with whom I engaged state their primary aim as increasing the understanding of atypical people, their behaviours and motivations. I am confident that my research and dissertation supports these goals and provides an accurate representation of their perspective.

CHAPTER 4

TOWARDS A PHENOMENOLOGY OF ATYPICAL CHILDREN

If we consider that both childhood and disability are social constructs, then the concept of ‘atypical children’ is both socially and culturally created (Manderson *et al.* 2016; Reynolds 1989; Ingstad & White 1995). How we view atypical children impacts on how we interact with them, how we conduct research with them, and how we care for and support them. To problematise the neurotypical or atypical body, Nancy Scheper-Hughes and Margaret Lock (1987) proposed a ‘mindful body’ approach, where the body is understood from three different perspectives. The first is the lived experience of the individual body, using the method of phenomenology. The second explores how the body is perceived socially in its relationship to nature, society, and culture, in the tradition of symbolism and structuralism. The third and final perspective is that of the ‘body politic’, where the body is viewed as a tool of social and political control, in the tradition of poststructuralism (1987:7-8). To examine the phenomenology of atypical children, it is thus crucial to suspend preconceived ideas about the body, in both its typical and atypical forms, and explore all realities and beliefs from each of these perspectives. As noted by Scheper-Hughes and Lock, the only assumptions that we can make is that the body is “simultaneously a physical and symbolic artefact, both naturally and culturally produced, and securely anchored in a particular historical moment” (1987:7).

Identifying the phenomena to be explored

Phenomenology is the investigation into the structure of experience. A fundamental understanding of human consciousness experienced by individuals as they engage with their everyday life (Ricoeur 1978; Valle & Halling 1989). To create a phenomenology of atypical children, the pertinent questions are therefore: What makes a child atypical? How do they experience their world? How does this make them feel? And how do they then make sense of, or derive meaning, from this? To answer these questions, I followed Robert Merton’s (1987) three step approach to identifying ‘cognitive and social patterns of practice’. The first step involved identifying the phenomena that I wished to explore, which I achieved through a detailed assessment of the various diagnoses and atypical behaviours that I observed amongst the children in my cohort and online atypical community. I then assessed the ‘specified ignorance’ that exists around each phenomenon, the dominant discourses in both biomedicine and popular culture, related to each diagnoses or perceived problematic behaviour. Finally, I developed a structure that positions the range of phenomena in a way that makes them easy to understand and engage with. Merton referred to this practice as developing ‘strategic research materials’, which enabled both my exploration and revealed new areas of enquiry (1987:1). I refer to this structure as an ‘atypical engagement model’, which aims to highlight key stages where challenges or differences showed up most acutely amongst my participants during my research. As an additional level of enquiry, I then mapped all the diagnoses detailed in the DSM-5 (2013), and a range of other medical journals relating to neurodevelopmental disorders, back onto the model to illustrate how this biomedical view links to the phenomenological model of engagement that I had observed. This process allowed me to identify the phenomena that I wished to explore, what was known and unknown about each area, and provided a framework for the analysis of meaning that atypical children and adults derived from their lived experience.

On stigma and atypical labelling

In studies of labelling theory and deviant behaviour, individuals who were assigned a social identity, such as being labelled as a delinquent or criminal, would often respond to this stigmatisation by entering careers that were considered deviant (Lemert 1951; Becker 1973[1963]; Erickson 1964). As noted by Howard Becker, in his seminal book *Outsiders*: “treating a person as though he were generally rather than specifically deviant produces a self-fulfilling prophecy” (1973 [1963]:34). For atypical children, what makes them atypical is not necessarily what they think about themselves, but rather how others perceive and label their behaviour. A review of the extensive popular literature and brochures which highlight the ‘signs’ of autism, ADHD, and learning disabilities reveals a list of labels assigned to children who are considered atypical. Descriptors of behaviour include words such as ‘inappropriate', ’strange’, ‘unusual’ and ‘excessive’, and all speak to how atypical children are perceived (illustrated in the brochures, Figure 14, on the following page).

In the tradition of labelling theory, these themes indicate where atypical behaviour is most acutely observed. However, they do not provide any insight into how these atypical patterns of behaviour emerged in the first place. As noted by philosopher Kenneth Burke, “a way of seeing is also a way of not seeing” (1935:70). By focussing primarily on the behaviours that society finds ‘inappropriate’, we have neglected to understand their origins, and possible uses or benefits to the children. This lack of understanding has led to a need to remediate or remove these behaviours, without considering how they could be important to the children and how they navigate their world.

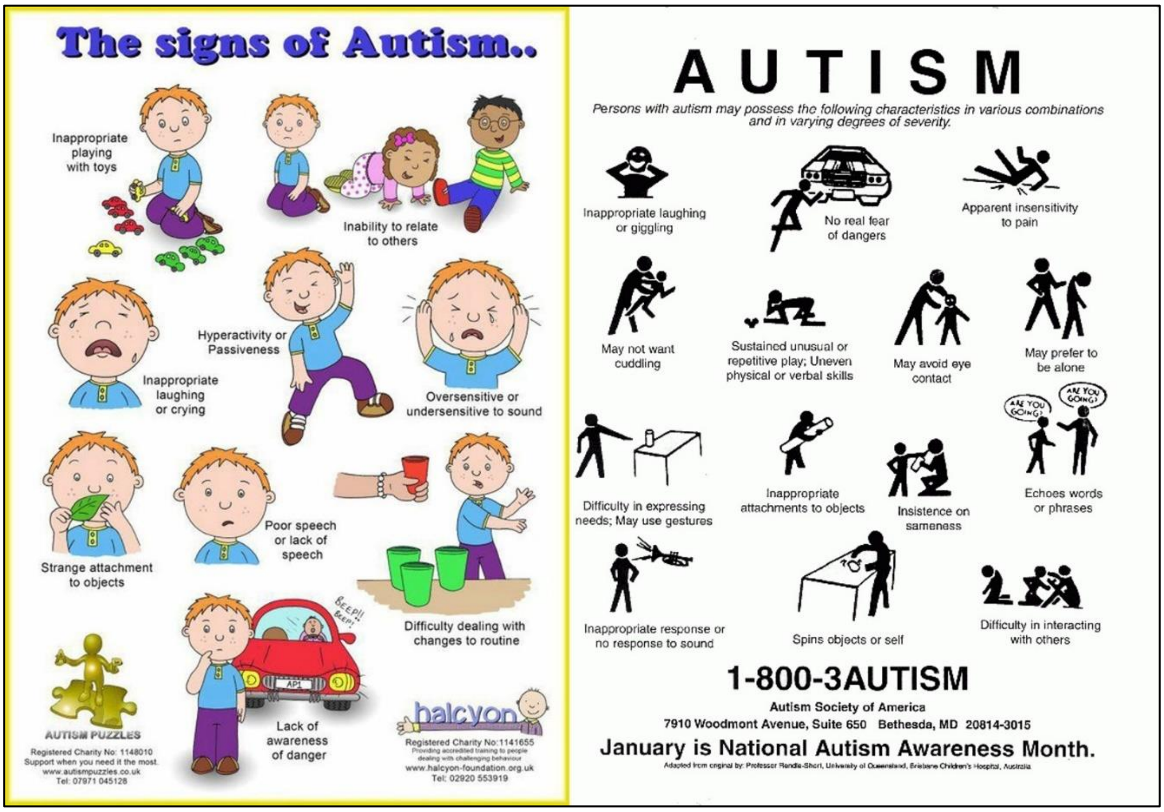

Figure 14.

Producing atypical children through ADHD diagnosis

Attention-Deficit/Hyperactivity Disorder (ADHD) was the one neurodevelopmental diagnosis and set of behaviours that was consistent for all my respondents, whether they were diagnosed primarily with a specific learning disability, general developmental delays, or on the autism spectrum. With no reliable biological markers (Thome *et al.* 2012), ADHD is diagnosed using a range of tests after a child has shown some of the recognised symptoms over an extended period of time, in what Goffman (1983) termed 'focussed encounters'. The DSM-5 describes ADHD as "a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development" (2013:59). The inattention behaviours relate to a child's in/ability to focus, sustain attention, listen, follow, or act on instructions accurately, organise tasks and activities (even those they dislike), and not to be distracted or forgetful. Hyperactivity and impulsivity behaviours are related to fidgeting, tapping, squirming, stopping an activity midway, inappropriate running or climbing, and being constantly 'on the go'. Impulsive children are noted to talk excessively, 'blurt out answers' at inappropriate times, refuse to wait their turn, and constantly interrupt or butt into conversations, games or activities (2013:59-60). Although these seem like typical behaviours of a 'dreamy' or rambunctious child, the question asked is whether these behaviours occur to such a degree that they have a detrimental effect on the child's development, ability to learn and social interaction with others. ADHD is typical of most neurodevelopmental disorders in that finding biomedical markers has proved almost impossible, given the range of behaviours and comorbid disabilities or illnesses diagnosed alongside it. However, through a process of 'diagnostic abstraction', clinicians are able to 'produce' ADHD children (Abbott 1988). They do this by removing 'extraneous qualities' and finding the 'right professional category' for the child to fit into, in this case ADHD (Abbott 1988:40-41).

An extensive list of comorbid and differential diagnoses is listed next to the category of ADHD in the DSM-5. This considerable list includes: oppositional defiance disorder; intermittent explosive disorder; other neurodevelopmental disorders; specific learning disorders; intellectual disability; autism spectrum disorder; reactive attachment disorder; anxiety disorders; depressive disorders; bipolar disorders; disruptive mood dysregulation disorders, substance use disorders; personality disorders; psychotic disorders; and neurocognitive disorders (DSM-5 2013:63-64). In addition to this list, and not contained in DSM-5, is sensory processing disorders (SPD), also known as sensory integration dysfunction. SPD is a neurological condition associated with atypical brain responses to internal and external sensory messages and is a typical comorbid condition of children diagnosed with ADHD (Ghanizadeh 2011). Beyond defined 'disorders', ADHD has also been aligned with high levels of intelligence. The American Association of Mensa, an organisation formed to nurture gifted individuals, found that ADHD is diagnosed in twice as many 'gifted' children as in the general population (The Economist, June/July 2019). Comorbid disorders are frequent in children diagnosed with ADHD, and in most instances more than 50 percent have one or more of the disorders identified above. Yet many parents and even medical practitioners still question whether ADHD is a disorder at all. Neurologist Richard Saul (2014) argues that a number of underlying causes can lead to symptoms of ADHD and each of these requires its own specific treatment. These include sensory sensitivity, sleep disorders, anxiety, and depression, amongst others. His major concern is that diagnosing ADHD as a 'catch-all disability' leads to the excessive medication of children with stimulant drugs such as Ritalin, Concerta (both methylphenidates) and Adderall (amphetamine and dextroamphetamine).

At the South African Association of Child and Adolescent Psychiatry and Allied Professions Congress for 2019 (SA-ACAPAP), the entrance exhibition was dominated by stalls of representatives from the various pharmaceutical companies selling these ADHD medications, or their generic forms. Outside the conference, members of the Human Rights Commission of South Africa held daily demonstrations with placards reading “Stop psychiatric drugging of our children”, and “Childhood is not a mental disorder”, indicating the high level of disagreement associated with this particular diagnosis and its treatment. Yet for some parents, the medication of ADHD ‘symptoms’ proved transformational, as one mother noted:

> We couldn’t function as a family, my husband was fighting with Craig every night, our whole family life became about managing him and his mood swings. Placing him on Ritalin has changed our lives. He’s a lot less manic and is coping much better in school, so I think he is happier (Shelly, mother to Craig, 12).

For other parents, the medication was profoundly detrimental:

> Andy went into a deep, dark depression, it was almost like I lost my child for the two years that he was on Concerta and for some time after that. He doesn’t like to talk about it; he just says it was a very bad time for him. But that is what the doctors prescribed so what could I do? (Dianne, mother to Andy, 11).

Estimates place ADHD diagnoses at anywhere between 7.2 percent to 13.5 percent of global childhood populations, and these percentages have been increasing steadily over the past two decades (CHADD, Accessed 09/07/2019). Yet there is much confusion around the disorder’s definition, its diagnosis, and its treatment. A noted child psychiatrist at the SA-ACAPAP congress (2019), and specialist in the field of ADHD, recommended giving children a drug trial of no fewer than three months “if they displayed ADHD type behaviours”. In a seemingly subjective approach to prescription, he suggested that if the drugs appeared to help the child, parents should continue with the medication, and if not, they should be stopped. Other parents I spoke to were told that they needed to place their children on medication for six months to a year to assess its effectiveness, a concerning period of time, considering some children’s responses, as in Andy’s case.

Producing atypical children through autism diagnosis

A similar challenge is noted with children diagnosed on the autism spectrum, where billions of dollars have been spent trying to map the genome of over 10,000 autistic children and their families, only to find that there are no specific genetic markers (New York Times, 13th June 2003). Geneticist Wendy Chung (2014) notes that although most neurological doctors and researchers agree that autism is transmitted genetically, between 200 and 400 genes have been identified as possible causes. The DSM-5 defines autism as a combination of "persistent deficits in social communication and interaction" and "restrictive, repetitive patterns of behaviour, interests or activities," with a range of associated diagnostic features and levels of severity (2013:50-59). As with ADHD, the list of comorbid conditions is extensive. Research as diverse as structural imaging of the brain; developmental macrocephaly; amygdala activity when scanning faces; autopsy studies of Purkinje cells in the cerebellum; hyperseratonemia; prenatal androgen exposure; and a range of environmental factors, have found no significant biomedical markers to date (Leventhal 2016). Diagnosis relies on an autism screening questionnaire, followed by diagnostic interviews and observation. Maynard and Turowetz (2019) note of this process:

> The doing of diagnosis… is interactional and ordered through those practices of talk and embodied behaviour that clinicians, parents and others, deploy in situated relationship with one another. This means that autism, as an interactive diagnosis, is also an interactional production, and that loose coupling between social structure and everyday clinic life requires attention to tangible order in talk and concerted behaviours (2019:110).

Ian Hacking (1986) supports this argument through his theory of 'making up people', noting how newly created individuals are influenced or changed by their categorisation. Over time, as understanding and engagement with the category grows, the 'created people' change and evolve the rules of the category in a form of 'looping effects'. Beyond the diagnosed individuals, the looping effect is expanded through institutions, knowledge production, families and biosocial communities. The definition of autism, despite detailed diagnostic criteria, is thus far from static. Eyal and colleagues (2014) argue that the label of autism is constantly being renegotiated, as our understanding of the condition evolves. This has prompted many autistic advocates to state: "If you meet one person with autism, congratulations, you've met one person with autism" (Silberman, 2015:14).

The instability of atypical diagnosis

Many of my participant's families noted how despite their children having a range of comorbid challenges, their initial diagnosis and treatment protocol was usually related to the area of specialisation of the doctor or therapist with whom they first engaged. A child may be diagnosed with sensory processing disorder, motor disabilities or hypermobility, if they have visited an occupational or physical therapist, noted experts in the 'physical world'.

However, the same individual could be diagnosed with a learning disability, dyslexia[21], dyspraxia[22], dyscalculia[23] and dysgraphia[24], often coupled with ADHD and executive functioning disorders, by an educational psychologist or remedial therapist in the 'intellectual world'. Psychologists and psychiatrists may diagnose anxiety, obsessive compulsive disorder, depression, or bipolar disorder in the 'emotional world', or autism spectrum disorder in the 'social world'. Rapp and Ginsburg (2011, 2013), in studying 'learning disabilities', observed how diagnoses and labels can change from mental retardation, to learning disabilities, to autism spectrum disorder, over the course of a single child's lifetime. My research participants displayed a range of challenges and atypical behaviour across physical, intellectual, emotional, and social worlds. Each of these challenges impacted how they experienced their world. However, each had a specific diagnosis and treatment protocol which placed them primarily in one world or another.

Grinker (2014) notes that diagnoses are inherently unstable, as they are usually historically and culturally constituted and frequently change over time. Autism was initially framed as a diagnoses of childhood onset schizophrenia in the DSM-1 published in the 1950s. This evolved into an extremely narrow definition that focussed primarily on the clinical assessment of small groups of middle-class white children in the United States, with little appreciation for its expression in other racial groups, economic sectors, or between genders. Growth in the popular understanding of autism, coupled with the expansion of diagnostic criteria to include a spectrum, saw a rapid increase in ASD diagnoses in the mid-2000s. The merging of ASD and Asperger Syndrome in DSM-5, published in 2013, along with comorbid conditions experienced by children on the spectrum, again changed our understanding and the possibility of a wider diagnostic scope. From a social perspective, autism is defined in terms challenging contemporary social environments and power imbalances between those deemed neurotypical in contrast with those with perceived social deficits, and thus labelled atypical (Fein 2015; Milton 2012; Belek 2018). The emergence of the 'neurodiversity' movement positions an autism diagnosis in the field of physiological evolution, environmental influence on epigenetics, and an appreciation of human diversity (Bagatell 2007; Grinker 2007;

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[21] A learning disorder that involves difficulty reading, related to challenges identifying speech sounds and the decoding of letters and words.

[22] A neurological disorder that impacts a person's ability to plan and process motor tasks.

[23] A learning disorder that involves difficulty with mathematics, recognizing numbers and symbols, analysing measurements of time or money, visualizing numbers, performing mental and spatial relation math problems, and applying rules to math problems utilizing formulas and strategies.

[24] A neurological disorder that that affects the fine motor skills needed to write.

Lawson 2008; Savarese 2013; Mychasiuk 2015; Silberman 2015). As noted by autistic social and medical anthropologist, Ben Belek, "autism is an emergent product of interrelated social as well as biological processes" (2019:4).

Although a diagnosis is related to and determines the kind of treatment, therapy or medication a child with disabilities requires to engage positively with their world, sometimes it is simply a means to access medical or social assistance (Ingstad & Whyte 1995). In South Africa, many parents struggle to get the support they need for children with neurodevelopmental disorders, primarily due to a lack of understanding around the various challenges (Schlebusch *et al.* 2016). KC's mother shared her struggles in trying to access support from the National Health Services (NHS) in the United Kingdom. After nearly a year of assessments she was only able to attain a 'speech disability' diagnosis for KC, who has since been diagnosed on the autism spectrum, with several comorbid challenges. However, this diagnosis enabled her to gain access to a special needs school and some remedial therapy in their district. She explained: "Everyone told me, you just need a pink slip to get into the system, even if it isn't for the main problem you are dealing with, at least you will be in the system." The therapy only addressed some of the challenges that KC was experiencing at the time, but this was better than no support at all. This leads us to question whether children are being diagnosed accurately and supported appropriately, or if they are just being placed in a predefined box that most closely resembles their dominant challenge, as identified by a medical practitioner, or the available resources.

Developing Strategic Research Materials

To understand the complexity of diagnoses, I conducted a detailed analysis of the hundreds of symptoms and related behaviours outlined in DSM-5, for each neurodevelopmental disorder listed, taking into account where comorbidity was specified. This analysis indicated a high degree of overlap between defined disabilities and their related diagnostic criteria. Each diagnosis appeared to merge into the next, and despite both medical practitioners and parents stating categorical differences between challenges such as 'Intellectual Developmental Disorders' and 'ADHD', or 'ADHD' and 'Autism Spectrum Disorder', there appeared to be as many similarities as differences. Arthur Kleinman (2012) notes that the category 'mental health' has become overly complex:

> In extending the reach of authorized mental health categories to include both clear-cut disease and vaguer, though no less serious, problems of everyday life as well as non-

> medical catastrophes, “mental health” became an unwieldy, even unbelievable, odd lot- now in DSM-IV (and soon DSM-V) with hundreds of subcategories. It seems to simultaneously trivialize the most serious of medical conditions and medicalize social problems (2012:118).

In its current format, each diagnosis is presented individually and although comorbidity is referenced, there is little understanding of how they may integrate in one person and impact their lived experience. Physical, intellectual, emotional, and social challenges are categorised and treated accordingly, rather than exploring where they may intersect and impact on each other.

This radical materialist approach not only individualises the human body but also what I term our ‘human tools of development’. These ‘tools’ include the physical, emotional, social and intellectual aspects that make up our personhood, as first defined by Émile Durkheim (1912) in the early 20th century and later by Marcel Mauss (1973) in his essay on *Techniques of the Body*. The clustering of conditions requires a holistic phenomenological perspective to ensure a true appreciation of the lived experience of atypical children (Williams 2005). To achieve this, I embarked on a detailed analysis of the atypical body and its relationship to the world it inhabits.

A model of atypical engagement with the world

My first round of analysis helped me to identity the specific areas of embodied experience, or phenomena, that I wished to explore further. The phenomena presented as a cycle of seven stages of engagement illustrated in Figure 15 below. These seven stages I describe as *presence, perception, control, participation, flow, communication,* and *adaptability*. All my atypical subjects experienced each of these phenomena in their day to day lived reality of their world. What was also interesting was that each stage represented where the children’s ‘atypicalness’ or difference to typical children, showed up most acutely. Each stage of engagement is discussed in-depth in the rest of this chapter, detailing comorbid challenges and experiences. The aim of listing these challenges and experiences on a stage-by-stage basis, is to illustrate how the atypical lived experience should be considered and understood holistically, rather than analysing each diagnosis independently of each other.

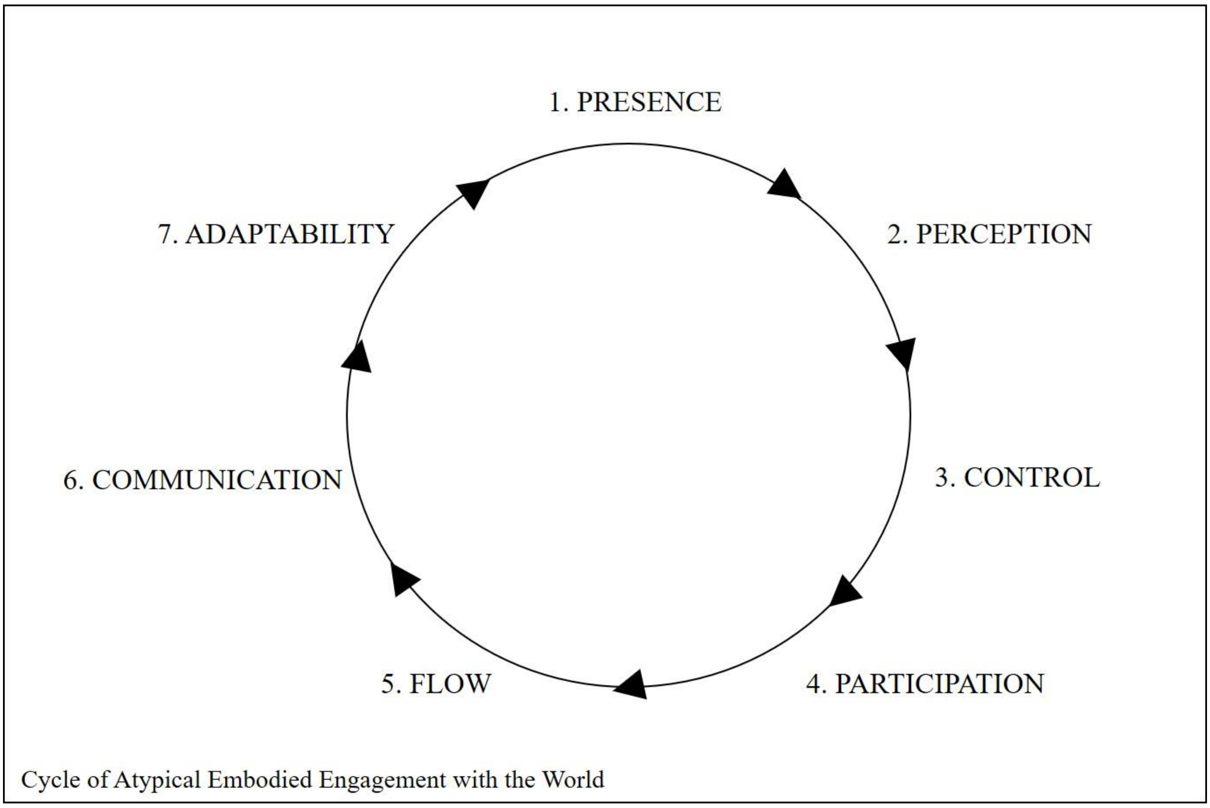

Figure 15.

Before exploring each of these stages, and as a further level of enquiry, I was intrigued by how my subjects engaged with their world using the previously noted 'human tools of development'. Although acknowledging their interconnectedness, most child development theorists follow the trajectory of physical, emotional, social, and then intellectual engagement with one's world. My atypical subjects, however, appeared to engage differently. One of my older subjects, Echo (16), described this process perfectly in a project he had completed on the topic of 'Utopia', where he described his 'perfect society'. Echo had found a reference to Maslow's 'Hierarchy of Needs'[25] on the internet, to assist him in explaining his views. However, instead of starting at the bottom and speaking to the basic physiological needs of food, water, sleep, breathing and health, he started at the top. In Echo's view, the first step in development is self-actualisation, or identifying one's purpose in life, how a person can contribute meaningfully to society and developing the skills to do this. This was followed by a clear articulation of societal values, respect, equality, and sanction for any forms of discrimination. Only once this had been clarified, should people

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[25] Abraham Maslow first introduced his concept of a hierarchy of needs in his 1943 paper 'A Theory of Human Motivation'. This hierarchy argues that people are motivated to fulfil basic physiological needs before moving on to other, more advanced needs such as safety, love/belonging, esteem and self-actualisation.

focus on social needs such as love and belonging to a family or community. Physiological needs were seen as an outcome once all of the above were in place, guided by the value of equality, as Echo concluded: “We need to build a society on morals and ethics not on how we survive”. To test this view, I asked my broader online atypical community, and their response was overwhelmingly in support of Echo’s perspective:

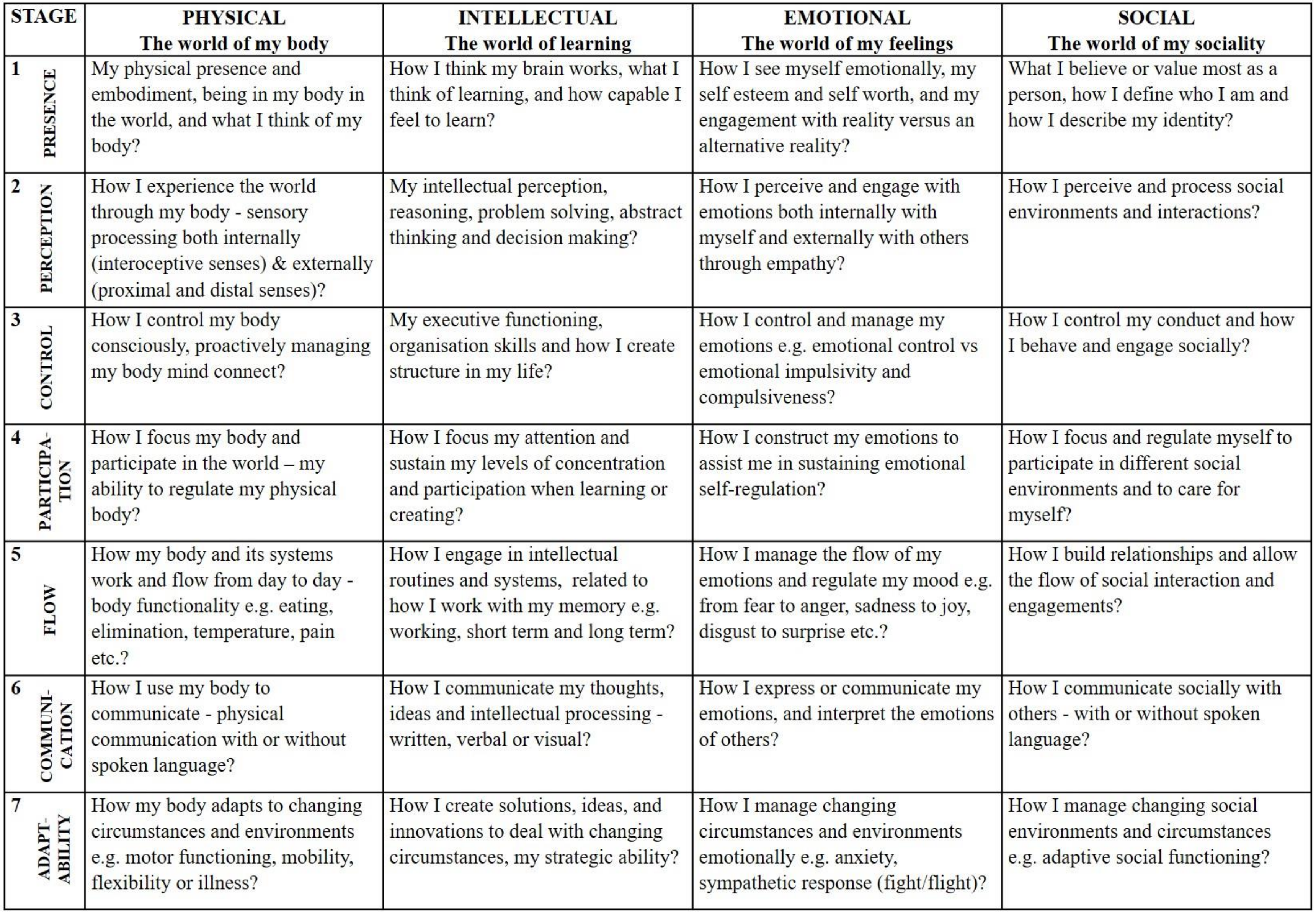
> I can definitely relate to needing to know the 'why' to want to do something. As for Maslow's pyramid, I consider the basic needs, well, basic, but from there I'd probably also say that first I need to know intellectually what the whole point is of the thing I'm doing. Then I need my emotional needs met, and then social stuff is the last priority, (Michelle, autistic adult)

> My mum always used to say that as a kid, my most important needs were intellectual. Like I didn't care about eating that much but I absolutely HAD to know how traffic lights worked or I couldn't feel at ease. (Sarah, autistic adult)

> Talking with my just turning 13-year-old, she definitely begins with the intellectual and from there forms values and beliefs based on the information and learning, so the values are rooted in her understanding of what is real and right. And these then lead the emotional, engaging in ways and circumstances that support the developed beliefs. (Evalyn, mother of an autistic daughter)

> It’s been an interesting discovery to me that most people don’t think this way. That ‘normal’ people are happy to blindly follow instruction with no explanation. (Tim, autistic adult)

My online community explained two different stages to physical engagement with their world. There was the unconscious practice of ‘just being in the world’, over which they did not believe they had much control. However, should they need to take conscious physical action, such as brushing their teeth, this must be preceded by a solid intellectual argument before it is willingly undertaken. The hierarchy of human motivations for atypical children, could thus be defined as unconscious physical, intellectual, emotional, social, and then conscious physical needs, actions or behaviours. By combining both the phenomenological stages of engagement that I had observed, with the atypical hierarchy of motivational needs, a new way of viewing the children emerged. The aim of this alternative methodological stance was to create a holistic way of assessing the data I had gathered, and to challenge how I viewed it, from an ‘integrated perspective’, as illustrated in Figure 16 below.



STAGE	PHYSICAL The world of my body	INTELLECTUAL The world of learning	EMOTIONAL The world of my feelings	SOCIAL The world of my sociality
1 PRESENCE	My physical presence and embodiment, being in my body in the world, and what I think of my body?	How I think my brain works, what I think of learning, and how capable I feel to learn?	How I see myself emotionally, my self esteem and self worth, and my engagement with reality versus an alternative reality?	What I believe or value most as a person, how I define who I am and how I describe my identity?
2 PERCEPTION	How I experience the world through my body - sensory processing both internally (interoceptive senses) & externally (proximal and distal senses)?	My intellectual perception, reasoning, problem solving, abstract thinking and decision making?	How I perceive and engage with emotions both internally with myself and externally with others through empathy?	How I perceive and process social environments and interactions?
3 CONTROL	How I control my body consciously, proactively managing my body mind connect?	My executive functioning, organisation skills and how I create structure in my life?	How I control and manage my emotions e.g. emotional control vs emotional impulsivity and compulsiveness?	How I control my conduct and how I behave and engage socially?
4 PARTICIPATION	How I focus my body and participate in the world – my ability to regulate my physical body?	How I focus my attention and sustain my levels of concentration and participation when learning or creating?	How I construct my emotions to assist me in sustaining emotional self-regulation?	How I focus and regulate myself to participate in different social environments and to care for myself?
5 FLOW	How my body and its systems work and flow from day to day - body functionality e.g. eating, elimination, temperature, pain etc.?	How I engage in intellectual routines and systems, related to how I work with my memory e.g. working, short term and long term?	How I manage the flow of my emotions and regulate my mood e.g. from fear to anger, sadness to joy, disgust to surprise etc.?	How I build relationships and allow the flow of social interaction and engagements?
6 COMMUNICATION	How I use my body to communicate - physical communication with or without spoken language?	How I communicate my thoughts, ideas and intellectual processing - written, verbal or visual?	How I express or communicate my emotions, and interpret the emotions of others?	How I communicate socially with others - with or without spoken language?
7 ADAPTABILITY	How my body adapts to changing circumstances and environments e.g. motor functioning, mobility, flexibility or illness?	How I create solutions, ideas, and innovations to deal with changing circumstances, my strategic ability?	How I manage changing circumstances and environments emotionally e.g. anxiety, sympathetic response (fight/flight)?	How I manage changing social environments and circumstances e.g. adaptive social functioning?

Figure 16.

Exploring each stage of engagement

The first stage of engagement is *presence*, or how atypical children 'show up in their world'. From a physical perspective, this relates to their physical presence and embodiment, or being in their body in the world, and can refer to sleep/wake cycles, body consciousness and body sense. From an intellectual perspective, presence relates to how the children think about their brains, how their brains work, the process of learning, and their ability to engage intellectually in their world. From an emotional perspective, presence relates to how they see themselves emotionally, their self-esteem and self-worth, and their ability to engage with different realities. From a social perspective, presence relates to what the children believe in or value most as individuals, how they define who they are, and their personal identity. This is the stage of engagement or phenomena where the children take a position on who and how they will be in the world.

The next three stages of *perception*, *control*, and *participation* are concerned with how the atypical child engages with the world through action, constraint, or behaviour. In the tradition of Bourdieu's habitus (1977), these stages are also concerned with how the world imposes its presence onto the children. Habitus is thus shaped through individual agency, but also reflects the social structure within which the individual is acting, and how this structure influences their habits, perceptions, actions and how they frame their world. Without exception, my observations revealed that the way atypical children perceive the world around them is different to that of neurotypical children. Jan Wilson, a 'universal design for learning' advocate, shared the atypical perception of her 9-year-old autistic daughter Zoe's interactions with her remedial therapist. She explained how the therapist was showing her daughter pictures of various scenarios and asking her what they represented. In one of the pictures, a mother was nervously waving to her young son as he got on a school bus. Instead of speaking to the narrative of mother and son, her daughter became "fixated" on a cat in the bottom corner of the picture:

> Despite her therapist's insistence that her focus was incorrect, Zoe refused to alter her gaze and continued to worry about the cat. To whom did this cat belong? Clearly this cat was hungry, who would feed this cat? The therapist grew more frustrated…. Why was Zoe's concern for the cat wrong or misguided? Why was attention to the mother and son more valued? Who gets to make this decision? Zoe's tendency to create knowledge from the margins allowed her to form new meaning about what she was

> seeing that disrupted and challenged the picture's master narratives (TedX, University of Tulsa, 21st May 2015).

This description of how atypical children make meaning in atypical ways reflected my experience of how my respondents perceived their world. Their insights were often based not on what would be deemed 'appropriate', but rather, what spoke to them first and most acutely, often from the 'margins'. This was often different to that which neurotypical children and adults observed and assigned importance to.

Perception, in the context of phenomenological engagement, relates to how atypical children first experience their world. From a physical perspective, it relates to how this experience is interpreted through their body, what is often referred to as sensory processing. Sensory sensitivity or processing challenges were experienced by many of my respondents in terms of their senses of taste, smell, hearing, sight, touch, proprioception, and vestibular sense of balance, posture, motion, and equilibrium. Beyond the senses that assist us in interpreting our external world, sensory processing also relates to 'interoception', and the systems and processes that manage our internal experience of our bodies. This relates to all major systems that regulate pain, temperature, movement, bodily urges, sympathetic and parasympathetic nervous systems, moods, and our very ability to survive as human beings. Intellectual perception relates to the children's ability to reason, problem solve, engage in abstract thinking, and make decisions based on these skills. Emotional perception relates to how the children engage with emotions, both internal to themselves, and connecting to the emotions of others through processes such as empathy, sympathy, and compassion. Perception in the social world relates to how the children engage with others, perceiving and processing social environments and interactions.

Once atypical children have perceived their environment, and before they can respond to it, the concept of control becomes very important to them. The ability to control one's body, mind, emotions, or social interactions was particularly challenging for the children, as this was where their 'different' or 'problematic' behaviours were most often noticed, criticised or chastised. Most spoke of a disconnection between body and mind, and feelings of 'disembodiment' rather than 'embodiment'. Thirteen-year-old non-verbal autistic teen, Naoki Higashida, shared this experience in his book, *The Reason I Jump*:

> In my gym class, the teacher tells me to do things like 'Stretch your arms!' and 'Bend at the knees!' But I don't always know what my arms and legs are up to, not exactly.

> For me, I have no clear sensation of where my arms and legs are attached, or how to make them do what I'm telling them to do. It's as if my limbs are a mermaid's rubbery tail (2014:83).

Control therefore relates to how atypical children consciously and proactively manage their body/mind connect. From an intellectual perspective control relates to executive functioning, organisational skills, and the children's ability to create structure in their lives, an ability that most of my participants lacked. Control in the emotional space refers to how the children manage their emotions and tempered impulsivity or compulsiveness. From a social perspective, control relates to conduct and how the children behave and engage in social interactions. Atypical children struggle in each of these areas. The very act of having to control themselves, often expressed as 'masking', saps them of their energy and makes them more vulnerable to being completely overwhelmed. Autistic advocate and academic, Dora Raymaker (2018), describes this as 'autistic burnout': "a state of physical and mental fatigue, heightened stress, and diminished capacity to manage life skills, sensory input, and/or social interactions" (2018: Slide 28). She explains how burn-out occurs when atypical children or adults are subjected to external expectations that they are unable to meet. Burnout can also be a result of changes in environments, where children or adults feel unable to adjust or cope with the changed circumstances.

The next level of phenomenological engagement, in the context of habitus, refers to participation, or how children act on what they have perceived. Participation is often dependent on whether they have managed to institute some level of control over their body, mind, emotions, and social conduct, and dictates their ability to participate in a conscious or unconscious manner. A mother of a nine-year-old autistic boy shared her experience of her son's 'meltdown' at Universal Studios on social media. Her account clearly illustrated the relationship between control and participation. In the busy environment of the theme park, several delays, and then the cancellation of his favourite Spiderman ride, her son had a very public emotional 'meltdown':

> He began sobbing, screaming, rocking, hyperventilating, and truly struggling to breathe. A woman who worked there … rushed over… and while I frantically kept trying to get him to stand up so he wouldn't get trampled on by people, she encouraged me to leave him on the floor if that is where he needed to be. Then she did this. She got down on the floor with him. She rested next to him while he cried his heart out, and she helped him breathe again. She spoke to him so calmly, and while he

> screamed and sobbed, she gently kept encouraging him to let it all out. She told people to keep on walking around them, so they would stop standing there and staring. And then she told him it was okay for him to be sad and feel this way. She understood. She would feel the same way too. His feelings were validated. And she told him he could lay there with her as long as he needed to until he felt better. (Inside the Magic, 10th June 2019)

All my participants experienced ‘meltdowns’, some frequently; none had any recollection of what transpired during these episodes. Their parents and carers, however, relayed the abject sadness they felt when witnessing their children in such utter distress. As one shared: “When we asked him what was wrong, he said, ‘everything is broken’.” Participation relates to how the children focus their bodies and then participate in the physical world, sometimes referred to as physical regulation. From an intellectual perspective, participation relates to the children’s ability to sustain their concentration and participation levels when learning or creating. From an emotional perspective, participation relates to how they construct their emotions and regulate them appropriately. Social participation relates to how they regulate their behaviour in social environments and interactions, and how they take care of themselves in these spaces.

The final three stages of phenomenological engagement relate to how atypical children manage the changing nature of their environment. Change was a particularly difficult concept for the children to interpret, understand and engage with. For most it was accompanied by extremely high levels of anxiety and chronic stress. Change relates not just to having to change from one activity to another, or from one physical space to another; it concerns how items in their home may change after being cleaned or replaced. Change could also refer to a parent changing their appearance, wearing makeup, or different clothes, shaving a beard, or getting injured or sick. The changing of seasons can be experienced particularly acutely by atypical children due to fluctuations in temperature, increased allergens, and different landscapes to be navigated. This dis-ease with change is captured below:

> My son is five and he gets really upset and frustrated when things break, even if they are simple things that are not unique. For example, if he accidentally drops his cracker and it breaks, he gets really upset, even if I show him that there are still more available in the package. If he spills milk he gets upset, even if I reassure that there is nothing to worry about, we just wipe it up. If he falls, he will get overwhelmed and

> sometimes even repeat the action of falling on purpose immediately afterwards, almost like an echo. If something gets stained, or if we get dirty with paint or markers, he will want it cleaned immediately. (Philippa, mother of an autistic boy)

The need to maintain particular routines and rituals is well-documented for autistic children and forms part of the diagnosis, specifically, their ‘restrictive repetitive behaviour’ and ‘insistence on sameness’ (Kanner 1943). Kanner noted how his patient’s behaviour was “governed by an anxiously obsessive desire for maintenance of sameness that nobody but the child himself may disrupt on rare occasions” (1943:245). He went on to describe how changes in routine, furniture arrangement, or the order in which every day acts were carried out, could upset the children intensely. In the DSM-5, this is described as “an inflexible adherence to routines, or ritualized patterns of verbal and nonverbal behaviour” (2013:50). Further examples include difficulties with transitions, rigid thinking patterns, greeting rituals, and the need to take the same route or eat the same food every day. Many of these ‘idiosyncrasies’ were observed among the children in my cohort.

The three phenomenological stages of engagement related to change include *flow*, *communication* and *adaptability*. Change is not seen as a ‘necessary evil’, but rather as a personal afront, even if the need for change comes from the children themselves. I had countless conversations with parents who were frustrated at how their child could be happily doing something, and then would suddenly and insistently stop for no apparent reason. I observed this ‘disruption of flow’ repeatedly. We would be comfortably drawing together, listening to music, or playing a game, and they would suddenly need to stop the activity. They could not explain why they wanted to stop, they just needed to move on to something else, or possibly return to what they were doing before I had arrived. Flow relates to how atypical children manage their ‘flow of life’ at every level of their being; for most this is not an easy task.

From a physical perspective, flow relates to the systems within the children’s bodies. These include functions such as eating, elimination, temperature control and pain management. From an intellectual perspective, flow relates to how the children engage with changing learning environments or subjects and has particular relevance to their working versus long term memory. It also relates to their ability to change from one working environment or subject to another. From an emotional perspective, flow relates to how the children managed the flow of their emotions in changing environments or circumstances. Amongst my respondents, any change could be accompanied by distinct shifts in emotional states, which were sometimes extreme. In the social space, flow relates to how atypical children build and maintain social relationships and how they allow for the flow of social interaction. As with all other aspects of flow, this was not a comfortable space for them.

Communication, in all forms, is a particularly difficult skill for atypical children. Whether spoken, written, or expressed through their body, all my respondents struggled with some or all forms of communication. A learning-disabled child may be comfortable speaking and engaging verbally, but their ability to communicate through the written word may be severely challenged. Many children diagnosed on the autism spectrum struggle with verbal communication and exhibit selective mutism or speech apraxia. As communication is a two-way stream, the process of listening and interpreting other's communication, especially unspoken, is difficult. Although highly creative, the children could be distinctly concrete in terms of how they perceive their world. Figures of speech such as metaphors, analogies and idioms were completely misunderstood, as were literary devices such as irony, sarcasm, and satire. In the physical space, communication related to the children's physical ability to communicate either with or without spoken language. From an intellectual perspective, communication related to how the children to expressed their thoughts, ideas and intellectual processing either in written, verbal or visual format. From an emotional perspective, communication related to how well they were able to express their emotional state, and to interpret and understand the emotions of others. From a social perspective, communication related to how social interaction impacts on their ability to communicate with or without spoken words.

The final phenomenological stage of engagement involved how atypical children adapt to changing circumstances. In the physical space, how their bodies were able to adapt to changing physical environments related to sensory processing, motor function and flexibility. Of particular concern in the physical space is the increase in hypermobility, as a comorbid attribute of many neurodevelopmental challenges. This could present as simple over flexibility, but at the extreme, Ehlers-Danlos syndrome (EDS) and Marfan syndrome could spell a lifelong disabling condition affecting all connective tissues within the body including the skin, organs and circulatory systems (Baeza-Velasco *et al.* 2018). As these conditions are treated in different medical fields, a clinical link has not been established, but the high incidence of comorbidity suggests a distinct relationship between EDS and Autism. *Adaptability* in the intellectual space refers to how the children were able to create new solutions, ideas, and innovations to deal with changing circumstances, through strategic thinking and approaches. In the emotional space, adaptability related to how the children were able to manage their emotional wellbeing within changing circumstances or environments. In the social space, I explored how they were able to engage with what is referred to as adaptive social functioning and behaviours. These behaviours relate to life skills such as personal care, grooming, dressing, taking care of oneself, handling food, working, managing money, making friends, social skills and generally taking 'personal responsibility' for one's life. They are broadly termed 'social competence' and are often noted in the context of assessing a person's ability to live independently despite being diagnosed with a disability. Children and adults on the autism spectrum often present with significant challenges in adaptive behaviours, in comparison to their cognitive level (Kim *et al.* 2017).

Mapping the biomedical to the phenomenological

Having defined these various levels of enquiry, or phenomena to be explored, I revisited the range of diagnoses that my respondents were given, or that were referenced in my discussions with them, their families and by members of my online community. The understanding of a diagnosis, comorbid conditions and the support or remediation of these conditions, takes up a huge proportion of conversation time in this biosocial world. The primary focus of many atypical groups is for people to share their lived experience of their challenges, and to support others who may be struggling with something that they have knowledge of. The purpose of this mapping process was not to focus on the biomedical challenges, but rather to be sensitive to the multitude of physical, intellectual, emotional and social challenges that my interlocutors often had to overcome or manage in the lived experience of their lives. It also revealed the collective experience of each of these conditions rather than interrogated them individually in the biomedical tradition.

By mapping the diagnoses to a stage of engagement, I was able to see how particular issues clustered around each phenomenon. Although there was some overlap of diagnoses, and each could be experienced at a physical, intellectual, emotional or social level, for the most part, this process indicated how at each stage of engagement, children were often dealing with a dominant challenge. This assemblage of conditions, behaviours, and disorders, when viewed by stage of engagement, revealed a new way of thinking about the atypical lived experience. A new type of 'spectrum' emerged, one which indicated how the children chose to engage with, or disengage from, the world around them depending on their level of resilience, or conversely the lack of resilience. This was my first indication that by simply viewing atypical children differently, in this case from a holistic perspective, a new kind of spectrum could emerge. This spectrum of engagement versus disengagement, by stage, is illustrated in the chart below (Figure 17):

STAGE	ENGAGEMENT	DISENGAGEMENT
1. Presence	To be present.	To be absent.
2. Perception	To perceive, process and experience.	To be oblivious or to avoid.
3. Control	To control and regulate.	To be uncontrolled or powerless to control or regulate.
4. Participation	To be focussed and attentive.	To be unfocussed and neglectful.
5. Flow	To allow life to flow.	To be stuck or to disrupt the flow of life.
6. Communication	To express oneself through communication.	To suppress oneself or be unable to communicate.
7. Adaptability	To be flexible and adapt to change.	To be inflexible and to limit change.

Figure 17.

Exploring the intersection of diagnoses by stage of engagement gave a particularly medical and, in many ways, negative perspective on children's lived experience, as it focussed primarily on the 'disablement' of their difference. However, in assessing the medical diagnoses in the context of a holistic lived experience, I identified how their different approach to engaging with the world also 'enabled' them in many ways. This is explained by autistic advocate Tania Melnyczuk, specifically how autistic people can 'optimise' themselves to live their best lives:

> Although autism is actually a physiological type, rather than a disorder per se, the only way to get officially labelled as autistic is to have a qualified, knowledgeable medical specialist identify enough things that are 'wrong' with you to actually pronounce you to have an Autism Spectrum Disorder. It is comparable to using dysmenorrhea and mood swings as criteria for diagnosing an individual as female. They wait until you break, otherwise it doesn't count. This means that many people who are physiologically autistic do not learn how to optimise themselves, because they never end up at a specialist and therefore never find out that there is a name for

> how they function. Knowing this about themselves could have led to connecting with other autistic people and learning from them about how their own lives can be enhanced (Tania.co.za 4th June 2013, Accessed 26/03/2020).

The atypical community primarily supports a social model of disability; however, most deal with several very real physical, intellectual, emotional and social challenges in their day-to-day lived experience. Rather than just disabling, the understanding of a diagnosis can also be enabling, in how it assists atypical children and adults to manage their symptoms. A brief overview of atypical challenges and differences are detailed below. A full understanding of the different stages of engagement are explored in the chapters that follow.

Challenges with Presence

From a physical perspective, many of the challenges associated with presence, or how the children showed up in their world, related to how well they slept. Issues such as sleep/wake disorders, fatigue, insomnia, narcolepsy, sleep apnoea, challenges with circadian rhythm, parasomnias and nightmares were all spoken about. The children had all experienced either full or partial shutdowns after challenging emotional episodes or meltdowns, sometimes referred to as presence disorders. Partial shutdowns included: sensory shutdown, related to a person's ability to comprehend sensory input; speech, receptive and/or expressive language shutdown, relating to a person's ability to comprehend or engage in verbal or written language; and motor shutdown, where a person is unable to engage in voluntary movement sometimes referred to as catatonia, stupor or catalepsy (Everything, 17th March 2005). Atypical children are physically cautious, and many struggle with conditions such as Chronic Fatigue Syndrome (CFS), Fibromyalgia (chronic pain), and hypermobility, all of which impact on how they experience their world. Connective tissue disorders such as EDS and Marfan syndrome, are typified with multisystem fragility and proprioceptive motor coordination dysfunction, which often leads to high levels of physical trauma and chronic pain. Due to communication difficulties, these syndromes are often not identified in atypical children, resulting in them living with extraordinary levels of pain and physical discomfort that may be untreated and unsupported (Baeza-Velasco *et al.* 2018).

From an intellectual perspective, presence challenges related to deficits in intellectual functioning, specific learning disorders and low scores in IQ assessments. The children also experienced challenges with developmental delays, often related to their premature birth.

From an emotional perspective, diagnoses related to detachment from the world, included reactive attachment disorder, paranoia, schizophrenia, delusions, hallucinations and dissociative disorders. These were not present in my initial cohort but emerged later during observational work in psychiatric environments, with clinical practitioners in this area, and members of my online community. All children in my research displayed some level of dissociation from their environment, they also had difficulties relating to and interacting with others, especially when feeling vulnerable, anxious, or distressed. From a social perspective, challenges ranged from introversion and social avoidance, to paranoia and antisocial behaviour. Issues such as dissociation and being disconnected from one's social environment were discussed at length among members of my online community. The new spectrum that emerged in the phenomena of presence indicated a conflict between the children's desire to remain in their 'own world' versus being forced to engage or interact in the 'real world'. This presence or absence was often not a conscious choice of the children, but rather illustrated how they lived their day-to-day lives. Their experience of absence was also not necessarily negative, as in many instances this was a time of intense dreaming, creativity, and imagination. These periods of apparent 'absence' had a profound impact on the children's personal identity and sense of self, calling for a more detailed analysis of atypical presence in the chapter that follows.

Challenges with Perception

In the engagement phase of *perception*, challenges were once again related to how one connects or disconnects from the world, and how individuals managed themselves in this space. From a physical perspective, challenges included sensory processing disorders, impairments and deficits related to hyper- or hyposensitivity, pleasure disorders and general somatic challenges, usually related to pain, fatigue or chronic allergies. Identified by Anna Jean Ayres, Sensory Processing Disorder (SPD) is commonly diagnosed in children with autism, ADHD and learning disabilities. Ayres (1972) notes how some children struggle with the neurological processes that organise the sensations they receive from their bodies and their physical environment, and this leads to a daily battle in social and educational spaces. Neurological research conducted by Owen and colleagues (2013) found that children with SPD have quantifiable differences in their brain structure, giving credence to a yet unrecognised disability in the DSM-5. They refer to children with SPD as 'out of sync kids', due to their related intellectual and social difficulties with communication, emotional regulation and concentration. Occupational therapist Winnie Dunn (1997) described how different children have different sensory profiles which impact significantly on their behaviour and participation in everyday life. Although these profiles occur from childhood to adulthood, they are particularly prevalent and more intense amongst people diagnosed as atypical:

> The evidence thus far suggests that vulnerable children (e.g. children with autism, ADHD, Asperger syndrome, Fragile X syndrome) are much more likely to have intense sensory response patterns. For example, children with autism spectrum disorders have a pattern of significantly different registration combined with avoiding. With this pattern, these children may fail to notice small stimuli (difficulty with registering), and then when the sensory input is strong enough for them to notice, they quickly withdraw (demonstrating avoiding). This pattern would make it very challenging for the children to respond appropriately; children have to sustain their attention to a stimulus in order to learn (Dunn 2007:90).

From a phenomenological perspective, Wood and Stuart, in their study on phantom limbs, describe sensory processing as the "motor resonance" between our bodies and the world they occupy: "A system of motor capabilities, abilities, and habitus that enable movement and the maintenance of posture and which function without the necessity of perceptual monitoring" (2009:493).

Sensory processing challenges are also experienced internally through interoception. Khalsa and colleagues describe interoception as "the process by which the nervous system senses, interprets, and integrates signals originating from within the body, providing a moment-by-moment mapping of the body's internal landscape across conscious and unconscious levels" (2018:501). This 'body mapping' starts in utero, during the third trimester of pregnancy, when a baby is moving and kicking its limbs against its mother's womb (LiveScience, 30th November 2018). This early spatial mapping creates the 'neural scaffolding' for all future sensory input, a 'mental map' of the body which lays the foundation for the child's future development (*ibid.*). The implications for the sensory processing abilities of children who are born prematurely or under difficult or traumatic circumstances, as with most of my cohort, are profound. In their study of interoception and emotion, Critchley and Garfinkel (2017) describe how human emotions are not only related to 'feeling states' within the body, such as anxiety and a churning stomach, but are also caused by them. DuBois and colleagues (2016) found that although the degree and directionality is not yet clear, interoception is atypical in people diagnosed with autism.

Wickremasinghe and colleagues (2013) found similar challenges in children born prematurely, who scored as atypical in auditory, tactile and vestibular processing. Any dysfunction in interoception can have a marked impact on mental health and disorders including anxiety, mood, eating, addiction, and somatic systems (Khalsa *et al.* 2018).

In the intellectual space of perception, challenges related to difficulties with understanding, reasoning, problem solving and abstract thinking. Conceptual skills were also deemed a problem, as were the children's ability to learn from experience and make decisions based on this. There is a high comorbidity between autism, ADHD and learning disabilities (McCarthy 2014), which include dyslexia, dysgraphia, dyscalculia, auditory processing, and non-verbal learning challenges. Rapp and Ginsburg (2012) note how the concept of 'learning disabilities' was only 'invented' by Samuel Kirk in 1963, but it is now the fastest growing category within IDEA's[26] 14 diagnostic areas in the United States (2012:176). In South Africa, the Education White Paper 6 (EWP6), on special needs education was introduced in 2001. It defines both intrinsic and extrinsic factors that impact on learning challenges, and an extremely broad criteria for the diagnosis of learning disabilities[27] (Nel & Grosser 2016). South Africa does not have a standard and nationally accepted tool to measure the prevalence of learning disabilities, or to differentiate disabilities amongst children. In UNICEF's (2012) study of childhood disability in South Africa, intellectual and learning disabilities made up just 15.7 percent, the highest being visual disabilities at 23 percent, and hearing at 21.2 percent. In comparison, IDEA's assessment of disabilities for the 2017-2018 period in the United States indicates that learning and intellectual disabilities made up 54 percent of total disabilities while hearing and vision impairment made up just two percent of the total childhood disability population (National Centre for Education Statistics, May 2019). This suggests that many children with learning disabilities are not identified and remain unsupported in South Africa. Beyond education, Rapp and Ginsburg (2012) argue that the differential brain development of learning-disabled children impacts profoundly on their academic and social life, forcing them to adjust to

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[26] The Individuals with Disabilities Education Act (1990) ensures students with disabilities are provided with Free Appropriate Public Education (FAPE) that is tailored to their individual needs in the United States.

[27] Criteria include: difficulty using cognitive strategies; poor attention, memory, and organisational skills; auditory and visual perceptual challenges and fine/grow motor skills; poor sensory integration; significant discrepancy between academic potential and achievement; difficulties with receptive and expressive language ability; difficulties with reading and spelling; difficulties with mathematics and dyscalculia; social and emotional problems related to academic challenges; and associated behaviours with ADHD.

bureaucratic school systems and an often-uncertain future. ‘Imperfect’ children and parents become members of what they term a “new kinship imaginary”, that resist the world’s narrow definitions of learning achievement. However, whilst they illustrate the creative and unique approaches of learning-disabled children, they also highlight the very real challenges that these children experience daily.

From an emotional perspective, all the children struggled with generally disorganised emotional states. Alexithymia is present in over 50 percent of all people diagnosed on the autism spectrum and describes their inability to understand bodily feelings related to emotions, or to verbalise their emotions or moods. Poquérusse and colleagues (2018) conducted a detailed analysis of the co-presence of autism and alexithymia, noting that it is both a cause and consequence of autistic behaviour. There has been much research into the ‘emotional competence’ of atypical children, and their ability to perceive, recognise and regulate their and other’s emotions (Ashwin *et al.* 2006; Lindner & Rosén 2006; Harms *et al.* 2010). Historically, the dominant discourse argues that atypical children, especially those on the autism spectrum, lack the capacity to engage with emotions as they are unable to recognise or express them appropriately (Rieffe & Stockmann 2000). There is evidence of ‘emotion recognition deficits’ in children diagnosed with autism, associated with the capacity to interpret facial expressions. However, Brewer and colleagues (2015) found that while individuals with autism may struggle to read neurotypical facial expressions, neurotypical individuals also struggle to read autistic expressions:

> Individuals with ASD produced atypical expressions, seemingly due to atypical representations of emotion, rather than simply having reduced comprehension of the use of emotional expressions, or awareness of their facial movements. These atypical representations also appear to be idiosyncratic, meaning members of the ASD populations may struggle to recognise emotional expressions produced by each other. (Brewer *et al.* 2015:270)

Beyond alexithymia and emotional understanding, the children frequently expressed cognitive ideation typified by feelings of rejection, humiliation, embarrassment, and a fear of causing offense due to their atypical behaviour. They often had challenges with body dysmorphia, and their appearance in general, and in some extreme cases personality disorders were noted among members of my online community.

In the social space, challenges with *perception* related to difficulties 'perceiving the social'. The DSM-5 groups these challenges into deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviours; and deficits in developing, maintaining, and understanding relationships (2013:50). The children displayed a particularly concrete view of the world, were often gullible to manipulation and most had experienced some form of bullying as a result. Atypical children are also believed to have a limited understanding of risk, which impacts on their social judgements and decision making. I did observe some questionable social judgements amongst my older participants, often in their efforts to appear 'rebellious' and 'cool', or just to fit in. All children had difficulties relating to and interacting with others, and this was exacerbated by their inability to make direct eye contact and their lack of awareness of facial expressions. There was also discussion of prosopagnosia or 'face blindness' amongst my online community, where individuals are unable to recognise even familiar faces, with obvious implications for social interaction (Weigelt *et al.* 2012).

In the perception stage of engagement, sensory processing, fatigue, allergies, pain, and interceptive challenges all impact on how children understand and process their world. In the academic space, specific learning disabilities influence their sense of self and ability to engage in an 'age-appropriate' learning curriculum. Difficulties with perceiving and understanding emotions both within themselves and others, as in the case of alexithymia, impacts on their emotional wellbeing and compounds their general challenges in 'perceiving the social'. The spectrum that emerged in the stage of perception appeared to indicate an ability to perceive, process and experience the world on the one hand, while being oblivious or actively avoiding the world on the other. However, a more detailed exploration of how atypical children 'perceive their world' revealed a far more nuanced experience. This related to how the children managed their bodily boundaries in the process of connecting or disconnecting with the world around them and will be discussed in the chapters that follow.

Challenges with Control

Diagnoses noted in the stage of control related primarily to the body/mind connection, highlighted earlier in this chapter. Physical challenges in this space relate to epilepsy, vocal and motor Tourette's syndrome, trichotillomania (excessive hair pulling), excoriation (excessive skin picking), apraxia, dyspraxia, and dysgraphia. Both children and adults shared that they had no control over these physical challenges. From an intellectual perspective, difficulties with *control* related to executive functioning, or the children's ability to organise and plan their world. Their 'disorganised thinking' was exacerbated by the physical challenges of dyspraxia (coordination), dysgraphia (the ability to write), and related issues with fine motor movement. From an emotional perspective, a lack of control related to issues such as obsessive-compulsive disorder or emotional outbursts. Challenges around control in the emotional space, resulted in behaviours such as echolalia (constant verbal imitation) and/or echopraxia (where the imitation is physical). In the social space, an inability to regulate their behaviour, frequently resulted in an emotional 'meltdowns' or 'shutdown'.

Atypical children's and adult's behaviour regulation is often expressed in repetitive motor movements, referred to as 'stimming'. Stimming can include making sounds, flapping, rocking, spinning, grunting, self-hitting and chewing of clothes. It is also referred to as 'autistic stereotypy' and in the DSM-5, it is noted as typical behaviour of children diagnosed with autism. Using wearable technology, researchers from Boston University proved that autistic adults and children use stimming intentionally to manage their experience of their environment (Spectrum News, 25th November 2019). Kapp and colleagues (2019) found that autistic adults "highlighted the importance of stimming as an adaptive mechanism that helps them to soothe or communicate intense emotions or thoughts and thus objected to treatment that aims to eliminate the behaviour" (2019:1782). This is an area of great contention in the autism community, as this behaviour is most directly targeted for remediation by therapists, often in the context of Applied Behaviour Analysis (ABA). The word is derived from the concept of 'self-stimulation' and is often used as a means of self-regulation. Autistic advocates argue that by attempting to remediate and remove this behaviour, therapists are depriving the child or adult of an important tool for self-management. Most argue that if one stim is removed, it is merely replaced by another, more socially acceptable one. Renowned actor, Anthony Hopkins, was diagnosed with Asperger's Syndrome at the age of 70; his 'stim' is his characteristic behaviour of rubbing his hands together. Beyond a distinctive acting mannerism, it represents his concerted effort to find a socially acceptable way to self-regulate. He notes of himself: "A lot of people with Asperger's are highly functional, but inconsistent, they have nervous ticks, nervous habits, inconsistently obsessive thinking" (Psychology Matters, 30th July 2017).

An inability to control oneself or self-regulate can lead to quite serious incidents of children 'acting out'. In these instances, they can display behaviours such as conduct disorder and destruction of property, and occasionally receive a diagnosis of oppositional defiance disorder (ODD). They are also noted to have difficulties with following rules and using inappropriate language, noises and sometimes crying, which can appear as ‘rebellious’ or ‘defiant’. My research participants did not oppose rules in general but did oppose those that did not make sense to them. As with all neurodevelopmental challenges, the comorbidity of ODD amongst atypical children is extremely high and reflects their frustration at the lack of understanding of their way of being in the world. Developmental psychologist, Mona Delahooke (2019), argues that ODD as a label should not be used to describe young children as their defiant behaviour is often a response to stress. I observed a few children who had been diagnosed with ODD and discussed it at length with psychologists and psychiatrists, who often explained the behaviour as a response to ‘fearing rejection’. My observations, however, mirrored Delahooke’s views that the children were in a constant state of stress due to challenges with their ‘neuroception’ and how they bodily perceived threats in their environment. Some of the children I observed had experienced excessive bullying and suffered from extreme sensory processing challenges. Ordinary sensations in their everyday lives presented as life threatening, and as a result, they were in a constant state of hyper-arousal and ‘survival mode’. The spectrum that emerged in the control stage of engagement was simply the child’s ability to control and regulate themselves, or to be uncontrolled and unable to self-regulate. However, rather than rebellion, defiance, abuse and destruction, this lack of control presented as a sense of frustration and powerlessness.

Challenges with Participation

Diagnoses related to the children’s ability to participate in the world focussed primarily on their capacity to maintain and sustain attention. From a physical perspective, attention difficulties relate to hyperactivity, impulsivity or hypoactivity. This was particularly challenging in the intellectual or learning environment, where ADHD type behaviours were felt acutely by the children, their teachers, and other learners. Children presented as either excessively hyperactive and impulsive, disrupting their class on an incessant basis, or conversely, entirely inattentive, dreamy, and appearing disconnected from the class and activities around them. Both these expressions of ADHD had an impact on the children’s ability to learn and to produce considered, accurate work, devoid of mistakes. From an emotional perspective, participation was associated with manic or conversely cyclometric disorders such as passivity and anhedonia, where the children were completely disinterested and unable to feel pleasure. From a social perspective, negative behaviours included excessive talking, blurting out of answers, disinhibition where the child was ‘over-familiar’, or conversely entirely disengaged. The engagement spectrum of participation related to the child's ability to be focussed, attentive and to participate versus being unfocussed, neglectful and either unwilling or unable to participate. Exploring how the children engaged in the world, revealed their daily struggle with energy management. Children were either dealing with excessive amounts of energy, which they struggled to find outlets for, or conversely had little to no energy and struggled to get to the end of their day, without being completely overwhelmed.

Challenges with Flow

As noted previously, the children had a number of challenges and diagnoses related to their embodied experience of change. Flow, in the context of the physical, related to how the children managed their daily bodily functions and activities. Just as they struggle with their body/mind connect, general somatic stress was constant. Many struggled with gastrointestinal dysfunctions such as stomach cramps, vomiting and diarrhoea which impacted on their behaviour and quality of life (Krajmalnik-Brown *et al.* 2015:1). In their study of gastrointestinal dysfunction in children diagnosed with autism, Kang and colleagues (2014) found that problems such as diarrhoea, constipation, bloating, vomiting and reflux existed in nearly 50 percent of the children. Penzol and colleagues (2019) found similar incidences of functional Gastrointestinal Disorders (fGID), associated with Intellectual Disability (ID), sleep problems and those on psychotropic drugs prescribed for behavioural challenges.

Many parents of ADHD and autistic children support 'elimination diets', where foods, particularly those containing the proteins casein (found in milk) and gluten (found in wheat), are eliminated from their child's diet. Other parents spoke of challenges with 'digestive enzymes' in their children's gut and the value of 'digestive enzyme therapy'. I engaged with two parents, who explained that their autistic children had an 'opioid' type reaction to eating apples, bananas, artificial preservatives, and colourants. They believed this to be linked to chemicals, known as exorphins, released by undigested casein and gluten, causing the condition referred to as 'leaky gut' (RaisingChildren.net.au 1st August 2017, Accessed 13/02/2020). The leaky gut and resulting brain disruption were believed to cause autism or exacerbate autistic and ADHD behaviours. Though widely questioned by the biomedical fraternity, a randomised, placebo-controlled trial of digestive enzymes in children with autism found that those who received therapy had significant improvement in emotional response, general behaviour, and gastrointestinal symptoms (Saad *et al.* 2015). Eating disorders such as anorexia, bulimia or binge eating were also noted by my online community. Eating challenges were exacerbated by sensory sensitivity to food textures, tastes, and smells, and this often led to a very limited diet. Other difficulties included pica, the eating of non-nutritive food, and issues with rumination and regurgitation. There was a high incidence of elimination challenges among the children such as bed-wetting and incontinence extending from toddlerhood well into childhood.

From an intellectual perspective, issues around flow related to challenges with the children's process of learning and their ability to access their working memory. Whilst most had exceptional long-term memories, especially for facts, movies, or media that they found interesting, struggles with short term and working memory made learning, and especially examinations, difficult. Autistic academic, Temple Grandin (2014) likens her memory to a vast library of video tapes that she can call on and play through, rewind and playback. She uses this skill to examine the detailed designs she is working on, or to decode social interactions that she finds perplexing. I noted this ability amongst many of my participants, especially in relation to their 'specialist interests'. The children's occupation with 'specialist interests', which included technology, gaming, design, science fiction and certain historical facts or periods, left little space for a more rounded educational curriculum. Most adults spoke of how their academic abilities improved as they focused on more specialist subjects at a tertiary level of education and in the working world.

From an emotional perspective an inability to manage the flow of life manifested in moodiness, dysthymia (feelings of intense sadness and emptiness), irritability and in some cases depression and bipolar disorder. Emotional distress at disruption and discontinuity is a typical comorbid trait of atypical children and adults and is expressed through challenges such as complex post-traumatic stress disorders (cPTSD), hoarding and obsessive-compulsive disorders (OCD). Over 70 percent of children on the spectrum have a comorbid psychiatric disorder, which usually includes OCD, anxiety, and/or depression (Spectrum News, 26th September 2019). Kerns and colleagues (2015) note that autism both influences the traumatic stress experienced, and increases the presentation of autistic symptoms. Many of the children struggled with pathological demand avoidance (PDA), the extreme avoidance of everyday demands and expectations (Autism.org.za 25th September 2019, Accessed 12/02/2020). These demands can be as simple as asking a child a question, asking them to choose between two options, or to get ready for school. The questions or 'demands' can trigger a 'survival response' in the children's highly sensitive neuroception. Porges (2014) describes neuroception as the process our neural circuits go through to distinguish between situations that are safe, dangerous, or life-threatening. If a threat is perceived, even if innocuous, the children's defence strategies are triggered. Where perception is a conscious process, neuroception occurs without awareness, making any response automatic rather than a choice. The range of recognised 'threat responses' include: 'freeze', where a child is unable to respond and presents as 'hypervigilant' (Bracha *et al.* 2004); 'flop' where the child falls asleep or shuts down; 'flight', which relates to the child either physically running away, or becoming hyper-focussed on another activity to the exclusion of all else; and 'fright', which can completely immobilise a child and is often seen as a last resort when flight is impossible (Kozlowska *et al*.2015). A final response recognised by some is 'fawning' and relates to 'masking' and 'people pleasing', where the child places other's needs over their own, usually after prolonged high stress situations (Walker 2013).

From a social perspective, allowing for the flow of social interaction was difficult for the children, as many struggled with extreme social anxiety. Relationship building was not a skill any had mastered, and friendships, although desired, were often few. Their social challenges were exacerbated with difficulties in learning even simple social skills such as appropriate greetings, taking turns and a willingness to share. Their seemingly obsessive attachment to particular objects or rituals epitomised their inability to allow for the general flow of life. The spectrum of flow related to the children's ability to allow things to flow, versus their almost compulsive need to disrupt the flow of their lives. When questioned about their 'difficulties with flow', they noted a disconnect between how they believed things should be, in contrast to how they experienced them. Their inability to comfortably accept the flow of life reflected their insecurities around their lack of control over their bodies and the world around them. Allowing the world to flow without trying to stop or control it or being unable to stop or control their world and how they experience it, appeared to create a high degree of anxiety and sometimes depression.

Challenges with Communication

From an anthropological perspective, communication and culture are intimately linked. Communication both creates culture through our customs, rituals and how we engage with each other socially, and is shaped by culture, through our diversity and different ways of being in the world. Linguist Charles Hocket notes that "communication is those actions by which one organism triggers another" (1958:573). In exploring comparative aspects of human communication, Clive Kluckhohn (1961) stated that language is both a part of culture and a vehicle of culture that forms a matrix for human experience. Sapir (1929) hypothesised that a person's understanding of their world and how they experience it is largely a result of the language habits of their community, and its predisposition to particular choices of interpretation. Our ability to communicate with one another is therefore critical in how we make space for ourselves in the world, how we experience our world, and how we make sense of our world. In the engagement stage of communication, physical challenges included a range of speech, sound, and language disabilities such as non-fluency, colloquially referred to as ‘stuttering’, vocal and verbal ticks, mutism, selective mutism, and apraxia of speech. Apraxia refers to the disconnect between a person’s desire to speak and their ability to produce the appropriate sounds. Global research indicates that around 40 percent of autistic children are non-verbal, and of the remaining children, many only use very basic functional naming words (Rose *et al.* 2016).

Beyond the spoken word, non-verbal autistic advocate and academic, Amanda Baggs (2010), communicates through her sensory stimming and typing. Baggs argues that neurotypical language is limiting and one dimensional. Whilst flapping her hands, singing, rocking, smelling, listening, feeling, and tasting her environment, she explains:

> My language is not about designing words or even visual symbols for people to interpret. It is about being in constant conversation with every aspect of my environment. Reacting physically to all parts of my surroundings…The way I naturally think, looks and feels so different from standard concepts or even visualisation, that some people do not consider it thought at all, but it is a way of thinking in its own right (Baggs 2007: Video).

Rather than ‘being in her own world’, Baggs explains that she is responding to everything around her in ‘real time’. However, as she is unable to engage in verbal communication, she notes that her cognitive abilities and even personhood is often questioned. Autistic anthropologist Dawn Prince (2010) also describes the language prejudice experienced by autistic people: “If you couldn't speak the *Lingua Franca* of the normal, then you had to be stupid and, therefore, disposable” (2010: 1055). If communication both creates culture and is influenced by culture, then what Baggs and Prince are proposing is a new form of atypical cultural communication that needs to be accommodated and understood by the neurotypical world. Belek (2019) notes that through their ‘unconventional linguistic structures’, Baggs and Prince are attempting to reshape their social environments and what is appropriate or acceptable in these spaces. Movements such as #EmbraceTheStim, #StimDancing and the #InternationalDayoftheStim, have all been created by autistic advocates to recognise stimming as an authentic form of communication.

In addition to speech and language skills, communication challenges include echolalia, giving unrelated answers to questions, a limited use of gestures, such as pointing or responding to other's pointing, and problematic inflection. Clinicians also note the previously mentioned 'concrete view of the world', which is thought to explain difficulties understanding jokes, sarcasm, teasing, or figures of speech such as irony, hyperbole, or personification. Language disorders also have a negative impact on learning and are often coupled with the specific learning disabilities outlined above. In the context of learning, therapists sometimes refer to the condition of aphasia, which impacts on a person's ability to produce or comprehend speech and to read or write. Autism and aphasia are viewed as 'related syndromic clusters' and are thus treated similarly (Cohen *et al.* 1976:605).

Communication in the emotional space relates to how children express their feelings. Challenges can present as selective mutism on the one hand or emotional outbursts on the other. Unable to contain their feelings, often in a state of extreme agitation or frustration, anger, aggression, and rage, are sometimes diagnosed as 'intermittent explosive disorder'. The ability to perceive and communicate empathy can also be challenging for atypical children. This is not to say that they do not experience empathy; however, it is often expressed in very different ways to neurotypical children. In my discussions and observations with both children and adults, it appeared that empathy was felt too much rather than not at all. Autistic adult Stephen notes: "I experience empathy as physical pain, especially in situations of injustice. My whole-body aches with emotion. Sometimes I melt down and sometimes I shut down." Beyond human interaction and communication, many children and adults noted profound levels of empathy between themselves and animals. Temple Grandin explained: "When I'm with cattle, it's not at all cognitive…I know what the cow is feeling" (Sacks 1995:268). Isaacson (2009) noted a similar interaction with his autistic son, who appeared to have a 'direct line' to animals and especially horses. Malcolm and colleagues observed the 'opening up' of autistic children during equine therapy: "autistic children came to 'surprise' parents and teachers with their intersubjective, communicative, and empathic abilities" (2018:21). The researchers argue that the empathy they observed between the children and horses' questions notions of intersubjectivity and the belief that empathy can only be experienced cognitively between humans, with the use of language.

Some researchers claim that autistic children have 'mind-blindness', or a deficit in 'Theory of Mind' (ToM), where a child is unable to see a phenomenon from the perspective of anyone other than themselves. Baron-Cohen and colleagues (1985) claim that autistic children lack a ‘theory of mind’ altogether:

> Our results strongly support the hypothesis that autistic children as a group fail to employ a theory of mind. We wish to explain this failure as an inability to represent mental states. As a result of this the autistic subjects are unable to impute beliefs to others and are thus at a grave disadvantage when having to predict the behaviour of other people (1985:44).

Theory of mind is believed to develop alongside communication skills, between the ages of two and five years (Milligan *et al.* 2007). It describes a child’s ability to focus their attention on an object or person, and understand that object or person’s intention, based on their beliefs, desires, emotions and knowledge (Premack & Woodruff 1978; Baron-Cohen 1991). Key to this ability is the understanding that other people’s desires and beliefs are often diverse, as is their access to knowledge, their ability to hide their emotions and their interpretation of ‘false belief’. False belief refers to a child’s ability to comprehend a particular situation from the perspective of someone other than themselves. It is this ability, that is seen to be deficient in children diagnosed with autism, schizophrenia, nonverbal learning disabilities or ADHD (Korkmaz 2011). Theory of mind is often linked to empathy, however, where empathy is regarded as emotional perspective-taking, ToM is defined as cognitive perspective-taking (Hynes *et al.* 2006). Deficits are thought to stem from a range of difficulties. These include difficulties with imaginative play, which is believed to be lacking in children on the spectrum (Leslie 1991), an assumed inability to interpret emotions (Hobson 1986), or specific developmental or cognitive delays (Baron-Cohen 1991). DSM-5 (2013) defines these deficits in ‘social-emotional reciprocity’ and ‘relationship building’ as an inability to adjust one’s behaviour to suit a particular social environment, to share or take turns, to show interest in one’s peers, and to appreciate how one’s behaviour impacts on others. Communication cognition, where knowledge is acquired and understood, is believed to be impossible without theory of mind (Sperber & Wilson 2001).

Frith and Happé argue that some autistic individuals have a “late acquired, explicit theory of mind” resulting from “effortful learning” (1999:82). In questioning autistic people’s ability to be self-conscious, the researchers were criticised for ‘delegitimizing autistic narratives’ (Yergeau 2013). However, the concept of ‘effortful learning’ resonates with some adults in their understanding of social communication and interaction. This learning is often acquired through mimicking others to the point of expertise. Beyond social engagement, the ability to mimic others accurately can lead to the acquisition of significant skills. Temple Grandin noted how when she needed to learn how to create detailed technical design drawings, she watched a draftsman drawing up some plans intently, and was then able to recreate this skill:

> I saw how he did it…I went and got exactly the same instruments and pencils as he used – a point-five-millimetre HB Pentel – and when it was done, I couldn't believe I'd done it. I didn't have to learn how to draw or design, I pretended I was David [the draftsman] – I appropriated him, drawing and all (Sacks 1995:266).

The spectrum that emerged in communication engagement related to the children's ability to express themselves and to communicate, either verbally or non-verbally, or to suppress themselves, either willingly or more often, unwillingly, and to not communicate. This stage of engagement could be conscious or unconscious, or something they had control over, or no control at all. The spectrum of communication was strongly associated with the children's values and beliefs, and their apparent dedication to honesty and integrity, which I discuss in more detail in later chapters. The children appeared physically unable to be duplicitous and struggled to understand this ability in others.

Challenges with Adaptability

The notion of adaptability is highly stress inducing and often met with resistance by atypical children and adults, especially those on the autism spectrum. Any change that interferes with their 'restrictive repetitive behaviours' and 'insistence on sameness' can lead to high levels of anxiety and maladaptive behaviours[28] (Kanner 1943). In the physical space, these behaviours could include stress related repetitive motor disorders such as shaking, rocking, head banging, biting, hitting, and stimming that borders on self-harm. An inability to adapt physically to one's environment can also be related to the sensitivity and fragility of atypical bodies. A number of chronic conditions, disorders and syndromes were noted and discussed amongst my participants. Medical doctor and psychiatrist Sharon Meglathery explains the clustering and overlapping of chronic medical conditions in atypical children and adults in her RCCX Theory.[29] Her theory identifies a number of genetic mutations and structural challenges around the vegus nerve, which manages our sympathetic and

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[28] Behaviours employed by atypical children or adults to avoid directly confronting the discomfort of new situations or environments.
[29] https://www.rccxandillness.com/ Accessed 11/02/2020.

parasympathetic response to the world. Other syndromes and disorders included: ‘Postural Orthostatic Tachycardia Syndrome’ (POTS), which impacts on a child’s ability to manage their blood pressure; ‘Paediatric Acute-onset Neuropsychiatric Syndrome’ (PANS); and ‘Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections’ (PANDAS), indicated by a sudden onset of OCD symptoms and behaviour. A high incidence of autoimmune diseases such as rheumatoid arthritis, lupus and inflammatory bowel disease were noted by members of my online community. In exploring the links between autoimmunity, autoantibodies and autism, Edminston and colleagues (2017) cite numerous studies where maternal autoantibodies that impact negatively on neurodevelopment were found in autistic children and their mothers. All these conditions have a serious impact on how atypical people engage with their world, especially in the rapidly changing and often harsh physical and social environments of our contemporary society.

From an intellectual perspective, adaptability related to the children’s ability to engage in abstract versus concrete thinking. Abstract thinking is believed to be a deficit in atypical children; however paradoxically, I observed all my participants apply distinctly strategic approaches to their management of change. Rules were created, rituals invented, and specific individuals identified to assist them in engaging with their world. The concept of rituals was explored in the popular television series *Atypical* (2017) about an autistic teenage boy. In an episode called “Ritual-Licous,” lead character, Sam, engages in a number of rituals for his sister’s birthday including: waking her up at her “happy birthday minute”; saying ‘happy birthday’ to her sixteen times, for each year of her life; and playing a game called “Ickle-bickle-bean-stalk”, which their mother had invented for them. Sam explains how it is critical for him to complete all the rituals; on one occasion when he did not, his pet turtle died. He notes: “Rituals are important, it’s how you know everything is ok, because that’s what rituals do, they make everything ok”. The National Autistic Society in the United Kingdom observes that rituals are common amongst autistic people and can be both a source of enjoyment and a cause for distress and anxiety (autism.org.uk Accessed 26/04/2020).

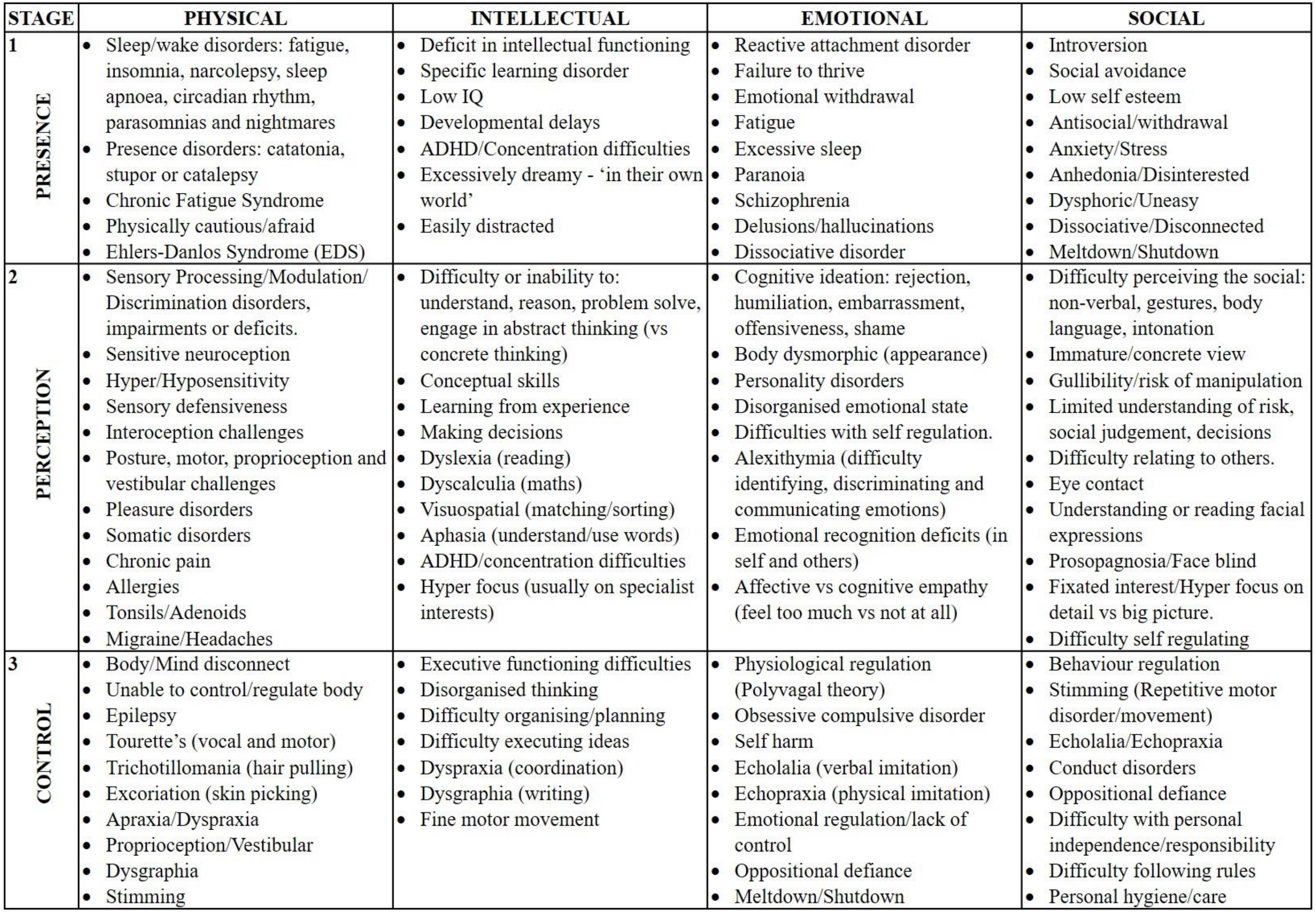
Some rules and rituals go beyond simple anxiety management into the realm of obsessive-compulsive disorder (OCD). OCD is typified by ‘obsessions’ and ‘compulsions’ over which an individual usually has no control. Obsessions refer to recurrent and persistent thoughts, urges and images that are intrusive and unwanted and usually cause high levels of anxiety and distress. To suppress these obsessions, the individual may engage in compulsive behaviour, which can include intense repetition, such as hand washing, or the obsessive ordering and checking of items or activities (DSM-5 2013:237). Research into the comorbidity of autism and OCD is limited and as a result, it is often undiagnosed due to the overlapping of symptoms (Spectrum News, 27th February 2019). Typical OCD compulsions are seen as being ‘stuck’ or obsessing over a particular item or behaviour, which can sometimes be confused with autistic rituals and stimming.

Despite both the children and their parents attempting to manage change proactively, a sudden and unexpected shift can result in fraught responses. In the emotional space, these included separation anxiety, panic attacks, trauma, excessive fear, pathological avoidance, and stressor disorders. In the social space, children displayed maladaptive behaviours, such as pathological demand avoidance, challenges with adaptive functioning and sometimes clinical distress. In trying to ‘fit in’ or pretend that they are coping with change, many children and adults will attempt to mask their ‘atypical behaviours’. The International Society for Autism Research (INSAR), notes that masking, or camouflaging, is a specific risk marker for suicidality and non-suicidal self-injury (Cassidy *et al.* 2018). Research places the risk of suicide and suicidal behaviour for atypical teenagers and adults at nearly ten times that of the general population and speaks to the high levels of comorbidity between autism and depression (Psychology Today, 10th February 2019). The spectrum that emerged around the stage of adaptability related to the children’s ability to be flexible and adapt to change, versus being inflexible and attempting to limit change whenever and wherever possible. Through in-depth observation and understanding, a more nuanced motivation was revealed, connected to how atypical children structure, and make sense of their world. It also, once again, illustrated their constant battle with control of their environment and their body.

Moving on to the lived experience

The primary focus of this study is to understand the lived experience of atypical children from their perspective, rather than how they are perceived and labelled by the medical profession, the remediation industry, and popular ‘neuro-culture’ (Rose 2014). It aims to explore the relationship between their embodied experience of their world, how the world impacts on this experience, and how they claim agency in this space. The detailed analysis of challenges, behaviours and diagnoses against a new phenomenological model of engagement, is the first step in moving beyond an individualised and medicalised approach to understanding neurodevelopmental disorders. Although predominantly biomedical, it illustrates a holistic way of exploring the atypical lived experience, as challenges are clustered together around the social, rather than treated independently of each other. The remainder of this dissertation will explore each of the ‘stages of engagement’ outlined in this chapter, from the perspective of atypical children, to uncover the meaning associated with each phenomenon identified.

A detailed summary of the neurodevelopmental and associated disorders discussed in this chapter are summarised by stage in the charts below (Figure 18.a and 18.b). The aim of this summary is to illustrate the combination of challenges that an individual may experience at each stage of interaction with their world. Whilst this approach to presenting information may appear to compartmentalise each challenge experienced, my intention is quite the opposite. In my process of detailed analysis, it became important to ‘segment’ each stage and diagnosis into parts, so that I could then cluster them into a more holistic picture of the total phenomenological lived experience of atypical children and adults. Although I have specified diagnoses, challenges and behaviours into physical, intellectual, emotional and social categories, the intention is not to separate them out, but rather to show their flow and connection, as they are experienced by stage from one to the next. It would be impossible to separate each challenge into a particular component, whether physical, intellectual, emotional, or social, as each is experienced often simultaneously by all categories as we engage in our lived experience of our world.



STAGE	PHYSICAL	INTELLECTUAL	EMOTIONAL	SOCIAL
1 **PRESENCE**	• Sleep/wake disorders: fatigue, insomnia, narcolepsy, sleep apnoea, circadian rhythm, parasomnias and nightmares • Presence disorders: catatonia, stupor or catalepsy • Chronic Fatigue Syndrome • Physically cautious/afraid • Ehlers-Danlos Syndrome (EDS)	• Deficit in intellectual functioning • Specific learning disorder • Low IQ • Developmental delays • ADHD/Concentration difficulties • Excessively dreamy - ‘in their own world’ • Easily distracted	• Reactive attachment disorder • Failure to thrive • Emotional withdrawal • Fatigue • Excessive sleep • Paranoia • Schizophrenia • Delusions/hallucinations • Dissociative disorder	• Introversion • Social avoidance • Low self esteem • Antisocial/withdrawal • Anxiety/Stress • Anhedonia/Disinterested • Dysphoric/Uneasy • Dissociative/Disconnected • Meltdown/Shutdown
2 **PERCEPTION**	• Sensory Processing/Modulation/ Discrimination disorders, impairments or deficits. • Sensitive neuroception • Hyper/Hyposensitivity • Sensory defensiveness • Interoception challenges • Posture, motor, proprioception and vestibular challenges • Pleasure disorders • Somatic disorders • Chronic pain • Allergies • Tonsils/Adenoids • Migraine/Headaches	• Difficulty or inability to: understand, reason, problem solve, engage in abstract thinking (vs concrete thinking) • Conceptual skills • Learning from experience • Making decisions • Dyslexia (reading) • Dyscalculia (maths) • Visuospatial (matching/sorting) • Aphasia (understand/use words) • ADHD/concentration difficulties • Hyper focus (usually on specialist interests)	• Cognitive ideation: rejection, humiliation, embarrassment, offensiveness, shame • Body dysmorphic (appearance) • Personality disorders • Disorganised emotional state • Difficulties with self regulation. • Alexithymia (difficulty identifying, discriminating and communicating emotions) • Emotional recognition deficits (in self and others) • Affective vs cognitive empathy (feel too much vs not at all)	• Difficulty perceiving the social: non-verbal, gestures, body language, intonation • Immature/concrete view • Gullibility/risk of manipulation • Limited understanding of risk, social judgement, decisions • Difficulty relating to others. • Eye contact • Understanding or reading facial expressions • Prosopagnosia/Face blind • Fixated interest/Hyper focus on detail vs big picture. • Difficulty self regulating
3 **CONTROL**	• Body/Mind disconnect • Unable to control/regulate body • Epilepsy • Tourette’s (vocal and motor) • Trichotillomania (hair pulling) • Excoriation (skin picking) • Apraxia/Dyspraxia • Proprioception/Vestibular • Dysgraphia • Stimming	• Executive functioning difficulties • Disorganised thinking • Difficulty organising/planning • Difficulty executing ideas • Dyspraxia (coordination) • Dysgraphia (writing) • Fine motor movement	• Physiological regulation (Polyvagal theory) • Obsessive compulsive disorder • Self harm • Echolalia (verbal imitation) • Echopraxia (physical imitation) • Emotional regulation/lack of control • Oppositional defiance • Meltdown/Shutdown	• Behaviour regulation • Stimming (Repetitive motor disorder/movement) • Echolalia/Echopraxia • Conduct disorders • Oppositional defiance • Difficulty with personal independence/responsibility • Difficulty following rules • Personal hygiene/care

Figure 18.a

STAGE	PHYSICAL	INTELLECTUAL	EMOTIONAL	SOCIAL
4 **PARTICIPATION**	• Hyperactivity • Impulsivity • Restless legs • Stimming (Repetitive motor movements) • Over/under sensitivities • Energy management	• ADHD • Hyperactivity • Impulsivity • Mind elsewhere • Dreamy and inattentive • Unable to sustain attention • Excessive mistakes	• Anxiety • Cyclometric/manic disorders • Disruptive behaviour • Restless/keyed up • Self harming • Concentration challenges • Autistic burnout	• Interacting with others • Impulsivity/social control issues: excessive talking, blurt out answers etc. • Disinhibited social engagement (over-familiar) • Hyperactive or passive
5 **FLOW**	• Gastrointestinal disfunction: vomiting, diarrhoea, bloating, reflux etc. • Gut/brain connection • Eating disorders: anorexia, bulimia and binge eating. • Pica (non-nutritive food) • Rumination & regurgitation • Elimination disorders: bed wetting, incontinence	• Flow of learning: input (sensory), processing (brain) and output (motor). • Difficulty conceptualising past, present and future • Stress/anxiety impact on memory and concentration • Forgetful/lose things • Hyper focus & ADHD • 'Inappropriate' play	• Hypervigilance/arousal • Depression/Self-harming • Disruptive mood disorders • Dysthymia (sad/empty) • Irritable/Moody/Angry • Bipolar disorder • OCD/Hoarding • Fixated interest/connections • Pathological Demand Avoidance (PDA)	• Feel alienated/isolated • Limited social participation • Difficulty transitioning • Avoids eye contact • Atypical facial expressions • Social anxiety • Relationship building/ friendship limitations • Social skills: greeting, taking turns, sharing, interest
6 **COMMUNICATION**	• Non-verbal • Language disorders: speech/sound, non-fluency • Vocal/Verbal ticks • Selective mutism • Apraxia of speech • Dysgraphia	• Language disorder • Non-verbal/Select mutism • Dyslexia (read/spell) • Dysgraphia (write) • Aphasia (words) • Concrete vs abstract view of world/thought process • Problematic inflection	• Anxiety • Selective mutism • Echolalia • Severe temper outbursts: anger, aggression, rage • Expression of empathy • Theory of mind questioned • Stimming to communicate	• Communication and language limitations • Impairment in discourse • Externalised anger and aggression (word/action) • Unrelated Q&A • Pointing/response • Social conventions
7 **ADAPTABILITY**	• Stress related repetitive motor disorder: shaking, rocking, head banging, biting, hitting • Joint hyper mobility/EDS • Mast Cell Activation Syn. • Chronic Fatigue Syndrome • POTS, PANS, PANDAS • Autoimmune diseases • Epstein-Barr/Lyme Disease	• Concrete vs abstract thinking • Difficulty integrating past, present and future (conceptually and literally) • Hyper focus & ADHD • Slow processing speeds • Atypical strategic abilities	• Anxiety/OCD • PTSD/Trauma • Panic attacks/Fear • Heightened sympathetic response: fight/flight/freeze • Phobias/avoidance • Stressor disorder • Excessive rules/rituals • Self harming & Suicide	• Restrictive repetitive behaviour • Insistence on sameness • Adaptive functioning issues • Maladaptive behaviour • Adjustment disorder • Hyper/clinical distress • Excessive social rituals • Masking/Burnout

Figure 18.b

CHAPTER 5

ATYPICAL WAYS OF BEING IN THE WORLD: ON PRESENCE

THE STORY OF PUCK[30]

Puck was diagnosed with autism at six months of age. His parents noticed that he did not like to be held or cuddled, and that they could put him down in his cot and he would self sooth rather than need their support. Challenges emerged around sensory sensitivity, fine motor movement, proprioception, learning challenges and attention. He also displayed typical autism traits such as challenges with eye contact, echolalia, and repetitive motor movement or stimming with his hands or objects. He struggled with sleep and has had a strict regimen for going to bed every night from a young age. He has been diagnosed with epilepsy, depression, anxiety and Tourette Syndrome, which has sometimes presented as angry outbursts, especially towards his mother, much to his mortification, as he is very close to her. These physical and emotional challenges mean that he has been and is on a range of medications which he believes have both helped and hindered him. His use of Ritalin caused major depression and significantly slowed his growth rate, leading to shorter stature in his teen years: his doctors are trying to remedy this with growth hormones as his lack of height concerns him greatly. The growth hormones and puberty have impacted on his levels of aggression, and he is thus also on mood stabilisers that have the added advantage of assisting with epilepsy prevention. Puck is disciplined about his medication and believes it helps him with life, learning and engagement in the world. This is very important to him as he is first and foremost a creative performer.

Puck's specialist interest is people. He loves to watch people interacting with each other, and especially when there is a bit of conflict, he notes: "Not in a bad way, but I love to see how people are with each other, it's funny and exciting." Puck is constantly studying how people engage with each other. He then files his insights away in his imagination, to share at a later stage with his parents or theatre coach as possible characters he could play one day. Puck has attended a children's theatre group:

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[30] Puck asked me to choose a pseudonym for him. After much thought and interaction, I chose the mythical figure of Robin Goodfellow, or Puck, from Shakespeare's A Midsummer Night's Dream. Puck is mischievous but endearing, and always keen to shake things up in human interactions to see how people will respond.

> I honestly love my career at the children's theatre, I have been going there since I was about twelve. We combine classes, we have physical dance, drama and music, my favourite is drama. I like any kind of theatre, like musicals, opera, drama. I have been to the theatre lots of times. Montecasino is one of my best.

For the most part, Puck has had a challenging time at school. He enjoyed play school as it was filled with games and music, he could play classical piano at the age of three, but eventually he was sent to a remedial junior school. Puck's experience of this school was not positive. He struggled with academic subjects and writing any test would bring on extreme anxiety. He would often get up and walk around his class or the school, leading to an occasion when he was physically restrained to his chair. Puck's parents moved him to a new school at the age of twelve, but by this point he was very subdued. As noted by the headmaster of his new school, "by the time he got to us, he was almost shut down, he didn't want to settle or do anything." Through a process of intense personal engagement, Puck started to open up again, interacting positively with his school friends and teachers, especially around music and theatre. The school started a rock band with Puck as base guitarist:

> Music inspires me. My favourite music is not only musical theatre, I also like rap and hard rock. I listen to it anytime, like in the middle of class, I would be listening to music, like in the middle of maths (his least favourite subject), I would be listening to music and studying.

Physically Puck is extremely cautious. He feels pain acutely, describing his 'worst-day' as the day he broke his arm during a horse-riding class, aged ten:

> It was unexpected and sudden, and I was very sad, and my arm was very painful. All I can remember was being rushed to the hospital and it was the worst experience of my life. Ever since that experience I have been very sceptical about riding another horse because I am constantly afraid of falling off.

Another bad experience he recalled frequently in our conversations was going to Jozi X, an extreme outdoor sports centre with an inflatable obstacle courses: "I don't like it, I went there with my school and I fell off the boxing thing, but I didn't break anything."

Puck's body is a constant frustration to him. Physical exertion is difficult. He has an ataxic gait due to challenges with proprioception and needs to wear special orthopaedic shoes, making any form of running or aerobic activity difficult. Puck has extreme sensory sensitivity to sounds, smells and textures, but as he notes, "thankfully my eyes are fine." Any physical irritations such as a piece of food stuck in his teeth are impossible to ignore, and he will sometimes hurt himself in his effort to fix it. His mother recalled that during winter when his lips get chapped, “he literally physically eats himself, chewing his lips until they bleed profusely.” When doing the body mapping exercise, Puck drew his stomach in his chest and his heart where his stomach should be, possibly indicating his physical response to stressful emotions such as being scared or anxious, which can sometimes lead to bouts of vomiting or diarrhoea. His brain is his favourite body part:

> The part of my body I like the most is my brain; I love the way it thinks and learns. When I am feeling strong, I feel it in my head and muscles, when I am weak, I feel it in my legs. My brain is like a whole bunch of gears working together, it always does what it needs to do.

Puck’s ideal physical environment is wrapped up warm in bed with a heavy blanket on top of him. His mother also noted that bathing calmed him significantly as a child. When he doesn’t need to go to school he will ideally wake up slowly, chatting to himself about his day, what he plans to do and how it will unfold: “I like to day dream a lot, I talk to myself, I talk about what I want to happen to me and how I would handle it.” Puck’s older brother described how he would often hear Puck practicing ordering a pizza or meeting someone new: “It’s almost like he is practicing life, before he has to do it.”

Puck, like most participants, did not like to talk about negative emotions such as feeling sad, angry, scared or anxious. When pressed to discuss them, he would do so reluctantly, and clearly found them overwhelming: “My favourite emotions are feeling love, calm, happy and excited, I don’t want to feel the bad ones [emotions], I can make them [emotions] for myself, I have control over them.” Puck feels the need for control acutely. If things are not going according to plan, he will often lash out and resist attempts to calm him down. His mother relayed one of her most distressing experiences with him when his father fell ill on a holiday:

> My husband got very ill and we had to get him back to Johannesburg. When the boys woke up, I was packed and ready to go. But when we got to the airport, Puck threw the biggest tantrum out, because when we go to the airport, he either goes to Wimpy or Spur to eat something, because he doesn’t eat on the plane. So, I’ve got the luggage, Puck’s dad is in a wheelchair practically passed out, I just grabbed him and wheeled him onto the plane. He was eleven, so we are not talking about a tiny boy,

> and he threw a fit. It was the one time I needed him to be ok and he wasn’t. He didn’t care he was shouting and screaming that his dad would not let him go to Wimpy. The ground staff had to get my luggage because I knew Puck would run off. He was screaming “how dare you, we are not getting on this fucking plane,” like only Puck can swear. I had to drag him on the plane, his arm was blue from me pulling. After my husband got out of theatre, I went straight to the support group, I needed to talk it out. The therapist was so wise; she advised that the reason he wanted to go to Wimpy was because if he went there it meant everything will be fine. He thought that because he didn’t go to Wimpy everything had fallen apart. The fact that his dad is mortal really upset him; he wouldn’t visit him in the hospital and avoided him until he was better. He doesn’t like to be faced with our mortality; it terrifies him.

One of Puck’s favourite pastimes is meeting and engaging with famous artists. His room is a shrine to various music stars, and he speaks with passion about meeting anyone who he considers to be talented and famous. He described his ‘best-day’ in a monologue that he presented to me:

> One of the best days of my life has to be when I was chosen to perform in an opera musical called La Bohème. What was even more exciting was meeting all my favourite opera singers [he named each of them] and many other talented opera singers who I am very fond of. I learnt a lot from the singers and the chorus master. This was the best day because I felt like such a theatre star and an experience I shall never forget. Also, one of the perks of being a theatre star is getting presents each time you perform and that’s what I loved the most about being on stage. Even though it was far to drive but that is one of the few endeavours of my life that I will never want to replace with anything else in the world.

Puck is very sociable and enjoys spending time with people if he is not too tired. Some days we would spend over an hour together; other days he would barely manage 20 minutes as he was tired and need some ‘alone time’. This was often related to the content of our discussions. He found it very taxing to talk about school or his emotions; however, if we turned to creativity, music or the theatre, his energy would be restored. On one of our outings, we went to the theatre together. It was an extremely challenging environment for Puck as it was loud, and due to the participatory nature of the show, we were subjected to windstorms, a giant spider’s web and bouncing balls over our heads. Puck loved the show, he participated, and managed his sound sensitivity with ear plugs. On our way home, however, he was emotionally overwhelmed and exhausted and was unable to stop crying. I was extremely concerned and called his mother later only to be told he was fine. He had raced in and asked for his “red rescue”, a red cooldrink with a beta blocker in it, and once he had time to decompress, he was back to his bubbly self, re-enacting the show to his parents.

From actively seeking out famous artists to engage with, to his family and friends, Puck loves to have people around him, but on his terms. He uses his very close community, --- his mother, father, brother, uncles, cousins, friends, teachers, coaches, carers, therapists and even pets -- to navigate the world. Each has a role to play from “challenging me to think differently” to “making me feel special”, and he in turn can be funny, charming and extremely mischievous, saying outrageous things just to see what happens next. He is extremely close to his mother, and outright refused to talk about his relationship with her, shedding a few tears and telling me, “don’t make me go there” when I tried to explore the relationship further. He adores dogs, not in his home, but as playmates that he can visit for play dates [at his uncle’s house]:

> I like dogs, especially Larry and Quincy, they are more fun to play with. I also like Honey the Labrador. They have a different sense of humour and you can play and run with them.

Puck would often interrupt a conversation by stating, “I wonder what Larry and Quincy would say about this,” or “Honey would love this”. His father talked about the important role that the dogs play in his life:

> The best coping mechanism is talking about Larry and Quincy, so at the airport, when he is stressed, he will say, ‘what would Larry do now’. I find it very easy to distract him with Larry, or I’ll bark at him, it’s kind of like a secret language. I’ll say to him, ‘Puck, if Larry was here now, he’d be running into that grass looking for a piece of boerewors’, it calms him down immediately, it’s like a bubble popping.

Puck would often talk about how open and honest his dog friends are, “if they are angry or want to shout at you, they bark, but most of the time they just want to play with you.” Puck has an extremely developed sense of right and wrong, and often gets fixated on what he views as bad behaviour, or people being rude or disrespectful. His parents note that he does not stick to this own moral code, but he does expect it of others. He often asks extremely direct questions to complete strangers or makes comments that they may find offensive, such as about their weight or physical appearance. He is also extremely gullible and has been manipulated by strangers and 'friends' alike in his attempts to help them.

Puck likes to portray himself as a rebel and a risk taker, sometimes placing himself in risky situations just to see what will happen, such as ordering alcohol on a holiday or leaving his home to go to a mall without his parents' knowledge. He would find these experiences both terrifying and exhilarating and take great joy in telling his mother to "tell her what I did", at my next visit. When discussing his favourite characters, he would always choose the 'bad guy' as his hero; this was consistent across all my participants:

> My favourite character is Scar in the Lion King. He is very sly, he is a bit mean, he is like the villain. I like the way he speaks; I mean, I like the bad guys. A lot of people ask me why I like them, and I say because they have a deep voice like me. I like the fact that they get everything, like big songs and stuff. They have the biggest parts.

When I asked Puck to describe himself using archetypes, he chose 'Rebel Creator'. Puck and I spent a lot of time creating a personal brand for himself which included designing a personal crest, a collage of his future dream world and a personal vision. He also defined his personal values and identified what he believes makes him special and unique. We then discussed at length the people and actions he would need to take to achieve this goal. His crest combined his love of dogs, the theatre, and the colour red [as an avid Manchester United fan]. He summed up his personal motto as "never give up", testament to his determination to flout stereotypes of autistic people. For Puck, autism is an important part of his identity; it is not situated in his brain but in every aspect of who he is: "it sits all around me," he describes:

> It means I like different things to others… others like football, I like drama. People usually find out when they get to know me better. I don't usually explain it to people, I let them find out for themselves. They just talk to me and realise that I like different stuff. On the boat I had a little autism bracelet [Puck had recently been on a cruise ship with his parents]. My parents instructed one of the team councillors that I am autistic and then he told everyone else. And everything was fine because they all knew. I got on well with everyone and they got on well with me, because they knew. I didn't have to explain it because I had the autism bracelet. Sometimes I feel sad because I think I will lose some of my friends, that's why I don't tell them, they must find out for themselves, but I haven't lost any friends because of my autism yet. The low point is that people closed the lift on me [Puck had an unfortunate experience

> when a group of people closed a lift door on him so that he could not get on, he assumed this was due to his perceived difference]. Then on the last day of the cruise, I met this nice African American couple and they held the lift for me and I said, 'thank you for holding the lift for me and not closing it, because people have been closing the lift on me'. Then one of them said I must go and complain to the concierge and they will tell the captain. I told them, 'I think they were just being horrible', and he said people had no consideration. It made me feel disappointed that there was no respect for others. I saw a couple of shows on the ship, 'Burn the Floor' and 'Rock of Ages', which I actually went to see a number of times because it was so good. I think the actors also knew I was on the spectrum because they high fived me and stuff.

In his future dream world and vision, Puck wanted to travel as a creative performer:

> I want to travel the world, New York, London, but I also want to bring creative shows to South Africa. I want to be a triple thread, a singer, dancer and actor. I just want to entertain people. I want powerful roles, where people are a little scared of you. I would love to go to Julliard [School of Performing Arts in New York].

Puck described his values as having respect for people and putting them first, having imagination and creativity, having commitment, being punctual and never giving up. He believed that what makes him special is his ability to endear himself to people. He also believed that he is good at creative writing, has a good sense of humour, is committed, and works and trains extremely hard, and he is always on time. Puck believed that the people who would help him achieve his vision were his parents, and a range of coaches in theatre, opera and dance who could support him in achieving his goal of becoming a performer.

The most interesting development in Puck's personal narrative, however, happened after we had spent our time together. I collated the story he had shared with me about himself into a book which I took back to him after number of months. I first shared it with his mother who got visibly emotional as I took her through the detail of what Puck had envisioned for himself. She then stated, "you don't know what has happened, do you", and proceeded to tell me a remarkable story of how Puck had used the work we had done together to change his lifepath:

> After you stopped working with him, Puck came to us one night and told us that his current school, which he was still very fond of, was not going to help him fulfil the vision he had for himself. He decided that he needed to go to a school for performing

> arts like Julliard if he was really going to become an actor. He looked up which school supplied the child actors to perform at Montecasino, from one of the old theatre programmes he has; he keeps all of them. He then contacted the school and asked for a meeting with the headmistress. He was coming to us [his mother and father] because he needed us to attend the meeting with the headmistress! We met with her and she said she did not see why Puck could not join the school. We advised her he was autistic, and she told us that she doesn't put limitations on her pupils, and if he was prepared to try, she was happy to give him the chance. So, he started at the school after the holiday break and he is loving it. What is amazing is that his academic results are improving. He is also doing ballet and tap to help him with his proprioception and so his movement and walking has also improved.

A few months later, Puck's mother contacted me to say that he wanted to invite a few key individuals to a show that he was doing as part of the school, and he would like me to attend.

Sitting in the packed audience in one of Johannesburg's largest theatres, I was stunned to see Puck taking part in a group dance number. After the break, Puck then appeared on a screen talking about being autistic and how he wanted to become a role model for other autistic children who want to become performers. The lights then went dark and a single spotlight followed Puck walking onto the stage in a formal suit. Puck then sang 'You raise me up', initially on his own and later with a fellow pupil and adult opera singer, whilst a deaf choir signed the words in front of them; the performance was breath-taking (see Figure 19). It was an incredibly emotional event and despite a few tears, a standing ovation that went on for some time, Puck stood proud, confidently embracing his new role as professional actor and autistic creative performer.

When I took Puck through his book that we had created together, he just smiled, nodded and then asked if he could dedicate it to Quincy, one of his favourite dogs who had recently passed away.

Photo Source: Born to Perform

Figure 19.

Presence: a phenomenology of personal identity

The first phase of phenomenological exploration involved understanding how my research participants ‘showed up in their world’. I explored their physical presence, being in their bodies in the world; their intellectual presence, what they thought of their brain, learning and their ability to learn; their emotional presence, relating to their self-esteem and feelings of self-worth; and their social presence, which incorporated their values, their desired personality, identity, and what they envisioned for themselves in their future. Personal identity relates to how individuals develop themselves as self-conscious beings, with a distinctive mind-body-self-awareness that is separate from others around them. It focusses on the importance of ‘self’ and ‘personhood’: How people identify themselves from others, how they learn who they are, how they communicate their identity to others, and how they defend who they are, if they feel their identity is being threatened. Identity is influenced by family membership, gender, age, ethnicity, race, language, culture, wealth, but importantly, atypical identity is often influenced by one or a range of disabilities. With atypical children it is important to explore how they see themselves in a society that sees them as different, and how they respond to this.

Self-narrative plays an important role in establishing the 'self' or 'I', and thus personal identity. Merleau-Ponty (2005 [1945]) argued that who and how one is in the world is a combination of a person's historical and cultural context, and how we respond to this by either identifying with or rejecting it. He termed this a person's pre-personal and personal existence. As noted by Peter Antich, "narrative decision is both founded on the life it narrates and also defines this life, giving it a precisely determined meaning" (2018:433). Through self-narrative, we make sense of our lives, interpret events in particular ways, and give them significance. Our lives are structured by our pre-personal existence, but by interpreting and narrating this in a certain way, we can alter our lives in the development of our personal identities, as illustrated by Puck's story. In the context of atypical engagement with the world, the first question to ask is: in which world do the children live?

Living in parallel words

KC (11) often struggled to spend any length of time talking to me about her world, and as a result, I spent many hours playing games with her, especially in the garden of her family home. Her favourite game was hide and seek, which involved me counting up to ten and KC running to find a place to hide. She often chose the same hiding spot, on a pathway behind her house that was bathed in sunlight during my afternoon visits. As I usually knew where she was, I would make a show of searching high and low and then quietly creep to the back of her house where I knew she would most likely be sitting in her favourite place. On more than one occasion I found her sitting quietly with her chin turned up towards the sun, eyes closed and a beatific smile on her face, seemingly in rapture. I would often spend a few minutes observing her in this incredibly peaceful state. As a generally anxious child, it was good to see her so completely happy and at ease. I would finally announce "there you are", but rather than squealing in excitement she would often look a bit disappointed, as though I had disturbed her. She would reluctantly leave her seat and walk back inside with me. When I asked her where she went when she closed her eyes in the sun, she would smile and say, "to Joy."

KC loved the Disney movie 'Inside Out' (2015), an animated fantasy that explored various emotions as caricatures in a teenage girl's head. The main protagonist in the movie was a blue haired pixie character called Joy, named for her eternally positive outlook on life, the embodiment of the emotion joy. When I discussed her various emotions with her, KC described Joy as her perfect way of being in the world; she once exclaimed to me: “I never ever want to feel sad in the whole wide world, I just want to be happy like Joy.” Although she has a very positive and bubbly personality, KC was usually quite anxious in my company, as she was with everyone outside of her immediate and very close family and support group. She was easily overwhelmed by changes in her daily routine. This could include not feeling optimal physically, if anyone asked her a question, or in reaction to loud unexpected noises such as a dog barking. Any of these could lead to an emotional meltdown when she would display extreme anxious behaviour, babbling to herself incessantly and completely panicked. Her facilitator noted of these emotional episodes, “she puts her hands to her head like it’s going to explode”. Her meltdowns present as abject sadness with much crying and a feeling of complete helplessness. It often takes days for her to return to her bubbly self again.

Many respondents had the ability to ascend into an almost zen-like state, completely oblivious to the world around them. Blaze complained that she was constantly admonished by her parents and teachers to “get your head out of the clouds,” but as she noted, “the clouds are my happy place”. Dynamo expressed similar frustrations: “I like it in the clouds, that is where my ideas come from”. Once the children entered this calm, dream-like state, it was sometimes difficult to get them to reengage in the real world. Parents shared stories of how they could call their children loudly, only to be ignored completely. The children would not even register that they had heard something and may require a physical shake to return to the present. Most participants described these altered states of consciousness as their own personal worlds, where they could be exactly who and how they wanted to be. These ‘own worlds’ were described in various forms to me. I was often surprised at how real they were, almost like a movie that played in their heads, where they had the leading role. The children described how they could enter their ‘own world’ state and engage almost as if they were in a video game. If they were disturbed, they could metaphorically push pause and return to their adventure later.

An online post to an autistic community asked if any autistic followers had imaginary friends whilst growing up. Over 45 adults shared vivid stories of dream worlds and imaginary friends from as young as three years of age, who they recalled in detail. Some explained that their friends left them in their teen years, but a few still had them well into adulthood. These imaginary friends and worlds were inspired by their own imagination, books or films that had resonated and come to life for them, or toys that they were particularly connected to. Some had different friends in different spaces, such as bedrooms or gardens, who provided company, support and even alter egos, as one respondent described: “The girl in the mirror was my best friend, her name was Nicky and she was my opposite in every way…I was aged 3 to 10 years of age.”

Whilst I was conducting fieldwork, the Stephen Spielberg movie *Ready Player One* (2018) opened. It illustrated a futuristic world where people engaged primarily in a virtual fantasy space called the ‘Oasis’, rather than their dystopic real world. All my older respondents watched the movie, and the boys especially spoke animatedly about how this represented their experience of playing video games. I observed most of them extensively in these virtual online spaces and their characters were entirely different to the ones that I engaged with in the physical world. Shy, cautious children, often with severe speech challenges, would become confident characters in their virtual games, interacting with other adults and children through their online character and live dialogue through headsets, without a second thought or speech disturbance. KC struggled to verbalise how she felt or experienced different emotions. However, playing Minecraft took her through a full range of emotional states, complete with running dialogue as she built and engaged with this blocky world. She told me how much she loved Meme (her dog), and she illustrated much excitement and enthusiasm in building a structure that would take care of her, stating: “Let’s do this, let’s build this wall”. She was furious at the Creepers (zombie type characters) for trying to hurt Meme and destroy her structure, exclaiming: “Go away you horrible zombie, get away from my Meme! Don’t worry Meme, I will save you!” I have spoken to a few parents, especially fathers, who have used video games as a way to engage with their autistic children. Keith Stuart, author of *A Boy Made of Blocks* (2016), described how he used Minecraft to connect and play with his autistic son:

> He’d spend as long as we’d let him just wandering the blocky wilderness, building little shacks, or just digging for precious materials like iron and gold. It was lovely to see him so happy, and so engaged in something… Whenever we asked him about school, or how he was feeling, he’d usually respond with a few words, or a shrug, or ignore us, but if we asked about Minecraft, he completely lit up… After several years of medical examinations and occupational therapy and hearing tests and visits to paediatricians, the problems that Zac faced had become our sole focus. Minecraft

> helped us to see and appreciate him as a funny, imaginative, and perceptive child – it helped us to meet our boy (WH Smith Blog, 27th March 2017).

These virtual worlds were not just on video screens. Blaze told me how she spent hours staring into her mother's large dressing room mirror acting out different scenarios and plays, as did Puck. Ara barely spoke to other children between the ages of 3 and 6 years, unless they met her in the incredibly elaborate theme park she created in Minecraft. Navigating through this creative world, she would give you a detailed personal tour, illustrating a mischievous sense of humour otherwise only evident to her family at the time. KC had hours of video footage on her iPad that she had taken of herself telling stories, introducing the viewer to her world, her toys and anything that was important to her. These virtual worlds are different to the intense dreaming of 'own worlds'; it is not quite a dream as it still requires consciousness, and physical engagement or interaction. However, a video, a mirror, a camera or a screen is a filter that provides a level of safety and allows the children to engage in far more risky social interactions than they would consider in the tangible world. As virtual worlds were often related to areas of special interest, the children had a far higher degree of confidence and often perceived themselves to be experts, leaders or heroes in these spaces.

The next world in the spectrum was the tangible or real world. This was a difficult space for the children to engage with for various physical, intellectual, emotional, and social reasons, and was therefore not a place they chose to spend a lot of time. It was an environment that they found difficult to comprehend. They were often overwhelmed by the cacophony of sensory inputs, which led to 'problematic behaviour' as they tried to gain control and regulate themselves. The tangible world was a space of conflict, judgement, guilt, and embarrassment. It was also a space where defiance and rebellion became a means of gaining some level of self-esteem and self-worth.

Beyond the tangible, there were various alternative states where, unlike their 'own worlds' or 'virtual worlds', control was limited if not inconsequential to the children. These altered states often acted as a warning of physiological change, problems with medication, or that 'burnout' or 'shutdown' was imminent. Some parents also spoke of a similar state just prior to their child experiencing an epileptic fit, as one mother noted: "James gets this 'aura feeling' which gives him just enough time to phone and then lie down in the recovery position to minimise harm to himself". These negative states are described by adults as 'dissociation' where one appears detached from reality, 'depersonalisation' where thoughts and feelings appear disconnected from oneself, and ‘derealisation’ where the experience of one’s world feels hyperreal or unreal, “like you are living in a dream” or “you feel floaty and completely disconnected from your body”. I observed many children experiencing these alternative states, but they were extremely difficult for them to describe. I therefore engaged with my online community, who shared their experiences:

> I have this thing where my consciousness feels kind of setback in my head and I am profoundly aware of the separation of my mind and body. My body kind of feels like a puppet being controlled by my mind. A friend of mine calls it "going on autopilot”, but for me it's almost like HYPER mindfulness…I've asked mental health professionals and teachers about it in the past and no one knew what I was talking about. I once thought maybe it was some kind of disassociation, until I learned what that actually meant! Then I realized that it is kind of the opposite of disassociation (Amanda, autistic adult).

> There are two different kinds for me. The first usually doesn't last very long, and it's a signal to make me understand that I'm about to shut down or meltdown. It can sometimes come with a drop in blood pressure that makes my vision go dark and makes me feel fainty. The second type can last for days or weeks and makes me feel like I'm one step away from my body, controlling it from a distance. Everything feels far away and the outside stimuli are all delayed a bit. When I speak, it's like somebody else is going through the motions. This state usually happens when I'm under a lot of stress and kinda feels nice, because I'm disconnected from all emotions. It's a relief, but it most often precedes a depressive episode (Cathy, autistic adult).

> It's a bit like... the usual multi-layered carefully calibrated filters are no longer in place, and instead there is just a thick layer of something between me and the world, but beyond that, everything happens at once, at the same intensity (Rob, autistic adult).

As a precursor to meltdown, or as a body’s approach to protecting them from overtly stressful environments, dissociation was clearly another world that most adults and children spent time in. Many adults linked their feelings of dissociation to long term trauma. They believe that this is often misdiagnosed by health care professionals, as there is little appreciation of the stress and anxiety of the lived atypical experience in a neurotypical world. They noted how dissociation is higher among people in the autistic community due to their general vulnerability, challenges such as ‘pathological demand avoidance’, and difficulties processing emotions, especially linked to experiences such as emotional abuse and bullying.

The final worlds that I observed the children experience were those of ‘meltdowns’, sometimes followed by ‘shutdowns’. A meltdown is an intense response to an overwhelming situation, which could have physical, emotional or social triggers. They present differently in the children and adults. However, the most common form involved some anger, but mostly abject sadness and a sense of helplessness:

> His meltdowns are depressing. He wants to be alone. He locks himself up in the room, you don’t know what’s wrong. I have learned to let him be and give him space. I think the world just gets on top of him. I wouldn’t know if it was something specific. He just comes out of his room and he’s fine and we can’t talk about it (Puck’s au pair).
>
> Tears. Sad tears. You can see he doesn’t look angry; he just looks sad. There’s no aggression…I don’t remember exactly what happened, but he complained about something and just started crying and I remember thinking why would something like this upset you so much (Puck’s teacher).
>
> She doesn’t scream, she does deep, deep crying. The tears start rolling down her cheeks and they don’t stop. She doesn’t want anyone to touch her, it is incredibly sad (KC’s facilitator).

Some parents shared experiences of angry meltdowns, but these were often related to a deep sense of frustration. On one occasion, whilst sharing a range of negative experiences at his school, one of my participants lashed out and slapped me on the face. He was immediately sorry and apologetic; it was as though his emotions had gotten the better of him and needed a physical outlet. Crying, shouting, screaming, kicking, hitting, lashing out, biting, running away, or just collapsing on the floor, meltdowns were a manifestation of survival or sympathetic responses to the world. As noted by autistic blogger, Melody Rain: “Meltdowns feel like a release of all the bad things I have absorbed in the past few weeks. During meltdowns I feel like my life is ending and nothing will ever be better again” (The Art of Autism, 15th January 2020).

‘Meltdowns’ were often followed by ‘shutdowns’, where children quite literally shut down their bodies into an almost catatonic state. Shutdowns did not need to be preceded by meltdowns, and could also have physical, emotional or social triggers. Some adults ascribed shutdowns to a range of mineral and vitamin deficiencies such as choline, magnesium, potassium, vitamin B12 or taurine. It can also be the result of a sensory shut down, which has a range of causes that result in inflammation and changes in blood pressure. It was most often associated with excessive anxiety and physical exhaustion, as one adult described: "It only happens when I'm overwhelmed, and only in public…My theory is that I'm trying so hard not to have a meltdown in a public space that my brain takes it upon itself to time out". Blaze (14) described how she would often "blackout" during exams or tests:

> There was a lot riding on this exam, and it was all about comprehension which has never been my strong point. The panic set in when my teacher put the exam paper on my desk. It was massive, endless pages of writing which I knew I could never get through in time. I started trying to read frantically, but the worst thing was, one of the smartest girls in my class was sitting next to me, and she was reading through the paper like a machine. She kept tuning the page and smiling, turning the page and writing, I couldn't stop looking at her. My chest was pounding faster and faster and I started struggling to breathe. Then I don't know what happened, it's almost like my body took over from my brain, it was really weird. I felt this wave of happiness wash over my whole body, like I was bathed in warm sunlight, it started in my head and washed down to the very tips of my toes. I lost a bit of time, but when I came too, I was completely calm, I looked at the paper, turned it over, put my head down on my desk and fell fast asleep. I only woke up when they were taking the papers in. I had even dribbled a bit on the paper, it was hilarious, but I got to the point where I just don't care anymore.

Shutdowns can be full, where a child is catatonic, or partial, where the child experiences a loss of memory, sense of time, sense of self and various aspects of cognitive thinking or abilities. Full shutdowns, as Blaze illustrated, involves the involuntary total loss of function and subsequent shut down of the body, often followed by sleep for short or longer periods of time (Loos & Loos 2004). This shutdown can lead to the child's body going limp or rigid during this period and rather than simple avoidance behaviour, it is associated with a significant stress response. 'Ask an Autistic' teenage vlogger, Amythest Schaber describes it as: "the brain's method of self-protection, when there's too much going on, it's a self-preservation technique to withdraw and save yourself" (Ask an Autistic, 13th November 2014).

I observed the children in my study, in all these parallel worlds, from 'own' to 'virtual', to 'real', to 'disconnected', to 'meltdown', and finally to 'shutdown'. All these states had an impact on how they experienced their world and how they perceived themselves. This is extremely relevant when one considers the amount of time the children spent in each of these worlds. Shutdown and meltdown occurred relatively infrequently, but given the choice, the children would prefer to spend far more time in their 'own' and 'virtual worlds' than in the tangible or real world. This is where they felt most confident and at home. These dream or partial dream states were often not possible due to school environments or intense remediation programmes, but they were certainly their most desired spaces to occupy:

> One of the things I can do because I'm autistic, it's an ability rather than a disability, is I've got a very, very vivid imagination. Let me explain it a bit, it's like I'm walking in two worlds most of the time. There's the real world, the world we all share, and then there's the world in my mind, and the world in my mind is often so much more real than the real world (Rosie King, autistic advocate, TEDMED, September 2014).

Diagnoses of dissociative states are usually treated as abnormal by the biomedical fraternity and associated with pathologies such as schizophrenia, multiple personality disorder and borderline personality disorder. However, in many non-Western cultures experiencing multiple selves through practices such as spirit possession and altered states of consciousness are perfectly acceptable (Scheper-Hughes & Lock 1987:16). For atypical children these altered states of consciousness were critical to their wellbeing, self-regulation and contributed to their identity and how they presented themselves to others.

Cautious bodies, adventurous brains

As I have already described, all my research participants had relatively difficult starts to their lives. Many were born prematurely, some had spent time in intensive care units, and most presented as physically cautious. According to their parents, all had displayed some challenges meeting their expected developmental milestones, and some had found creative ways to make up for this. Ara's mother described how she never crawled: "she used to scoot around on her bum using her legs to propel herself forward, much to the amusement of everyone who watched her, like a little jack-in-the-box". Puck didn't say a word until after his first year and then started speaking in full sentences.

The most vulnerable child at birth was Buzz (14): “The worst day of my life was probably the day I was born. I had a heart condition and I never left the hospital for a long time. All I remember was there were lots of tubes and stuff and I wasn’t happy about that at all”. Buzz was born at thirty-six weeks, with a hole in his heart, and had nine operations in the first year of his life. These physical challenges have continued well into his teenage years. He is not interested in placing his body in any risky situations, and as with all the children, his ideal place is in his lounge playing video games, watching his favourite movies or wrapped up in bed. Like Puck’s experience of risky physical environments, Buzz explained: “I don’t like sports, I’m a bit of a scaredy-cat for ball sports or tackling sports like rugby, and my worst nightmare is paintball”.

My body when it is happy

I spent a lot of time exploring the children’s physical presence and embodiment, and what it felt like to be in their body, in the world. Using the outline of a body, I asked the children to draw what they thought was going on inside their bodies when it felt good and when it felt bad (see Figures 20 and 21 in the following pages). The pictures they drew and the insights they shared revealed an often-fraught relationship between their bodies and minds. Where their bodies appeared fragile and often unpredictable, their minds were perceived to be creative, imaginative, and strong.

In this exercise, most of my respondents struggled to conceptualise what was going on inside their bodies, as noted by KC: “I don’t know what my insides look like”. However, after some discussion, an interesting picture emerged. Rather than physical exertion and pushing their bodies to the limit, as many of their neurotypical friends or siblings did, the children felt happy if their bodies felt contained, warm and calm. They were particularly concerned that everything worked as it should, revealing a fear that this may not always be the case. Echo (15) described his happy body as “everything is in good working order, my lungs are nice and big, my heart is fine and the blood is flowing normally, my brain is red and full of blood, it’s golden”. Most associated a healthy happy body, with healthy happy emotions, as Ara (11) shared: “When my body feels good it feels happy and joyful”.

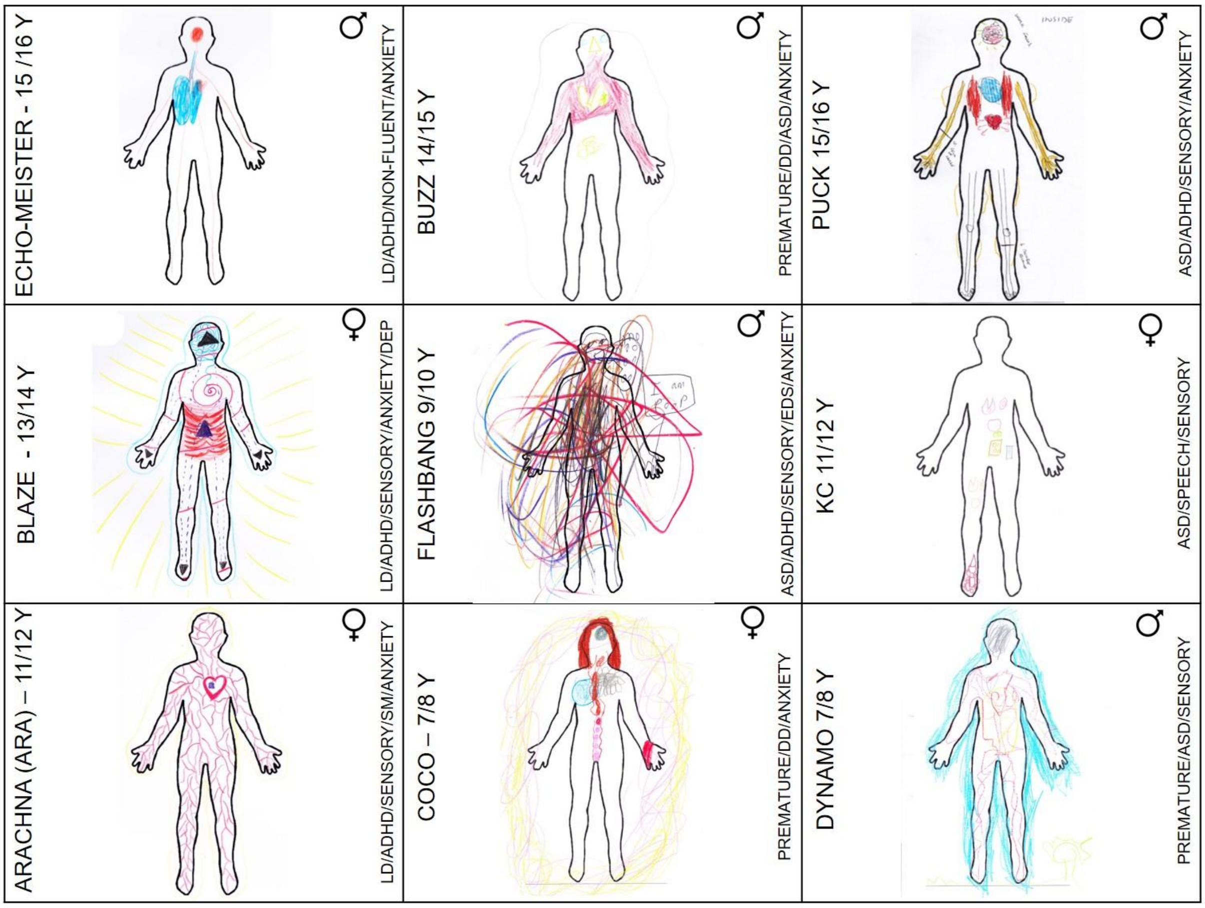

Figure 20.

The most important organ to all the children, in a happy body that feels good, was the heart, and the blood that it pumps to the rest of their body. As noted by Blaze (13), “when my body feels good, it starts in my heart and spirals out from there, energising my whole body”. Coco (7) drew a silver flower for her heart and explained: “I feel strong here”. When asked where she feels happy, Ara (11) advised: “I feel it mostly in my heart, it feels like a butterfly fluttering around, it can be big or small, it spreads all the way through my body”. Even KC (11), who had difficulty conceptualising the inside of her body, described how she felt happiness in her chest. In addition to the heart, blood is seen as critical for bodily functioning and where energy and life emanate from. Dynamo (7) drew an intricate map of vessels reaching throughout his body and explained “blood is very important to your body”. Only Puck noted any challenges with his heart, as he explained, “sometimes it feels not so good, it is still red but more intense, it is opening up rather than closing down”, describing how even when his heart does not feel optimal, it still feels open to the world.

The brain was deemed the second most important organ by the children and was usually directly connected to the heart. It was described as a tool of focus and bodily connectedness. Buzz (14) described his brain a, “focussed on the future”, and drawing his brain as a triangle, he explained “I am very observant”. Puck (15) explained that his brain “helps me work and focus”, and that it “always does what it needs to do”. When picturing his brain, Puck described how “although it’s all gooey, there is stuff working in there, like gears working together”. This connection was mirrored by Blaze (13), who stated: “My brain is interconnected and powerful, its connected to my heart, where it gets its power from”. Other organs of power related to lungs, described as “big and healthy”, and muscles that can “make you feel strong”.

All children shared some level of understanding of sensory processing and how their sensory abilities allowed them to engage differently with the world. As noted by Blaze: “My senses are an intricate strategic network of triangles and they communicate in a mystical way”. However, their heightened sensory ability was also seen as a double-edged sword, as too much sensory input could cause them to become overwhelmed and experience intense pain. The last organ to be spoken about was usually the stomach, which was seen as: “Ok, as long as it remains calm and relaxed” (Echo, 15). When exploring the negative aspects of the body, the stomach was usually the primary culprit and all areas of concern emanated from it. It was viewed as an organ that could not be trusted. If it can be contained then it was viewed positively for its ability to “hold things together” (Blaze, 13), however, as noted by Buzz (14), “my stomach is a bit anxious even when I am feeling good”.

The children also depicted an aura surrounding their body. In each instance it was described as protective, containing the body and keeping everything securely inside, as noted by Buzz (14), “I have a strong protective aura around my body”. Dynamo (7) described his aura as “blue, like water washing over me”, and Blaze (13) described hers as “calm internally, but it radiates sunshine to everyone else, people feel warmed when they are near me”. When exploring the context in which their body felt happiest and most at ease, all children described various forms of nature or the natural world. This was supported by my experience of playing with the children, who visibly relaxed when outside, as Dynamo (7) explained: “Nature is where my body feels better and happier”.

My body when it is unhappy

Exploring the body in the negative sense brought on high levels of anxiety in all the children as they recalled injuries, operations, and painfully traumatic experiences that they were still struggling to process. Even drawing showed their distress as they violently stabbed or scribbled on the page. The children noted a real sense of disconnection in an unhappy body, as explained by Buzz (14), “my brain, heart and limbs are all square boxes and disconnected from each other”. Blaze (13) described her unhappy body as, “feeling broken and spilling out all over the place”. Dynamo (8) physically acted out how he feels sickness all over his body, and then illustrated how it felt like his life was being “sucked out” of him as he slowly collapsed on the floor in front of me. Like Puck (15), all the children felt particularly sensitive in the morning. Dynamo (8) noted, “I always want to go back to bed”.

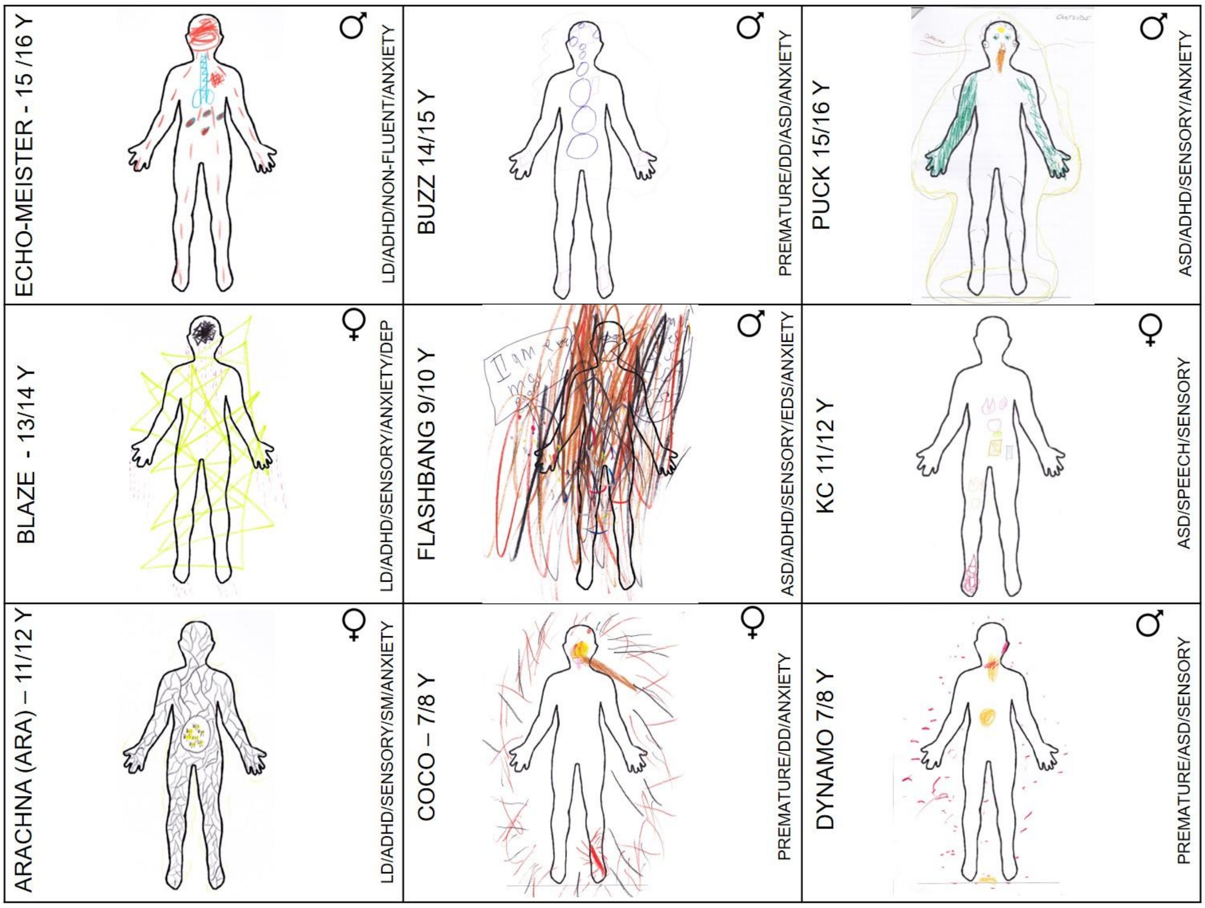

Figure 21.

From an embodied perspective, the most distressed child was Flashbang (9), who like his older brother was battling with the early stages of Ehlers-Danlos Syndrome (EDS). This syndrome is a group of disorders that affect the connective tissue that supports the skin, bones, blood vessels and internal organs. Flashbang struggled with both EDS and extreme sensory processing challenges. His mother once stated in response to his often-erratic behaviour: “Don’t forget, he is in pain all of the time”. The over-flexibility of joints and blood vessels can lead to major problems with blood pressure, frequent subluxation [partial or full dislocation and relocation of joints], and almost constant, chronic pain:

> He has constant IBS (Irritable Bowel Syndrome) and nausea; transit issues, or how food moves through the gut, are typical problems with EDS as there is a lot of collagen there. He has cervical instability, you don't see it as much with Flashbang, but his brother is constantly adjusting and clicking his neck [mimics wrapping her hands around her neck and chin and twisting upwards until it clicks loudly]. I believe his dysautonomia (a disorder of the autonomic nervous system), hypertension (high blood pressure) and fibromyalgia (widespread musculoskeletal pain) have to do with a compression of his vasovagal nerve (manages para/sympathetic nervous system). If you look up the RCCX theory, there is a Dr Sharon Meglathery, who developed mast cell activation, POTS, CFS and a range of other syndromes that overlap with EDS. She describes it as a clustering of genes that makes you susceptible to a whole range of illnesses, but it is also associated with really gifted children who are often on the spectrum. Flashbang is a happy child, he has a plan for himself, but I don't think anyone appreciates what it takes for him just to show up. Teachers will say he's just not delivering enough but imagine never being completely in control of your body, it's completely unpredictable…The instability of his body gives him a great sense of insecurity, his knee cap is loose, so it sometimes just gives way. His brother is constantly experiencing dislocations and subluxation of his joints, his hip will go out, and then because his joints are so loose, it will flop back in again. He pops his collar bone back in with his finger, his knee tracks incorrectly and he is at real risk of getting hip dysplasia. No one understands this condition, but now that I know what to look for, I see it in lots of children. As a teacher, I see the kids who are constantly adjusting their joints, roaming around the school, fidgeting and falling off their chairs, it's a big issue that we need to start taking seriously (Flashbang's mother).

Flashbang attacked both body contour pictures with a high level of aggression, indicating the distress he feels in both his happy and unhappy body-states (see Figure 22). For the former he wrote "I am poop", in a speech bubble, and for the latter, "I am more poop", suggesting little to differentiate the two. For his 'unhappy body', he forcefully stabbed the page with the pencil crayons. He scribbled across the body contours and when I queried this, he shared that this was because he often felt like he had no control over his body.

Figure 22.

The primary source of an ‘unhappy’ atypical body starts in the stomach, the seat of all their anxiety, often illustrated through the physical act of vomiting. Buzz (14) described how anxiety and stress started in his stomach and eventually bubbled out, and he shared how he had physically vomited during a recent maths test. KC (11) drew a grey box to illustrate where she felt anxious or afraid: “It’s like a square in my tummy”. Ara (11) noted how anxiety felt like a swarm of bees in her stomach that spreads across her body. Puck (15) drew his stomach where his heart was, and vice versa. He described it as “light blue when it works well”; however, “it sometimes doesn’t feel good like when I get diarrhoea” which he admitted to experiencing frequently. Although feelings of distress and anxiety start in the stomach, they often move up into the head, causing it to ‘malfunction’. Echo (15) explained “my brain is all over the place, I can’t do anything, it just bounces all over the place”. Blaze (13) described her brain as “a sieve with a black hole, where everything important is sucked away into nothingness”.

Although most children believed they had ‘superior sensory abilities’, their sensory sensitivity, along with their fear of over stimulation or sensory shutdown, was also a cause for concern. Blaze (13) described how sensory overload can leave her feeling “cut and bleeding and I can’t feel anything, or actually I feel everything too much”. Puck (15) has a sensory pack that he carries with him to ensure that he does not get overwhelmed by sensory inputs, as he notes:

> I have ear plugs because I have very sensitive ears, gun shots and loud noises hurt them. My eyes are fine, but I don't like the smell of bad things. There is a drain near my school that is down, and I can't concentrate with the drain smelling like that. I also don't like people touching me.

Most children associated bodily feelings of distress with the breakdown of their body and often described it as faulty or letting them down in some way. Echo (15) explained: "When I'm upset it doesn't matter how much I breathe, I'm always out of breath, my lungs just don't want to work". Beyond being unruly, there was a clear sense that when they felt distressed, their bodies lacked integrity. This was most clearly illustrated in the aura that surrounds an unhappy body, which was drawn and described as jagged and broken by most of the children. Their bodies either "spilled out into the world" (Blaze, 13), or due to their permeability, were vulnerable to the world infiltrating them. What was most troubling for the children was that they felt they had very little control over these bodily boundaries. Ara (11) noted that her aura was "all broken up", and Buzz (14): "My protective aura no longer covers my whole body, sometimes I just shut down". Coco (7) drew her unhappy aura as intersecting lines as though it was broken, and Dynamo (7) drew his aura by stabbing red dots all around his body that "allows the sickness in and the vomit out".

In contrast to their often-fractious bodies, all the children valued their brains and their ability to think creatively and differently. When asked to describe how their brains worked, most children used the analogy of a machine, either gears or a computer, as described by Echo (15):

> My brain feels like the biggest computer, there are electrical impulses of ones and zeros, all strung together in long lines of code which makes up my memories and experiences and thoughts. My brain naturally pulls everything together into strings of code.

Puck (aged 15) described his brain as an intricate set of gears that whirl around his head. Dynamo (8) drew his brain as a well-oiled machine where race cars pull his blood around his body at a very fast pace. When I asked him how his brain works, he drew a small circle with a tiny car inside it and explained "that car drives my memories around". Flashbang (9) was in awe of how his brain works, noting: "It is all that I need". When I asked him about his future 'dream world', he explained that he could achieve anything as his mind was "infinite".

Both Ara and KC described their brains as having a large control centre with a number of levers and buttons that can be pushed to control their brains and emotions. Ara (11) described her memory as a library, run by a librarian:

> When a memory is needed, he goes to the library and asks for the memory and the librarian finds a book where the memory is kept. He returns to the control centre opens it and puts the memory in a machine, and then I remember. But sometimes the book is very faded, and I can't remember. I have no control over my brain when I'm sleeping, it is just resting, but sometimes the guy gets a memory from the library and puts a dream in, and that's what I dream. My dreams are so exciting, they should be made into movies.

Some children noted a clear conflict between the structured analytical side of their brain, and the creative more imaginative side. Buzz (14) drew a battle between robots and freedom fighters, explaining his constant battle between being creative and trying to remember things like maths. Coco (7) drew an intricate picture of soldiers and foxes working together to fill a river of blood that takes energy to the rest of her body. After much discussion, it became clear that the soldiers represented structure and the fox was the creativity in her life. The struggle was to try and get them to work together to put blood into the river, because, as she noted: "They don't always work together well".

On learning and learning environments

Despite their predominantly positive views on their brains and how they function, all children had been diagnosed with some form of learning disability and spoke at length of subjects that they struggled to comprehend and engage with. Tests were highly stressful events, as Buzz (14) noted: "When I see the maths test, I start to feel the vomit bubble up inside me until I actually [acts out vomiting on his desk]". Despite all having excellent memories, high stress test situations caused them to forget everything, as Ara (11), explained: "With maths, it just falls out of my head and I can't remember it. It's how your brain works; I have to enforce my brain so my memory isn't so faint". Learning challenges of dyslexia, dyscalculia and dysgraphia were all coupled with difficulties in concentration and ADHD. Despite extensive research that illustrates the difference between intellect and the neurological circuitry required for reading and mathematics, children are often labelled as stupid, lazy and wilful, and this impacts directly on their self-esteem and self-worth (Wolf & Stoodley 2007).

Maryanne Wolf (2007) argues that human beings were not born to read, and that this skill was developed through adaption and evolution over many thousands of years. Wolf explains that through neuroimaging, researchers were able to assess how different brains, those of a typical reader and a child diagnosed with dyslexia, 'fire' when reading. The neural signature of the dyslexic brain indicates specific disruptions to the posterior reading systems that are crucial in the decoding of words and sentences. Echo's mother shared her frustration, when trying to help him practice for spelling tests when he was around seven years of age:

> I would show him a word and he would get it wrong. We would practice writing it for ages, and then the next day, it was as though he had never seen the word before. He would also constantly reverse 'b' and 'd' or 'a' and 'o', it was very frustrating.

Wolf (2007) notes how in a learning environment, a child could be shown the word 'stone' and rather than that information being sent to the reading circuit of the left brain, it shifts across to the right brain, which is associated with conceptual, creative and holistic thinking ability. The child interprets the word as something to do with a round object that you can throw and may respond by saying the word 'rock'. In a classroom environment, the child appears wilful and disrespectful, as clearly, they understood the meaning of the word, but have chosen to be disobedient in their response.

All children shared stories of how they felt misunderstood in the classroom, and many had been bullied by both teachers and classmates. While some had positive experiences, most described instances of humiliation, usually in front of their peers:

> In grade two I was struggling to read, and my teacher wouldn't help me with the words. I couldn't figure it out and she said you can't keep asking me [for the answers], but I couldn't do it myself. I was trying but I couldn't. Sometimes it made me *woes* [cross], and I struggled to manage my anger. I didn't tell my mom and dad, cos I thought I could handle it on my own (Ara, 11).

> In grade three we had spelling tests every Friday and I would always get nought out of ten for all of them. My teacher, she had long red nails like talons, started by putting me at a table all on my own at the front of the class. One time she told me to hold my hands out in front of me and smacked me across my fingers with a ruler, because she thought I was being naughty and switching letters around on purpose. I repeated grade three at another school and I remember spending whole breaks writing the word 'they' over and over again on the black board. Then I would have to use it in a

> sentence, and I would write ‘thay’ again, it just didn’t make any sense to me (Blaze, 13).

> At my old school I had a horrible teacher and cycle tests were hard. She used to shout at us if we made a mistake and I didn’t like that (Puck, 15).

Most children expressed high levels of frustration at their school’s inability to see them as multifaceted individuals with diverse interests, as noted by one adult: “They just see you as clever or stupid and there is nothing in-between”. There was a clear sense of exasperation at much of what they were being taught at school, and how this had very little relevance to their specialist interests, which they all hoped to pursue as adults. There was also a high degree of conflict between the children’s views of their brains and ability to learn, and the school’s assessments of their abilities through tests and examinations. All the children were either in a special learning environment or had to attend a range of remedial support solutions. Some saw the relevance and value of these remedial interventions, but others found them to be frustrating and boring. Their presence in these environments also seemed to compound their feelings of difference and ‘disablement’ in the intellectual space. This appeared to have a marked impact on their self-esteem, and most spent a lot of time trying to prove their maturity and intellect. They did this by either seeking out the company of older children or adults to spend time with, or sharing endless streams of facts and information, as Echo (15) once proudly informed me: “My friends call me Google, because I know so much stuff”.

Technology, although embraced in some learning environments, is often treated as a ‘necessary evil’ rather than a tool to enhance learning. Parents are regularly chastised for allowing their children to have ‘too much screen time’. Atypical adults argue that “screen addiction” is an “ableist view”. For most, technology has changed their lives profoundly for the better, enabling them to communicate, attend school and make social connections:

> My phone helps me self-regulate in new or overwhelming environments. People constantly comment and shame me, but they have no idea how much I freak out without it (Amy, autistic adult).

> An activity that occupies the busy parts of my brain, for me, is essential to processing information. I get this from playing an online video game or digging around on the web. It is as if the logic parts of my brain can't make sense of the information I take

> in, in the course of the day until I give those parts that crave repetition something to do (Ralf, autistic adult).

> I can't handle many relationships in person. I live my life mostly in forums online. It's where I am most comfortable talking to people. I also can form my thoughts better in writing (John, autistic adult).

Beyond assisting with writing and spelling, technology provides an important filter for many atypical children, assisting them with self-regulation and providing them with a safe social space to engage with the world around them. Rather than a resented accommodation in the learning environment, all participants believed their phones and tablets were critical tools that enabled them to engage positively with their world.

Dyslexia is often associated with famous creative and entrepreneurial individuals including Thomas Edison, Henry Ford, F. Scott Fitzgerald and Pablo Picasso. Richard Branson, founder of the Virgin group, and renowned Hollywood producer and director Steven Spielberg, have spoken about how dyslexia helped them to think differently about the world.[31] These ‘successful dyslexics’ are not necessarily the norm, but there is evidence of right brain dominance and a preference for careers in creative thinking, performance arts and design amongst people diagnosed with this learning challenge (Wolf & Stoodley 2007). Creative abilities are often related to specialist areas of focus or interest, which were present in all my participants. Echo built his own super gaming computer at the age of twelve from watching YouTube videos; Dynamo was obsessed with any form of engine or vehicle and created Lego constructions that defy belief for his eight years of age (Figure 23):

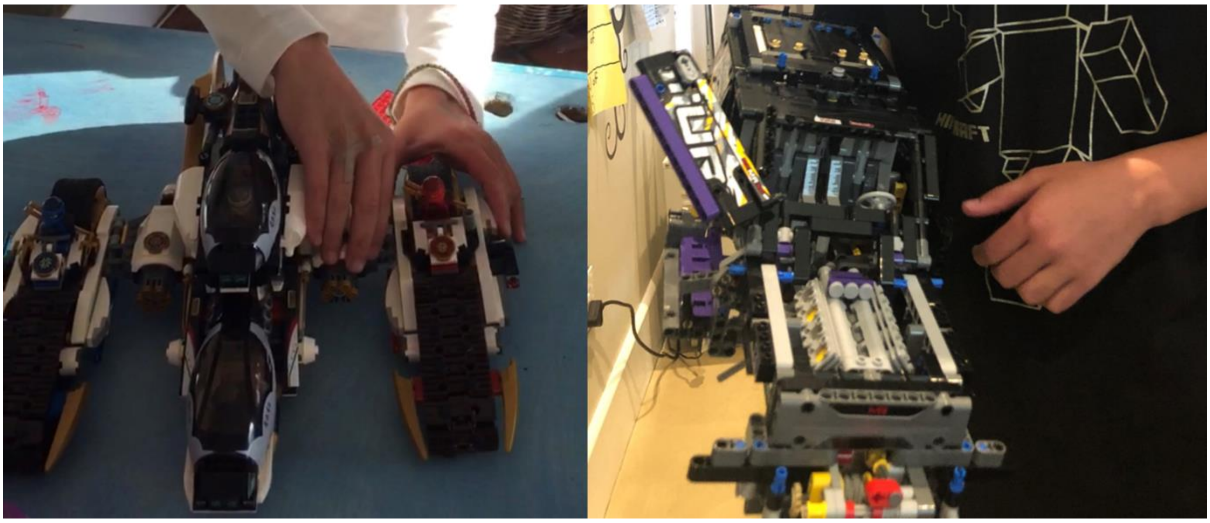

Figure 23.

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[31] https://www.dyslexiaonline.com/basics/famous_dyslexics.html Accessed 27/09/2019

Coco (8) writes and illustrates children's books; Ara (11) engages in complex design projects on her iPad; and Puck (16) has thrown himself into a career on stage. Brock and Fernette Eide (2011), explored these specialist interests and abilities, which they describe as different patterns of optimisation and cognitive function. They note a distinct 'trade-off' between areas of skill and other cognitive sets, which are required in the learning environment. This trade off in many ways mirrored the children's descriptions of the struggle that exists between the creative and structured sides of their brains.

The children noted that many of their struggles with learning related to their school environments, which most found to be extremely stressful. I asked the children to describe or design their ideal learning environments. The results included libraries, spaceships, creative art studios, movies, theatres, playgrounds, waterparks, tech campuses and online settings. All children felt they learnt better outside, in nature, than inside a classroom, and all desired a learning-by-doing approach: "I wish everything could turn into Star Wars one day. We could explore the galaxy and space. We would get briefed on our daily mission and we would learn by doing. We would learn about the ship and how it works. We would explore new worlds for science" (Buzz, 14). Many of these ideal learning spaces incorporated sensory accommodations and called for multiple approaches to learning: "There is lots of white, and music is playing in all the classrooms. There are no uniforms, and you can wear comfy clothes like your PJs. There are comfy egg chairs that you can hide in and no desks" (Ara, 11, describing her ideal school design pictured in figure 10 in the methods chapter). Dynamo (8) ran to get a 'Playmobile' brochure when I asked him to explain his ideal learning environment. He showed me a picture of a water park that he had clearly spent a lot of time studying. He described how you could "splash around all day" whilst learning about nature, animals and the environment. The children who struggled with anxiety all desired environments that felt more like home, especially their bedrooms. Of paramount importance was the focus on the child, and their unique learning styles, rather than developmental stages and milestones.

Many parents of autistic children choose home-schooling due to the stress, anxiety and trauma that they experienced in the traditional school environment:

> The real world of school gave my kid PTSD at age 6. Screw that. We have home-schooled ever since. She is 13 next week. At home and with home-schooled kids of all ages and abilities (with parents present to teach and expect kind behaviour) my daughter has had the chance to become strong, happy, and healthy. She has developed

> the inner resilience to handle the 'real world'. Something that could not have happened while immersed in it. It's like saying someone will learn to swim while the sharks are biting at them. They have better chances if they are a strong swimmer equipped to handle sharks. Throwing a bunch of same age kids in a box and hoping they learn great social skills is nonsense. My daughter plans to attend high school in a year. It will be a testing ground, but I think she'll be ready because she has been able to grow into herself rather than into whatever a lot of other kids push and pull her to be. She was never going to fit in, and she's ok with that. (Denise, mother of an autistic teenager)

Education and learning styles are a highly contested space in the atypical community. Most traditional and mainstream schools follow a structured developmental approach to learning, founded in a belief of universal development pathways (Piaget 1936; Steiner 1996 [1923]; Montessori 1966; Gardner 1983). This approach is often criticised for its lack of cultural relativity, its ‘deficit’ view of children, and its prescriptive approach to teaching (Nolan & Rabin 2015). In the world of autism, Applied Behaviour Analysis (ABA) claims to be the only evidence-based ‘treatment’ for those on the spectrum. However, it is widely rejected by the autistic community for its use of behaviour modification theories and practices pioneered by Pavlov (1960 [1927]), Skinner (1974) and Bandura (1977). My discussions with children, despite their young age, revealed a desire for multiple pathways to learning. Knowledge was viewed as relative, and meaning was obtained through engaging in multiple social realities and contexts in the tradition of post-structuralists such as Foucault (1972), Bourdieu (1973) and Canella (1997). This was most keenly observed in Puck’s decision to find an educational environment that would support his vision and desired identity for himself, and his exercising of agency to pursue this. The new educational structure that he sought was no less complex than a traditional school environment. The fundamental difference was that it focussed on his needs and abilities, rather the dominant biomedical discourse of what he was thought to be capable of, as a child on the autism spectrum.

From sense of self to social identity

In his debate on the self, identity and culture in anthropology, Martin Sökefeld (1999) examines how in a modern world defined by plurality and difference, identity is no longer about sameness, group identity and belonging, but rather about how the self relates to groups, societies and shared identities. ‘Atypical-ness’ is about difference, or a collection of differences, that sets certain children and adults apart from the neurotypical majority.

Sökefeld notes that identity is not static but rather constantly transforming, as we interact and engage with others in our social environments creating a “maze of competing and antagonistic identities” (1999:424). Through our narrative self, we can define what is important to us and how we wish to be seen, a ‘sense of self’ that expresses our agency in the world. However, it is also subject to the dominant discourse of society. Personhood can be threatened if this dominant view sees a particular ‘self’ as problematic. We must constantly negotiate our individual identity within the context of these different power relations, a “reflexivity between self and everything else” (1999:430).

Puck personifies this endless negotiation and has worked hard to overcome feelings of negative self-worth and low self-esteem. From being diagnosed and labelled as autistic, ADHD, learning disabled and a range of other challenges, his specialist interest in music, dance and theatre has helped him to create a desired social identity. Despite his natural skills in music, his success has largely been due to hard work and perseverance, as defined by his personal motto, “never give up”. Rather than being negatively defined by his diagnoses, he has embraced his autism, not as a label but as something fundamental to who he is, as he explained: “It sits all around me”. Some children were less confident in embracing their difference. Blaze (14) noted: “It was helpful to know that I am dyslexic, but I hate the way people treat me, like I use it as a crutch or something, as though I am just pretending, just so I can get special help”. For most, their unique way of seeing and being in the world defined their identity and personal sense of self. When asked what they felt made them special, all children spoke of their ability to see things no one else could, and the creativity that this enabled. From design to innovation, drawing to writing, they all claimed ‘enhanced strategic abilities’.

Self-esteem is described as confidence in one's own worth or abilities. This is a difficult notion to embrace when you are constantly told that you are different and that your abilities are possibly sub-standard:

> The idea of seeing myself as more than average is hard. Mostly because I value truth so much. Trying to convince myself 100 percent I'm exceptional is incredibly hard because I see myself as just... existing (James, autistic adult).
>
> I don’t think any of us gain autism acceptance for ourselves until we are older and out of school. I believe it is because we are forced into a primarily neurotypical space where all of our social "oddities" are scrutinised. While I was not diagnosed as a

> child, I did know I was different. I hated that difference because my peers liked to point out that difference. I didn't fit in. Now that I am older and have found my community, I am completely happy with my neurology. I am able to reason now that I am just like everyone else in that I have strengths and I have weaknesses. But as a child I could never have come to that conclusion because the differences were too pronounced. It was like being under a microscope and every single thing that made me different was ammo for the other kids or at the very least a reason to not be included (Mary, autistic adult).

> Being pressured to conform to a society actively engaged in warring on our kind of people is pretty damn stressful, and for many of us that war goes all the way into our own homes and bedrooms. Because our families are socialised to perpetuate those abuses, large and small, in the very way we are treated by our parents, teachers, family, friends and providers. That we are, genetically speaking, already prone to anxiety disorders or other health issues that aggravate stress states, doesn't help us at all. I think rather than saying fear is the primary emotion felt by autists, we should say that the majority of autistic people experience high levels of stress due to internal and external factors that are often not addressed appropriately in our current society (Amber, autistic adult).

Feelings of inadequacy can lead to increased anxiety, especially when performance is important, such as during tests, exams, or public appearances. For most participants, general and social anxiety was crippling. Flashbang (9) noted how he felt anxiety almost constantly, and because of this, his worst day was “every day at school”. Ara (11) described her anxiety in her worst day, as a litany of humiliating and painful experiences: “I do a terrible test and the teacher shouts at me and tells me to do better. Girls laughing at me at break because of how I did, pushing and shoving me. I fall down the stairs and have to go to hospital”.

Ara was particularly fearful of not being able to do things correctly, which led to select mutism during nursery school. She also refused to try any new academic concepts, until she had perfected them in the remedial space. Coco (7) constantly apologised for her behaviour, which was not problematic, and Echo (15) struggled for years with ‘non-fluency’ [stuttering] in all social interactions until his parents started treating his anxiety proactively with medication and play therapy.

All my research participants spoke at length of their fear of behaving inappropriately, as noted by Morgan, an autistic adult: “The single most constant feeling I had for most of my life was guilt.” Her guilt was due to emotional outbursts, expressions of anger and meltdowns that she experienced for much of her childhood. These were, however, usually a result of sensory overload and system shut down, none of which she had any control over. Popular social work scholar, Brené Brown (2010), who some adults referenced in our discussions on self-esteem, describes guilt as ‘I did something bad’ and shame as ‘I am bad’. For Brown, guilt focusses on behaviour, whilst shame focusses on self. Amongst my respondents, these definitions appeared blurred. The children may feel guilty because they believe they have done something wrong, but the response to these perceived indiscretions was often communicated to them through shaming, as noted in their recounting of negative school experiences. Feelings of shame are exacerbated by practices such as referring to individuals on the autism spectrum as ‘low’, ‘medium’ or ‘high functioning’. To be functional relates to an individual’s value, usefulness, and ability to cope. However, to be dysfunctional, is to refer to something that is flawed, broken or defective.

For many atypical children and adults, guilt and shame were also associated with depression, which they frequently linked to their inability to cope with the demands of everyday life:

> I have low self-esteem and don't know how to get past it. I've known about it my whole life, but I've dealt with severe depression for years because of dealing with not being able to handle normal daily stuff like neurotypicals. I sometimes wish I could do everyday activities and chores (dish washing, etc) without feeling like it causes extreme anxiety and feelings of doom. I’ve never been able to keep jobs in the past because working makes me severely depressed and anxious, it severely impacts my quality of life. I would work, then quit for a while and finally want to work and I get tired of it again in terms of stress (Aimee, autistic adult).

> I had depression for a lot of reasons, and shame about not being able to handle day to day stuff was a big part of it (Amber, autistic adult).

Many adults noted how not being diagnosed and supported as children led to increased levels of anxiety and depression:

> I didn't have a diagnosis as a kid, and I think it would have actually helped a bit. That ‘click’ that validates the feeling that I must be different but don't understand why - I

> got that as an adult, but I think I would've appreciated it as a kid, too. The most important bit for me was learning that people's reactions to me were not my fault. It wasn't anything I could have changed; it's just who I am, and people didn't get it. I find a lot of older generations are opposed to labels, because they feel like labels are restricting. But I find younger generations love them, probably because the label helps us find community [particularly online now] (Dorothy, autistic adult).

Conversely, some therapies, treatments or attempts to cure autism could also have a profoundly negative impact: "I don't have depression because I have autism, anymore. I had depression when I was being treated for autism, in fact, I only accepted and grew when I left my treatment. Self-advocacy is the best for me, as no one knows me better" (Caren, autistic adult). For most respondents, diagnosis was liberating, allowing them to embrace an 'authentic self', as Puck explained: "Everything was fine because they all knew [that he was autistic], I got on well with everyone, and they got on well with me, because they knew".

One strategy that the children employed to assist them to reconcile their perceived difference and to build their self-esteem, was to identify with rebels and rebellion. Puck's love of the villainous characters Scar (from The Lion King 1994) and the Joker (from Suicide Squad 2016) were joined in a rogues gallery that included Deadpool (Marvel 2016, 2018), Jafar (from Aladdin 1992), Chick Hicks (from Cars 2006), Bucky (from Captain America, the Winter Soldier 2014) and Darth Maul (from Star Wars The Phantom Menace 1999). These were all mentioned as heroes by the children. KC (11), who has an extremely conservative worldview, chose female singers performing open rebellion such as Lada Gaga and Taylor Swift (Bad Blood) as her heroes. Her prized possession is a picture of her face superimposed onto the character Ahsoka Tano, a rebel warrior from the Clone Wars series (2008). And although she stated that she would like to be a princess in her future dream world, the princess turned out to be Leia, leader of the rebellion in the Star Wars franchise (1977 to 2019). Atypical behaviour and icons appear to be gaining traction amongst mainstream youth, as seen with the meteoric rise of Billie Eilish, self-confessed 'Bad Guy' and vocal activist for mental health challenges. Eilish shared how the songs on her first album were inspired by challenges she encountered as a child and continues to grapple with as a young adult, including Tourette's Syndrome, anxiety, night terrors, sleep paralysis, body dysmorphia, panic attacks, self-harming and depression. The children in my cohort, often quite conservative, loved rules and structure in their world, but when asked which personality traits best represented them, all chose the archetype of 'rebel' first, with additional descriptors of ‘creative’, ‘explorer’ and ‘jester’ as secondary dimensions to their personalities. In the autistic boxing programme, l noted how the label of ‘being a boxer’, and the perceived ‘street cred’ this gave the children, had a profound impact on how they viewed themselves. I noted a similar sense of pride when Puck showed me his bass guitar and advised me that he was part of a rock band which played “hard core rock music”.

I conducted two visioning exercises with the children to help them define their future selves. The first included the creation of their own personal crest complete with an animal and icons that represented how they saw themselves, and a personal motto or tagline (Figure 24). I then asked them to create a picture of the world that they would like to live in when they grew up.

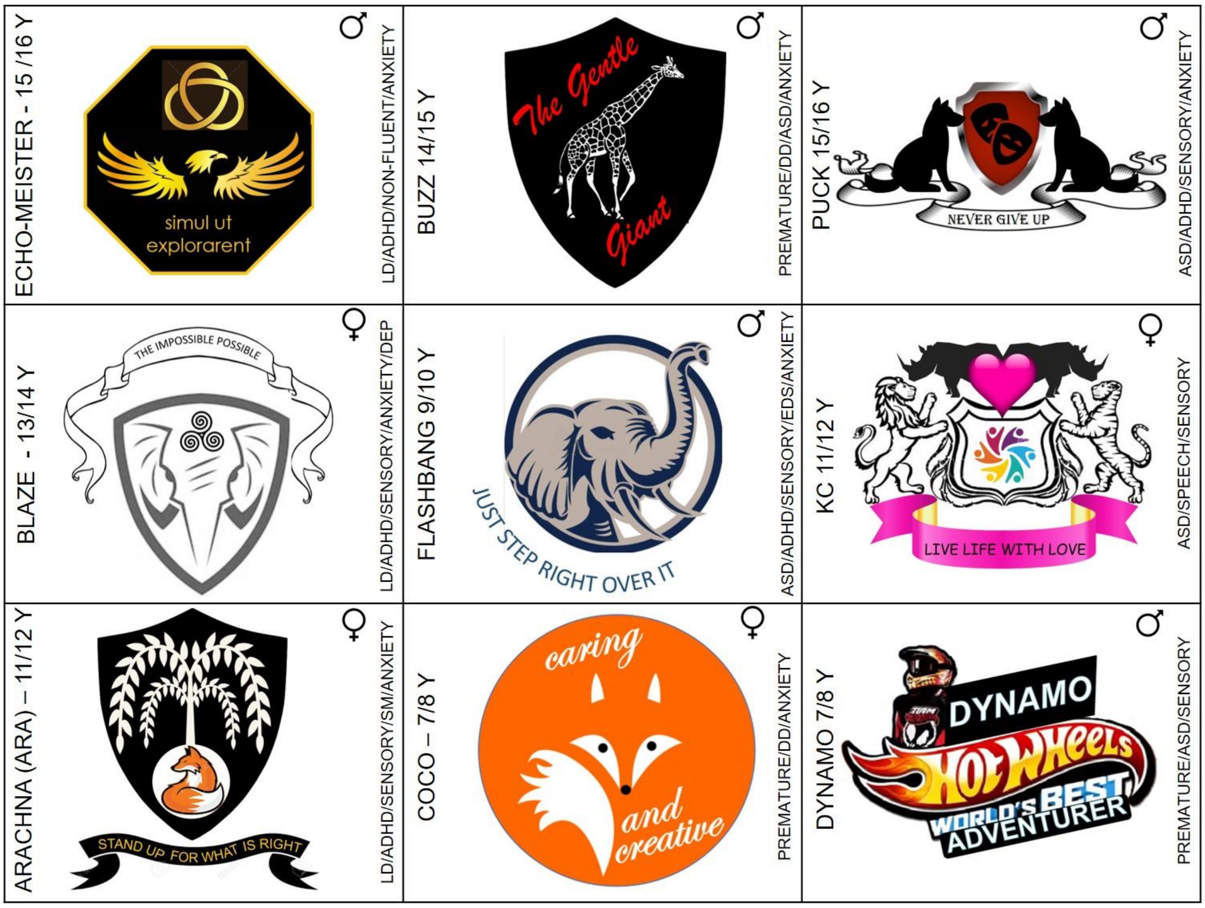

Figure 24.

Buzz (15) struggled with both exercises and appeared indecisive and unsure. We discussed which animal he thought represented him today, and whether this would change when he grew up:

> I guess today I see myself as a cow. I'm kind, I love to eat a lot, and I'm not very big. I'm cute, but I can get aggressive when something irritates me, I can stand my ground. In the future, I guess I will have to become a tiger because that is what people expect of me. It's proud and aggressive, you need to be that when you grow up. It's also smart and strong; it really is a beautiful animal. But it can be scared, its wary of fire, and it can be a scary world.

After much discussion, Buzz confided that he experienced a real conflict between who he felt himself to be, and what he thought society expected of him. When discussing his future dream world, he refused to take the exercise seriously, joking around and telling me, "well maybe I could be a fighter-pilot in Star Wars". It became apparent that he could not vision a future for himself beyond being seen as 'normal' or trying to 'fit in'. His mother noted that he always resisted any discussion about his future:

> I suspect his Asperger's is half the problem. Typically Buzz just focusses on what is happening now, not tomorrow or the next day. When I questioned him [about the exercise] I tried to find an example for a typical answer, so I asked him if he knew what his brother would say if he was asked the same question, he knew the answer immediately and mentioned three careers right away, but he still struggled to do it for himself.

Buzz eventually agreed that 'being caring' was a good thing, and he settled on a giraffe to represent himself in his personal crest. In his view, it is a large animal that can stand its ground, but it is caring and likes to live with its family. He chose the tagline "the gentle giant", describing what made him special as his love of animals, his patience, and his care for his family and others. Once he had established these points he talked of his love of history, strategy and video games, and a more authentic future started to emerge.

Puck, conversely, was clear on what he wanted to be when he grew up from the start and had been working on this vision for many years through engaging in his specialist interests of music and theatre. His parents nurtured his desire to perform by finding him an acting group and encouraging his love of all forms of music including singing, piano, drumming and bass guitar. For Puck, the impetus to pursue his vision seriously came from picturing the kind of learning environment and the people that he would need to surround himself with, to achieve this vision. His definition of his future world as "a triple thread… a singer, dancer and actor" was not new. However, when we discussed who he would need to partner with to help him achieve his vision, his demeanour changed. As with the other children, he spoke of needing his family to help him navigate his world. However, he then identified that he would also need a “proper theatre coach and opera teacher”, to ensure he achieved the future he had envisioned for himself: “This is all I need, people who will help support and train me”. The children who had identified a ‘specialist interest’ had a clarity of vision that contradicted the struggles they experienced in their day to day life. From designers to scientists, adventurers to performers, they chose careers and life paths that would challenge them immensely. Their current experiences of school appeared to have very little relevance or impact on what they wanted to achieve in adult life.

As a final personal exercise, I asked the children which values would help them to achieve their vision, explaining that values are driven by personal beliefs and guide day-to-day behaviour. I have run this exercise with many children around South Africa from a range of backgrounds, spanning poverty to privilege, and I was stunned at the clarity of thinking amongst my atypical cohort. From youngest to oldest, they barely hesitated when I asked what was most important to them and proceeded to define a few key values that guided their daily behaviour. The two dominant values that all the children mentioned included creativity or imagination, and family or community, in stark contrast to dominant medical discourses on autism. More than half of the children spoke about being loving and caring, with some mention of happiness and joy. Honesty was a further value that all of them subscribed to, and the boys desired respect from their peers. Beyond being guiding principles, the children’s values appeared to impact profoundly on their emotional states. This is not to say that they did not misbehave, or that their behaviour was always exemplary, especially when they felt overwhelmed by the world around them. However, the decisions they made and actions they took were usually based on a profound sense of what they viewed as right or wrong, or what they considered important or not. This intersection of values and emotional states was explored by autistic advocate, Terra Vance:

> While watching the documentary about Ruth Bader Ginsburg, RBG, I had an epiphany. She said, “Justice and mercy …They’re very grand emotions”. And it hit me, that to me, those are two of my deepest-felt emotions. Justice, equality, fairness, mercy, longsuffering, work, passion, knowledge, and above all else, truth. Those are my primary emotions. I didn’t have the language before to be able to explain how profoundly these emotions affected me, conceiving them more as ideas than feelings. At least, that’s what I was told they were. In the pursuit of those emotions,

> other feelings are secondary, superficial, misleading, and trite. Sadness, grief, jealousy, fear, joy, shame, sympathy… those are emotions which serve only me; but truth and work, passion and justice, longsuffering, and equality… those are emotions which serve the Greater Good. Those emotions are the mobilization of love (Neuroclastic, 24/03/2019).

Vance appears to confuse values -- what she believes in, -- with emotions, or how she feels. However, I observed these ‘grand emotions’, or rather emotions guided by strong values, at play in all the children during my fieldwork. They had a distinct sense of self, despite experiencing often daily reminders of difference, and in many cases criticism for their behaviour or lack of conformity to the world around them.

CHAPTER 6

ATYPICAL ENGAGEMENT WITH THE WORLD: ON PERCEPTION, CONTROL AND PARTICIPATION

The harsh environment of the boxing gym does not feel right for an autistic child. There is a strong acrid smell of sweat, bright colours, loud noises and rough edges. This space feels too challenging for a child struggling with intense sensory sensitivity, which most of the children attending these boxing classes appear to have. Yet they arrive with smiles on their faces, greeting their coach, shaking his hand, smiling shyly as he connects physically with them by patting their arm and holding their shoulder firmly. This is intentional: "They love the physical feedback," veteran boxer and coach Anton Gillmore tells me. "They come in here all over the place and you *klap* them around a bit (using the boxing pads, he illustrates how he pats them firmly on their hips, arms and head) and next thing, they are centred and ready to box, it gets them back into their body and into the present". I watched this on many occasions: children who have been diagnosed on the autism spectrum, walking around with bodies that look like nothing is connected. Arms hang loosely, tummies are out, knees are hyper extended backwards, and all seem to slouch, with no apparent sense of where they are in space or time. Then their coach taps them firmly on the sides of their body, starting on the outside of their thighs, moving up to mid arm and then ending on either side of the head, right and left, slap, slap. It's not painful, but it is certainly not soft. From being seemingly discombobulated, they are suddenly present. Their arms are up in the boxing position, their weight is forward, they are centred with their feet planted firmly on the ground. They are focussed entirely on the coach in front of them; they are boxers ready to box!

The ritual at the Fight with Insight[32] 'Autism Boxing' programme is carefully designed and structured from the minute the children get to the gym to the minute they leave. As they arrive, they see hero posters of Mohammed Ali and Nelson Mandela in his boxer pose, with inspiring quotations such as: "The impossible is nothing". A schedule of classes, safety principles and children's rights are clearly displayed on the wall. There are graphic signs on all pieces of gym, safety and hygiene equipment. The children must wash their hands and then greet their coach, ensuring, if not eye contact, at least body contact by shaking hands or holding shoulders. The children then select and put on their boxing gloves. This is the first transformation. They go from being disabled and different, to boxers; this appears to

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[32] https://www.fightwithinsight.com/ Accessed 28/01/2020

give them a great sense of pride. There is a large mirror on the wall, right next to the boxing glove shelves, and next to the mirror, a poster illustrating all the body's muscles. Children often linger at the mirror, observing themselves, flexing different muscles, sometimes pulling a boxing pose. Mostly, they are just observing their bodies, making connections between their different muscles and the instructional poster, murmuring each muscle's name as they touch or flex it.

The second transformation occurs once they step onto the boxing mat. They are now getting ready to box, and they start to bounce around in anticipation. The children joke with and bump into each other, generally finding a space for themselves both physically and emotionally on the mat. Programme founder and coach, Luke Lamprecht, notes: "This is a safe space for them, it frames the class. It is safe as it has boundaries which are important to them and there is a sense of reverence when they step onto it". I have watched the children in my research respond incredibly negatively to intense sensory inputs, especially loud noise. Yet, when the shrill bell sounds for the start of the lesson, and the electronic dance music blasts from the speaker with a distinctive duff-duff-duff preparing them for what lies ahead, rather than recoil, they appear completely in the moment. The coach takes them through a range of exercises designed to warm them up; to engage with the boxing bags; to spar with the coaches; to condition their bodies; and finally, to warm down. Each exercise is introduced with a loud instruction, a hand signal using the Makaton[33] sign language that the children use in their everyday school environment, and a physical demonstration of what is expected of them.

Making sense of our senses

Each boxing session was attended by occupational therapists who ensured that the children were participating optimally. They spoke enthusiastically about the impact that the boxing lessons have had on the children and their sensory processing abilities. All the children in my research had notable sensory challenges. From an external sensory perspective, there are three proximal or hidden senses and four distal or foreground senses. The proximal senses include touch, related to messages received from the skin; proprioception, related to messages received from muscles, tendons, and joints; and the

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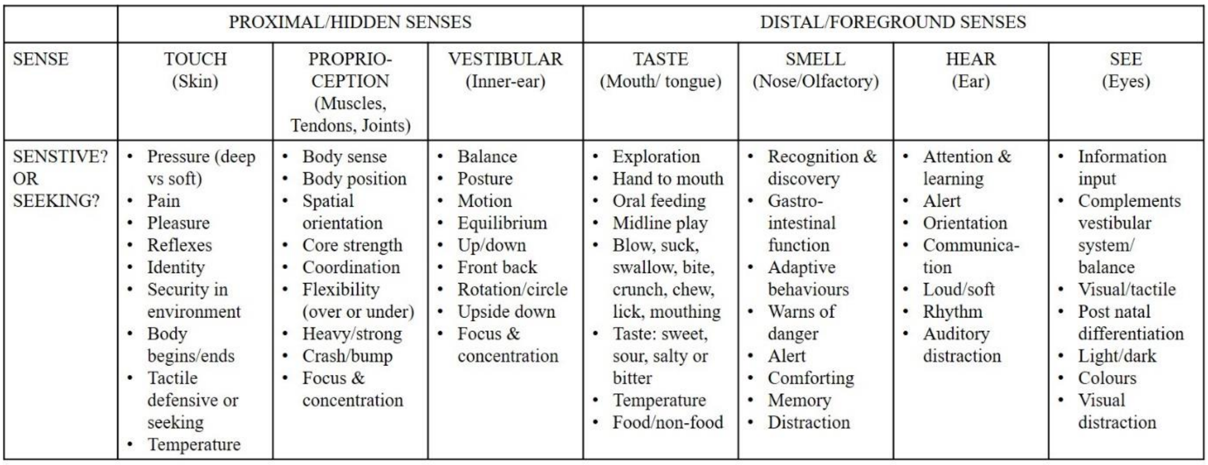
[33] Makaton is a global language programme using signs and symbols to help people to communicate. It is designed to support spoken language and the signs and symbols are used with speech, in spoken word order. The Johannesburg Autism school uses Makaton as a standard signing language, along with verbal instructions See https://www.makaton.org/aboutMakaton/ accessed 07/05/2019

vestibular system, related to messages received from the inner ear. Distal senses refer to taste, smell, hearing, and sight, as illustrated in in Figure 25 below (Lombard, 2007):



	PROXIMAL/HIDDEN SENSES			DISTAL/FOREGROUND SENSES			
SENSE	TOUCH (Skin)	PROPRIO-CEPTION (Muscles, Tendons, Joints)	VESTIBULAR (Inner-ear)	TASTE (Mouth/ tongue)	SMELL (Nose/Olfactory)	HEAR (Ear)	SEE (Eyes)
SENSTIVE? OR SEEKING?	• Pressure (deep vs soft) • Pain • Pleasure • Reflexes • Identity • Security in environment • Body begins/ends • Tactile defensive or seeking • Temperature	• Body sense • Body position • Spatial orientation • Core strength • Coordination • Flexibility (over or under) • Heavy/strong • Crash/bump • Focus & concentration	• Balance • Posture • Motion • Equilibrium • Up/down • Front back • Rotation/circle • Upside down • Focus & concentration	• Exploration • Hand to mouth • Oral feeding • Midline play • Blow, suck, swallow, bite, crunch, chew, lick, mouthing • Taste: sweet, sour, salty or bitter • Temperature • Food/non-food	• Recognition & discovery • Gastro-intestinal function • Adaptive behaviours • Warns of danger • Alert • Comforting • Memory • Distraction	• Attention & learning • Alert • Orientation • Communica-tion • Loud/soft • Rhythm • Auditory distraction	• Information input • Complements vestibular system/ balance • Visual/tactile • Post natal differentiation • Light/dark • Colours • Visual distraction

Figure 25.

All the occupational therapists referred to Winnie Dunn's model of sensory processing (Figure 26), when explaining how the children engaged with various environments:

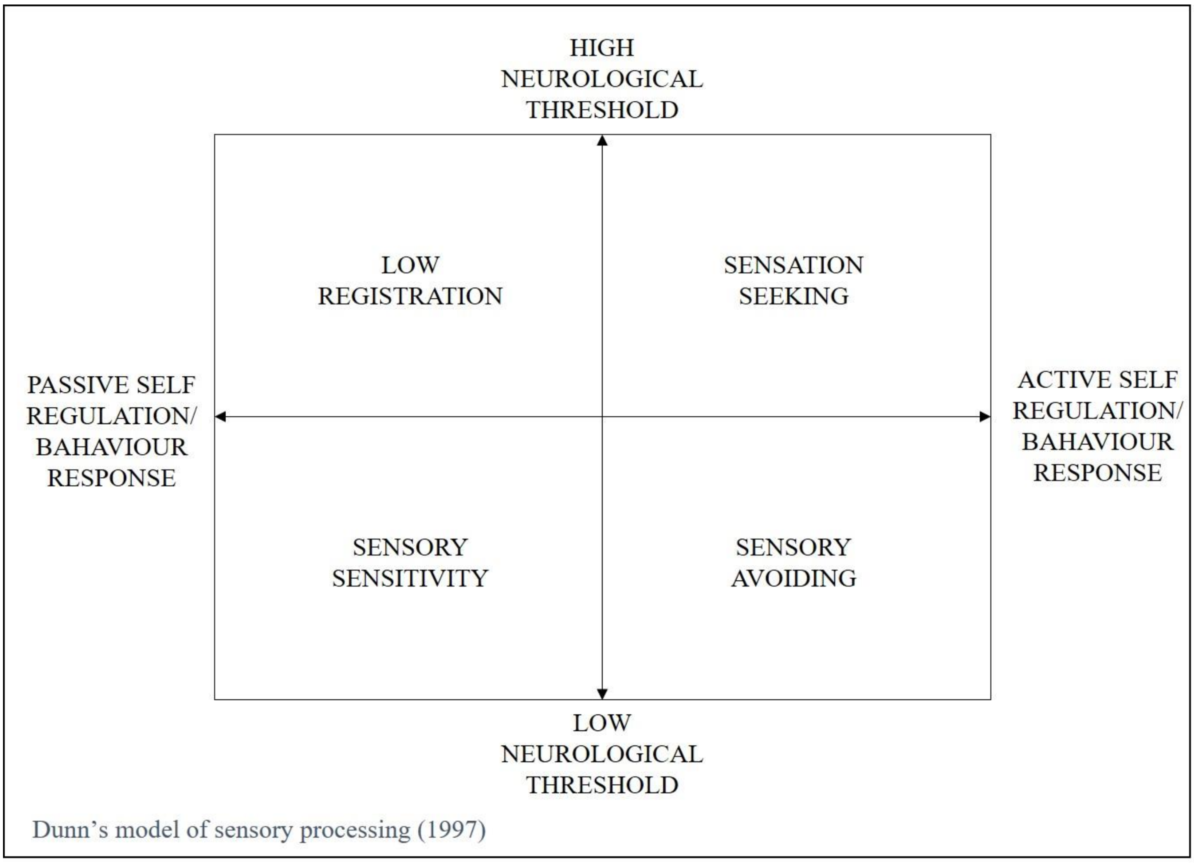


Figure 26.

Dunn (2007) argues that there is a relationship between a person’s nervous system and self-regulation strategies, and identified four basic patterns of sensory processing using two spectrums of analysis. The first is the child’s neurological threshold, or the number of stimuli required for a neuron or neuron system to respond, which can be high or low. The second is how the child responds to the sensory input, which can be passive, when the child does not take control of their environment, or active, when the child takes control of their environment and how they experience it. In the high neurological threshold, the passive child has ‘low registration’, and accordingly requires intense amounts of stimulation but does not necessarily seek this out. These children most often present as ‘dreamy’, with a low attention span and seeming disinterest in classroom or other structured activities. Active children in the high neurological threshold are referred to as ‘sensory seeking’, and present as constantly in motion as they search for experiences to stimulate their different senses. In the autism boxing class, a coach described a child who would come to lessons and literally throw himself headfirst into the boxing bags, walls and the floor, in some cases resulting in injury in order to “get some sensory feedback”. In the low neurological threshold, passive children often struggle to stay on task as every little bit of sensory input from their environment and even their clothing distracts them. The active low threshold children are referred to as ‘sensory avoiding’, and they proactively seek environments with low sensory inputs. An important strategy used by many of my research participants was to utilise tools to mask their sensory inputs –they used ear plugs, muffs or noise cancelling earphones, tinted glasses and soft clothing with all labels removed. Dynamo explained that labels on his clothes “feel like barbed wire in my underpants”, and that after a short period of time, “my skin feels like it’s on fire”. Sensory avoiding children are very easily over-aroused and distracted in classrooms. They struggle to concentrate as they are constantly focussing on the world around them and how it is seemingly invading them physically and emotionally.

During my research, I observed all these profiles, sometimes within the same child. On a particular day, when a child was feeling less resilient, they may be extremely sensory avoidant or sensitive; on another day they may be seeking sensory input which borders on self-harm. Puck never leaves home without his sensory support pack around his neck, in which he keeps his ear plugs, glasses and lip balm. When we visited the theatre together, he diligently put his earplugs in before the show begins to ensure that the music did not overwhelm him. He also mentally prepared himself by working through the concert programme to see what he could expect by way of sensory inputs. However, I once observed

Puck floss his teeth to remove a piece of *biltong*, to such an extent that he caused significant bleeding of his gums. His mother shared how he had once removed a permanent molar with a glue stick during a school class as “something was worrying him in his mouth!” KC loved the idea of having braids, but every time she went through the long and painful process of getting them woven into her hair, she would pull them out overnight, as she could not deal with the intense itchiness that followed. Researchers acknowledge that although pain and itch have similar neurological pathways, they are often used antagonistically (Schmelz 2015). Both children appeared to use pain to mask or control itchiness, as Puck noted: “I can control my body when it’s sore, but itchiness drives me crazy”. These extreme responses had a powerful impact on the children’s day-to-day behaviour and how they engaged with their world. It also influenced their ability to focus on a task or social engagement. Intense sensory input often led to them being overwhelmed and at risk of ‘sensory meltdown’ and ‘physical shut down’.

During the boxing class, all major internal and external sensory systems were engaged to a greater or lesser degree. Internal sensory processing systems include somatosensory, immune, genitourinary, urogenital, gastrointestinal, cardiovascular, respiratory, chemoreceptive, endocrine, central nervous, nociception[34], and thermo regulation. These senses involve how we engage with and process messages related to touch, pleasure, pain, temperature, position, movement, vibration, feeling full or empty in one’s bladder or stomach, heartrate, breathing, compression and shock. Internal sensory systems stimulate the emotions of fear, anxiety, depression and elevation. Coach Luke noted: “You see some children engage with their sympathetic nervous systems in the class, and some who are completely oblivious to it; we call it the fight, flight, freeze or flop response”. In line with Dunn’s sensory profile quadrants, I observed profiles of very low versus very high neurological thresholds among my respondents when processing the interoceptive messages they received, especially in the case of pain (somatosensory system) and incontinence (urogenital and gastrointestinal systems). Figure 27 illustrates the different internal sensory processing systems, interceptive senses, and their associated physical impact.

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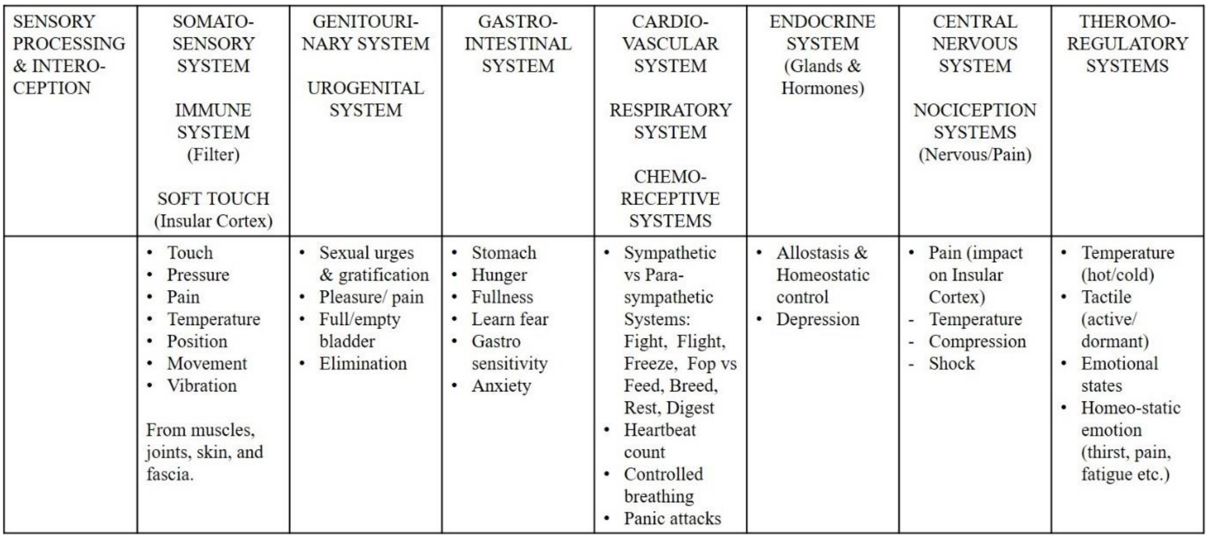
[34] The sensory nervous system's response to certain harmful or potentially harmful stimuli.



SENSORY PROCESSING & INTEROCEPTION	SOMATOSENSORY SYSTEM IMMUNE SYSTEM (Filter) SOFT TOUCH (Insular Cortex)	GENITOURINARY SYSTEM UROGENITAL SYSTEM	GASTROINTESTINAL SYSTEM	CARDIOVASCULAR SYSTEM RESPIRATORY SYSTEM CHEMORECEPTIVE SYSTEMS	ENDOCRINE SYSTEM (Glands & Hormones)	CENTRAL NERVOUS SYSTEM NOCICEPTION SYSTEMS (Nervous/Pain)	THEROMOREGULATORY SYSTEMS
	• Touch • Pressure • Pain • Temperature • Position • Movement • Vibration From muscles, joints, skin, and fascia.	• Sexual urges & gratification • Pleasure/ pain • Full/empty bladder • Elimination	• Stomach • Hunger • Fullness • Learn fear • Gastro sensitivity • Anxiety	• Sympathetic vs Parasympathetic Systems: Fight, Flight, Freeze, Fop vs Feed, Breed, Rest, Digest • Heartbeat count • Controlled breathing • Panic attacks	• Allostasis & Homeostatic control • Depression	• Pain (impact on Insular Cortex) - Temperature - Compression - Shock	• Temperature (hot/cold) • Tactile (active/ dormant) • Emotional states • Homeo-static emotion (thirst, pain, fatigue etc.)

Figure 27.

Chronic pain is common in children and adults diagnosed with autism and/or ADHD (Asztély *et al.* 2019). As with interoception, my observations of the atypical experience of pain appeared inconsistent. Pain could be felt acutely when visiting the hairdresser or dentist, accompanied by violent outbursts and meltdowns, yet not registered at all in the case of a self-injury such as removing a tooth with a glue stick. Some adults spoke of their inability to verbalise the pain they felt, resulting in selective mutism. Others spoke of being able to "make sense of the pain" and were thus able to endure high pain intensity without needing to manage it with medication. These individuals were often believed to have a 'high pain threshold', but in discussion this was not the case. They did feel pain, sometimes to the point of paralysis, however, they appeared to be able to rationalise it as part of their daily existence:

> I'd say both [high and low pain threshold] but have always thought people wouldn't understand that. Example: I gave birth naturally to a large baby boy whose shoulders got stuck for several hours, resulting in a fairly difficult 24-hour labour, but I never felt any need for pain relief. It was painful to an extent, but I'd been used to terrible period pain all my reproductive life and it wasn't much worse than that. The only truly painful part was the head crowning as I tore slightly. But I was far more disturbed by the burning pain of using the toilet for the next three days even though that was technically less painful. My experience in general is that I cry easily with things that surprise me like stubbing my toe, but when it comes to childbirth and kidney infection, I'm like, "I guess it's a 6 or 7 maybe?" (Dianne, autistic adult)

A younger respondent agreed with this atypical experience of pain, but also highlighted the issue of low registration of pain medication. This is widely spoken about online by atypical communities, but not researched:

> A light touch such as a feather or soft object is excruciating for me. However, thuddy type deep impact doesn't affect me much even if bruises are left that can last weeks. Extremely high pain tolerance to what I call "general pain". Example of kidney stones. I can be writhing in a ball and white as a sheet and it's an 8 for perspective. I take some Tylenol. Narcotics like Percocet and Vicodin have no effect on me, besides a high on the first pill only. It is part of the issue when seeking pain meds because what else can they give me really? Telling them those don't work is "drug seeking behaviour", so then I get nothing. Especially when my presentation doesn't match the declared rating (Kristy, autistic adult).

Both Ara and Flashbang experienced this low registration of pain medication, making visits to the dentist traumatic experiences where they felt misunderstood and unheard. Ara noted: "The dentist will say, 'you can't possibly feel anything now', but I do, and it hurts".

In her blog titled 'Performing Pain', autistic writer, poet and playwright Rhi explains:

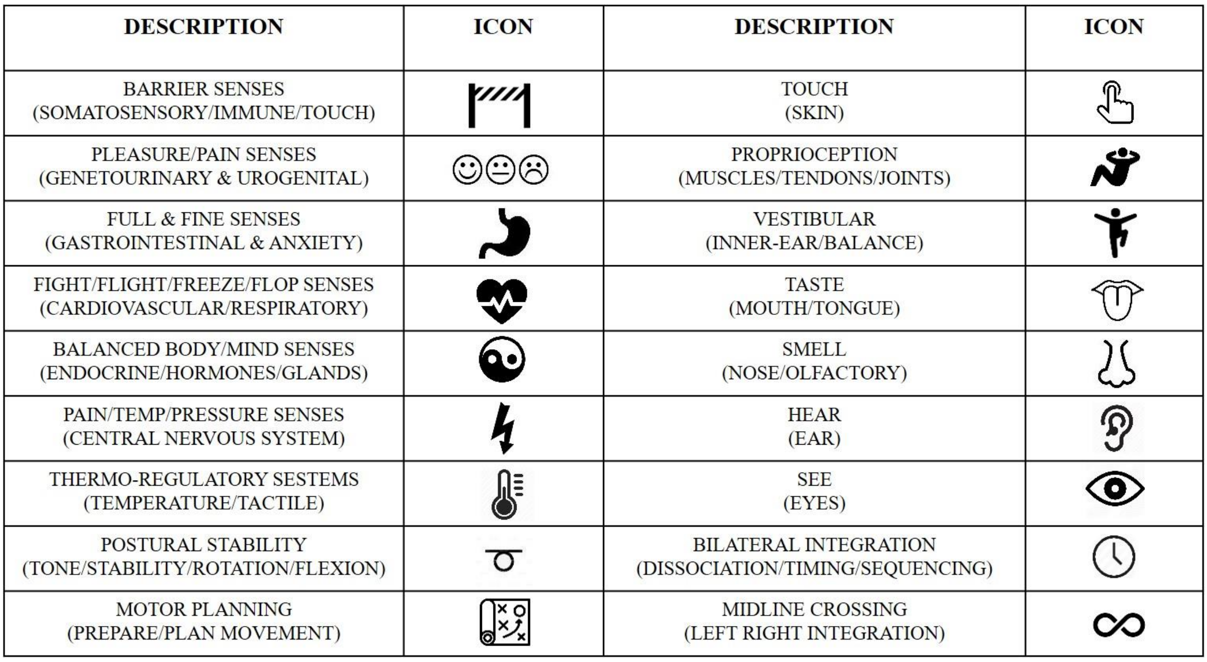
> When I am in pain my expressions fall, my lilting, musical intonation becomes low and flat, my face blank, my shoulders stiff. When I am in pain I react in my natural way, in my intuitive way. I become silent and passive and connecting to other people seems like a distant dream. Words are in my head, but I struggle to get them out. Talking feels strange and alien. All the ways I know to ask for help slip through my fingers and I watch them as they fall. Pain makes me 'authentically' autistic, it strips back my mask and my connections, and it sits me down, silent and alone (Autism and Expectations, 6th December 2017).

There is a higher prevalence of incontinence (nocturnal enuresis, daytime urinary incontinence and faecal incontinence) in children on the spectrum compared to typically developing children (Niemczyk *et al.* 2018). KC (12) would engage completely in creative exercises or play with me, and then suddenly frantically run to the toilet in a blind panic because she had a full bladder or had wet her pants without realising it. Her teacher described how she could regularly spend a full day at school and not feel hungry or need to go to the toilet. However, when asked, she appeared to 'check in with her body', and then state that she was indeed hungry or needed the toilet. Many of my respondents struggled to feel or read internal bodily senses and had to consciously check when reminded. Several parents shared stories of their child being unaware of their farting and burping in social environments. When they chastised them, they realised that their child had not even registered their perceived social indiscretion.

Most of my respondents or their parents noted how bedwetting had continued well into their childhood. This was remembered with considerable embarrassment when discussing the ‘low points’ in their life journey exercise. A lack of interoceptive awareness prompted the following public announcement on a popular autism support group site:

> To autistic people who don’t sense hunger and thirst: this is a reminder to go eat and drink something. May seem funny to some but that 8th sense, interoception, is hard to tap into and respond to for some of our autistics (posted 12 July 19).

By observing the children, and talking to the occupational therapists who support them in the autism boxing classes, I created a summary table with icons to understand which exercises impacted on their internal or external sensory processes (Figure 28):



DESCRIPTION	ICON	DESCRIPTION	ICON
BARRIER SENSES (SOMATOSENSORY/IMMUNE/TOUCH)	⊓	TOUCH (SKIN)	👆
PLEASURE/PAIN SENSES (GENETOURINARY & UROGENITAL)	☺😐☹	PROPRIOCEPTION (MUSCLES/TENDONS/JOINTS)	🏃
FULL & FINE SENSES (GASTROINTESTINAL & ANXIETY)	●	VESTIBULAR (INNER-EAR/BALANCE)	🤸
FIGHT/FLIGHT/FREEZE/FLOP SENSES (CARDIOVASCULAR/RESPIRATORY)	♥	TASTE (MOUTH/TONGUE)	👅
BALANCED BODY/MIND SENSES (ENDOCRINE/HORMONES/GLANDS)	☯	SMELL (NOSE/OLFACTORY)	👃
PAIN/TEMP/PRESSURE SENSES (CENTRAL NERVOUS SYSTEM)	⚡	HEAR (EAR)	👂
THERMO-REGULATORY SESTEMS (TEMPERATURE/TACTILE)	🌡	SEE (EYES)	👁
POSTURAL STABILITY (TONE/STABILITY/ROTATION/FLEXION)	⊽	BILATERAL INTEGRATION (DISSOCIATION/TIMING/SEQUENCING)	🕓
MOTOR PLANNING (PREPARE/PLAN MOVEMENT)	✕○	MIDLINE CROSSING (LEFT RIGHT INTEGRATION)	∞

Figure 28.

All these sensory systems were challenged in the boxing classes, and there was also a high degree of processing challenges. Sensory processing disorder is characterised in three main areas: sensory modulation disorder, where children have difficulty modulating or processing sensory input; sensory based motor disorders, which relate to dyspraxia or postural disorders; and sensory discrimination disorders, where children are unable to recognise or interpret differences or similarities in sensory stimuli (Children's Therapy Centre, 23rd February 2014). Sensory modulation is further differentiated according to whether children are over- or under- responsive to sensory input, or sensory craving, where they actively seek out sensory input. In the boxing gym, an over-responsive child may present as sensitive to the environment, flinching at loud noises, displaying tactile defensive behaviour to scratchy clothing, such as the Velcro of the boxing gloves, and finding the often-pungent gym smells extremely distracting. They were generally quite fearful, especially during the sparring exercise, sometimes curling into a ball to prevent being hit or touched. Under-responsive children in contrast would wander around the gym seemingly oblivious to the class around them. They were particularly interested in their bodies, and how or if their bodies made contact with other items, especially the boxing bags. Those who were characterised as sensory cravers would crash around the gym, bashing into other children and the boxing bags, and appearing impulsive and fearless. They would frequently put items in their mouths, or mouth their gloves, and bite other children to gain sensory input. One young boy refused to modulate his behaviour, and a coach tried to remove him physically from the gym. He held onto a pole, refusing to let go until the coach gave up. Seconds later he was running around the gym again, crashing into everyone and laughing loudly, seemingly unaware of the destruction and distress he was creating for those around him.

Sensory discrimination disorder (SDD) was particularly interesting in the gym environment, as the children were all required to wear boxing gloves. This sensory challenge is often likened to the feeling of wearing gloves, as it relates to the inability to discriminate between different stimulus input. As one occupational therapist remarked: “Imagine not being able to tell the difference between different things in your bag when trying to find your car keys, this is what all stimulus feels like to children with SDD”. The inability to discriminate and make sense of sensory input is not only a tactile challenge but can also impact on all proximal and distal senses, including visual, auditory, olfactory, gustatory, proprioceptive, vestibular, tactile and interoception. This muffling of senses impacts on the children's lived experience of their world, as Chantal, a young autistic woman who suffers from SDD, once remarked: “The whole world feels muffled to me”.

Sensory based motor disorders were present in most of the children. Many had postural challenges associated with poor muscle tone and difficulty with balance and body control. Simple exercises like sitting, standing, or trying to balance caused extreme tiredness and much complaining, moaning, and groaning during the boxing warm-up and warm-down sessions. Dyspraxia, a chronic lack of coordination, and difficulties with motor planning were also a challenge for the children, who often appeared clumsy and awkward. They understood what was required of them -- most had done these exercises many times before – but they lacked the ability to prepare their bodies for the anticipated activity and to act on this. Physical motor planning around the execution of basic movements took intense concentration and focus, and this was extremely difficult for them to sustain. Rather than all their bodily systems working together autonomically, it appeared that it took conscious effort to enact this. This was most evident when children literally forgot to breathe, sometimes to the point of collapse.

Exercises that required right and left arm or leg coordination were also a constant frustration, as observed when the children engaged in 'boxing combinations'. They would have to say the words, "right, left, right," or "left, left, right," to ensure that their various body parts followed the instruction, but most could not achieve these exercises without mirroring a coach next to them. The occupational therapists referred to this as a lack of 'bilateral integration and coordination' and explained this in relation to the child's (in)ability to coordinate both sides of their bodies at the same time in a controlled and organised manner. Central to this was the children's ability to 'cross the midline' with their hands, feet, and eyes without thinking about it. I observed all my participants struggling to coordinate both sides of their body. Daily living challenges included an inability to dress or tie shoes, catch a ball or run. KC's facilitator created a detailed list of how she should get dressed in the morning, complete with the directionality of clothing (front versus back by virtue of labels), and order of clothing, from underwear to t-shirt and shorts, and then tops or jackets. KC (11) would frequently get confused. Her facilitator would arrive to take her somewhere, only to find that she had given up and was walking around naked. Actions involving fine motor movements such as buttoning up a shirt, and visual motor tasks such as writing, drawing, cutting, and catching or throwing an object, were extremely difficult for the children to master. Gross motor movements such as walking, running, riding a bike, or trying to balance on a skateboard were also challenging for many.

Sensory processing also impacts on children's emotions and how they understood and engaged with them. As previously noted, alexithymia describes the inability to explain or express emotions or moods due to a lack of appropriate language. It also makes emotional recognition extremely difficult as the children are unable to distinguish between or connect different bodily sensations to the appropriate emotion (Rieffe & Stockman 2000; Brewer *et al.* 2015):

> Alexithymia is a problem for many of us, particularly in the period just before a meltdown. Because some of us don't seem to have built-in sensors and spend so much time concentrating on behaving "properly", there is no spare mental capacity left to self-monitor. Having to self-monitor basically requires incredibly difficult multitasking, plus you have to develop the ability to observe your signs from the outside and interpret them… 'Hm, my leg is bouncing more than usual and I seem to have a flat affect and I am getting loud, therefore I probably need to go to sit inside the broom cupboard and stim'… it's a difficult skill to acquire (Morgan, autistic advocate).

The children were often overwhelmed in our day-to-day interactions; it appeared as though their emotions had taken them by surprise. Although confident to talk about their emotions individually, they were easily confused by them when experienced in real-time. Fear often presented as angry outbursts, happiness or excitement as manic behaviour, and anxiety as extreme emotional withdrawal.

By the end of the boxing sessions, the children would collapse on the floor in a 'corpse' yoga position, their bodies exhausted but emotionally happy and content. Rather than being disconnected from their bodies, as they had when they arrived, the children appeared completely connected to them. The coaches and occupational therapists would walk around the children, crossing their arms over their chests and pushing down hard, to give 'deep pressure' to all their major muscle groups. This was usually accompanied by gurgles of pleasure from the children. Lenore Manderson notes: "We take our bodies for granted, attending to them only when there is unpredictable marked discomfort, pain, anomaly or distress" (2011:27). However, for atypical children, this is their constant lived reality. Unable to rely on unconscious perceptive, kinaesthetic, and proprioceptive responses, the children are constantly made aware of and have to sustain their bodily boundaries. They often appear to question where their body ends, and the world begins. Their day-to-day lived experience becomes an endless battle, or balancing act, to protect or reinforce these bodily boundaries.

Perceiving the world atypical

The children often had difficulty in trying to understand and separate themselves from the physical environments they found themselves within. This was best illustrated in my observation of their interaction with the boxing bags in the autism classes. The bags, which they would intermittently punch and then hug, were an interesting presence in the children's lives. They appeared to love the solidness of the bags, the fact that they could hit or push them, and they would push or swing back. The coaches spoke at length of how the boxing bags gave the children a sense of 'security' and 'predictability' in the class. After doing a physical warm up, the children were told to find a punching bag and stand in a boxing stance in front of it. They were then told to "measure". This entailed standing with their left foot forward, boxing gloves held up to their face, and then extending their right arm until their boxing glove touched the bag in a slow-motion punch. This ensured that the children were at the perfect distance from the punching bag before starting their boxing combinations. The children would often reach out to touch the bag, and then crane their heads around their arm, to see if they *were* touching the bag. They didn't seem to trust their bodies to give them this feedback and sought visual confirmation of where their fist or glove ended, and the bag began.

This simple exercise reinforced the children's visual representations of their lived experience of their bodies, as outlined in the previous chapter. Bodily boundaries appear to be fluid and permeable. Scheper-Hughes and Lock describe how a body is "good to think with", in the tradition of symbolic and structural anthropologists (1987:18). We use our bodies to experience the world, to explore, reason and problem solve, and to engage with our emotions and various social interactions. Before an atypical child can take the first step of simply perceiving the world around them, they must work through barriers of problematic sensory processing, intense pain or itchiness, and a disconcerting sense of body permeability. Perceiving the world is difficult for atypical children as sensory messages are confusing, muted or so intense that the experience is akin to physical and emotional abuse.

Engaging with the world, if it is to be experienced positively, needs to be considered, structured and systematic. This is perfectly illustrated in relation to how I observed most of the children eating meals. Beyond specific food allergies, all the children in my cohort where 'picky eaters' and avoided certain foods due to their taste, texture, smell and/or 'mouthfeel'. Puck's mother noted that he "only eats Woollies chicken vienna's (sausages)." Dynamo (8) had an extremely limited diet and meals could take hours for him to finish; he often noted that "eating is boring". Like Dynamo, Echo's (15) approach to meals mirrored how he consumed or perceived the world around him. He chose simple food, with little to no additives or sauces. He placed each item on his plate separately, ensuring that nothing touched. He then slowly consumed the small stacks of protein, starch, and vegetables in order of preference, taking his time with each mouthful, much to the frustration of his family at mealtimes. Beyond the physical act of consuming and digesting food, this systematic approach to eating paralleled how many of the children consumed and digested the world around them, intellectually, emotionally, and socially.

Atypical intellectual perception

Silberman (2015), citing a range of studies, notes the intensity that atypical children have of learning in their area of specialist interest. He observes how in these areas, they enjoy "learning for its own sake", as opposed to learning for "approval and reinforcement by others" (2015:215). The children spent hours researching and discussing specialist interests, from Lego to weapons, video games to movies, historical events to factual anomalies in the world around them. They were passionate about learning and sharing seemingly arbitrary facts with family, friends and even strangers in endless monologues. Echo's mother remarked: "Sometimes he just lectures me all day, fact upon fact, 'did you know' upon 'did you know', until I have to shout STOP…and forget querying any facts, he will make it his mission to prove me wrong, and in my experience, he is never wrong". She shared how he would prefix all fact sharing with the exclamation, "fun fact". Dynamo's mother shared similar experiences. Dynamo would announce "light bulb", and then launch into an exhausting explanation of facts that he assumed she would find as scintillating as he did, sometimes for hours at a time.

This passion for learning finds little fertile ground in typical academic school environments. Rather than focussing on one subject at a time, ensuring that concepts are understood and embedded before moving on, children are required to stop and start subjects, in primary school on average every thirty minutes. The environment is loud, boisterous and constantly changing, and atypical children are often left behind. One of Ara's teachers explained:

> The bell will go, and I will ask the children to get their books out and turn to a particular page. I then start teaching, but halfway through the class I realise that Ara still hasn't got her book out. She is staring out the window in her own little world. If

> I chastise her, she falls apart. Her books are all over the place. If she has the right one with her at all, she can’t find the right page. And whilst the rest of the class are taking down notes, Ara is still figuring out that we have finished maths and are now doing history (Ara’s Grade 3 teacher).

For effective intellectual processing, all children stated the need for supporting teachers and positive reinforcement. Many used accommodations such as playing music on their headphones to help them concentrate and remain focussed. Fidget spinners, chew toys, reinforced tips for pens and pencils, and even fluffy toys were used to focus attention and to relieve anxiety and stress. “I use a fluffy toy when I write my tests, it absorbs all of my stress”, Ara noted. Likewise, Coco explained: “I like cuddling with the teddies in my class, especially if we have to do something new”.

All children had a range of different ‘learning strategies’ that assisted them in coping with their learning environment:

> I have lots of little riddles and memory tricks, especially when it comes to trying to remember how to spell certain words. My best one is ‘eight’…a fatty and a thinny and a ‘g’, ‘h’, ‘t’ [said as sounds]. I have always thought that was really funny (Blaze, 13).

> When you are born with a learning disability, you literally spend your life coming up with strategies so that you can cope at school, so strategy is a big part of your life, because you have to live it every day and that means we are very good at it (Echo, 15).

Strategies often included self-stimulation or ‘stimming’, or just getting up and walking around, much to the frustration of their teachers. Ideally, as with their eating habits, learning needs to be broken down into parts and slowly consumed in dedicated and often extended time frames.

Once they had managed their environment appropriately and were able to learn optimally, all the children were incredibly observant, often seeing exceptional detail in the world around them. When asked what they liked most about being autistic or atypical, many referred to their ability to see and feel things that others cannot, due to their sensitivity to their environment. This was enhanced by their ability to see patterns and connections between seemingly random or disconnected things, and being able to make sense of these patterns in a pragmatic way:

> I love my unique perception of the world in regard to my hypersensitivity (Rod, autistic adult).

> I notice details others don’t. I see beauty in things others don't. I can see and feel music. I feel connection with words and poetry (Sarah, autistic adult).

> I feel like I have clarity of meaning when I can find patterns in things, and I like to use this skill in conjunction with direct language so that I can guide more effective problem-solving between people. Good communication skills can be learned, and it is great! It just takes some time for allistics [neurotypical individuals] to learn and adjust to it (Amanda, autistic adult).

> I have a way of seeing things rationally which my NT peers see through emotional eyes, enabling me to understand and explain things in a way that could be new and fresh to many (Bill, autistic adult).

While their sensorial ‘openness to the world’ can be difficult to manage and sometimes overwhelming, it also makes atypical children and adults open to extraordinary insights, patterns and connections. This theme is often highlighted in popular representations and movies of historical figures considered atypical creative and intellectual geniuses, such as Vincent van Gogh, Albert Einstein, Srinivasa Ramanujan, Alan Turing, John Nash, and Temple Grandin.[35]

Atypical emotional perception

Emotional perception was challenging for all my research participants. There was often a disconnect in how they perceived and engaged with their own emotions, and how they understood and perceive the emotions of others. As with all interoceptive awareness, if the messages that you receive from your body are muted or confused, this impacts on how you respond to them. This ‘confusion’ of emotions was present in all participants. An attempt to protect themselves from a busy sensory environment was often interpreted as being disinterested or disconnected. A scary environment, where the children felt threatened, afraid, and anxious, could result in extreme outbursts of anger as they struggled to differentiate the somatosensory messages of fear and flight versus that of anger and fight. An apparent lack of emotional response to a fraught environment, for instance, where the

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[35] Films include: Loving Vincent (2017); Genius (2017); The man who knew infinity (2016); A Beautiful Mind (2001); and Temple Grandin (2010).

children were exposed to the intense pain or suffering of others, was seen as lack of care and indifference, and often interpreted as a lack of empathy. However, as noted by Puck’s mother, his irrational response to his father’s illness was not because he did not care, but rather because he was afraid of his father’s mortality.

In his book *Zero Degrees of Empathy* (2011), Simon Baron Cohen argues that for autistic people, “other people’s behaviour is beyond comprehension, and empathy is impossible” (2011:117). In response to this now dominant discourse, autistic teen advocate, Dylon Dailor, argues that although autistic children and adults may have difficulties with ‘cognitive empathy’, they often have high levels of ‘affective empathy’. He defines cognitive empathy as “the ability to look into someone else’s mind and understand why they do the things they do,” and affective empathy as “that moment when you are sitting in a room and you just feel like there is this tension, but you can’t quite explain how you know”. He notes how a lack of cognitive empathy is not as bad as a lack of affective empathy, as this “would make me a psychopath or a narcissist, so I’ll take the loss of cognitive empathy” (TEDx Allendale Columbia School, 17th May 2016).” Coach Anton noted how the children in the autism boxing classes could pick up when he was ‘out of sorts’ emotionally, despite his attempts to mask this:

> They know when you are not ok, they pick it up, no matter how upbeat you are. If you are distracted because of other stuff, they know, and it impacts on them and how they respond to you.

KC’s sister shared a similar insight:

> I would say she [KC] has difficulty interpreting what you are feeling, expressing and your vibes. But her senses are very heightened, she feels things ten times more than we do. You know how dogs don’t really know what is going on but when you’re sad they console you even though they don’t really understand. It’s kind of like that. She is really empathetic, and she really does care, she always wants to cuddle you. I remember one day when I came home, and I had such a hectic day and I just cried, and she just sat with me. She didn’t know what was going on, but she just sat with me and we played Wii all afternoon (KC’s sister).

Rather than lacking empathy, most adults believed that they felt empathy too much. However, as with physical boundaries, emotional boundaries were extremely difficult to reinforce:

> I feel whatever is in the room when I walk in. It becomes a huge pain in the centre of my chest that consumes me. I physically hurt so much that I sometimes have to leave the room… I never know what to say or do so I just try to go on with my day with this agonising pain either filling up this huge black hole it creates inside me, or with my whole body in pain and feeling like I'm ever growing to be able to hold the pain. it's like I lose the concept of where my body stops and so I feel like I'm somehow way bigger, yet I know that I still fit in my chair, or car, or the doorway or room. It is very hard to describe what it feels like to know you are the same size, but your body is way bigger to accommodate all the pain (Alison, autistic adult).

Most autistic advocates argue that neurotypical people are the ones who lack empathy, particular for atypical people’s daily struggle to live in a world that does not understand them or cater to their needs.

Beyond empathy, my observations and discussions with the children indicated that they felt emotions deeply. Using a mind-mapping approach, I endeavoured to explore when certain emotions were felt, the embodied experience of those emotions, and the meanings that the children associated with them. Similar to Puck’s desire to only experience positive emotions, most of the children resisted or refused to talk about what they perceived as ‘negative emotions’ such sadness, anger or anxiety, and were often only able to represent this feeling visually.

Figure 29.

Coco’s visual representation of sadness is depicted along-side in Figure 29, she notes:

> When someone hurts my feelings, but I can’t remember, it was not very nice (Coco, 8).

> I never get angry and no one ever gets angry with me. No one ever makes me angry; I don’t want to feel grumpy (KC, 11).

> I don’t know, actually I don’t know, I don’t remember being cross, I don’t get cross with my friends or family (Dynamo, 8).

In contrast to perceived deficits in cognitive empathy, sadness was usually associated with other people's or animals' suffering. Coco's mother noted how Coco would always remind herself of when her dog died when she was sad: "It's as though this very sad event, possibly the saddest she has ever been, has become an anchor for what sadness represents to her, she cannot talk about being sad without say, 'like when Pip died'". Negative emotions were related to feeling powerless and were usually located in the stomach and lungs. Blaze (13) noted: "When I was told I was staying back at school and there was nothing I could do about it, I was really sad, I felt so powerless, I felt sick, it was like I couldn't breathe".

Anger was associated with being diminished or disrespected, or perceiving unfairness, injustice, or a lack of care. This was often experienced in connection to their perceived challenges, as Puck explained of his cruise ship holiday. The most challenging aspect of the emotion anger was the lack of control the children felt they had over it, and the fact that they found it extremely difficult to 'dissipate', often leading to high levels of anxiety:

> I feel angry inside my head, it crowds around like a thunderstorm…I try and use my thinking tools, to breathe, walk away and then calm down. Sometimes I can control it. Sometimes I can't (Ara, 11).
>
> When people upset my friends and family, I feel it in my heart and my back. My blood starts pumping, I get properly angry, my muscles in my back start tensing up (Echo, 15).
>
> When I have to stop playing video games [because his mother has told him to], it [anger] stays in me for a while. Cuddling my dog helps make it go away (Buzz, 14).

Anxiety was experienced by all children on a regular basis, as noted by Flashbang (9), "this is more than half of my life". The act of worrying or stressing was a source of great anxiety in itself, as noted by Ara (11), "sometimes I just worry about worrying!" Tests and exams were a major source of stress and anxiety, especially around the fear of "running out of time" and "forgetting things". The children all shared experiences of obsessing over things that caused them anxiety; as Echo (15) noted: "It stays on my mind". 'Perseverance of negative emotions' and emotional dysregulation were spoken about frequently by my adult participants: "A vicious unproductive cycle of rumination". Intrusive negative thoughts and the emotional distress, resistance and defensiveness they caused were experienced as debilitating and disempowering: "The negative biased defensive brain projects skewed perception onto my reality, it autogenerates thoughts and a negative story line for my life" (Stephen, autistic adult).

For children, physically dangerous and sensorially challenging environments often brought on anxiety, but probably their greatest concern was the fear of a close family member getting hurt or dying. Beyond his experience with his father, Puck refused to visit any friends or family members in hospital:

> The hospital environment totally freaks him out. We know that we can't push him in a hospital environment. And it is a very sensory hectic space. He doesn't want to see that people are sick or hurt. He doesn't like to be faced with that mortality. We have had many family members who have been ill. Puck doesn't even want to think or entertain the idea (Puck's mother).

Ara (11) noted of being scared or afraid:

> I get anxious when I think there is danger, I get stressed, scared and nervous. I can't sleep and this stresses me out. I had a nightmare that my brother stayed up for so long [playing video games] he got a world record, and then the second night he died.

Whilst the children experienced positive emotions, they found these difficult to express verbally. Puck adored his mother and could not contemplate his world without her, however, when I asked him to describe his relationship with her, he responded by saying "don't ask me to do that, I just can't". Positive emotions were usually felt and expressed physically, with spontaneous stimming such as jumping up and down and flapping of hands:

> I can't explain it [happiness], I feel it in my head and heart. My head starts to feel dizzy; it can be a bit scary and out of control. I like feeling this way (Ara, 11).

> Emotions, for me, are a strong form of energy. And they refuse to just exist. they demand action. flapping, or stimming in another way, yelling, flailing about. It has to get out of my body (Ana, autistic adult).

> When something happens that affects me emotionally, my body seizes up as if struck by lightning. 'Seizing up' doesn't mean that my muscles literally get stiff and immobile – rather, it means that I'm not free to move the way I want. So by jumping up and down, it's as if I'm shaking loose the ropes that are tying up my body. When I jump, I feel lighter, and I think the reason my body is drawn skywards is that the motion makes me

> want to change into a bird and fly off to some faraway place (Naoki Higashida, 13, 2013:77).

This physical expression of emotion often results in in expressions of happiness or joy being misunderstood:

> It is like we only have one gear for heightened emotions, at least in my experience. Joy looks exactly like distress! Can you imagine having an action that you mustered as a small child to express your need to be removed from an overwhelming situation, now being stuck so that every time you lunge at your mom and pinch her cheeks? Or where you managed to avoid an impulse that may hurt another instead resorting to exerting an impulsive action on yourself to get attention, and now having that be stuck? Joy becomes slightly tainted if it triggers those around us to experience stress (Jordyn's Rocky Journey, 17th January 2020).

Emotional perception and experiences are felt acutely by the children and adults, but their expression is often atypical and therefore frequently misunderstood. In the tradition of Clifford Geertz (1973), many psychological and medical anthropologists argue that emotions only exist and have meaning in the context of culture; however, in the realm of emotional perception, neurotypical and atypical cultures often collide.

Atypical social perception

'Difficulty perceiving the social' is noted as a distinct deficit amongst atypical children, including challenges with 'social-emotional reciprocity', 'nonverbal communicative behaviours', and 'developing, maintaining and understanding relationships' (DSM-5 2013:50). Their lack of understanding of non-verbal body-language, gullibility and concrete view of the world is an area of major concern for parents, as the children are believed to have little understanding of risk or duplicitousness:

> The world will not look after Puck, we worry about the world preying on him. He had a friendship that we had to end because the kid kept asking him to send him airtime. His friend Frank said to me, you know you pack Puck a big lunch, but he never eats it. I said I know. He said you shouldn't do that because everyone else eats his lunch. I said but if I don't do it, no one will sit with him at break time. I know I buy people into Puck's life. That's life. You need to sweeten Puck a bit. For a few minutes at school he has friends because everyone comes and raids his lunch box. I told Frank not to tell him. He is too generous, and that is what worries us because he will give

> everything away. If Puck sees someone wants something, he will get it for them. That's why we have to have the scaffolding in place [their financial plan for his future], otherwise he will spend it all in a month. His honesty as well, when he still had his phone, he was scammed by everyone because he was always calling the scammers back (Puck's mother).

Beyond their inability to identify deceit, many adults claimed they often felt unable to lie:

> I'm pretty heavily biased towards truthfulness. I hate almost all lies and lose a lot of trust in people if they lie to me. Even as a child I would avoid lying unless I was very afraid of the outcome of telling the truth. This has kind of resulted in a more blunt approach to most situations. My close friends appreciate this, and I generally get positive responses from others, but on occasions I can get some backlash for being "rude" etc. (John, autistic adult).

> My parents found me really odd because I couldn't lie and would tell them as soon as I'd broken anything by accident or done something naughty on purpose. I remember learning how to tell a lie when I went to school and telling my first lie when I was 5. I was so amused/shocked by it, "No, I haven't seen X person today," that I burst out laughing and said, "I just told a lie!" Suffice to say I'm still shit at it. Logically, I don't really see the point in lying. You just end up building up a whole load of stories you have to keep track of. It wrong foots people better if you just straight up tell the truth. I remember the teacher at school going round the class asking why various of us hadn't done our homework, everyone else was coming up with elaborate excuses and when they got to me I just said: 'I didn't find it very interesting, so I didn't do it'. And the teacher just sort of looked at me, blinked and then walked away (Lauren, autistic adult).

Research into autistic children's ability to tell lies indicates that while they were able to tell 'simple lies', they were often not able to maintain the deception (Li *et al.* 2011). Most participants supported this finding, that as they were not particularly good at maintaining a lie, it felt redundant to tell one in the first place. Malcolm Gladwell's (2019) exploration of our inability to identify dishonesty in strangers due to humanity's innate 'default to truth', and the impact of factors such as alcohol, sleep deprivation or stress, implies that most of us have a high degree of 'gullibility', we just think we do not. The children, however, were also oblivious to irony, satire, or sarcasm, and were understandably angered when this lack of understanding was criticised or laughed at. Some adults noted how social cues could be learnt through extensive watching of movies or reading of books and plays. Rather than a lack of maturity, most ascribe their 'concrete views' to a strong belief in, and desire for, a better world, mirroring the 'grand emotions' outlined in the previous chapter.

Further proof of atypical children's and adults' inability to relate to others is often ascribed to the struggle they have with making eye contact, recognising facial expressions and sometimes faces. 'Ask an Autistic' vlogger, Amythest Schaber, shared her difficulty with prosopagnosia: "I can walk past a family member and if they have changed their hairstyle or outfit, I would not be able to recognise them." However, when Amythest describes the strategies she uses to help her identify people, a similar pattern emerges to that identified in the physical, intellectual and emotional perceptual skills of the children:

> When it comes to people's appearances, most people would rank the face as the primary identifying characteristic. I would say that there are secondary and tertiary characteristics. Under secondary characteristics I list things like hairstyle, style of makeup, clothing, jewellery. Anything that contributes to a person's appearance, that isn't a face, I can remember…This can be a real problem when people dye their hair or cut it, or wear a different hoodie…sometimes you can't rely on those secondary characteristics. That is where the tertiary characteristics come in. Under this category I would list people's voice and I don't know if this sounds weird but their gait and the way that they move…for myself I have synaesthesia, and so when I hear a person's voice, I see a colour… so I often use the sound, and a colour and appearance of peoples voice to identity them if all else fails (Ask an Autistic #24, 28th June 2015).

Amythest notes how she focusses on individual features, rather than the "overall big picture". Nonverbal autistic media personality, Carley Fleishman, shares how taking in all of this detail often makes it difficult for her to look at faces: "I take over a thousand pictures of a person's face when I look at them, that's why I have a hard time looking at people" (ABC News, 8th August 2012). Many of my participants noted their ability to see and sense infinite detail as a major strength. Ara proudly claimed this as her "super sensory ability". Ingela Visuri (2019) explored 'supernatural agency' amongst young autistic adults in Sweden, who claimed that they could sense presence, feel touch and see visions without somatosensory stimuli. Her autistic participants reported far more incidents than their neurotypical peers, leading her to conclude that unusual somatosensory experiences are more prevalent among people on the autism spectrum. Ara was particularly sensory sensitive and struggled to cut out the various sensory inputs that she received from the world around her. Her parents noted that she had a “sixth sense about people” from a very young age: “Even as a toddler, she has seen right through people who are dishonest…even if she has never met them before, she will refuse to greet them”. Ara explained that she often has a physical reaction to people who she thinks are ‘bad’ or ‘liars’, exclaiming “I can’t do people like that”, whilst holding her head in a protective manner.

Eye contact is seen as important in neurotypical social engagement; however, this caused high levels of stress and anxiety amongst my participants. The children were usually able to make eye contact if they felt comfortable and were talking to someone they knew and trusted, but strangers were a challenge:

> I can make eye contact in situations where I am calm and comfortable and there is little demand for cognitive processing. Bring stress, intellectual challenge or high emotion into it and I feel assaulted (Steve, autistic adult).
>
> I never realized I had a problem with eye contact until I was looking for a job. I would get interviews, and then never get called back because I was so nervous that I would either stare past them or look at their desk (Mandy, autistic adult).
>
> When I was anxious and in sensory overload, there were months when I had to have conversations with my eyes closed so that I could filter out all the projections of thoughts and feelings that come from the other people's eyes, so that I could concentrate on the words (Morgan, autistic adult).
>
> Eye contact feels like seeing into souls. I look away for the same reason I don't stare at people on the loo. Too intimate, too much emotional input. I feel too many things seeing people's eyes. I have many tricks for pretending to have eye contact while actually staring slightly aside or at my shoes or whatever (Amber, autistic adult).

Behaviour therapy that forces eye contact was considered very problematic. Some adults explained how eye contact could be physically painful. They believed that forcing eye contact was akin to abuse. Most agreed that eye contact was not critical to effective social communication; however, given its importance as a social and cultural norm in the neurotypical world, this is an ongoing battle.

Whilst visiting a small rural village in KwaZulu Natal for my child protection work, I encountered two young boys who were considered extremely atypical by their community. The boys would visit the community centre daily for food, but never spoke to anyone whilst there. I was warned, "the minute you try to make eye contact with them they will run away". During a break, I sat down next to one of the boys and pointed to some old sunglasses he was holding. I made a point of not looking at his face, but rather at the vista in front of us. I pulled my sunglasses off my head to show them to him, and put his sunglasses on, which prompted him to put my sunglasses on. We both laughed uproariously at this. We engaged for a while longer, me chatting and him making sounds and pointing at various things. When we started our workshop again, one of the coordinators noted that this was the longest interaction she had ever observed with the young boy. At the end of the day when I drove out of the compound, the young boy ran to the gate with his brother and opened it for me. He looked directly at me and waved with a big smile on his face.

Control and the atypical body

During my time with him, Dynamo attended weekly sessions in the Snoezelen Room[36] at his school. This is a controlled multi-sensory environment used to provide therapy to children who display 'maladaptive behaviours' due to developmental challenges. The room is a predominantly white space, with white crash mats, beanbags, and a ball pond. Sensory stimulation is added through water bubble tubes, textured walls, light panels, optic fibre, and video projection. The aim is to allow children to calm their senses in a relatively sensory free environment, and then introduce on demand various sensory elements including textures, colour, graphics, sound, and deep pressure. I observed Dynamo in one of his 'Snoezelen' sessions and was astounded at the positive impact that it had on his behaviour and general sense of wellbeing (Figure 30).

After removing his shoes, Dynamo entered the room and insisted that the lights remain off. He then crashed around in the dark, bashing into the soft mats, jumping on the bean bags, shouting, and squealing in delight. He slowly calmed down, and sitting on an elevated mat, he introduced the colours blue and pink into the dark room. Using a portable console that he controlled, he also selected a projection on the wall that looked like a planet. He sat on the mat dreamily looking out at space for some time, and then dived into the ball pond. He then asked to be covered by the balls and for his therapist to "squish" him. This

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[36] www.snoezelin.info

entailed pressing down onto the balls with a weighted blanket.   He told me later: “I love it, I like going in the pond and it’s got nice air conditioning, I like to be cool, it’s like little balls squishing in the water”. By the time he left the room, half an hour later, both his appearance and emotional state had changed significantly. From seeming anxious and quite ‘hyper’ before the class, he now had a dreamy calmness to him. I asked him how he felt, and with a beatific smile on his face, he said “happy”. I asked him if he was ready for school and he said “yip”, and promptly skipped off to his class, a different child to the one that met me at the school gate early that morning.

Figure 30.

Dynamo’s mother explained the impact of the sensory therapy room on his coping mechanisms and his ability to self-regulate:

> Dynamo often struggles with his emotions and tends to ‘march to his own drum’. He has several sensory issues and battles with too much noise, physical discomfort or big changes in his routine and environment. He is very distractible, unless it is something that he likes, like Lego, where he then becomes hyper-focussed. He seeks a lot of physical feedback, bashes, and crashes into things and is a big hugger. From his very first session, I noticed a change in his behaviour when I collected him from school.

> On a Snoezelen day, Dynamo makes greater eye contact with me when I see him, engages with his friends as we leave the playground and then continues to regale me with happenings from his day at school. This is in sharp contrast to other days when he normally responds with an "I don't remember" or silence. I do believe there has been an accumulative effect over time; the positive impact does not completely disappear when he does not have it. He is able to self-regulate (with some prompting) far better than he used to. This may be due to him getting older, but I find that the sessions have given him a referential index and muscle memory of what feels good and what helps when he is out of sorts. He will now request deep pressure when he needs it and likewise can say when it is enough. He can also sometimes explain what is distracting him and what would work better for him to concentrate. I remember being in a school meeting, near tears, explaining that I felt my little boy was steadily disappearing from us… I believe that this room has bought our little boy back, given him a safe space where he can just be, and opened up a future that is full of possibilities for his beautiful mind (Dynamo's mother).

Beyond managing various sensory inputs, all the children had challenges around controlling their bodies. In discussion with parents and therapists, I was advised that there is a body/mind disconnect in children with proprioception challenges, ADHD and autism. Autistic blogger, Cat McGill, describes this disconnect: "Ever since I was a child, I've struggled to get my body to do what I want it to do, to feel how I think it should feel… I have real trouble 'feeling' my body, if I'm not looking at it, I can't quite tell where it is, it's like my mind is not properly connected to my body" (catmcgill.uk 29th April 2019, Accessed 23/01/2020).

Autistic author and poet, Sydney Edmond, speaks of the deep frustration felt by atypical people who tell their bodies what to do, but whose bodies seemingly have a mind of their own:

> People need to know because society apparently thinks autistic people are lacking intelligence. Our wandering wayward eyes and hands flapping, screaming, and anxious stimming don't help, either. But in truth, we polish our souls deep down inside where they can't see us, while our dastardly bodies act in ways we can't control. That's right. I told you I have lousy control over my behaviour. Can you relate? Perhaps you have moments when your body does things without your permission? When you lose control and shout at someone or hit out? Well imagine

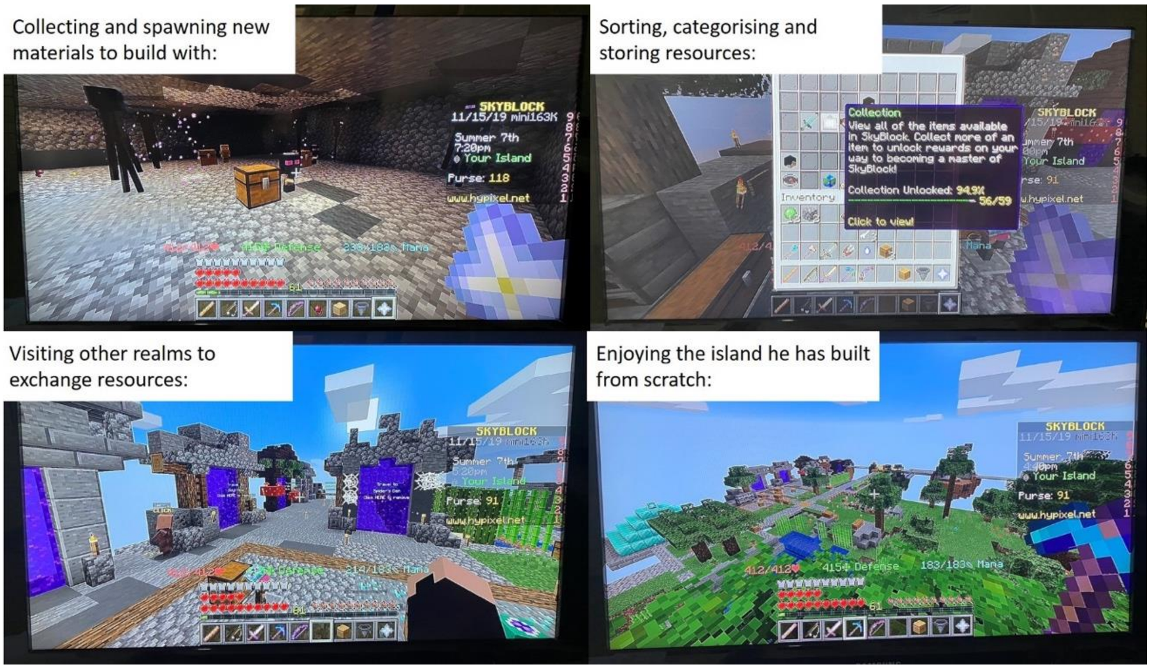
> what it would be like if you were just the opposite, and were always out of control with little solid gold moments when all the pieces come together, and knowledge passes impulse? For those moments we are the captain of our ship and we feel unbelievably perfect. But passing time wipes it away. Possibility becomes disability again. Look at your fellow students with autism deeply and with patience. We are in here. And we are exhausted, panicked, and lonely (Emma's Book of Hope, 18th March 2014).

Shame and guilt at their lack of control of their bodies is felt by many and is a source of deep anxiety to them.

Stephen Porges (2003), through his Polyvagal theory, argues that if children are unable to regulate their physiological state, they will be unable to learn or socialise with others. The vagus nerve plays an important role in the development of adaptive behavioural strategies linked to our brain's evolutionary responses to threat. It inhibits the sympathetic nervous system (fight or flight) by stimulating 'rest and digest' or 'feed and breed' activities and responses, referred to as the parasympathetic nervous system. Rather than trying to control behaviour, which can create an oppositional response, stimulating the dual vagal pathways aims to turn off defensive responses by fostering feelings of safety and trust. A range of therapies appears effective in creating this environment -- sensory rooms, music therapy, art therapy, yoga, mindfulness practices and in my observation, boxing. Adults also shared how online spaces, through gaming or social media, can provide an environment in which they feel more in control of themselves and how they respond to the world around them. I once observed Echo in this relaxed but engaged state, playing Minecraft. He chatted away to me, explaining how the game works, how he 'mines for resources', and stores them in a complex but efficient filing system. He then uses these resources to build beautiful environments that are not only aesthetically pleasing, but provide him with the space he needs to unwind:

> I don't play Minecraft that much anymore [he sees it as a game for younger people, not serious gamers such as himself], but when I am feeling stressed, it's really nice to go in there and just mess around. It relaxes my brain and helps me calm down. It's almost mindless, I don't really have to concentrate, but I am still creating things. Just being in the worlds I make, helps me to relax and reset (Echo, 15).

Examples of Echo's Minecraft meanderings can be seen in Figure 31.



Collecting and spawning new materials to build with:

Sorting, categorising and storing resources:

Collection
View all of the items available in SkyBlock. Collect more of an item to unlock rewards on your way to becoming a master of SkyBlock!
Collection Unlocked: 94.9% 56/59
Click to view!

Visiting other realms to exchange resources:

Enjoying the island he has built from scratch:

Figure 31.

Regulating emotions and behaviour was extremely challenging for my participants, especially when so much of their world is beyond their control. From a physical and emotional perspective, uncontrollable conditions such as epilepsy, Tourette’s syndrome, trichotillomania (pulling of hair), excoriation (picking of skin), apraxia, echolalia (verbal imitation), echopraxia (physical imitation) and behaviours associated with obsessive compulsive disorder, are all common comorbid challenges (DSM-5 2013:50-59). A lack of control of one’s body makes action and participation almost impossible.

A method used by many of my participants to regulate their bodies, minds and emotions was self-stimulation or stimming. This assisted them with their self-regulation by stimulating, calming, or refocussing them when they were anxious, distressed, or experiencing a sensory meltdown. Behaviour therapists claim that stimming can interfere with social interaction and prevent learning, but my participants argued that it assists with learning:

> The more all of us (autistic or not) use rocking, balancing kinds of movement in the course of our day, the more Purkinje cells we all produce and the cleverer we all become. Lemme put that a different way: autistic people often have a problem with Purkinje cells not working optimally. STOPPING AUTISTIC PEOPLE FROM STIMMING LITERALLY DAMAGES THEIR BRAINS (Morgan, autistic advocate).

Puck could sit for hours in his room listening to music and rocking backwards and forwards. KC would sing to herself all day, sometimes her favourite songs but often just narrating her activities or chores she was undertaking. Dynamo would insist on taking my pen or pencil apart when we were working together, he could do this more 20 times in a row, until I redirected him. He would also randomly squeal and make popping noises, to see how my recorder registered the sounds. All the children regularly tapped fingers, hands, feet, legs and heads. The sensory seekers like Dynamo, Flashbang and Echo would spin or bounce and all loved to swing for hours on end. For all, it was a form of self-soothing, and a visibly enjoyable experience:

> When my imagination takes hold, my body takes on a life of its own. When something very exciting happens in my inner world, I've just got to run, I've got to rock backwards and forwards, or sometimes scream. This give me so much energy and I've got to have an outlet for all of that energy (Rosie King, autistic adult, TedMed, September 2014).

Popular autistic advocate, Sarah Jane Harvey, shares extensive 'stimming advice' on her Facebook page 'Agony Autie'. Harvey illustrates and describes her 'stimming toolkit' which includes: skin chewing; hand waving; biting; skin picking; pacing; oral stimulation (mouthing items); stim dancing; nervous stims; stim gadgets; teeth grinding; gum chewing; skin rubbing; hair plucking; echolalia; visual stimming (with fidget spinners and moving toys); flapping; pimple popping; scar tissue picking; toe nail biting; visual stims (using toys such as a kaleidoscope); joint cracking; shaking; squeezing; rocking; rubbing; and tapping. Following a diagnosis of Ehlers-Danlos Syndrome, Harvey shares how she had to 'embrace her stim':

> I've been ashamed of the way I move and behave all of my life since I was a young child. I never understood the way I moved the way I did, or interacted with the world the way I did, or communicated the way I did…I didn't understand my behaviours and a lot of people described them as weird and strange and broken. It made me hide, it made me become ashamed it made me practice "quiet hands" … and it made me shut down. When I got chronically ill of Ehlers-Danlos syndrome two years ago, when I lost the ability to walk, to go for jogs and dance and move the way I wanted to, my stimming entered my life in a way that has changed everything…Stimming is a natural, physical human – not just autistic – human response to sensory overwhelmment, emotional excitement or trauma. What better way to express yourself, when you

> can feel the emotions coursing through your body…It's how we communicate, it's how we play, it's how we explore and it's how we understand this world, by repeating things over and over and over again…This isn't about fixing us, this is about utilising what you naturally have. It's been taken away from you and you're told that its broken. Bring it back, reclaim the stim (Harvey, 2018: Lecture).

Harvey's reference to "quiet hands" relates to the ABA practice of stopping autistic children from flapping their hands. Through ABA's Discrete Trial Training (DTT), any attempts to stim are met with physical restraint, such as folding the child's hands in their lap, and telling them to have "quiet hands". In the midst of an often-gruelling therapeutic regime (practitioners recommend forty hours of weekly therapy for autistic children), ABA appears to remove one of the children's primary coping mechanism:

> Grabbing my hands when I stim the way ABA recommends would NOT help my day go better. It would be an excellent way to piss me off and make me feel frustrated and anxious, though. It's one thing to stop a child from hurting themselves by banging their head. It's another to stop a harmless stim like hand flapping. You're causing the child emotional discomfort just because the behaviour strikes you as weird (The Aspergian, 29th March 2019).

Many participants noted how stimming is a primary source of self-regulation and management. Nonverbal autistic, Carley Fleishman, notes how she uses verbal stimming such as shouting, loud moaning, and chanting as a barrier to external noise inputs: "It's a way for us to drown out all sensory input that overloads us all at once, we create output to block out the input" (ABC News, 08th August 2012). While telling me his stories, Buzz would bend his hands at his wrists under his chin first one way and then the next, in a characteristic stim. When I asked him why he did it, he said, "because it feels nice". I noticed how he could practice this stim when he was in a stressful situation or extremely happy. Beyond being a means of self-regulation, it was also a form of communication for him. It showed those around him, who knew him well, that he was feeling anxious or if he was happy or proud of himself, reminiscent of Baggs (2007) 'physical conversation' with her environment.

Observing Dynamo's experience of his therapeutic sensory space, I developed similar rooms at the autism boxing centre and at a psychiatric ward with which I was working in my child protection programme. Beyond autism, children in this psychiatric space also struggle with mood and anxiety disorders; trauma and attachment-based difficulties; self-harm and suicidal behaviour; and aggression and relational difficulties. The head of occupational therapy for the children's ward described that children often struggle in identifying and using appropriate coping mechanisms and communicating the need for help. She explained how this difficulty related to the child's "way of being in the world", especially with others, and their understanding of their body, their needs and feelings:

> Through the use of different sensory inputs available in the room, such as movement, heavy proprioceptive input, deep pressure, lights and tactile toys, the child's understanding and awareness of his or her body and capacity to engage is discovered and developed. The child is encouraged to actively explore and direct engagement, with reflection from the therapist to make sense of their effect on the environment and the feedback on their own sensory systems. Participation is guided to facilitate exposure to different stimuli and assist in regulating the nervous system through activity or environmental adaptation when necessary. This contributes to the child's ability to reach optimal arousal levels (the "Calm Alert state") and to notice the balance between his or her focus and energy levels. Children in the unit have often reported the room to be a "safe space" in which feelings of calmness are experienced, as well as a place for expression and release where the body can be used to move, identify and release energy and emotion (OT Therapist – Children's Psychiatric Ward).

Rather than feeling out of control and powerless, the room created a space for children to connect with their bodies and to regain a sense of control. They went from feeling disempowered and disconnected to empowered and connected, not just with their bodies but with the world around them.

Atypical participation in the world

Pierre Bourdieu (1990 [1980]) argued that human beings are shaped by social structures that define their habits, skills, and ways of being in the world. Habitus is gained through imitation, as experienced in the socialisation of children into adulthood. This social structure both generates and organises practices and representations that allow individuals to act intuitively to achieve a particular aim. They do this through automatic and intuitive responses that are collectively and socially shaped. Manderson notes: "We experience our bodies and so embody ways of experiencing the world" (2011:28). But this is not the lived reality of many children and adults, who have little to no social or embodied memory of their world. Puck's mother once remarked:

> Imagine waking up every morning, and everything is completely new to you? You have to learn everything again, as if for the first time. You have no proprioception, no sense of where your body is in space and time. That is what it's like for Puck waking up every morning. It's like waking up in a stranger's body, in a strange world, and it's very disconcerting for him.

We use our bodies as a tool to experience our world, to understand it, and to create relationships and social meaning within it. However, when our bodies dissent, it becomes difficult to maintain a sense of self and our relationships with others: "People whose bodies change in undesired and unpredictable ways must rethink themselves, challenging unconventional ideas of the integrity of the body and mind in order to understand themselves in light of physical reconfiguration and conferment" (Manderson 2011:30). 'Rethinking' one's body on an almost daily basis is exhausting, and if not managed over time, can lead to burnout. 'Autistic burnout' presents as a complete lack of motivation, a loss of executive functioning abilities, difficulty with self-care, lethargy, and exhaustion (AWN, 5th July 2017). Extreme cases can lead to selective mutism, illness (usually stomach related), memory loss, meltdowns, and shutdowns. Causes of burn-out are usually related to high levels of activity coupled with high levels of stress, sensory overload, and any form of change. This is exacerbated by a lack of sleep, poor nutrition, and dehydration linked to interoceptive challenges.

Another important cause of burnout is that of 'masking', or the camouflaging of difficulties, by trying to 'act neurotypical'. Masking takes an enormous amount of energy and often has a detrimental effect on wellbeing, especially if it occurs over a long period of time. For the children, masking was particularly evident in the school environment. They often spoke of how tiring school was for them, as they struggled to behave in a way that was expected. Sitting still, not being able to get up and wander about, and forced to focus on instructions without stimming often led to exaggerated yawning episodes, where they look as though they may swallow the world. This frequently culminates in sleeping on their desks during class or falling fast asleep during breaktime. Researcher Laura Hull identified emotional, cognitive and physical consequences to masking: "Most qualitative research has suggested that masking of autistic characteristics leads to negative outcomes, such as exhaustion, lack of support, and feeling like your true self is being hidden" (Neurology

Advisor, 18th April 2018). The ability to mask well was seen as extremely problematic by my adult participants, as it led to some adults being unable to secure an autism diagnosis, and the associated support:

> I feel I'm on antidepressant medication due to my continued failure to match up to neurotypical characteristics (executive function and giving/receiving the right emotional signals) on an ongoing and comprehensive basis. This is exacerbated by the trauma of having failed to measure up all my life, and the fact that I have little explanation for my failures, except that it has happened before, and so it is only what I should have expected. I am not diagnosed autistic (though I have an adult ADHD diagnosis), and those with whom I have floated the possibility with think that it is preposterous, so I don't know if I am diagnosable. My mask is too good, but also not good enough. And I'm not sure what supports I could get at this stage anyway. I'm already in therapy. But this view of, "you aren't having (obvious) difficulty navigating the world as if you were a neurotypical, therefore I will not diagnose you with autism or help you access any supports", is an expedient political decision, not in the best interests of the patient. Sometimes I think I would have to give up entirely to get any assistance. As long as I am unwilling to give up, I am on my own. And then I think of others, and I realise that even that is seen, not as a call for help, but as a flaw in character. We need to change the way we see these differences. But how do we do that when we are not the majority voice? (Jane, autistic adult).

All bodily action, rather than intuitive, becomes a daily drain on physical resources and sense of self. Both children and adults are encouraged to ‘act as normal as possible’, however, this creates a further drain on their already sensitive systems. Rather than being understood and supported, their “unruly embodiment”, is interpreted as a “fundamental failure or decay in character” (Manderson 2013:35).

A young graphic designer, who struggled with extreme sensory sensitivity and anxiety, created the illustration in Figure 32, documenting her movements as she paces nervously up and down a room: “The concept of the illustration is to convey the anxiety a person with generalised anxiety disorder constantly feels and the courageous battle they wage every day” (Alice, 22 years).

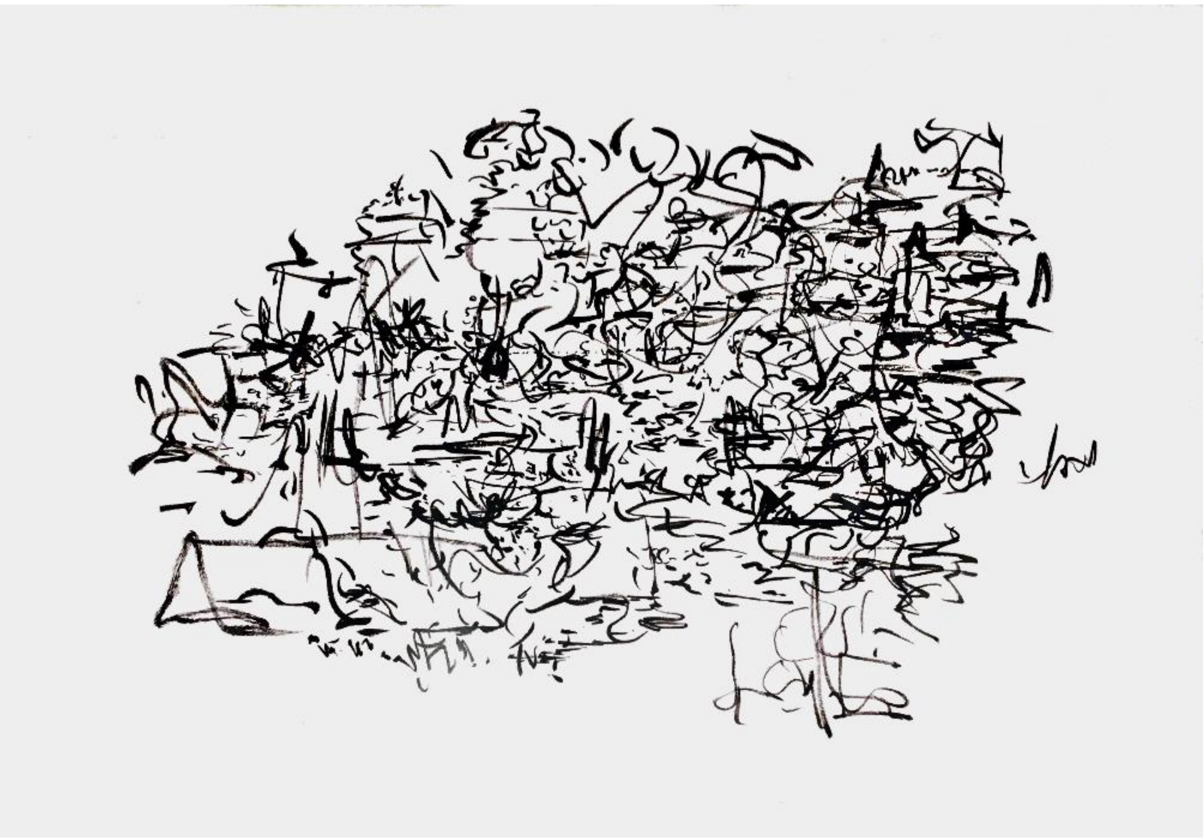


Figure 32.

Another young autistic adult with whom I spent some time, explained how her fear of social engagements were often misunderstood and perceived as 'antisocial:'

> It's not that I'm antisocial, but sometimes when I have low energy, I'm a-social. This means I don't mind people; I just can't cope with them all at once especially in a noisy environment. 'Antisocial' has negative connotations, like you hate people, I don't hate anyone, but sometimes I can get overwhelmed when I am around lots of different people, and then I need to get out of there (Chantal, autistic adult).

The management of energy is a critical factor in how atypical children and adults are able to engage with the world around them. All my participants spoke of how difficult it was to modulate themselves appropriately for different social interactions. Some felt that they were too engaged and appeared "overenthusiastic," whilst others spoke of their daily struggle or inability to get up and go to school or work in the morning:

> I struggle socially sometimes, to regulate myself. Sometimes when I am having fun with my friends, I talk too loud or act stupidly (Echo, 15).

> Sometimes I get a bit hyper, people often tell me I'm overenthusiastic, apparently that is a bad thing, but I do hate feeling like I am 'a bit much', especially for my friends, people really don't get me at all (Blaze, 13).

And conversely:

> I am soooo tired. I find this planet so difficult to live on. Cognitively I can speak the speak and navigate and filter the world through balances and checks I have learnt. But I am so tired. I struggle so with sensory overload and do not know how to explain that any better/more clearly to those around me. Seems the better you are with description the less you convince people of its profound reality. I am so tired of feeling like my skin has been ripped off and every nerve exposed just navigating a mall with my mother (Amber, autistic adult).

For atypical people, everything takes energy, especially when other people are involved. The simple act of trying to make eye contact can be utterly exhausting:

> Do I look into the left eye, right eye? Now I'm staring or even worse they are staring, and I've completely forgotten what I was saying, or what they were saying. I'll look away, re focus, come back but now it's uncomfortable and I'm scrambling to get things back on track. So much energy goes into trying to master eye contact. Uggghhh! (Adele, autistic adult)

Most of the children in my study were diagnosed with ADHD, and all displayed the diagnostic traits of inattention, hyperactivity, and impulsivity at different stages in their day or week. Some were medicated to assist them with 'concentration difficulties' and others had strict food and supplement regiments, such as reducing the level of sugar in their diet and taking Omega 3 tablets. Many of the children would not be able to go to sleep at night due to excessive amounts of energy, but when they were woken in the morning, they would barely be able to get up to face their day. Energy management was a constant and daily battle for all.

Beyond medication and diet, many adults referred to their need to manage their energy levels, using the analogy of 'spoons'. The 'Spoon Theory' was developed by Christine Miserandino (2013), who suffers from Lupus and often struggles with exhaustion due to high and incessant levels of pain. She describes how most people, "start the day with an unlimited amount of possibilities, and energy to do whatever they desire, especially young people". This, however, is not her reality, and in trying to explain her daily struggle to a friend, she created the analogy of spoons as energy units. Miserandino describes how a person starts each day with only 12 spoons. If not managed carefully, that person might run out of spoons before the end of their day. She explores daily activities such as getting out of bed, driving to work, having meals and meeting with people. For people struggling with illness or conditions that are physically and emotionally draining, the simple act of getting out of bed could take half of their daily spoon allocation:

> You don't just get up. You have to crack open your eyes, and then realize you are late. You didn't sleep well the night before. You have to crawl out of bed, and then you have to make yourself something to eat before you can do anything else, because if you don't, you can't take your medicine, and if you don't take your medicine you might as well give up all your spoons for today and tomorrow too (Miserandino, 2013:Paragraph 10).

In online chat rooms, it was not uncommon for people to refer to being "way beyond my spoon limit", or needing advice on how to "increase my spoons" for a particularly stressful event:

> I had a long, difficult appointment today and I was waaaay beyond my spoon limit (but it was 100 percent worth it for the results) and when I left, I got in my van and I'd forgotten how to drive essentially. Controls etc. were a puzzle to me, I had to essentially walk myself through everything step by step. I did not drive until I was absolutely confident that I could and it took quite a while to get there by using coping techniques (Alex, autistic adult).

All my participants struggled with a range of energy sapping physical, intellectual, emotional and social challenges. Every day involved trade-offs between what they wanted to do, and what their bodies felt capable of doing. Participation was not simply a question of whether they wanted to participate or not, but rather if the were able to control their body and balance their energy levels and to participate optimally and appropriately. This in turn was influenced by the children's ability to reinforce physical, emotional, and social bodily boundaries.

CHAPTER 7

ATYPICAL IN A CHANGING WORLD:

ON FLOW, COMMUNICATION AND ADAPTABILITY

Having worked in the child protection community for over a decade, I have spent some time engaging with children who have been abandoned and/or abused. I have watched them live in a constant state of 'fight or flight', afraid of where the next infringement to their body or emotions will come from. Despite their loving and supportive home environments, the children I engaged with during my research presented very similarly. Both groups displayed behaviours of hypervigilance, hyperarousal, physical withdrawal, obsessive behaviours, self-harming, anxiety, irritability, anger, fear, lethargy, speech challenges, and often intense sadness. The shared experience of these children was one of trauma, the former as a result of their birth and struggles growing up, the latter through their engagement with their day-to-day environments. My participants appeared to experience abuse from the world around them -- its loud noises, rough edges, itchy air, bright colours and incessant busyness. In addition to this constant assault from their environment, all struggled to internalise the fact that it was also constantly changing. Just as they got used to a new space or activity and created a structure or ritual around this, something would change. Whether large or small, for them change was often momentous. It interrupted the flow of their day, or week, or train of thought, and very quickly turned into an insurmountable challenge. As they often struggled to communicate their concerns, the disruptions would grow in import and frequently lead to outbursts, meltdowns and shutdowns, as they tried to comprehend, internalise and adapt to them.

KC was extremely resistant to unexpected change. The change of a teacher at school or a scheduled extra mural activity could create high levels of stress for her, as could the sound of her dog barking unexpectedly, or when the lights in her home went out suddenly due to electricity load shedding. Her fear of change and the emotional episodes that followed, presented as intense anxiety, as her father noted:

> A meltdown for KC is extreme anxiety. She doesn't understand something and it's just panic. She doesn't flap as much as a lot of kids do but her hands go up to her head often and you can see the anxiety. It's almost like her brain is going to explode, because she wants to understand but she can't. I think she's self-conscious enough to know that she should know, but she doesn't, and that must be totally distressing. That

> anxiety then leads to her vocalising saying she doesn't understand, and she begins babbling about everything that has ever made her anxious.

Her parents have tried a number of approaches to help her address her difficulties with day-to-day living, the most effective being her attendance at a school that offers behaviour therapy for children with autism. At the school KC was taught to engage in simple life skills in a step by step approach, with caring facilitators. Her various daily activities, such as getting dressed in the morning, eating meals and learning, are broken down into a range of steps that she can work through. KC has made significant progress, although even the school can cause anxiety in her world.

The school has a number of rules that she obsesses over, frequently exclaiming to herself, "What's your rule!" if she thinks she has broken one. She lists these rules as: 'no speaking in third person;' 'no copying;' 'no imitating;' 'no speaking to yourself;' and 'no TV talk'. Unfortunately, many of these rules are also her coping mechanisms. KC spends much of her day learning through imitating or copying her sisters, her facilitator, music videos and movies. If she starts getting anxious, she immediately starts talking herself through the step by step approach for that particular task. When we worked together, it was not unusual for to hear her say, "you've got this KC, keep going", only to chastise herself a second later with, "KC, stop speaking to yourself!" KC's facilitator, Leanne, noted of autism, "it stops you making sense of your world". Much of her day-to-day work with KC consisted of trying to help her to make sense of what was going on around her, often answering an endless stream of repetitive questions:

> We have a detailed schedule for her, but the minute we start a new thing, she will want to know, "what comes after". She knows what is happening, but she wants reassurance. I will answer the same question over and over again, but if I make a mistake, then it's on. She will ask me why I made the mistake and won't let it go. Sometimes she works herself up and gets really upset about it (Leanne, KC's facilitator).

KC gets to a point every day where she needs time alone. She will ask her mother when she gets home from work, "When is Leanne going home", an indicator for Leanne to head out, and for KC to have some 'down-time' in her room. As with many of the children, alone time is calming and helps them to recharge from an often-exhausting day of just being in the world.

Trauma and the atypical child

Despite similarities between the experience of autism and post-traumatic stress disorder (PTSD), very little research has been conducted on their comorbidity (Spectrum News 26th September 2019). Unlike neurotypical individuals who suffer from PTSD after seeing or experiencing a frightening or life-threatening event, the children and adults in my research experienced this trauma from day-to-day lived reality, often referred to as ‘complex’ post-traumatic stress disorder (cPTSD). Ongoing bullying, remedial or behavioural therapies and sensory sensitivity can all have a major impact on their emotional wellbeing. Puck noted how he had to leave his school sports day due to the trauma he experienced every time the starter gun was used in a race: “It felt like the gun was going off inside my head!” When this experience is repeated on regular basis, the trauma becomes embedded and the response to it becomes an ongoing battle with panic attacks, extreme fright, fight and flight reflexes, and constant flashbacks and perseveration:

> I can barely remember my childhood. I was constantly punished to normalise behaviour. That was "what was done at the time" and "girls aren't autistic". I no longer speak to my immediate family due to their inability to understand that there was anything wrong with how they treated me. I have profound anxiety, cPTSD and a very limited sense of self (Rene, autistic adult).

> I couldn't find my words. I try. It's too much. It took my therapist six months to get me to talk this out with her in therapy in my trauma timeline. It's just everywhere. Abuse isn't a few bad things in my life, it's like fine chillies were sprinkled over everything I ever did in my whole life. Every memory burns in unexpected ways when I try to chew on them (Amber, autistic adult).

Many of the effects of cPTSD were present among my participants: sleep problems, anger and defiance disorders, challenges with memory, concentration and focus, and debilitating depression.

The lack of awareness of cPTSD amongst atypical children is ascribed to their atypical way of being in the world. Just as they interpret and express emotions differently, psychiatric conditions such as cPTSD are also communicated atypically, leading to a lack of recognition, diagnoses and treatment (Spectrum News 26th September 2019). Many shared how they were often not taken seriously when talking about the trauma they experience, as it was not related to a ‘big event’ involving extreme violence, disaster, or war:

> It feels like I'm saying these really big feelings, but people are just like, "ok." Like, I'm suffering, I'm trying not to tell you explicitly that I'm suicidal, because I don't want you to lock me up in a traumatic place again, but I need help. I need better options than death, because I don't really want to die. I just don't know what else to do, and they're like, "ok sorry to hear that, have a nice day" (Angela, autistic adult).

As noted in the previous chapter, severe sensory inputs can also cause significant trauma, especially if the child or adult is unable to explain what they are feeling. Psychologist and autism specialist, Bill Nason, describes this as a 'sensory bombardment':

> Many of the nonverbal people on the spectrum, who also experience severe sensory defensiveness, are often experiencing intense physical and emotional trauma from the overwhelming sensory insult to their nervous systems. Since the child never knows when the 'sensory bombardment' is going to occur, it often attacks without warning, leaving the child helpless in defending against it. The constant 'fight or flight', panic reaction has long term effects on the nervous system, leaving the individuals battling stress and anxiety for many years. Each time the nervous system experiences intense sensory bombardment, the 'stimulus characteristics' of the event becomes associated with a severe 'panic response'. At other times in the future, when these common stimuli occur again it can produce an immediate 'panic reaction' that was originally associated with the traumatic event (Autism Discussion Page, 19th January 2015).

Nason explains that these 'sensory memories' could be of a simple sound, colour or smell, but the emotions associated with them can be overwhelming. To family and carers, the response seems excessive given the stimulus, but this is not so for the child, as one adult recalled: "It doesn't feel like a choice, my body just immediately flees at the smallest sign of danger". Autistic children and adults display a specific form of PTSD referred to as 'hyperarousal', where everything is experienced at a more extreme level. All the children were easily startled, and they often struggled to fall asleep and suffered from insomnia in addition to their anxious and sometimes angry outbursts.

In the long term, ongoing trauma and associated physical exhaustion can lead to a range of different illnesses and diseases spoken about frequently in my online community:

> Autistic children are particularly prone to streptococcal infections, and to PANDAS, a hectic immune disorder (caused by streptococcus) that makes you go nuts overnight. PANDAS can be managed, but it's best to treat the streptococcal infection ASAP to

> prevent long-term issues and flare-ups later on. The scary thing is that we will now not only have to make doctors aware of PANDAS (which they easily mistake for "regressive autism"), but also of the risks involved in treatment (Tracy, autism advocate).

In addition to PANDAS (Paediatric Autoimmune Neuropsychiatric Disoder), other conditions included: Mast Cell Activation Syndrome (MCAS), Postural Orthostatic Tachycardia Syndrome (POTS), Chronic Fatigue Syndrome (CFS), Ehlers-Danlos Syndrome (EDS), Chronic Lyme Disease, Fibromyalgia, and Epstein Barr Infection. Psychiatrist Sharon Meglathery identifies all of these 'overlapping conditions' in her RCCX theory, which she has identified in many of her patients, along with "a predisposition toward brilliance, gender fluidity, autistic features, and stress vulnerability, as well as the entire spectrum of psychiatric conditions" (RCCXandIllness.com Accessed 15/04/2020).

I observed this "stress vulnerability" throughout my research as both childern and adults succumbed to a range of conditions that could appear unrelated in individual cases, but were clearly connected in this biosocial environment. Participants frequently discussed sensitive metabolisms, gut problems and compromised immune systems, as one advocate explained: "We need to start with a healthy immune system, the complexity lies in ensuring that our environment and lifestyle supports that". Many shared their frustration at how very real physical challenges were often explained away as 'somatisation', where mental phenomena are given physical or somatic symptoms. Flashbang's mother described how a number of medical practitioners who she had visited with both of her sons, due to their EDS, had advised her that that many of their challenges were imagined or 'not as bad as they appeared'. She noted how she would have to spend a large proportion of her time just trying to get them to take her son's challenges seriously, before they would consider treating them appropriately:

> There's no cure, so you are constantly stressed about a step down [where Dynamo's EDS condition deteriorates further], when he gets sick, you stress that this is a signifier. He is anxious, but you also can't put it down to a psychosomatic issue, there are real physical challenges, and more than one EDS adult has been accused of being a pain winging opioid addict, and then they end up in a wheel chair with a feeding tube!

This suggests that a number of health challenges go unrecognised, undiagnosed and untreated amongst the atypical community:

> Somatic disorders or somatizations are so not a commonplace thing. Recent studies are flipping the lid on the role of this concept in oppressing minorities and women in medical settings who express they have pain… Somatization is generally used to gaslight Psychiatric patients into accepting nothing can be done to change their situation or health and should just be borne gracefully. Try again. How about looking at EDS, RCCX gene theory, the Chronic Constellation[37] and some of the history and philosophy behind somatization theory just in the event you have doubts…There are, very rarely, people who experience this level of serious physical manifestations of mental issues. But mostly there's just physical health issues. Do NOT suggest it as a first line response EVER man. That stuff kills (Amber, autistic adult).

Alongside his autism and EDS diagnoses, Flashbang struggled with fibromyalgia and managing his energy levels, presenting as either hypo or hyperactive at intervals throughout his day. Other participants also noted struggles with fibromyalgia and chronic fatigue syndrome (CFS). The ‘overlap’ between these two conditions and autism prompted research that indicated all three are linked to a deficit in nutrients that regulate energy production (Geier *et al*. 2011). Aches and pains are often dismissed as ‘growing pains’, and low energy levels as ‘lazyness’ or proof of ‘difficult behaviour’:

> I was always in pain, especially my knees and elbows, and it was dismissed as growing pains. I was in gymnastics and ballet, so I probably did lots of damage to my body that I’m paying for now. I also am constantly finding out that things I’ve always done aren’t things that other people have to do, like having to reset my hips every morning since I was a child. I’ve been dislocating since I was a kid, but didn’t realise it (Kate, autistic adult with EDS).

> Frequent dislocations, hypermobility, pains…My fainting, and dizziness, which is the result of POTS was never found to have a cause when I was younger. As I was going through all of my testing, and they were going down a list and asking me if I had these certain symptoms, I really had to think about it. I have been ignoring everything

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[37] The ‘constellation’ of symptoms including EDS/HSD (Hypermobility Spectrum Disorders), MCAD (Mastocytosis or Mast Cell Activation Syndrome), and POTs (Postural Tachycardia Syndrome) or Dysautonomia.

> for so long, that it was hard for me to be honest about it. Or maybe I should say hard to acknowledge them? Or realise that I really DID have these things going on, that it wasn't all in my head and I wasn't just making them up? It was a very strange thing to have actual validation of things that I had been ignoring all of my life because I was told that I was "just being a girl" or that "everyone has those things. Suck it up" (Morgan, autistic adult with EDS).

> Pain, fatigue and so called laziness. I was always told I was lazy because I couldn't or wouldn't do a lot of things and would actively resist doing them. The hypermobility was excused away, as were the excruciating 'growing pains'. I had major GI [gastrointestinal] and constipation issues as well but the number one issue was my fatigue (Elaine, autistic adult with EDS).

Elizabeth Nickson, describes her chronic fatigue syndrome as ‘forced hibernation’, as she notes: “Push your brain too hard, and your Autonomic Nervous System (ANS) gets stuck on fight, flight or freeze, and then your body triggers hibernation, you become a bear in winter whether you like it or not” (Medium 3rd June 2019). She explains that this hibernation can take many forms, including the activation of Epstein-Barr or mono virus, herpes simplex and cytomegalovirus. As with sensory and neuroceptive sensitivity discussed in the previous chapter, research is indicating a link between fibromyalgia, CFS and structural challenges around the vagus nerve that affects the flow of cerebrospinal fluid (Van Elzakker 2013).

Beyond the physical, many participants reported cPTSD following negative school experiences or extreme remedial behavioural therapy. One mother described that she could not get her son to do his homework at home, as he did not want to bring anything from school into his home environment:

> It’s almost like he has these two separate worlds, one is school and one is home. One he hates, and one he loves, and he doesn’t want the one contaminating the other. So homework is a nightmare, we can’t get him to do it at home at all (Sherry, mother of an autistic son aged 10).

She eventually identified ‘interim spaces’ between school and home, such as coffee shops, where he could do his homework without fear of one space ‘contaminating’ or influencing the other. As noted previously, all my respondents struggled in traditional school environments that were not designed for them or their way of learning. Ara’s mother once stated: “I just have to get her through school with her self-esteem intact, then she can focus on what she loves”.

Many remedial therapies of atypical behaviour focus on compliance. Advocates believe that this compliance encourages children to ignore their interoceptive sensory responses, their ability to ‘listen to their gut:’

> My son was taught compliance through ABA and now he doesn’t know the difference of when he should or doesn’t need to comply, if he doesn’t want to, or he’s uncomfortable. This scares me as I feel it makes him an easy target to be taken advantage of (Sharon, mother of an 8-year-old autistic boy).

> My son is seven, nonverbal, no words, just a couple of signs. He has become so prompt dependent that he won’t even potty unless the word potty is said, eat unless you say eat, drink unless you say drink. He has done this before, and it eventually went away, but this time it’s getting worse. He was up crying in the middle of the night and we couldn’t figure out why and then we said potty he jumped up, potted, came back and fell right back to sleep. I’m scared for him. When he was younger, he had ABA… after I realised how bad it was, we stopped, but I’m scared he has PTSD (Stacey, mother of a 7-year-old autistic boy).

> ABA is, at its core, about compliance, forced and required. It forces you to forgo your own internal feelings and not trust them, and not all, but many ABA practitioners still try to eliminate stimming, or only allow it if you have complied with them enough. So, we are taught the way our body’s naturally move is wrong, we are taught to not trust our insides, and we are taught to comply, regardless of how it makes us feel (Mary, autistic adult).

Beyond compliance, some adults spoke of experiencing trauma after being forced to engage in ABA therapy as children. Others noted how they have significant gaps in their memory of their childhood due to the therapy. Kupferstein (2018) found that both children and adults on the spectrum had more than a 50 percent chance of meeting PTSD criteria after four weeks of commencing an ABA intervention. This included a negative impact on self-esteem and perceptions of self. She hypothesised that this was due to the ‘Functional Behaviour Assessment’ (FBA), where the children are taught to constantly evaluate their own behaviour.

Most parents view ‘behaviour modification’ as a typical form of parenting and often used it successfully in teaching their neurotypical children. My participants, however, usually responded to the concept of rewarding good behaviour and punishing bad behaviour very negatively. Where some would see this often-subtle encouragement as a guide to appropriate behaviour, my respondents saw it as coercion and control, often responding with expressions of anger. Puck’s mother recalled how she had once tried to remind him of their ‘house-rules’ whilst walking through a shopping mall, only to be angrily rebuked by Puck: “Does this look like the house to you!” My online community spoke of the importance of intrinsic rather than extrinsic motivation to ensure appropriate behavioural responses:

> ABA does not help autistics develop emotional regulation. It breaks down our sense of self and creates a Pavlovian response of compliance as a defence mechanism. To truly develop emotional regulation, there needs to be intrinsic motivation to do so. Intrinsic motivation is the opposite of extrinsic motivation and comes from within. It’s what causes you to want to do something, without any external influence. Like when you greet someone when you enter their home because you appreciate seeing them. Extrinsic motivation in that instance would be greeting someone when you enter because they’ll give you 3 M&Ms if you do (Amy, autistic advocate).
>
> We become reliant on other people telling us what is 'correct' and 'right' at the cost of relying on our own internal feelings about situations. If we get rewarded for doing things that we have previously avoided doing because they cause us distress, then what are we learning: our pain and distress doesn't matter, we should disregard it. But where do we draw that line? If we are reliant on others to tell us what is correct, normal and appropriate, and we are taught that our own instincts and feelings can't be trusted, that's setting us up massively for abuse and manipulation. It means we have no trust in our own ability to navigate scenarios and that other people do not care about our pain and distress (Ingrid, autistic adult).

The need for intrinsic motivation supports the children’s top down approach to need fulfilment, illustrated in Echo’s ‘inverted hierarchy’ detailed previously. The children first need to understand the meaning and reasoning for a particular action or behaviour, before they see its relevance to their lives and consider enacting it. Extrinsic or external motivation is experienced as manipulation rather than motivation, or just not understood. This lack of understanding was evident in the autism boxing classes where some children would not respond to any external interactive stimulus such as sparring with a coach: “They just let themselves be hit, they don't put their gloves up to protect themselves, it's as though they don't understand why you are hitting them and so they just freeze or curl into a ball" (Coach Luke).

However, not all therapies are rejected. Many adults spoke positively of body awareness therapies such as occupational, speech, music, equine and sensory therapy. Communication therapies that allowed non or partially speaking autistics to communicate were also viewed positively, such as Makaton sign language, Rapid Prompting Method (RPM), Augmentative and Alternative Communication (AAC) and Spell to Communicate (S2C). From a developmental perspective, some parents noted the success of programmes like Relationship Development Intervention and D.I.R. Floortime,[38] which encourages meeting atypical children at their current developmental level and then building on their strengths, as used by KC's facilitators. Advocates noted that the most important element of any therapy was that it did not try to "fix the child" or engage in what some referred to as "normalisation tactics". All stated the importance of ensuring that the children had a voice or a means of communicating their perspective.

At a structural level, Scheper-Hughes and Lock (1987) note that when a social group feels threatened, it responds by purging what it views as social deviants from its ranks. This feeling of social ostracism was felt acutely by parents. Many described how applications for their children to attend mainstream and even some remedial schools were often rejected after they had disclosed their autism diagnosis. They felt as though their children were "damaged goods", and that there was no role for them in mainstream society:

> The school application asked for full disclosure. I said my son is on the autism spectrum and he would be a candidate for facilitation. This is not a new concept in South African schools… For weeks now after I handed in our applications, I have been dreading the outcome. I felt like a ping pong ball, emotions all over because I can't control the outcome… I tracked the applications to mainstream schools via the Education Department. They loaded a tool where schools must load all applicants for 2019, in order for parents to track the progress on applications. Out of the 4 schools I applied to, only 2 schools loaded his application. Now past Friday... the time has come to get feedback. We have been notified by email: "We regret to inform you that we are full. You can be placed on a waiting list and should there be a space open, we

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[38] www.icdl.com Accessed 08/02/2020

> will contact you". There is a school 900 metres away from where we live. They said they were "full". The other just opposite the road from the above school is 1 km away from our home. They didn't load the application via WCED. Now I am not going to want my son to go to a school where they don't want him in the first place. It is clear, we will not have a good relationship and my son would probably be a victim of ableism, internal ableism, abuse, neglect, and being misunderstood (Linda, autistic mother of an autistic child).

Beyond parents, some health practitioners shared similar concerns. During my fieldwork, I engaged with a psychiatrist who refused to give written proof of any diagnosis related to autism or mental disabilities for school accommodations, as she believed that this could be used against the child in later years. Hurley-Hanson *et al.* (2019) note that stigma manifests itself in multiple ways in the life and work experiences of persons diagnosed on the autism spectrum. This stigma often follows a formal diagnosis of autism but can also be experienced by individuals who displays characteristics of autism. The authors note that the stigma experienced by individuals on the autism spectrum is different to that felt by people with other disabilities, as it is considered an 'invisible disability'.

As noted in the chapter on presence and identity, autism is an integral part to the children's way of being in the world, leading many advocates to reject therapies that refer to it as a disorder or offer claims of a 'cure'. In the words of @NeurodivergentRebel: "You can't take autism out of me without changing who I am". Advocates reject practices and organisations that attempt to remediate, exclude or eradicate autistic behaviours and individuals from society. Exploring the details of an increasing number of publicised autistic child murders in Canada, Anne McGuire (2016) notes that rather than random and individualised tragedies, "ableist violence" against autistic people needs to be understood in the context of this problematic sociocultural phenomenon (2016:3). In South Africa, the launch of the Afrikaans drama *Raaiselkind* [39] ('Riddle Child') in 2018 created a heated debate within the autism community as it was believed to justify the dehumanising and killing of autistic children. Interviews conducted around its release suggest that the film perpetuated the dominant discourse of autism as a burden to parents and society, and autistic children as deviant and abnormal:

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[39] Based on the novel Raaiselkind, by Annelie Botes (2012).

> The powerful South African film *Raaiselkind* explores the unrelenting burden of autism on an average, loving family and shows the disintegration of the family as a result. It drives home the inescapable truth that society can be cruelly indifferent to whatever it perceives to be aberrant (Writing Studio, 13th February 2018).

Several film reviewers asked, “what would you do in this situation?”and appeared to condone the euthanasia of the autistic child. Autistic advocates were labelled ‘radical’ and ‘rude’ in their criticism of the film, but their concerns mirrored McGuire’s:

> If you read what actual autistic people have written (speaking and non-speaking), then autism will be less of a *raaisel* (mysterious). The deliberate, malicious, concerted effort to silence autistic people, to push a mystery narrative and to maintain power, that is why parents don't get to hear about hope, and the makers and distributors of *Raaiselkind* are complicit… Disabled people are not allowed to enter the discussion about whether murdering them is justified, because disabled people are regarded as subhuman. *Hulle het hom probeer mens maak, want hulle het hom nie as 'n mens beskou nie* [They tried to make him human, because they didn't consider him human] (Morgan, autistic advocate).

While some parents view disability and autism as separate to their children, and a target of their frustration, the children view it as part of their identity and fundamental to who they are, with devastating consequences for the children’s sense of self (McGuire 2016).

In the context of the ‘body politic’, references to the increase in autism, ADHD and learning disabilities as ‘epidemics’ that are ‘attacking our children’ position these challenges as ‘cultural idioms’ for social distress and dis-ease (Scheper-Hughes & Lock 1987:24). The increase in atypical children highlights society’s inability to control or create the kinds of bodies that they require. From the perspective of the child, attempts to remove a threat that is inseparable from themselves creates feelings of disconnection and alienation, as noted by autistic rights activist Julia Bascom:

> One of the cruellest tricks our culture plays on autistic people is that it makes us strangers to ourselves. We grow up knowing we’re different, but that difference is defined for us in terms of an absence of neurotypicality, not as the presence of another equally valid way of being. We wind up internalising a lot of hateful, damaging, and inaccurate things about ourselves, and that makes it harder to know who we really are

> or what we really can and cannot do. If no one acknowledges that we have a voice, we can forget how to use it. We might even decide not to (2012:8).

Some advocates challenge neurotypicality as the only authentic way of being in the world:

> I'm autistic, which means everyone around me has a disorder that makes them say things they don't mean, not care about structure, fail to hyperfocus on singular important topics, have unreliable memories, drop weird hints and creepily stare into my eyeballs. So why do people say you're the weird one? (Chris Bonello, Autistic Not Weird, 21st January 2020).

However, for children unable to rationalise their feelings of difference, their sense of alienation persists, as Alan (12) explained: "I believe I was born perfectly me; it is the world that doesn't understand".

A Paradoxical Relationship with Flow

When discussing her 'life history', KC (11) went through a number of family photo albums with me. The albums were arranged in order on a shelf, but she chose them at random, and took me through each in extraordinary detail. There was no chronology to her story as she told me about birthdays, holidays and special events from infancy to pre-adolescence; it was as though each had just occurred. She would point to a picture and then launch into a monologue with minute details of everyone's names, even if they were not close family, their familial or friendship connections to her, and what they got up to. Pointing at a range of pictures of a birthday party she attended at the age of 6, she explained:

> There's Jamie, Sandy's brother, and this is the party. There is Andy and Sandy and Helen and Dan and Donne. And we went on the submarine. We were at the restaurant. And we went to do ballet. She did Swan Lake with her friends, isn't that cool! It was Andy's party. And we had to put all the plates out. And I had to sleep in my own bed. Helen went on a racing car. This is all her friends having fun.

KC continued this monologue over 10 years of photo albums, at the same pace, with the same clarity of detail, spoken as a train of thought, recalled entirely in the present. As with their ability to traverse a number of parallel worlds, the children all appeared to have distinct moments where they focussed entirely on the past, perseverating over memories or infringements, or entirely on the present, sharing an interesting fact or story in a lengthy monologue, or entirely on the future, worrying incessantly about what might come to be. Tense -- past, present and future – was not integrated nor flowed from one to the other in their perception or presentation of their world. The children appeared to have a paradoxical relationship with the 'flow of their lives'.

From a physical perspective *flow* relates firstly to the flow of natural bodily processes such as eating, digestion and elimination. As illustrated in their 'negative body diagrams', all the children struggled with gut problems, usually in association with heightened anxiety. A clear distinction can be seen between Ara's 'happy body', where she does not register her stomach, and her unhappy body where her stomach is 'filled with furious bees' (see Figure 33): "They are buzzing around and stinging me…I feel it in my stomach and then it spreads like rapid fire across my body. It doesn't feel nice in my body, I feel a little sick. It is an *uncomforting* feeling" (Ara, 11).

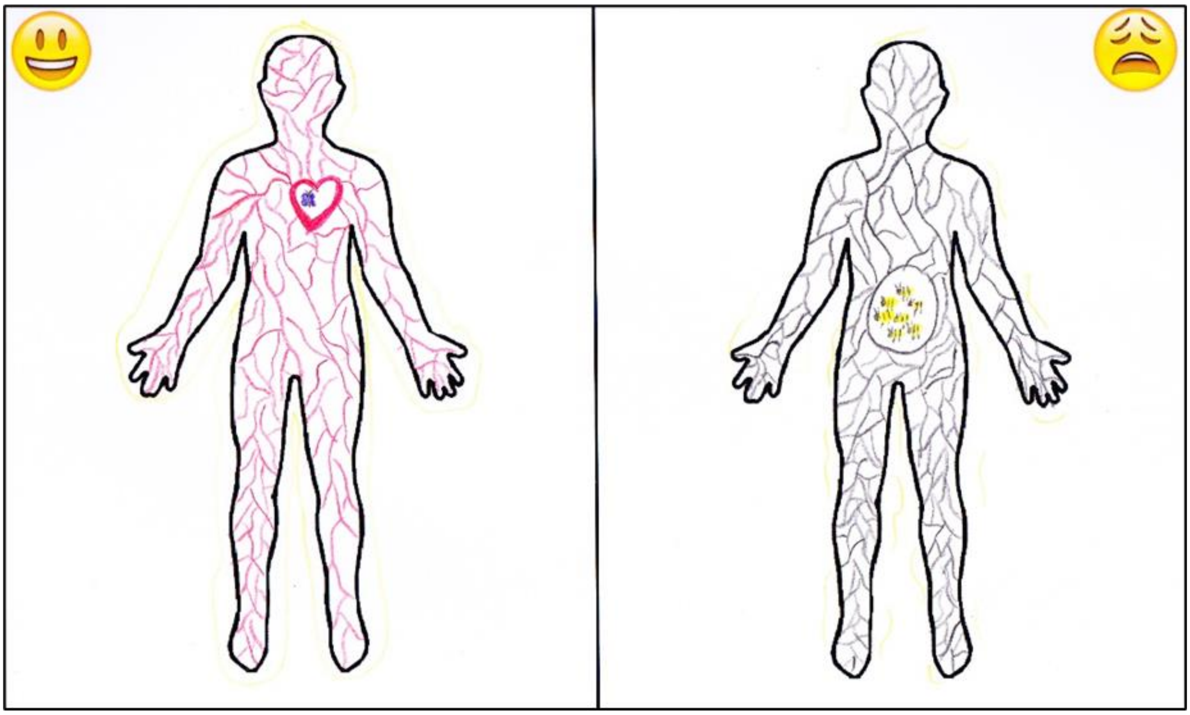

Figure 33.

Rather than healthy blood vessels taking energy to the different parts of her body, they have become black and atrophied, and her aura is "all broken up."

Blaze had violent vomiting episodes that could last for weeks around the age of seven to eight, coincidently the age she was diagnosed with learning disabilities and made to repeat grade three. Flashbang was diagnosed with irritable bowel syndrome, Ara and Coco struggled with constipation when worried, and Buzz frequently felt nauseous and sometimes vomited in test situations. Puck mentioned nausea, vomiting and diarrhoea, especially when stressed, such as when his father took ill or during air travel. Following his life-threatening diagnosis of necrotising enterocolitis at birth, Dynamo's mother described that mealtimes were always a struggle. He refused to eat anything with texture or the colour green, preferring only highly processed food. He could also take well over an hour to eat a miniscule amount. His chronic vomiting episodes as a new-born continued into childhood, especially when anxious or sick, usually in association with asthma. Dynamo drew his unhappy body as a tight ball of vomit in his stomach, which then spilled out of his mouth and onto the floor in front of him. Many of the children described similar experiences (see figure 34):

> My anxiety and stress starts in my stomach and then bubbles up through my chest and into my head making it hurt [he mimics vomiting] (Buzz, 14).
>
> This is about sore throats and vomiting (Coco, 8).

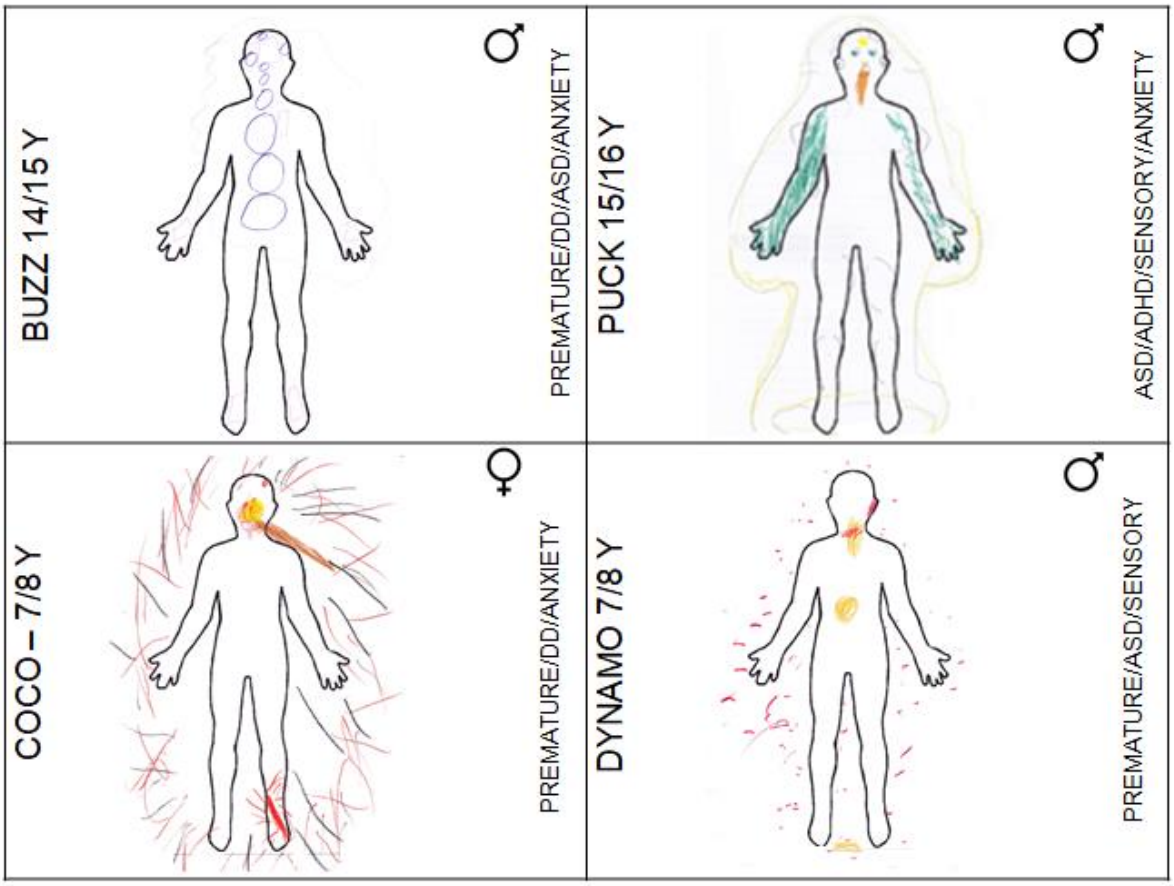

Figure 34.

As the children carefully 'digested' their world in the perceptual stage of engagement, these gastrointestinal disruptions mirrored their relationship with the 'flow of their lives'. From learning and play, to emotional regulation and social relationships, all appeared to be in a constant battle between letting things flow or stopping their world in its tracks. In one instance, they could appear dreamlike and content; a moment later, they would call an immediate halt to proceedings and refuse to move forward. Stopping or 'disrupting the flow' could take the form of suddenly getting up and walking away, angry outbursts, anxious mumblings, or extreme physical and emotional meltdowns. The children were often unable to articulate why they felt the need to stop what they were doing, but once stopped, all were unable to continue, no matter how much one might try to encourage, coerce or insist that they do so.

Neurodevelopmental specialist, Melodie de Jager (2006) describes how for learning to flow, all children's 'learning equipment' needs to be integrated, including their sensory, brain and motor systems (2006:11). Just as the brain has left or right dominance, so too do the organs of the sensory and motor systems. Information flows in through eyes, ears and hands, is processed by various layers of brain functioning (from survival to emotional to cognitive) and is then acted on by hands and feet. Any barriers in the flow of information between these areas, from right to left, or left to right, can block or confuse the flow of learning (2006:46). Ara's mother noted that Ara often struggled with learning, as her right- or left-hand dominance was never established. Ara still writes with her left hand but plays all sports with a right hand and foot dominance. Barriers to neurological development are also caused by children not engaging or developing their various protective reflex systems that are triggered before, during and after birth. This is often a result of complicated or caesarean births, relevant to most of the children in my cohort. 'Flow of learning' can even relate to a child's posture in a classroom. Sitting up in a chair, facing forward, feet planted directionally towards the teacher, allows for seamless learning. However, most of my respondents slouched or folded over their desk, feet twisted up in the legs of their chair and head directed towards the window or any source of noise competing with the teachers' voice.

Disruptions to the 'flow of learning' impact on the children's ability to listen, see, concentrate, write, speak, read, spell, problem solve and remember (de Jager 2006:95). These learning challenges occurred with all children in this study, especially in the context of tests or exams, which triggered intense feelings of anxiety and fear. In these states of heightened stress, the children felt unable to access their memory. As with many aspects of engagement with their world, the children displayed an atypical relationship with memory. They could recall a movie they may have watched years before, word for word, whilst miming the actions, and yet claim that they did not have a good memory. Blaze referred to her memory as a “black hole, where everything disappears”, and Ara explained that her memories “sometimes became faded”. Buzz and Coco spoke of trying to remember things, as akin to a battle inside their heads. KC spent hours looking at letters and words at her school but struggled to make sense of them or connect them into the process of reading. Yet her facilitator noted that she could take any book off the extensive bookcase in her bedroom, open it at random and tell you what was written on the page, “even the bible!” All the children appeared to have an extensive library of information stored in their memory, that they often drew on to address particularly difficult social interactions. If asked how they were feeling or what they thought of a particular situation, they would launch into a movie dialogue to explain their views or lack of comfort. KC’s facilitator Leanne noted how after a particularly difficult afternoon together, KC (11) exclaimed a line from a movie: “Am I being rude? Did I break your heart? I guess I should say sorry!” This treasure trove of information, however, appeared solely focussed on their favourite movies or areas of specialist interest. School work or instructions from a parent often had little to no recall.

Despite being diagnosed with ADHD, Echo recalled how even as a young child he could focus intently for hours on end on a project that captured his imagination. Echo’s mother queried his diagnoses because she had seen him in hyper-focus mode, but her doctor explained that the diagnosis referred not to his ability to concentrate, but rather to concentrate on the “correct things”, for instance, school work. Dynamo would get so caught up in his Lego or marble game that he would not even register that I was asking him questions. Adults noted similar challenges with hyper-focus:

> I know now that if I start any of these activities, my day and night and early morning are just gone. I will likely get a migraine. If it's a more physical project, then because of my previous hand surgeries, my hand will be cramped up and I won't be able to use it for a day after, and my back will likely be out of place the next day. But it's usually worth it for me. These are all the things I love and am good at, which is why I feel like the hyper focus is just so strong (Rachel, autistic adult).

Among the children, hyper-focus was reflected in their play and the attachments they formed to their toys or other items that they found interesting. Playing with toys often involved sorting, categorising or lining up various items. The DSM-5 refers to these activities as ‘inappropriate play’, but this label is rejected by advocates:

> Lining toys up is considered problematic because it’s seen as an autistic trait. They [neurotypicals] want us to play with toys in a storytelling, "pretend" way (either make the objects interact with each other or pretend they are the real versions of whatever they are, so for two toy cars, either make them talk to each other or drive them around saying zoom). They find it disturbing for us to enjoy the material properties of the objects in and of themselves or to collect and compare things. Apparently when allistics [neurotypical individuals] use or look at objects, they primarily see the social story (including purpose for which it was built). If they see a scarf from a trip, they are thinking about the trip rather than just touching the material, or if they have a wooden box, they think about what it can hold rather than that they could use the boards for something else (Roger, autistic adult).

Therapies that attempt to teach appropriate play are seen as “turning play into work”, one adult explained: “Instead of enjoying himself and lining toys up, he's now focused on how to play ‘right’, how to make the adults happy, it's exhausting, and will lead to burnout”. The grouping and categorisation of toys is often far more complex than simply lining them up. The children often identify specific characteristics that speak to intense skills of observation and insight. A father noted how his 4-year-old autistic son grouped domestic cows and goats with wild buffaloes and giraffes. When he asked his son why they went together, the boy indicated that they all had cloven hooves.

Dynamo could play for hours with his marble collection, lining them up, inspecting them closely, and racing them down a metal tube. He would crouch down to the level of the marbles, as though he were picturing himself hurtling down the shoot. Once the marble landed on the floor or crashed into the rest of his pile, he would squeal in delight and flap his hands with joy. He also liked collecting things, “things that I have never actually found before”. Blaze had piles of stones, shells and feathers in her bedroom that she had collected over several years, and could recall the exact provenance of each, despite all appearing very similar to me. Puck treasured his theatre programmes, and KC loved her toy collection, and was able to tell me when she had received each one. Losing any of these items could be traumatic. Many parents noted how their children hated to throw anything away, from sweet wrappers, to pizza boxes, everything was stored for possible use or ‘recycling’:

> My daughter collects rocks, sticks, coins, pieces of paper. Whiteboard pens, bottles, erasers. Throwing them away can cause meltdown. At one point she was collecting butter knives under her bed and I probably didn’t handle it very well because I

> overreacted. Eventually I just made a rule about the specific object that would cause a problem and she respected it. I leave her to the harmless collections though (Alice mother to an autistic daughter).

Participants noted how much of their concern for discarding something related to their giving the items anthropomorphic feelings, rather than just needing them for comfort or security. Echo recalled that as a young boy, he cried when his father decided to upgrade their family car, as he felt it was a part of his family:

> I hoard stuff because I feel so guilty leaving them behind as though they are not inanimate objects (Sandy, autistic adult).

> I forget the fancy term for it, but some of us relate to objects as if they are beings. Most children will do that with favourite toys but some of my clothes, dishes and other things were also like pets or something to me. It's painful for me to discard something I have spent a lot of time with or have memories attached to and if it's spoiled in a way that it's just going to rot in a trash heap somewhere it's even more painful (Paul, autistic adult).

> Many Auties get attached to inanimate objects. Have you ever watched a YouTube clip of a child feeling very upset because their daddy shaved his beard? That's what it feels like to lose an inanimate object that you loved. It messes up your whole sense of safety. It alters your reality (Rose, autistic adult).

The intensity of their connection to items and focus on their specialist interests or games appeared to be visceral. This was noted by many parents and teachers, when trying to get the children to refocus on another activity. Flashbang and Buzz explained how angry they became when their mothers tried to stop them from playing video games or watching YouTube. Their mothers had imposed strict time limits on their use of electronic devices, but every day was a battle to get them to stop. The boys, in turn, explained that this 'interruption' felt physically painful to them. Although they had agreed to a certain time limit, they found the sudden stopping of their train of thought or the flow of their game particularly stressful and frustrating.

While the children had trouble stopping things, they also struggled to start new things. They would procrastinate endlessly, especially if they knew they had to do it, such as taking a bath or shower. One mother noted: "First you struggle to get them into the shower, and then they never want to get out". Transitioning appeared to be particularly stressful:

> I have trouble with transition. Why? Because when I am truly comfortable and at peace, being dragged out of that feels like...pain. It feels like...you know when you're in the middle of a sound sleep and a comfortable dream and you are jarred awake and have to get up and function? Like you're leaving on a trip or something. When I am interrupted from a book or something engrossing on a screen, I feel groggy and wrong and it messes with my head. And I can be angry and easily frustrated (Catherine, autistic adult).

> I know for a lot of people, being aware way ahead of time that the transition is going to happen helps make it smooth. For me it seems to just build the anxiety for the impending doom. I get anxious while waiting for therapy appointments that I have no anxiety about. I get anxious while sitting in class before it starts when I'm not at all anxious about the class itself. Once these things start, the anxiety goes away (Rae, autistic adult).

Ara frequently felt stressed when having to transition from one thing to another, especially at school. To manage her stress, cupping her ears to mimic her earphones, she explained that she would listen to music: "My best work happens with music". Adults also referred to listening to music to 'distract' a busy and anxious brain during transitions.

Dynamo's mother had a number of strategies that she put in place to move him gently into his day. These include "morning cuddles" to signify that it was time to get up; setting out his clothes and anything he needed for the following day, the night before; and calling out positive reinforcements during his morning routine to ensure he dressed, ate breakfast, and brushed his teeth. Despite this support, the family would often get to the time when they needed to leave the house, to find Dynamo half-dressed playing with his Lego and completely lost in his own world. This led to huge frustration in the family, and Dynamo would become extremely distressed. On one such occasion, almost at the front door, he announced that he needed to go to the toilet. His mother noted: "This can be a very lengthy process, so we had to restructure our entire morning as we did not want him to have a meltdown". Conversely, on weekends, when the family have no plans or commitments, Dynamo jumps out of bed at 6am, ready to face his day. The challenge was not that Dynamo had become distracted by his toys, which is typical of many little children, but the extreme anxiety and stress responses associated with this. Dynamo could transform from a happy little boy to extreme hypervigilance and outright panic in a matter of seconds, as his fight or flight responses took over, a response referred to as Pathological Demand Avoidance from a biomedical perspective:

> My daughter is intensely difficult, and meltdowns are always filled with fear and horror. If disturbed during a meltdown (even if you enter the room she is in) she screams, and her eyes nearly pop out from pure fear. It’s very sad to watch (Amy, mother of a 7-year-old autistic daughter).

> We keep everything calm at home and instead of giving direct instructions we allow him to make his own decisions without him realising that he is actually doing what is requested. Example: Telling him to go shower, he would give us a flat out NO response and would turn into meltdown and rage. Instead, we ask him if he would prefer to bath or shower and then do an activity that he is interested in. He now thinks that he is in control of the situation and his anxiety levels are lowered and he goes to bath. He is 10 years old so at this stage it is easier to manage him in this manner. Since taking this approach we have peace in the house, and I can count the outbursts on my hand as opposed to having several outbursts per day followed with rage (Roger, father of a 10-year-old autistic son).

> Many PDA people seem to suffer from sensory overload. Over, and over, and over, and over, parents and teachers and other people in authority insist that children who suffer from this should expose themselves to conditions which are painful, distressing and intolerable. The victim resists, but the demands persist. Eventually, any demand is viewed by the victim as something which must be resisted, because any demand is seen as potentially harmful. Combine this with the natural questioning nature which many autistics have, the need to understand a thing before it can be executed, and you will have someone who looks obstinate and rebellious. The pattern is reinforced by therapies which attempt to break the obstinacy, strengthening the resistance pathways. Epigenetic factors compound the effect. An all-out "giving in" may eventually occur, as in the case of some people who are subjected to torture in a war, where you snap or crumble, and give up on the hope of ever being able to save yourself. You do as they say mechanically, withdrawing your soul from involvement. At this stage, if you have not become catatonic, they think they have won, because you start to comply (Morgan, autistic advocate).

Sometimes the children would completely ignore my instructions for a particular task if they felt anxious about engaging in it, behaving as though I had said nothing at all. Some would start chatting about different things, hoping to distract me, and on occasion some children would strike out physically, usually much to their horror in retrospect. I understood these responses as demand avoidant behaviour and I would spend much time explaining the relevance of the exercise to the development of their personal books, before they would consider engaging in it. Some adults noted how they felt unable to pay bills or to answer simple correspondence. Any form of authority was often rejected, not because they were being difficult but because they felt a deep sense of injustice and inequality in these interactions. Many noted how they were often ignored or side-lined due to their questioning of ‘neurotypical norms’, as one adult noted: “You should listen to the defiant, not diagnose and medicate them”. I observed some of the children in my cohort ‘giving in’ to demands made of them. They appeared completely deflated, disempowered and emotionally broken. This moved well beyond compliance to outright surrender, as though they had not just given up a fight, but their very will to take part in life. When I tried to talk to the children about how they felt in this instance, their responses would be deflated and dejected. Flashbang once stated that “it doesn’t matter…I don’t matter”.

PDA is also linked to general social interactions. The children would get excited about going to a park, the gym or visiting the zoo, and would even tentatively engage with other children in these environments, especially if prompted. However, the minute more than one or two children joined the conversation, they would extricate themselves and return to playing on their own. Much of their concern with socialising and interacting with others mirrored the challenges they expressed in the previous chapter around sensory issues and their inability to enforce physical, emotional and social boundaries. In these social interactions they felt exposed and vulnerable. Both children and adults noted how although they may not want to personally interact with other people, they did like to be around other people, a practice they referred to as “parallel play” or “quiet togetherness”. Finding a way to interact without social pressure or expectations, or ideally with a filter, such as through social media or gaming, appeared to allow for a far more seamless flow of social interaction:

> When I was small and non-verbal, I liked my mom or family being in the room but did not necessarily want to interact with them when playing or lining things up. I did enjoy being carried and talked to at other times but interacting with other people was more about their needs than my own. Quiet togetherness is a lot (Gill, autistic adult).

> I liked when someone was in the room with me and did a similar activity. I still do actually; parallel play is great socialising. And stimming together is always fun, it shows fun, acceptance, and understanding (Nick, autistic adult).
>
> I much preferred playing by myself as a kid and it was annoying when people tried to join in because it interfered with what I was trying to do. It is, however, nice to spend time together in the same room, even if we're doing different things. I enjoy the company of people who just let me get on with whatever I'm doing without wanting to get involved in it (Amber, autistic adult).
>
> My whole family does it. As my kids got older, they would narrate their parallel play aloud without really speaking to each other directly, but since they took turns it was clear they were playing together without actually interfering in each other’s game. Fast forward to video games, where while one boy narrates his play aloud, the other one comments on it. These days they carry on extended conversations with each other, facilitated and structured by the game (Phil, autistic adult).

Echo and Buzz engaged in this individual yet communal play on their computers, with their friends or fellow gamers. Contrary to many parent’s concerns that gaming is antisocial, it appeared to be an extremely social environment where both boys, who were often very shy, appeared relaxed, engaged, and confident.

Communication

The inability to communicate in neurotypical ways is a primary signifier of ‘neurodevelopmental’ challenges spanning learning disabilities, ADHD and autism. Puck did not make any ‘baby sounds’ but started using full words at the age of one; he could recite full books that were read to him as a toddler, and often engaged in echolalia. Ara was selectively mute between the ages of two and four, she was non-verbal whilst attending her play school, but she was extremely chatty in her home environment. She did, however, attend speech therapy from four to eight years as she struggled to articulate words and often mixed up letters or syllables. KC was initially diagnosed with a communication disorder and attended extensive speech therapy as a young child. Her mother noted how she “did not pick up on stuff” and tended to repeat everything that was said to her in the manner of echolalia. Echo developed a chronic stutter and a range of verbal ticks (diagnosed as non-fluency) from six to nine years of age. and attended extensive speech therapy to address this. The children and their parents all ascribed their language and communication difficulties to a lack of comfort either in their environment or with their own ability. Puck and Ara said that they only felt comfortable speaking once they were confident they could do this proficiently, and until then they refused to speak or write. Echo said his non-fluency developed after extreme bullying at his school which caused him high levels of anxiety. He finally managed to address his speech challenges after he left the school, and his anxiety was treated with medication. All children showed exceptional listening skills and as already noted, they could often recall books or movies almost by rote. I observed a distinct difference between early conversations when I was new to the children, and later ones when the children were more comfortable with my presence in their lives. The ability to communicate was primarily linked to comfort levels, and any form of anxiety, stress, or trauma would have a marked impact on their ability to converse.

As none of my cohort were non-verbal, I spent time observing children with this challenge online and in the autism boxing space. What was apparent is that despite being unable to speak words or sentences, the children still communicated almost constantly using their entire bodies. They did this through stimming, making sounds, singing, dancing and sometimes with the help of sign language or an assistive communication device. Stims could also serve as a social catalyst among children: one child would start rocking and moaning, only to be joined by the children around them. This joint stimming could stimulate the children and calm them down. Some parents noted that one of the best ways to 'join their child's world' was to stim with them:

> Sometimes the way he plays is by stimming it seems. So I had an idea that maybe imitating his stimming is a good thing. He likes to make sounds with his throat or movements with his head and immediately when I copy him, he notices and smiles, laughs and tries to get me to copy more. It's the best way I know to join his world (Erica, mother of a 3-year-old autistic boy).

Adults spoke of how validated they felt as children when their parents participated in their stims. Stimming is a form of communicating both with others and with oneself. Some participants noted how they were attuned to certain kinds of stims, which were coping strategies, and alerted them to a possible anxiety attack, growth spurts, if they were getting sick, or if they were responding badly to a particular medication. Despite challenges with interoception, it appeared that their bodies used stimming to communicate their needs.

Like KC, many children sang or chanted almost constantly. Participants noted how singing was a form of communication, but also an important tool for self-regulation:

> My stutter was so bad when I was younger that I was often unable to speak at all; my speech therapist taught me to sing my words and this helped tremendously. It's interesting what you say about singing as a sensory activity... I sing constantly and make musical vocalisations, sing people's words back to them, tongue click, hum and whistle when I am happy, depressed, scared, over-excited or feeling boxed in (Max, autistic adult).

> I used to sing a LOT when I was suffering from severe anxiety. It was my automatic way of trying to drown out thoughts that scared me. I tend to use mindfulness nowadays when I am anxious, I learned that, so that I can 'handle' the thoughts rather than block them out. But I do still default into singing 'Somewhere over the rainbow' from the Wizard of Oz when I am anxious, and the mindfulness takes a conscious decision (Morgan, autistic adult).

The inability to communicate was often expressed as frustration and anger:

> He does mostly gestures, whining and screaming. His tantrums from his lack of communication is getting kind of bad. It's more of a frustration thing, because I don't always know what he wants, because he doesn't always make sense when he's trying to tell me what he wants… I wish he could talk more. I hate seeing him so frustrated all the time (Amelia, mother of an autistic 7-year-old son).

Autistic media personality, Carley Fleishman, explained the frustration she felt at not being able to communicate before learning how to type: "Autism has locked me inside a body that I can't control" (ABC News, 08th August 2012). Peri Savidge shared this frustration in a dialogue between herself and her brain (The Mighty, 4th April 2019):

> My brain: "You're hungry, you need to ask for some food".
>
> Me: …
>
> My brain: "Come on, just say 'Dad, I'm hungry'. He's right over there".
>
> Me: …
>
> My brain: "Come on, that's it, walk up to him".
>
> Me: "Aaaaaaruuuaaaa!" *Falls in front of dad and begins to scream.*

> My brain: "Oh here we go again, you know what you want, why can't you just say it?"
>
> Me: *full blown meltdown* "Aaaaaaa! Noooooo! Aaaaaaaaaah!"
>
> My brain: "You did this the other day when you were in pain, but couldn't tell your siblings so you just screamed, cried and were aggressive. Look, he's asking if you want food, you just need to nod".
>
> Me: "Aaaaaaghhhhaaa! Hmmmmmm!" *Loud humming.*
>
> My brain: "Too far gone, I suppose".

Peri explained that she knew exactly what she wanted and how to solve a particular problem but was completely unable to express her wants and needs. This led to high levels of frustration and frequent meltdowns. Both young women spoke of their utter relief at finding a means of sharing what was going on inside their mind. Carley noted of her pre communication stimming:

> If I don't [stim] it feels like my body is going to explode. It's just like when you shake a can of Coke. If I could stop it, I would. But it's not like turning a switch off. I know what is right and wrong but it's like I have a fight with my brain over it. I want something to put out the fire (ABC News, 8th August 2012).

All of my participants noted that the primary focus of any therapy should be to enable a child to find their inner voice: "Don't give up, your inner voice will find its way out, mine did" (Carley).

Ara struggled with word and sentence formation between the age of two and four years but appeared to speak comfortably in her home environment. Her parents were shocked when her nursery schoolteacher advised them to seek a speech and psychological assessment at the end of her first year, as she was all but mute in the playschool environment and communicated only through gestures and sounds. Selective mutism was not uncommon amongst my participants, especially in social environments. Rather than a conscious choice, this was usually a result of particular situations or environments and entirely unintended, prompting alternative naming suggestions such as "sporadic" or "situational" mutism:

> I am not selectively mute...I don't want to be mute. It is situation dependant and usually "overwhelmed by sensory input so my brain has switched off my speech centre" mute! (Anton, autistic adult).

> I’m so, so tired of this term [selective mutism]. It sounds like it’s a choice and it absolutely is not. I become literally unable to speak. It happened for me at school a lot. I prefer intermittent mutism or involuntary mutism which I know now was caused by severe social anxiety (Cathy, autistic adult).

> It’s involuntary. When my kids become nonverbal, it’s not a choice. A bit of the system just shuts down (Dianne, mother of autistic children).

Most participants noted that selective mutism was a result of sensory overload or feeling overwhelmed, although both Ara and Puck stated that they did not talk because they were not ready to do so.

A lack of Theory of Mind (ToM, as indicated in Chapter 3) was also noted as a distinct deficit amongst atypical children (Baron-Cohen *et al.* 1985; Korkmaz 2011; DSM-5 2013). Most participants struggled to communicate, especially with neurotypical individuals. However, many questioned aspects of their supposed lack of ‘theory of mind’. They argued, that as with other intellectual, social, and emotional processing, their approach to interpreting intentionality in others was not lacking but atypical:

> According to the speech therapist, she lacks "theory of mind.” I don't know what that means 100 percent but from what I've read, my daughter absolutely has theory of mind. She is so observant and so empathetic. She just shows it differently sometimes. She cries if someone is hurt in a movie. And she always knows how someone is feeling. Almost in a psychic way (Donna, mother of an autistic daughter).

> I can sense tension between people and I can tell fake from true…I've always thought that, although I have a brain set that works differently to the supposed norm, that it was the life of having to be seen and not heard that heightened those senses. Perhaps it is the same for you - when everything you do is hyper-focussed upon, then perhaps the hyper-focus itself becomes the driving force that results in the ability. Very useful, I must add, to determine goodwill in others. It's interesting to note that I can do this sensing across a room - I do not have to be in conversation with the parties concerned. I can tell when hearts are hurting even around the corner, or before entering a room. Perhaps this is a form of Deja-vu, and perhaps this pre-empts my behaviour when I do enter said vestibule (Ronald, autistic adult).

Advocates argue that ToM and empathy models used in autism research are out of touch with the autistic experience.

Whilst engaging with other humans is described as perplexing, many participants appeared to have an intuitive understanding of the emotions and needs of animals. Most of my respondents had an innate connection with their animal friends. Puck (15) could talk for hours to dogs as though on a play date, and Ara's (11) entire phone was filled with '*selfies'* she had taken with dogs she had met. She could share detailed anecdotes of each dog and their unique character traits. Buzz (14) would get home from school each day and lie with his face buried in his dog's fur, breathing deeply; he noted: "She absorbs my stress". KC (11) engaged with her little 'Meme', a Maltese poodle, as a friend, chatting to her about her day, getting cross with her if she barked and frightened her, and using her as a 'go-between/interpreter' when she found conversations particularly challenging within her family. When I asked about their relationships with animals, most children described how easy it was because they knew what the animals were thinking and feeling. The children appeared to enjoy the simplicity and honesty of the relationship, as Buzz (14) explained: "Lady never lies to me, she is always honest. If she wants to be with me she stays, and if not, she leaves to go and do something else".

Interactions with people, however, were often considered mystifying and sometimes terrifying. All my participants spoke of their confusion of social interactions where people would say one thing but mean or do another. They also found it confusing when they felt that a person was anxious, scared or unhappy, but behaved as though they were happy and carefree:

> Many autistics can sense tension between people, and can feel when someone is faking goodwill, and feel when others are distressed. And yet, they are not encouraged to learn how to deal with these senses but led to believe that they have poor theory of mind. As a result, they try to suppress these feelings whilst being taught to read people's emotions in artificial training programmes using exaggerated depictions of emotion acted out or drawn as cartoons. The tension of having to suppress real sensing and replace it with a clumsy system for detecting someone's intent causes a lot of anxiety to the autistic person. Try teaching a dog to suppress his natural suspicions and to rely on your judgement, and you will find that you have to beat him into obedience. In the end, your behaviour therapy teaches him to respond only upon your command and not on instinct, rendering him useless as a watchdog and lacking in spontaneity as a pet. Why have a dog if you are not going to optimise his canine senses and if you are not going to learn how to interpret and depend on his judgement

> in situations where his specialised senses make him better qualified to provide an opinion? (Morgan, autistic advocate).

In all my observations, my participants could understand the foundational emotions of others, or what they appeared to be feeling viscerally. However, they struggled when these emotions did not match the person’s demeaner or actions that betrayed those visceral feelings. Beyond trying to read ‘divergent’ social cues, my participants were often criticised for not asking questions of other people, not showing an interest in other people’s lives, and focussing too intently on their own lived experiences:

> I never understood the "asking questions to be polite" thing. I just wouldn't know what to ask that would sound sincere. I am also empathic to the point of ignoring people a lot of the time because it's just too much to absorb all their conflicting crap going on. I learned how to do it, though, as I got older. It just made it so much easier to function among humans. I mostly just copy the people around me who do it well (John, autistic adult).

> When autistics want someone to know something, we pretty much just blurt it out, whether or not they want to hear it. *LOL*. I guess we expect the same of others. If they aren't saying anything, it means they don't have anything to say. Also, sometimes it's extremely uncomfortable to share space with someone and be quiet. It's extremely intimate. So, I just keep talking, to fill the uncomfortable silence. I figure if they have something they want to talk about, they'd be doing it. If they don't, that means they either don't have anything, or would rather listen to me. I have been informed that sometimes it's because I don't give them a chance to speak because I'm too busy with my nervous chatter. Talking is one of my stims. Sadly, it's also one of my partner's stims, and it drives me nuts because he never shuts up. That's how I learned how annoying I am when I carry on without thinking about what the other person might be thinking (Rae, autistic adult).

My participants noted that they only felt comfortable talking about their own experiences, as this is what they had real knowledge of. When they tried to empathise with others, they often ended up talking about themselves. They were frequently criticised for being ‘self-centred’, however, they viewed their sharing of their own experience as a genuine attempt at empathy on their part. In his exploration of autistic people’s struggle with social conventions, Ben Belek (2018) notes how despite their continuous grappling with the principles of social etiquette, his research participants were unable to put them into practice. Instead, he notes: “they turned to subtly shaping their social environments in attempts to redefine the terms under which the appropriateness of their actions is evaluated” (2018:161). Belek argues that social ineptitude is a “contemplative craft”, and an important part of social interaction.

Frith and Happé argue that autistic individuals who display theory of mind, have acquired this through “effortful learning” (1999:82). The concept of ‘effortful learning’ resonates with some autistic adults in their understanding of social communication and interaction. Those that excel in understanding and interpreting other people’s intentions often claim that their ‘specialist interest’ was people. Puck could spend hours watching people interact and could even be a catalyst to that interaction “just to see how they will respond”. This ability to understand people’s motivation was ascribed to years of observing and ‘storing’ information about people in what one adult referred to as her “autistic filing cabinet”:

> I observe and evaluate, and soak up every interaction like a sponge, this allows me to build a mental puzzle of a person based on their experiences and how they behave. I often find myself justifying my ‘abilities’ especially to other autistic people. This isn’t something that I do naturally, it takes a lot of energy and I have to mentally ‘switch on’. I am able to pick up on body language, micro expressions, tones etc. as I have been fascinated with all things psychology since I was a teen, reading books about body language and endless documentaries about the mind. I honestly believe that it is my brains way of avoiding the anxiety that often comes with not ‘getting it’ (Andy, autistic adult).

KC’s whole family shared many examples of how KC would answer their questions with a movie quote or interjected a quote into a conversation. While this may have appeared disconnected at first, in the context of the quote in the movie, it was often uncannily appropriate:

> She always remembers things in the right context, she will say, “I can if its true love”, from Frozen, or “True love is right”, from One Direction. Movies help her make sense of stuff. So, she will spend hours playing different characters in a movie, like Barbie in the Mermaid Tail, she can repeat whole scenes (KC’s sister).

Her father noted how her ability to quote movies, and ‘rephrasing’ has revealed a new level of intellect for him: “It’s not easy to be that witty and she knows when something is funny and when to laugh”.

For many, difficulty in social communication was merely about ‘processing speeds’. Although it may take them longer to get to a similar conclusion, they believed they would get there in the end. One adult discussed this in the context of finding it difficult to apologise for something ‘in the moment’:

> When we are able to process our feelings and figure out a way to communicate them, then, a genuine apology will come. I’m better at writing to people than talking. I like writing my apologies because then, I can say how I feel and put my thoughts down without overwhelming feelings and having to process the person’s reactions (Susan, autistic adult).

Social conventions were often difficult to comprehend, but not impossible. As with their processing of sensory inputs, the challenge lay not in their ability to understand the issue, but rather because they were often dealing with a range of competing inputs. Some shared how Keri Opai’s definition of autism for the Maori vocabulary captured their lived experience. Opai noted of his naming protocol: "In my experience, people with autism tend to have their own timing, spacing, pacing and life-rhythm, so I interpreted autism as *takiwatanga* meaning 'his or her own time and space'.[40]

Adapt or die

All parents with whom I engaged spoke of the importance of consistency in their children’s lives. Many said that this was particularly noticeable if they had an argument or even a simple disagreement. The children would pick up on their conflict instantly and want it resolved before moving on:

> If Puck picks up on something, he will immediately react badly. We have to show a united front and tell him everything is fine. Any kind of strife or argument, even about road directions, he is so attuned to this. If there is something on the news. If we discuss it and have different views, because we both have strong opinions, he can’t deal with that, he will say you are fighting. He will say ‘stop fighting’ or ‘Dad are you going to divorce Mom’. For him even directions can lead to divorce. I know

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[40] https://www.bbc.com/news/blogs-news-from-elsewhere-40493398 Accessed 11/02/2020

> other families and they have the same issue. It's that consistency that they need otherwise the world doesn't make sense (Puck's mother).

Sudden changes, unexpected events or accidents often resulted in a 'survival response':

> My 10-year-old son has some crisis behaviour that really concerns me. He is diagnosed autistic with selective mutism. The problem is that when he is hurt, physically or emotionally, he runs away. He will not let me look at cuts or bruises etc. Fortunately, he has not been seriously injured, but I'm terrified that a day will come when he is badly hurt but will not let me address it. What can I do differently to allow him to feel safe or encourage him to ask and allow help in these situations? I have tried to talk to him about it in neutral times, but he refuses to discuss it and will revert back to monotone repeating of random words or phrases (Kate, mother of a 10-year-old autistic son).

> When startling things happen often autistic people need time to process. And extra input from another person can exacerbate the overwhelming feelings… Also, when my sons were little, I noticed it really helped them when I didn't emotionally react to injuries that even looked kind of bad. when I started doing that, they seemed more comfortable coming to me with issues when I didn't add extra emotional input (Ashleigh, autistic mother of two autistic boys).

Any change, even the threat of change, had an enormous impact on the children, as Ashleigh noted; her best response was to carry on as though nothing significant had happened.

Many participants noted that they were in a constant state of 'fight or flight', or hypervigilance. This was possibly why they viewed all change as a provocation. Mirroring Puck and Ara's views on speaking, both children and adults voiced their frustration at being "pushed" to do or achieve things before they were ready:

> We are often discouraged from asserting our own boundaries and doing things in our own way and in our own time, in favour of doing what other people think we should do, in ways other people think we should do them. This leads to feeling constantly under pressure to please others, feeling like our lives are not our own. Feeling like we are being manipulated by everyone around us and this leads to break down (Amber, autistic adult).

> I was 16 before I could wash my hair properly on my own, I was in my twenties before I could eat soup comfortably or eat with strangers watching. I'm now nearer 30 than 20 and I still struggle with going places on my own but guess what: I just travelled overseas ON MY OWN. ABA teaches us that there is a 'correct' way of being and of doing things, it ignores the fact that we are not 'normal' and do things differently. I've achieved loads as an adult that I could not have done as a child, cos we're human and we grow and change and learn at different speeds and in different ways (Trish, autistic adult).

These concerns were frequently cited in the context of behaviour therapies. Most believed that they would achieve the necessary outcomes of communication and behaviour, if they were given the opportunity to achieve these objectives in their own time frame.

Adaption to changing environments or circumstances, however, was possible. Both Puck and KC spoke very positively about their experiences of international travel with their families, despite often dealing with completely different environments every single day. Their parents worked hard to ensure that they knew what to expect on these trips, by sharing their travel schedule well in advance, talking positively about what they could expect, and ensuring that sensory inputs could be managed through earphones, glasses and supportive stimming aids. Puck's parents noted how travelling on a ship was the ideal environment for him, as he had a 'base' [his room] where he could put his things and where he could escape, should the environment become too much for him. When visioning his future world, Dynamo invented a "travel car" that would provide a safe and familiar space for him as he travelled the world (Figure 35). He explained how the car "could go anywhere" due to its big wheels and hydrofoil abilities, including up mountains, over the sea, and even upside down. The car would have many windows that "you can see out from anywhere". In this safe environment, he believed he could become an explorer:

> I would live in the car and travel the world as an adventurer. There is a special window out the back that has a telescope to look at the stars. It has a satellite dish that has GPS, so you know where you are and where you are going. I would spend lots of time in nature, because the car can camouflage itself (Dynamo, 8).

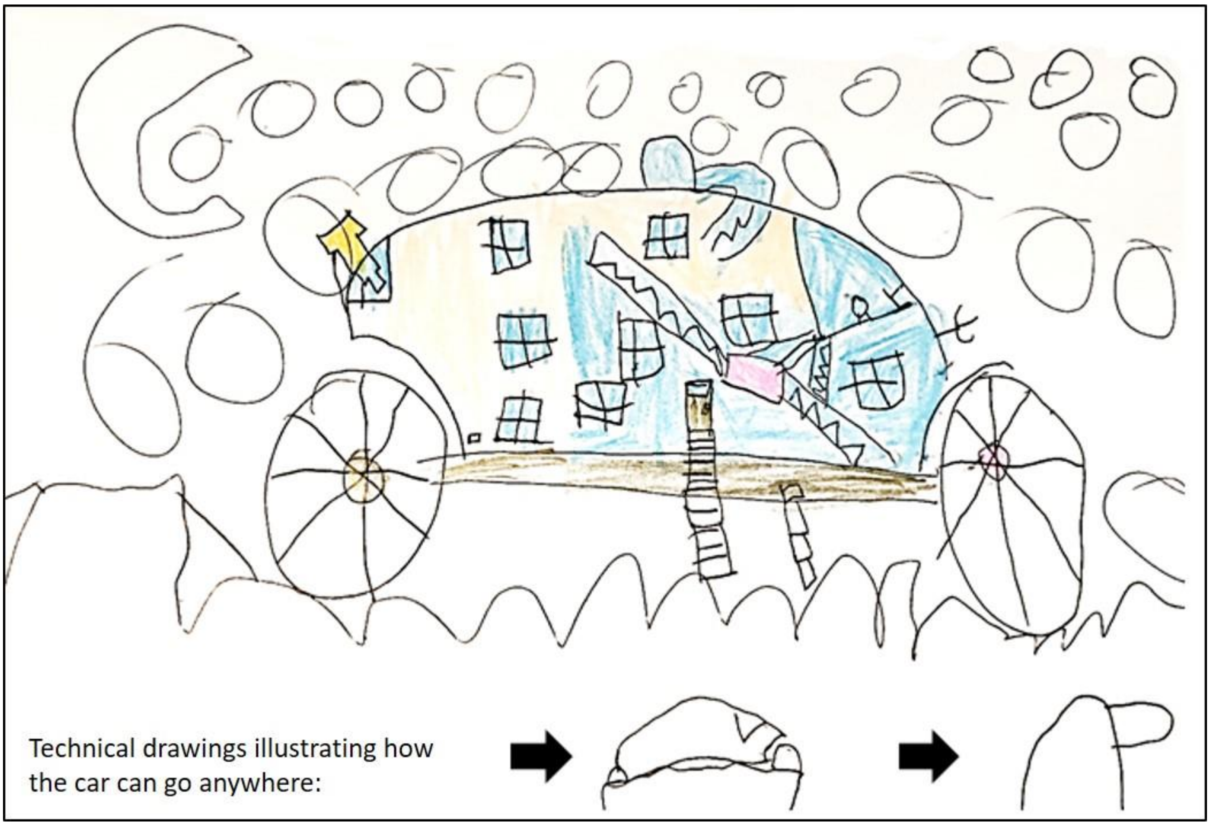

Figure 35.

Similar to Dynamo's 'travel car', during the Covid 19 Pandemic, which has proved to be a difficult time for some of my participants, one young girl noted:

> Today I was tested for Corona Virus. It was an adventure of sorts. I saw workers in masks and gowns and shields and gloves. They were all so professional and kind. It was calming to witness their confident manner. It was way wild to have a swab thrust way, way, way up my nose, but it was swiftly over, and we were on our way. I want to say how thankful I am to have had it done in the privacy of our own car. I want to say how much better that is than to sit in a waiting room with sick people I don't know (Sarah, autistic child 14).

Adults also spoke of the desire to control or be in control of one's environment:

> I often try to control my environment because it makes me feel more comfortable not to have surprises or too much intensity in my sensory experience that I do not feel prepared to handle. What I didn't realise is that this has also caused me a lot of fear. I also struggle with anxiety from negative past experiences which also probably increased my need to feel some sense of control (Adam, autistic adult).

The ability to control one's environment and to interact with the world on their terms, was transformative for both children and adults. This insight prompted scientists to test 'environmental stimulation' amongst laboratory rats exposed to 'autism risk factors' (Favre *et al.* 2015). Not surprisingly, the researchers found that rearing the 'autistic animals' in a predictable environment prevented the development of hyper-emotional features such as sensory overload, social withdrawal, fear and anxiety. However, unpredictable environments led to negative outcomes at a physical, emotional, and social level. While most autistic children and adults reported amplified sensory sensitivity, memory formation and hyper-emotionality, most research has focussed on the autistic brain as hypo-functional (2015:2). As a result, therapies have focussed on overstimulation, often in unpredictable environments, which tends to 'accelerate autistic symptoms' rather than supporting the children in their engagement of their world. Both Dynamo's and Buzz's mothers reported how much the boys enjoyed the experience of quarantine during the Covid 19 Pandemic. Without the pressure of having to go to school and social engagements, both boys blossomed. Buzz helped his mother with household tasks and was noticeably more relaxed and Dynamo would often walk up to his mother and exclaim: "Happy Dynamo, happy mummy".

Having familiar people act as a filter to their world was also an important strategy to engage with change. KC's mother explained how her family provided KC with security in even the most challenging social environments:

> Her happy place is all five of us travelling together, she is a brilliant traveller. We have taken her to Disney World twice, when she was 6 and when she was 9. We put her in a push chair the first time, as she struggled with walking and it allowed her to rest between rides. She came alive at Disney; she loves to live in her imagination.

KC's mother travels with a file containing all the information pertaining to KC's adoption and autism diagnosis, due to an alarming experience at American passport control. An immigration officer singled KC out, possibly because she is a different race to her family, and asked her if they were her parents. KC interpreted the question literally and stated that they were not: she is their adopted not their biological child. KC was separated from her parents, who then had to spend hours explaining that she was adopted and diagnosed with autism. Her mother understandably fears that KC would not be able to advocate for herself in highly stressful situations such as this. Puck (16) liked wearing a bracelet indicating that he was autistic on his cruise ship, as it helped define his challenges, and made explaining his atypical ways far easier: "Everything was fine because they all knew, I got on well with everyone and they got on well with me, because they knew”. One of KC’s favourite T-shirts proudly claims, “Autistic Jedi” with a lightsabre, from her beloved Star Wars franchise. Signifiers of difference, such as a medical bracelet, an autism pin or advocacy T-shirts received mixed reactions online. Some participants noted that it decreased their anxiety and others’ judgement of them or their children; other adults had concerns around “outing children” without their informed consent.

The children would often ‘coach’ themselves through their day-to-day activities, however, their greatest coping mechanism for stressful situations was to create a ritual around it. KC had a repertoire of appropriate responses to help her cope with stressful circumstances, which often involved reciting movie lines and actions. Puck’s distress at not being able to go to the Wimpy or Spur prior to getting on the aeroplane when his father was ill, created untold anxiety in his world. Engaging in his ritual implied that everything would be fine, however, not completing the ritual could mean that everything would not be fine with specific implications to his father’s mortality. For many atypical children, the failure to complete a ritual could have disastrous consequences. Practicing rituals was not just a comforting pastime, but rather a matter of life or death.

Rituals are identified as different from routine events, often involving a collective performance to achieve a particular goal, and generally have an order or structure to them that must be followed (Tambiah 1979). The rituals I observed included keeping special objects in a specific place, drinking only from a specific cup, asking questions the same way and expecting to be answered in a specific way, and a range of greeting performances. They could increase levels of comfort, but could also create anxiety if not followed appropriately:

> Our one child has multiple steps to his bedtime routine that he feels he must complete and is distressed if he can't. Part of this involves saying goodnight to every other individual in this house, including all the family pets, often starting over if he gets interrupted or side-tracked. This becomes stressful for siblings who need their space and have their own struggles when it comes to transitions and settling for the night. Overall, this is a ritual that seems to lead to outbursts and conflict rather than peace and comfort. So, part of me wants to encourage him to replace it with a simple "Goodnight, everyone!" but part of me is concerned about taking away an important aspect of his day where he seems to want to connect with other family members (Gladys, mother of an autistic boy).

Illustrating Mauss’ (1972) view, the rituals the children’s created, usually reflected their beliefs, representations of those beliefs and actions aimed at a specific outcome, such as the safety of family members and those they love.

Parents and adults noted how rituals were increased, and become more inflexible when their child was stressed, anxious or nearing emotional burn-out. Some parents noted that the ritualistic behaviour, was similar to that identified with obsessive compulsive disorder, and that it was sometimes difficult to differentiate OCD and autism:

> OCD can be related to fear/bad things will happen, but can also be about the "just right feeling”, not tossing out the mental trash... It's quite complex. And can intertwine with ASD stims and rituals. Doing the ritual feeds the beast when dealing with OCD. The "stop" button gets broken. For my kid, dropping down in the street in traffic to make sure a leaf gets picked up is a compulsion to have things feel complete (she has every leaf she sees on the street picked up). Going ahead and doing obsessive/compulsive things is not the same as allowing someone to stim freely. At times, my daughter was spending up to 75 percent of her day engaged in OCD behaviours and thoughts. She would wash her hands until they bled. Count until she was in tears, melting down, mentally exhausted. Having to touch and retouch every person in the room. She couldn't verbalise a coherent reason or motivation. The brain just glitches and she gets stuck. That is harmful. It prevents learning, playing etc… OCD is a very nasty beast (Phil, mother of a child diagnosed with Autism and OCD).

Blaze noted how she often struggled with OCD, and intrusive and obsessive thoughts. As a coping mechanism, she tended to focus on counting things in her environment, numbers that she sees around her, on houses, car number plates, people’s ages, dates of birth or the number of steps it takes to get somewhere. She explained that by focusing on counting, she was able to avoid intrusive thoughts that batter her imagination often without warning:

> I’ll be fine and then suddenly I will have a terrible thought about someone or something that could happen, especially to the people I love, and my brain takes off. It digs deeper and deeper into the horrible thought until I am beside myself with fear, it can be paralysing. The worst part is that some of the things I imagine are really disgusting, and I start to think I must be a really bad person to think these things. I then get really stressed because I start thinking, ‘but what if I did this and I just don’t remember’, or ‘what if I am going to do this because I have no control over myself’.

> The thoughts sometimes come back in my dreams and then I wake up with a huge fright. It sometimes takes ages to get over a really bad thought, I have to be careful about what I read, or watch as I'm really scared, I will get sucked back into this awful reality (Blaze, 14).

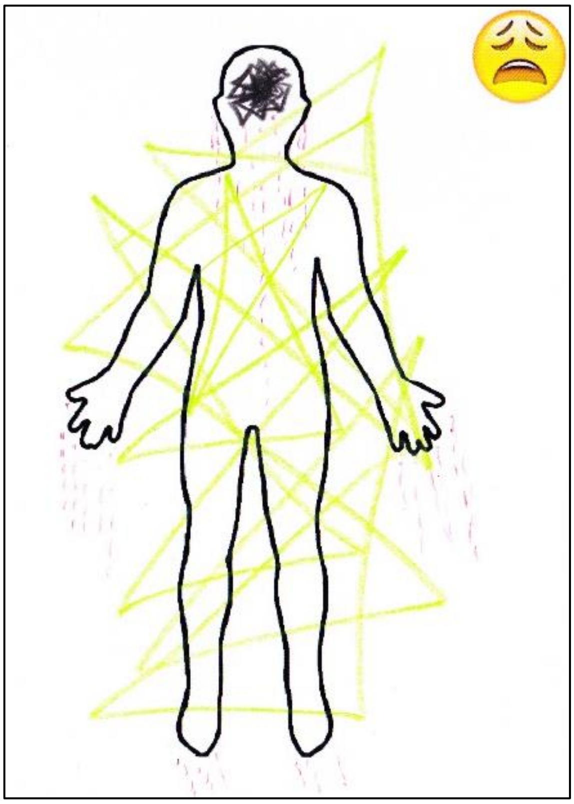

Figure 36.

Her negative perseveration mirrors her depictions of her body when she feels unwell or unhappy (Figure 36). Sickly green lines intersect her body, and she feels like she is "spilling out all over the place". These lesions allow the world and intrusive thoughts to invade her consciousness completely out of her control. Blaze explained that her thoughts about herself did improve when someone explained to her how OCD works, and that just because she imagines these terrible things, doesn't mean she is capable of doing them. She noted that with OCD, imagination can become frightening, rather than a wonderful tool for escaping.

Rituals are an important concept in anthropological texts, as they often reveal insights into common social behaviour, in a more intense format (Peirano 2000). For the children, whether autism or OCD related, the rituals they created appeared to be a mode of control, as uncertainty was a hard vector for them to engage with. In developing the ritual themselves, as with their 'own worlds', they were able to create a temporal space that allowed them to establish order and predictability in their worlds. Despite their difficulty with adaption to change, the children desired new experiences and the opportunity to explore the world around them, but ideally in safe spaces and in their own time. As KC noted: "I like it when things move fast, thinking while I'm sleep-chilling and watching movies, I want to feel new things".

Possibly the greatest anomaly I observed amongst my participants was their ability to move beyond their day-to-day struggles and achieve significant accomplishments. Writing and illustrating children's books and creating astounding Lego constructions at aged eight, designing beautiful graphics and logos at eleven, building super computers at twelve, and performing on a public stage to a capacity audience from the ages of nine to sixteen. The children achieved these unbelievable accomplishments despite their sometimes daily trauma and physical or emotional difficulties. They were able to do this because they had identified a ‘purpose’ for themselves, often linked to their specialist interest. Once defined, and ‘on purpose’, their imagination appeared infinite and their tenacity to achieve a particular goal inexhaustible. In Michael Carrithers’ (2005) exploration of anthropology as a ‘moral science of possibilities’, he considers three ‘threads’ that speak of the discipline’s ability to understand shifting social and cultural potentiality. The first is the fundamental belief in cultural relativity: there are many diverse possibilities for any one moral code, which often leads us to question our own moral certainties. The second is how the anthropological method of participant observation forms its own ‘interactive moral aesthetic’ in the relationship between researcher and participants. Finally, in the realm of sociality, the power of persuasion to create new possibilities in dynamic, interactive and interwoven social and cultural environments. In the context of atypical children, this reflects their ability to create new possibilities for themselves, despite social dictates and limitations, and the environment or context that enables this.

As a brand strategist, I have spent many hours assisting organisations to identity their vision or purpose, and to help align their people behind this purpose. Developing successful brand visions is no easy task, and takes much research, collaboration, and negotiation. Yet in my research, the children appeared to have an intuitive understanding of their own personal vision. This was illustrated in the ease with which all of them defined their own ‘motto’ when developing their personal crest. When I asked them to sum up a personal rallying cry, there was little to no hesitation. Three distinct themes emerged. The first spoke to tenacity and perseverance: “Never give up” (Puck, 16); Make the Impossible Possible (Blaze, 14); and, “Just step right over it” (Flashbang, 10). The second theme spoke to taking a moral stand: “Be caring and creative” (Coco, 8); “Stand up for what’s right” (Ara, 12); “Live life with love” (KC, 12); and “Be a gentle giant” (Buzz, 15). The final theme spoke to adventure and exploration: “The world’s best adventurer” (Dynamo, 8); “Together we explore” (Echo, 16). Carrithers notes how narrative, even in the form of a single phrase, can create moral certainty for an individual, Malinowski’s ‘charter for action’ (2005:443). These ‘story seeds’ were supported by the children’s ‘grand emotional values’, outlined in the chapter on presence, as tangible expressions of their desired identity.

The method of co-creating a personal brand allowed the children to think through their own moral agency, with a sense of 'what could be' rather than 'what is' or 'is not' (Carrithers 2005:433). Anthropology focusses much of its attention on social structures and cultural frames; however, in a constantly changing world, these structures and frames evolve. Renato Rosaldo (1985) identified both physical and conceptual 'borderlands' and 'borderlines' of ceaseless social and cultural invention in class, gender, and race. Atypicality is just such a 'biosocial borderland' for cultural creativity and inventing new ways of being in the world. When it came to their purpose, the children were very clear on what they wanted to be and how they wanted their worlds to look when they grew up. They moved effortlessly beyond the structure of disability to a locus of possibility. The only time this purpose was not clear was when their personal vision was clouded by perceived expectations of society or a desire to be viewed as neurotypical, as demonstrated by Buzz (15 years). For some, mirroring their rebellious natures, the very act of telling them 'you can't be this', or the fact that no-one had any expectations for them and their future, created a blank canvass on which they could imagine anything for themselves.

Beyond my participants, the transformative impact of being 'on purpose' was clearly illustrated by two children who have changed perceptions of atypicality and autism in recent years. Winner of America's Got Talent 2019, autistic and blind musician Kodi Lee, shared Puck's vision of becoming a 'creative performer'. In his 'golden buzzer audition', which has been viewed more than 30 million times on social media, Kodi's mother explained:

> We found out that he loved music really early on. He listened and his eyes just went huge. He started singing, and I was in tears, cos that's when I realised, 'Oh my gosh, he's an entertainer'. Through music and performing, he was able to withstand living in this world. Because when you are autistic, it's really hard to do what everybody else does. It actually has saved his life, playing music (America's Got Talent, 28th May 2019).

During the audition, Kodi's atypical behaviour and speech were evident when introducing himself to the judges. However, in stark contrast to the nervous young man who had first walked onto the stage, when performing, his demeaner changed to a confident, engaged and riveting entertainer. Beyond his optic nerve hypoplasia and autism, Kodi also has a diagnosis of Addison's disease, an endocrine disorder that results in abdominal pain, weakness and weight loss. Kodi's mother noted how prior to finding music, Kodi could tantrum up to thirty times a day and struggled to interact with people outside of his family.

She shared how after the competition, Kodi's communication and social skills had improved significantly. He was now able to speak full sentences and engage socially with new people in crowed environments without becoming overwhelmed (Epic Top Trending, 21st October 2019).

Greta Thunberg's mother, Malena Ernman, noted how prior to Greta finding her purpose as a 'climate activist', she was extremely socially withdrawn and about to be admitted to hospital for treatment of severe starvation. Greta was not anorexic; rather, the extreme bullying she had endured throughout her school career had created an environment where she was no longer able to eat. A simple meal of five *gnocchi* could take over two hours to consume. Her diagnosis of 'high functioning Asperger's' and subsequent sharing of her experiences of bullying went some way to addressing her challenges. However, it was as a 'climate activist' that she started to thrive. During her self-devised, planned and executed yearlong 'Skolstrejk for Klimate', Greta started to eat a varied diet again, engaging confidently with people in large gatherings. Her mother noted at the time: "Greta's energy is exploding. There doesn't seem to be any outer limit, and even if we try to hold her back, she just keeps going. By herself" (The Guardian, 23rd February 2020).

Greta managed to overcome her fear of other children who, as the instigators of much of her social suffering, were often catalysts for a cPTSD response in the early days of her strike. For both these children and my participants, being 'on purpose' created a new reality for them. It helped them to embrace new ways of being in the world that seemed to cut through or subdue their physical, intellectual, emotional, and social challenges.

CONCLUSION

Whilst there is much contestation over the homogenisation of ‘neurodiverse’ brains (Ortega 2009), the lived experience of atypical children and adults appears to have a high degree of consistency. Despite being diagnosed in a particular clustering of disabilities, such as ‘learning’, ‘developmental’ or ‘behavioural’, all my participants had a range of challenges that spanned physical, intellectual, emotional, and social categories. From a theoretical perspective, whilst most ascribed to a social model of disability, where society lacked understanding of them and did not support them sufficiently, all were struggling with a range of very real physical challenges, disorders, illnesses and syndromes that they described and treated in a biomedical framework. My adult participants engaged in rich biosocial communities in the social media space, and all claimed their diagnoses as a distinct part of their identity. All used a spectrum analogy to explain their lived experience but struggled to comprehend this beyond comorbid biomedical definitions. Whilst rejecting ‘functional labels’ they had difficulty conceptualising their differences beyond sensory processing, motor, language, perceptual and executive functioning skills. Beyond medical and social models, the ‘cycle of atypical engagement’ (Figure 37), appears to provide an accurate representation of the shared lived experience of my participants.

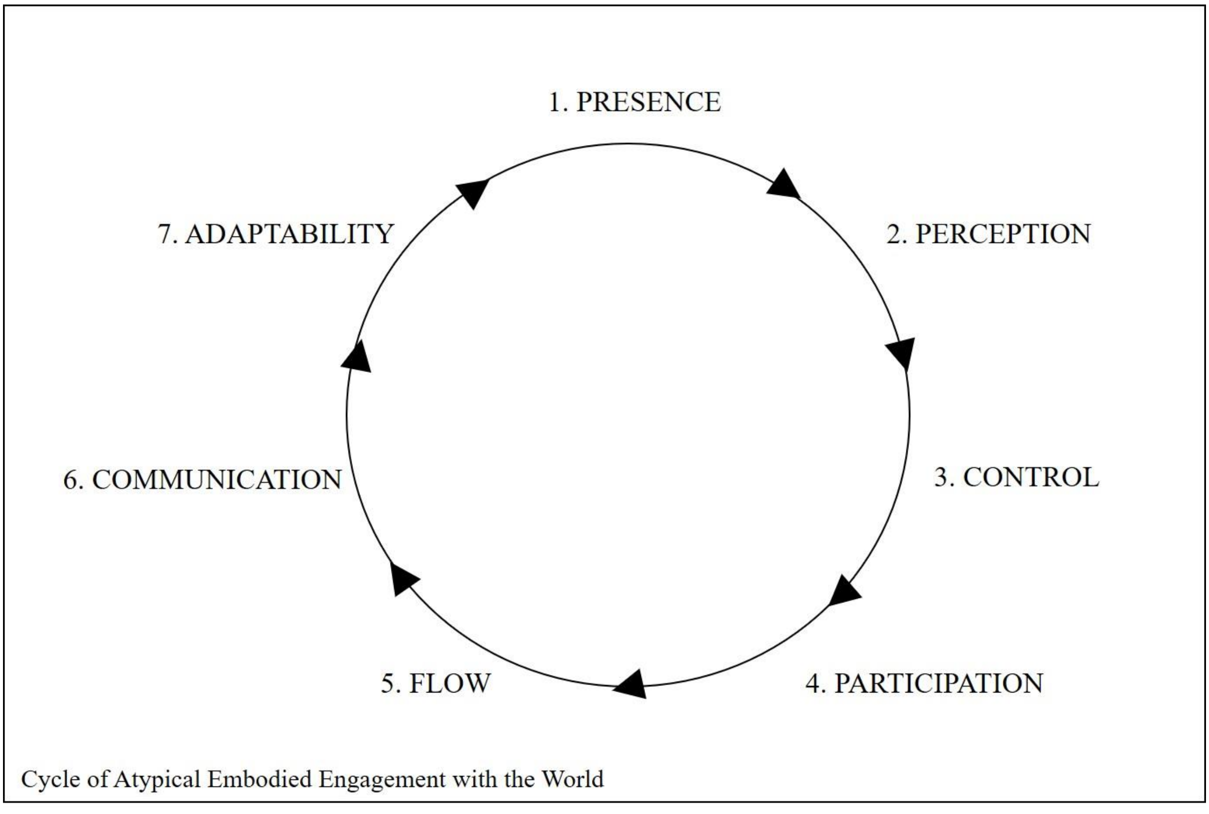

Figure 37.

At the stage of *presence*, and how my participants ‘showed up’ daily, all spent time in a range of parallel worlds, spanning dream, to own or virtual, to tangible, to dissociative, to meltdown and finally to shut down. Each world impacted on their personal identity and how they defined themselves. Most had cautious bodies but adventurous brains, and whilst celebrating their unique and different way of seeing the world, all struggled with a range of physical, intellectual, emotional and social challenges that impacted on how they perceived their bodies and experienced their world from an embodied perspective. All appeared to struggle in neurotypical school environments and desired multiple pathways to learning, in support of their specialist interests and defined ‘future possibilities’. Their sense of self and self-esteem were closely aligned to presenting themselves as authentically atypical. They embraced their differences in learning approach, ADHD, and autism, often claiming it as part of their identity, and most positioning themselves as rebels and intellectual rather than physical risk takers. They all had a strong sense of ethical and moral consciousness, which guided their attitudes to life and perceptions of others.

In the stage of *perception*, all struggled with distinct internal and external sensory perception, discrimination, and modulation challenges at a physical and emotional level. All presented as sensorially ‘sensitive’ or ‘seeking’, depending on their levels of resilience on a particular day or time in their lives. All felt pain and itch acutely, and most struggled with a range of allergies that impacted on how they were able to process the world around them. All appeared to struggle with bodily boundaries and lacked an intuitive understanding of where their bodies ended, and the world began. These boundaries were impacted by both physical and emotional feelings of wellbeing, if the children felt particularly vulnerable, they experienced this as either ‘spilling out into the world’ or as though the ‘world was invading them’. Rather than lacking, most experienced empathy as overwhelming, describing it as an affective and embodied rather than cognitive interaction with others. Emotions were experienced, interpreted, and expressed atypically, which often led to a disconnect between how they were feeling and how they expressed themselves or were understood in neurotypical environments. Their challenges with social perception including their concrete view of the world, difficulties with facial or emotional recognition and eye contact, appeared in stark contrast to their intuitive sensorial and intellectual insights. The semi permeable nature of bodily boundaries created high levels of anxiety, but there were also distinct benefits to being so ‘open to the world’. This was illustrated through the children’s detailed observations of their environment, their extensive knowledge, and the unusual insights they shared from making connections and seeing patterns in the worlds they occupied.

In the stage of *control*, both children and adults shared their struggle with the 'disconnect' they felt between their bodies and minds. Behavioural therapies that attempted to exercise control over the children were often experienced as threatening, triggering 'fight or flight' oppositional responses, defined by anger and defiance. Despite my initial concerns, the autism boxing classes appeared to be a challenging yet safe, consistent, and contained space for the children to explore and reinforce their bodily boundaries. In this environment, the children could engage in stimming activities free from judgement, and the emotional and social positioning of 'being a boxer' helped to build their self-esteem. However, the greatest impact that these sensory and virtual environments had on the children was to help them reconnect with their bodies, to claim a sense of control, and to assist them in participating optimally in the world around them.

In the stage of *participation*, all the children appeared to struggle with a disconcerting lack of *habitus*. Rather than having automatic and intuitive responses to their environment, the children appeared to lack this embodied memory and had to constantly 'rethink themselves' in their engagement with the world (Manderson 2011). This was often an exhausting process and could lead to physical and emotional burn-out. Additional drains to their energy included crippling social anxiety and attempts to mask their atypical behaviours to 'fit in'. Rather than being antisocial, my participants described themselves as a-social, all wanted and sought out friendships, however, these were often carefully chosen and used strategically. The friendships I observed were clustered into three distinct areas. The first were friends, and often family or carers, who helped them navigate and sometimes filter their world. The second were friends, deemed to be popular or famous, who helped them to avoid the stigma of atypicalness and made them look 'cool', 'rebellious' or 'in the know'. In the tradition of 'biosociality', the third group were friends who were also deemed atypical, who did not judge them, and could share their lived experience, provide advice and empathise with the challenges of life in a neurotypical world. Any social participation required careful management, as many struggled with modulating their energy levels. Ensuring sufficient 'spoons' (Miserandino, 2013) to complete a task or engage in a particularly stressful social event became a careful trade-off between what they desired and what they felt capable of doing.

My participants often presented as ‘hypervigilant’, experiencing their ever changing physical, intellectual, emotional, and social environments as traumatic and even abusive. Many shared how a combination of sensory bombardment, stress vulnerability, relentless remedial therapies, social exclusion, and bullying had led to complex post-traumatic stress disorders. The trauma they experienced, often on a daily basis, created high levels of alienation, both externally between themselves and their communities and internally, in their sense of self and feelings of belonging, safety and comfort in their environment. This trauma was often expressed in the stage of *flow*, or how my participants either allowed or stopped the flow of their lives. Disruptions of flow were experienced physically through simple bodily processes such as eating, digestion and elimination. Rather than easily ‘digesting’ the world around them, my participants often experienced violent disruption at a physical and emotional level, typified by a range of gastrointestinal dysfunctions which impacted significantly on their social behaviour. At an intellectual level, flow was hampered in the learning process due to challenges with hyper-focus, concentration difficulties, stress, anxiety and their impact on short-term and working memory. Conversely, all had exceptional long-term memories, often developing extensive mental libraries of information and appropriate comments or actions on which they called in stressful social engagements. Challenges with flow were also experienced in their attachment to certain items or toys that they had collected, to which they often felt deeply connected. All struggled with transitions from one activity to another, one environment to another, and even one season to another. Simple questions, requests, choices, or planned activities were often met with opposition or avoidance, as they struggled to maintain consistency in their lives. All enjoyed what they termed parallel play, where they spent time in other people’s company, but did not directly engage with each other. They referred to this as ‘quiet togetherness’.

My participants struggled with a number of challenges in the stage of *communication*, spanning echolalia, non-fluency, selective and full mutism. Many used stimming techniques not just to self-regulate, but as a communication tool with their environment, their community and themselves. Stimming often took the form of singing or chanting, which had the added benefit of ‘creating output’ to manage or mute auditory input, which was often experienced as overwhelming. Participants noted that both selective and full mutism was not something they were able to control; they described it as ‘something shutting down in their brains’. This was often associated with comfort levels or not feeling ready to communicate. Any form of mutism was experienced as highly frustrating, and all noted the importance of finding other means to ‘express their inner voice’ either through sign language, assistive communication devices or typing. ‘Theory of mind’ was not thought to be lacking by my participants, as commonly believed. Rather they struggled with the disconnect they felt and observed between people’s feelings and intentions, and their actions and behaviours. They experienced this disconnect as an inherent dishonesty in the world around them, which they often struggled to come to terms with. Some noted that empathy and theory of mind models were out of touch with autistic experiences. This was revealed in the children’s relationship with animals. The children noted how much easier relationships with animals were as they lacked the capacity to be deceptive. My participants were often criticised for focussing too much on themselves, but they noted that their own experience was the only one they felt comfortable sharing and was thus a legitimate attempt at empathising with others. For many, difficulties with communication quite simply expressed their need to process information and interactions in their own time and space.

The final stage of *adaptability* explored the difficulty that many of my participants experienced in engaging with changing physical, intellectual, emotional, and social environments. Most desired consistency in their day-to-day lived experience, and found any change from small to large, especially if it was unexpected, extremely difficult to process and often resulted in high levels of fear and anxiety. Many noted that they felt “pushed to do things” when they were not ready, as noted in the stage of communication. My participants used a number of strategies to adapt positively to change. These included using select people, often their family, to filter their world for them, using sensory management packs, creating strict routines that they could coach themselves through, and developing rituals around particularly stressful events. Rituals, sometimes associated with OCD, were designed to ensure a particular outcome, such as the safety of their family or loved ones. Rituals often became more inflexible when the children were stressed or anxious, and many believed that the failure to complete a ritual appropriately could result in dire consequences. For my participants, rituals became a mode of control that helped them to establish a level of predictability in their world. They all desired new experiences but preferred to engage in these in ‘safe spaces’ that allowed them a level of control. Despite their resistance to change, the children were often able to achieve great personal feats often linked to their areas of specialist interest. They did this through developing personal visions that were unencumbered by other’s expectations of them. If ‘on purpose’, the children displayed resilience and tenacity that belied their physical, intellectual, emotional and social challenges.

Their narratives, in the form of personal brand visions, created moral certainty for the children, supported by their 'grand emotional values', and allowed them to move beyond a locus of disability to one of possibility.

Towards a new kind of spectrum

In the tradition of phenomenology, while the model of 'atypical stages of engagement' assisted in identifying a shared lived experience, it was also important to explore the meaning that my participants associated with each stage. This meaning would assist in moving beyond biomedical definitions of an atypical spectrum to one that supported their different ways of being in the world. In the stage of *presence,* the children appeared to be grappling with several conflicts: their desire to remain in their 'own' or 'virtual' worlds versus being "forced" to engage in the 'real' or 'tangible' world; their fragile bodies often in conflict with their adventurous and creative brains; their vision for themselves and what they believed they could achieve, versus what their school environment and society believed they were capable of, given their various diagnoses. Rather than just being present or absent from the world, as initially hypothesised, a far more complex sense of self was revealed. The entanglement of different worlds that they occupied, sometimes simultaneously, implied that they did not wish to disconnect from society, but rather to manage this connection in an appropriate way. Spending too much time in the 'real' and 'tangible' world could lead to feelings of dissociation, 'meltdown' and 'shutdown', which had a profoundly negative impact on their self-esteem and self-worth. Spending time in their 'own' and 'virtual' worlds enabled them to build their identity as experts and leaders in control of both themselves and their future. Their intentionality of bodily existence was a constant balancing act to engage and function at an ideal level, allowing for interaction that did not overwhelm them. They exercised their agency by trying to find a balance between creativity and structure, rebellion and obedience, and authenticity, as neurodivergent individuals. This dynamic equilibrium of identity management, although desired, was not always achieved; however, all practiced it intentionally in their everyday lives.

In the stage of *perception*, their ability to perceive the world physically, intellectually, emotionally and socially was hampered by sensory processing challenges both within and without their bodies, high levels of pain and allergies, and a disconcerting sense of body permeability. Rather than being oblivious and avoidant of the world, the children desired environments that helped them to create appropriate bodily boundaries. These boundaries enabled their 'openness to the world', when feeling strong and resilient and supported their desire for exploration and discovery. However, the boundaries protected them from being overwhelmed when they felt vulnerable and sensory inputs became too intense. Whilst desiring *control* of their bodies, their ability to wander freely in their minds and allow creativity to flow was also noted as an ideal emotional state. Tools that enabled them to regulate their bodies and minds in both physical and virtual environments allowed them to manage feelings and experiences of powerlessness, anger, destruction and disconnection, through reconnecting them to their bodies and the world around them. When it came to engaging with the world, the key to optimal *participation* appeared to be one of balance, from creating conscious barriers for sensory and emotional inputs, to self-regulation and energy management.

Engaging positively in a changing environment required approaches that effectively mitigated the trauma many of my participants experienced, due to the inconsistency of their lives. Understanding the meaning associated with each stage of engagement, spanning *flow*, *communication* and *adaptability*, revealed a means to empower my participants to engage positively, and to experience change as a legitimate process of life rather than an injustice meted out to them. In the stage of *flow,* disruptions were usually a result of low trust and feelings of insecurity. These were often resolved by creating an environment where the children felt safe and had a sense of belonging. In the stage of *communication*, challenges related to a desire for honesty and truth, and the ability to interact in their own time and space. In the stage of *adaptability*, the key to positive engagement was the ability to define a 'purpose' for themselves, and then to pursue this. This purpose could relate to a call to action, but could also be about developing a level of comfort in just being present to their environment, as observed when the children stimmed, danced and chanted.

In understanding the meaning that my participants associated with each stage of engagement with their world, a new kind of spectrum emerged. This spectrum moved beyond the disabling biomedical labels of sensory processing, motor skills, language, perception and executive function, to one of enablement. The vectors of this spectrum could travel in either direction, without implying dysfunction or defectiveness. The axes of this new spectrum include *connection*, *permeability*, *control*, *flow* and *purpose* and is illustrated in Figure 38 below:

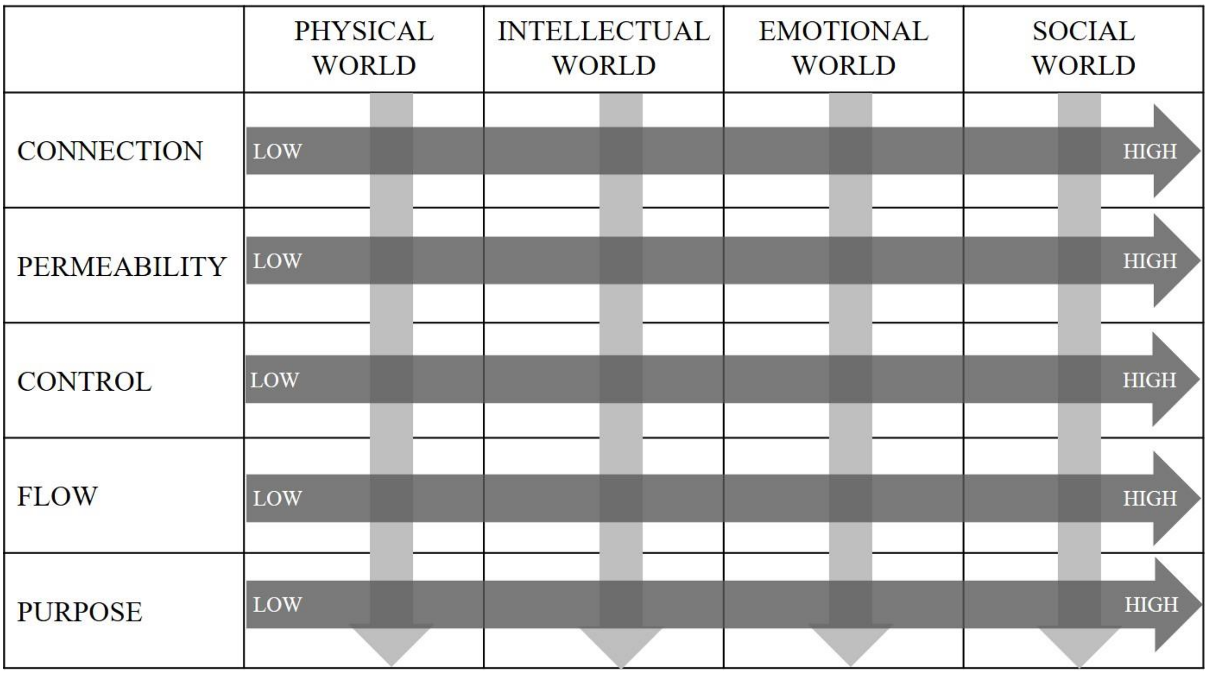

Figure 38.

Each of these new spectrums is considered within the hierarchy of 'human tools of development' from physical, to intellectual, to emotional and finally to social. In the spectrum of connection, one could feel highly connected or highly disconnected, there are benefits to both states depending on which activity one is engaging in at the time. Time in one's 'own world' is a time of disconnection from the tangible or real world, but possibly reconnection with one's imagination and dreams. Levels of connection are thus not positive or negative; they are simply different states of being which can be experienced at a physical, intellectual, emotional or social level. High levels of permeability allow for intense insight into the world but being able to create barriers to that permeability when feeling vulnerable or anxious speaks to positive self-management and regulation. Being in control of one's body and mind brings calm and a sense of security, but being able to lose oneself, for instance whilst stimming or dreaming, can create alternative positive states of wellbeing. Allowing one's life to flow is appropriate when one feels safe and secure but being able to manage the speed and velocity of that flow is critical in ensuring comfort alongside resilience levels. Being 'on purpose', while enabling the achievement of seemingly impossible feats, can be balanced with focussing intently on being present to one's body or the world as one finds it, such as when stimming. Each of these spectrums illustrates the multiple ways my atypical respondents had of being in the world.

In this dissertation, I have attempted to move beyond the binary and often oppositional nature of medical and social models of disability, to focus on the holistic lived experience of atypical children. Moving beyond enablement or disablement, I have tried to view the intersections and diversity of their differences. From a linear biomedical spectrum, their embodied experience of their world revealed a multitude of cultural and social creativity and invention, which they continue to expand in the ‘biosocial borderland’ that they occupy.

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APPENDIX A

PARENT & CHILD CONSENT AND ASSENT PROCEEDURE, AND ETHICS CLEARANCE

Before conducting my research, I spent some time with the child’s family, and with their permission, with the child participant, to assess their feelings towards my research. I used this opportunity to ascertain their level of understanding and comfort with discussing their diagnosis to ensure that it would not cause them distress during the research process.

Once they had indicated their comfort with the nature of the research and my approach/method, I then obtained written consent from the parents or caregivers in the home and verbal assent from the child.

I used a child friendly information sheet, over page, using graphic pictures where possible, to explain the nature of my research and research process in a child friendly manner. This was to ensure that the children understood the question of ‘participation’ and that they did not feel unduly pressurised to take part in the study.

An assent form was completed verbally with each child prior to commencing each research session.

With the parent and child’s consent and assent, I approached the children’s teachers, therapists, facilitators and various other members of their support team, to ascertain their level of comfort for me to observe therapeutic sessions and to interview them separately.

I ensured that I obtained written consent before any observation or interviews took place.

Prior to my biography workshops with the children, I assessed their level of understanding of their diagnosis from their parents. If the child had a clear understanding of their diagnosis: in that it has been shared openly with them; it has been discussed in detail with them; and it is part of their everyday reality; I proceeded with the exploration of their diagnosis with them. If, however, it had not been shared openly with them and there was still a lack of understanding as to what their diagnosis was, and how it had been defined, or if the diagnosis was a cause of distress for them, I did not include the child in my study.

RESEARCH INFORMATION SHEET FOR PARENTS

Researcher:	Deirdre Blackie
Research Title:	The lived experience of learning disabilities and developmental disorders.
Institute:	University of the Witwatersrand (Wits)

Hi, my name is Dee Blackie, and I am a researcher from the University of the Witwatersrand (Wits). I am doing research for my Doctoral Degree in Social Anthropology. In my research, I will be trying to understand 'what is means to be defined with a learning disability and/or developmental disorder', or what is sometimes referred to as 'being on the Autism spectrum'.

In order for me to understand what it is like to live one's life with a diagnosis like this, and the associated challenges, I would like to spend time with and talk to young people (aged between 7 and 16 years) who have been given these kinds of diagnoses. I would also like to talk to their family, their friends, their teachers, and their therapists, to understand their relationship with each other.

I will be doing this research in several different ways, which could include:

- Spending time with people diagnosed with a learning disability or developmental disorder, in what is referred to as 'participant observation'.
- Talking to them and asking questions about their life and what is important to them.
- Spending time observing them in different social environments such as at home, in social environments and at occupational and remedial therapy sessions.
- Talking to their parents, siblings and friends about their lives and relationships
- Conducting semi-structured and structured interviews.

The research may take a few weeks, but the individual discussions will only be one hour each (or as long as the research participant is happy to meet and talk for). There will be around eight of these one-hour discussions with the children who have been diagnosed and no more than two one-hour discussions with their family members and therapists. All will be scheduled at the participant's convenience and with their informed consent or assent.

During these sessions I will be taking notes and recording what is discussed on a tape recorder. All these notes and recordings will be kept securely locked in my office, to ensure that no one is able to gain access to them.

It is entirely your choice whether you would like to take part in this research or not. You may also choose to take part in one aspect of the research and not in another. If you do choose for your child and yourself to take part in this research, you will be asked to sign a consent form and your child will be taken through an assent process. The consent form will ask for your and your child's participation in the research. Should you consent, your child will be taken through an assent process which details participation and consent in a child friendly manner and will ask for your child for their participation. These forms will give me permission to use the information that you give me or tell me about. This will take the form of a research report and could also take the form of a published article in an academic journal or book. If you change your mind at a later stage and decide that you do not want to participate in the research anymore, even if you have already agreed before, you can stop participating immediately. You will not be paid for your participation in this research, and there will be no direct benefit to you from the research. I do, however, hope that this research will help to explain what it is like for someone to grow up with a diagnosis of a learning disability or developmental disorder, and what this means for them. This is your opportunity to tell your story from your perspective.

If you, or any member of your family, become upset during the research process, I can also provide you with information on support services and a counsellor, who can assist you. The counsellor who has agreed to support me with this service is called Gail Williams, an educational psychologist with a number of years' experience in counselling children and parents with learning disabilities and developmental disorders (Gail's contact details can be found at the end of this information sheet).

Any time we spend together, or information that you tell me will be completely confidential. This means that no-one will be able to identify who has told me this information. I will use a pseudonym (a made-up name) in all of my research notes and in the final dissertation or research report.

It is important that your life is not disrupted in any way, and I will try to make sure that this is the case throughout the time we spend together.

This research has been approved by the Wits Faculty of Humanities and the Wits Humanities Research Ethics Committee.

If you have any queries, or are uncomfortable about anything that we discuss, you can speak to me at any time. I will also tell you, and show you, what I have written about our discussions.

Alternatively, you can raise any concerns you may have with my research supervisor (Dr Nolwazi Mkhwanazi), or the research ethics coordinator (Lucille Mooragan).

These are the necessary contact details:

Deirdre Blackie

Researcher

Cell: 083 3765672

Email: dee@bobi.co.za

Dr Nolwazi Mkhwanazi

Dept. of Anthropology

Tel: 011 7174407

Email: Nolwazi.Mkhwanazi@wits.ac.za

Lucille Mooragan

Human Sciences Ethics Department Coordinator

Tel: 011 717-1408

Email: Lucille.Mooragan@wits.ac.za

Gail Williams

Psychologist

011 783 2813

jengailwilliams@telkomsa.net

RESEARCH INFORMATION SHEET & ASSENT FORM

FOR CHILD RESEARCH RESPONDENTS

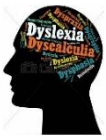
(This information sheet was read and shown to the child research respondent in the process of gaining assent.)

Hi, my name is Dee and I am a researcher from Wits University.

I am in the process of trying to get my PhD or Doctorate degree.

I am doing research in the field of Anthropology, which is the study of different kinds of people and how they relate to each other.

I am trying to understand what it means to be diagnosed with a learning disability like dyslexia or developmental disorder like ADHD or Autism.



To understand this better I would like to spend time with lots of different children (8 to 15 years), their families and their therapists to discuss what their life is like in lots of detail.

I would like to do this research in different ways, which could include:

- Playing fun games and doing creative exercises with you.
- Talking to you about what is important to you.
- Watching or observing you in different places such as at one of your remedial or therapy sessions.

- Talking to your parents, your brother or sister and your friends.

If you agree to this research, I would like to talk to you for around an hour at a time (or however long you are comfortable talking to me). We will probably need about 8 meetings, but I will make sure that this fits in with your diary and that your parents are happy with the time we agree to.

You can choose to take part in this research, and you can also choose not to take part on this research it is entirely up to you.

You can even choose to take part in the research and then choose not to take part in the research at a later stage.

You will not be paid for this research, but it will be a chance for you to tell your story, from your perspective.

If you get upset during our discussions, we can stop immediately.

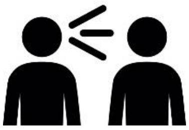
If you would like to talk to someone about what we have discussed, I can also help you to do this, with your parent’s approval and support.

I will be using a ‘made up name’ (that you can help me choose for you) in my notes and in the research, so no-one will know that the answers you give me are from you.

I will take notes of our discussions, so that I can remember exactly what you say, but I will always use your made-up name in my notes.

I may make a voice recording of our discussions, if you are comfortable with this, but I will not let anyone listen to it, other than myself.

If you are unhappy at any point, we will think up a special word which will act as a warning bell to me. If you say this word, I will know that you want to stop our discussions or my observation straight away.



It is important that you are happy and comfortable at all times during our discussions. If at any point you do not feel happy and comfortable, you can say our special word and I will stop straight away.

😃 😀 😁 ✅ 😔 😞 😪 ❎

CHILD RESPONDENT ASSENT FORM

(This assent form was read and shown to the child research respondents in the process of gaining assent prior to commencing each research session.)

Date of research: ____________________________

Name of child: ____________________________

Has the research information sheet been read and explained to you? YES/NO (Circle appropriate answer)

Do you understand what the research is about? YES/NO

Do you have any questions about the research? YES/NO

If yes, please ask the questions? (The researcher should respond appropriately)

Are you happy with how your questions have been answered? YES/NO

Do you understand what taking part in the research means? YES/NO

Do you understand how long the research process will take? YES/NO

Do you understand that no one will know that the answers you give to me in the research are yours because we will give you a made-up name? YES/NO

Do you understand that you don’t have to take part in this research? YES/NO

Do you understand that you can stop taking part in the research at any time you like, even if you have already said yes earlier? YES/NO

Do you understand that written notes and/or a voice recording may be made of this research discussion? YES/NO

Do you understand that all written notes and voice recordings will be kept securely to ensure that no one other than the researcher can gain access to them? YES/NO

Do you understand that the information from this research will be used in a research report and could be used in a published research article? YES/NO

Do you give verbal assent to continue with the research discussion? YES/NO

Signature of researcher who facilitated verbal assent: ___________________

RESEARCH INFORMATION SHEET FOR THERAPISTS & TEACHERS

Researcher:	Deirdre Blackie
Research Title:	The lived experience of learning disabilities and developmental disorders.
Institute:	University of the Witwatersrand (Wits)

Hi, my name is Dee Blackie, and I am from the University of the Witwatersrand (Wits). I am doing research for my Doctoral Degree in Social Anthropology. In my research, I will be trying to understand 'what is means to be defined with a learning disability and/or developmental disorder', or what is sometimes referred to as 'being on the Autism spectrum'.

In order for me to understand what it is like to live one's life with a diagnosis like this, and the associated challenges, I would like to spend time with and talk to young people (aged between 7 and 16 years) who have been given these kinds of diagnoses. I would also like to talk to their family, their friends, their teachers, and their therapists, to understand their relationship with each other.

With teachers and therapists, I would like to focus my research approach into two key areas:

1. An in-depth discussion, which should take no more than two hours, with the teacher or therapist discussing the child in question. A discussion guide that outlines key areas of interest is attached to this information sheet for your reference.
2. If appropriate, selective observation of therapy sessions with the child in question. Consent and assent will be obtained by the therapist, parent/guardian, and child prior to the session. You may decline the observing of specific sessions or parts of sessions, even if you, the child and their parent/guardian have consented to participate in the study.

During the in-depth interview I will be taking notes and recording what we discuss on a tape recorder. All these notes and recordings will be kept securely locked in my office, to ensure that no one is able to gain access to them. I will not record the therapy session; however, I will take notes on my observations.

It is entirely your choice whether you would like to take part in this research or not. You may also choose to take part in one aspect of the research and not in another. If you do choose to take part in the research, you will be asked to sign a consent form. This form will give me permission to use the information that you give me or tell me about. This will take the form of a research report and could also take the form of a published article in an academic journal or book. If you change your mind at a later stage and decide that you do not want to participate in the research anymore, even if you have already agreed before, you can stop participating immediately. You will not be paid for your participation in this research, and there will be no direct benefit to you from the research.

Any time we spend together, or information that you tell me will be completely confidential. This means that no-one will be able to identify who has told me this information. I will use a pseudonym (a made-up name) in all of my research notes and in the final dissertation or research report. I will, however, identify your area of expertise to ensure relevance of the information e.g. occupational therapist, speech therapist or remedial teacher.

It is important that your life is not disrupted in any way, and I will try to make sure that this is the case throughout the time we spend together.

This research has been approved by the Wits Faculty of Humanities and the Wits Humanities Research Ethics Committee.

If you have any queries, or are uncomfortable about anything that we discuss, you can speak to me at any time. I will also tell you, and show you, what I have written about our discussions.

Alternatively, you can raise any concerns you may have with my research supervisor (Dr Nolwazi Mkhwanazi), or the research ethics coordinator (Lucille Mooragan).

These are the necessary contact details provided as above.

FAMILY GROUP DISCUSSION CONSENT FORM

I agree to my family and I participating in this research project. I am familiar with the General Information Sheet and this Focus Group Consent Form. I have had the opportunity to ask questions about the research and I understand what participation could entail. In addition:

- I understand that we will not be identifiable in any way in this research.
- I understand that we are not obliged to take part in this research project.
- I understand that we have the right to withdraw from this research project at any stage.
- I agree to let the researcher take written notes and a voice recording of our family group discussions and individual conversations.
- I understand that all notes and recordings will be kept securely by the researcher to ensure that no one else has access to them.
- I understand that the findings from this research will be used in a research report and possibly also academic articles.

Name and signature of family participants:

Name: ______________________ Signature: ___________________

Name: ______________________ Signature: ___________________

Name: ______________________ Signature: ___________________

Name: ______________________ Signature: ___________________

Researcher's Name and Signature:

Name: ______________________ Signature: ___________________

Date: ______________________

REMEDIAL THERAPIST/TEACHER CONSENT FORM

I agree to participate in this research project. I am familiar with the General Information Sheet and this General Observation and Conversations Consent Form. I have had the opportunity to ask questions about the research and I understand what participation could entail.

In addition:

- I understand that I will not be identifiable in any way in this research.
- I understand that I am not obliged to take part in this research project.
- I understand that I have the right to withdraw from this research project at any stage.
- I understand that I have the right to decline the observation of specific therapy sessions or parts of sessions with particular children, even if they, their parents or I have consented to participate in the study.
- I understand that written notes/a voice recording may be made of situations and conversations which I am in, in the process of this research.
- I understand that all notes and recordings will be kept securely by the researcher to ensure that no one else has access to them.
- I understand that the findings from this research will be used in a research report and possibly also in academic articles.

Name and signature of participant:

Name: ______________________ Signature: ___________________

Researcher's Name and Signature:

Name: ______________________ Signature: ___________________

Date: ______________________

APPENDIX B

ETHICS CLEARANCE CERTIFICATE

Research Office

HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)
R14/49 Blackie

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: H16/05/05**
PROJECT TITLE	The lived experience of learning disabilities and development disorders
INVESTIGATOR(S)	Mrs D Blackie
SCHOOL/DEPARTMENT	Anthropology/
DATE CONSIDERED	20 May 2016
DECISION OF THE COMMITTEE	Approved unconditionally
EXPIRY DATE	06 June 2019

DATE 07 June 2016 **CHAIRPERSON** ______________________________
(Professor J Knight)

cc: Supervisor : Dr N Mkhwanazi

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to completion of a yearly progress report.**

____
Signature

______/______/______
Date

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

APPENDIX C

INFORMAL PARTICIPANT DISCUSSION GUIDES

Much of my research was conducted using participant observation, in the ethnographic tradition, however, I did conduct some semi/structured interviews. The following discussion guides assisted me in conducting these interviews.

DISCUSSION GUIDE FOR A CHILD

Please note this discussion will take place over several days/weeks rather than in one session.

1. Tell me about yourself? (Creative Exercise: Draw picture of self as a superhero – exploring self-esteem and values)
   a. What is your name and what do you like people to call you?
   b. If you could create a special or super-hero name for yourself what would it be?
   c. How old are you?
   d. What are your most favourite things in the world and why? (I will explore colours, sounds, movies, music, books, games, and anything else that comes up).
   e. What are your least favourite things in the world and why?
   f. What is your most favourite thing to do and why?
   g. What is your least favourite thing to do and why?
   h. Who are your most favourite people to spend time with and why?
   i. Who are your least favourite people to spend time with and why?
   j. Who do you look up to the most, and what do you admire about them?
   k. What do you think the best things about you are? What are the things you are really good at?
   l. What do you think your areas of improvement are? What are the things that you are not so good at or that you think you struggle with?
   m. As a superhero, you would have an honour code, what is your honour code? (What do you believe in as a person? What is most important to you as a person?)
   n. How do you think people describe you to other people? What do you think you are known for?
   o. How would you like people to describe you to other people?

2. Tell me about your growing up experience so far: (Creative Exercise: Timeline pictures – exploring personal history)
    a. What is your earliest memory?
    b. Tell me about the most important times in your life up until this point? (I plan to systematically work through the various years of their lives in a timeline format).
    c. What are your best memories and why?
    d. What are the memories that you don’t like and why?
    (Each memory would be explored in terms of the sensory experience, e.g. do you remember what you saw, what you heard, what you felt, what you smelt or tasted. I will also explore good versus bad sensory experiences.)

3. Let’s discuss your different emotions. (Creative Exercise: Emoticons to stimulate discussion – exploring emotions)
    a. When do you feel happy? What makes you happy?
    b. When do you feel sad? What makes you feel sad?
    c. When do you feel angry or cross? What makes you feel angry or cross? When you are angry or cross, how easy is it for you to forgive the person you are angry or cross with? What does that person need to do to make you not be angry or cross with them anymore?
    d. When do you feel scared or afraid? What makes you scared or afraid?
    e. When do you feel curious or interested in something? What makes you curious or interested in something?
    f. When do you feel excited or really look forward to something? What makes you excited and look forward to something?
    g. When do you feel calm and content? What makes you calm and content?
    h. When do you feel embarrassed? What makes you embarrassed?
    i. When do you feel worried or anxious? What makes you worried or anxious?
    j. When do you feel love or tenderness towards someone else? What makes you tender or loving towards someone or something?
    k. Do you feel any other emotions? When do you feel them? What makes you feel them?

4. Let’s talk about school and learning? (Creative Exercise: Draw a picture of this world – exploring attitudes to learning and learning/developmental challenges)

    a. What do you think about your school?
    b. What do you like about it?
    c. What do you like about going to it?
    d. What don’t you like about it?
    e. What don’t you like about going to it?
    f. What are your most favourite things to learn about?
    g. What are your least favourite things to learn about?
    h. What is the stuff you are really good at, at school?
    i. What is the stuff that you struggle with at school?
    j. Has anyone ever told you that you have difficulties with your learning and/or behaviour?
    k. What did they tell you about these things?
    l. When you were told this, what did it mean to you?
    m. What does it mean to you now?
    n. What do you think caused your difficulties?
    o. How do you experience these difficulties? (This will be explored in a range of different contexts, e.g. at school, in the playground, at home, out and about etc. Again, I will explore these experiences in terms of their senses as well where possible. I will also be observing my participants in many of these environments firsthand.)
    p. Do you explain your difficulties to other people?
    q. How do you explain your difficulties to other people?
    r. What do other people say about your difficulties?
    s. How does this make you feel?
    t. What would you like them to understand about your difficulties?

5. Let’s discuss your body and how it works for you? (Creative Exercise: Using a picture of a body, draw what the different parts mean and where they feel strong/weak and how you think they work for you – exploring body image, embodiment, self-esteem and creativity)
    a. What do you think about your body?
    b. What do you like about your body?
    c. What don’t you like about your body?
    d. When do you feel strong? Where do you feel strong in your body?
    e. When do you feel weak? Where do you feel week in your body?

f. When you have been sick, where does the sickness show up in your body most? Why do you think it shows up there?
g. Where do you think your difficulties come from in your body? Why do you think they come from there?
h. Describe to me how you think your brain works? How do you see it working? (Draw this for me)
i. Do you ever get frustrated about how different parts e.g. your brain works?
j. What do you find interesting, different, or special about how your brain works?
k. Do you ever come up with new ideas? When do you come up with these new ideas? What ideas have you come up with? How did you come up with these ideas?

6. Let’s talk about the special skills you have developed to help you cope with your difficulties. (Creative Exercise: Your super-hero toolkit, draw what is inside and how it all works – exploring coping strategies and taking action)
    a. Do you have any strategies that you use to help you to cope with the difficulties that you have?
    b. Who taught you these strategies, or did you work them out for yourself?
    c. How did you figure these strategies out?
    d. When do you use these strategies most?
    e. When you use these strategies how do you feel?
    f. Do you go to any therapy sessions to help you with your difficulties? Describe these to me? What do you like about these sessions? What don’t you like about these sessions? What do you think your most helpful therapy is? Why do you think this is? What do you think your least helpful therapy is? Why do you think this is? (I will explore each therapy individually as each will have a unique impact)
    g. What is your most favourite thing to eat? What is your least favourite thing to eat? Do you have to eat anything or take anything special to help you with your difficulties? Do you think this works for you? Describe your perfect meal?
    h. If you could create a special pill to give you special powers, what would the pill taste like and what would it help you do?

7. Let's discuss the different people in your life. (Creative Exercise: Partnership bubble exercise and toys to be completed with the facilitator – exploring partnership and relationships).
    a. Tell me about all the people in your life who are they?
    b. Let's draw a picture with the most important people standing near to you and the least important standing further away? (I used animals and toys to represent the different individuals).
    c. How do each of these people help you in your life?
    d. What do you like most about them?
    e. What do you not like about them? Or what frustrates you about them?
    f. How do you make them feel happy?
    g. How do you make them feel sad or cross?
    h. When do they make you feel happy?
    i. When do they make you feel sad or cross?
    j. Would you change anything about your relationship with them?

8. Let's discuss what you dream about for yourself? (Creative Exercise: Draw a picture of yourself grown up and living in an adult world – exploring external vision)
    a. What would you like to become when you grow up (or in the future, for young adults)?
    b. Finish this sentence, "The world would be a better place if…"
    c. If you could help to create this better world, what would you be doing? Who would you be? Why would you be this person?
    d. Do you worry about your difficulties in the future? What do you worry about?
    e. How do you think you will overcome your difficulties to achieve your dream for yourself?

9. Let's discuss your daydreams? (Creative Exercise: Draw a dream scape using comic books icons provided by the facilitator – exploring internal vision)
    a. Do you ever daydream about yourself and the world around you (where you are awake and conscious, but your mind wanders)?
    b. What do these daydreams look like?
    c. What happens in these daydreams?
    d. What do you look like in these daydreams?

e. Who else is in your daydreams?
f. How do your daydreams play out? (I will ask them to describe specific dreams and discuss them in detail to understand this better).
g. How are your day-dreams different from your real-world experience?
h. If you could change something about your real-world experience to be more like your day-dreams, what would it be?
i. Describe your perfect day?
j. What advice would you give to people who have difficulties like yours?
k. What advice would you give to people who live or interact with people who have difficulties like yours?

DISCUSSION GUIDE FOR FAMILY MEMBERS

Please note, these interviews will be less in-depth as they serve as support to the primary story that has been told by the person diagnosed.

1. Introduce yourself and describe your relationship with the family member who has been diagnosed with a disability/disorder (mother, father, sister, brother, aunt, uncle, grandparent, family friend etc).
2. What is your first memory of X?
3. When did you first notice that they have difficulties?
4. How would you describe these difficulties?
5. What do you think caused these difficulties?
6. How have these difficulties shown up (good, bad, or indifferent experiences) through the years?
7. Did these difficulties have an impact on your relationship with X? What was that impact?
8. What are the things that you find most frustrating about how X behaves/says/does?
9. What are the things that you find most endearing about how X behaves/says/does?
10. How have you tried to help X cope with his/her difficulties? And what impact have these strategies/interventions had on him/her?
    a. Personal interactions?
    b. Personal therapies?
    c. External therapists/therapies?
    d. Diet?
    e. Medication?
    f. Other?
11. Have you ever had to stand up for or fight for X? Tell me about this?
12. What are your greatest concerns for X?
13. What is your dream for X?
14. What would you like X to know about how you feel about him?

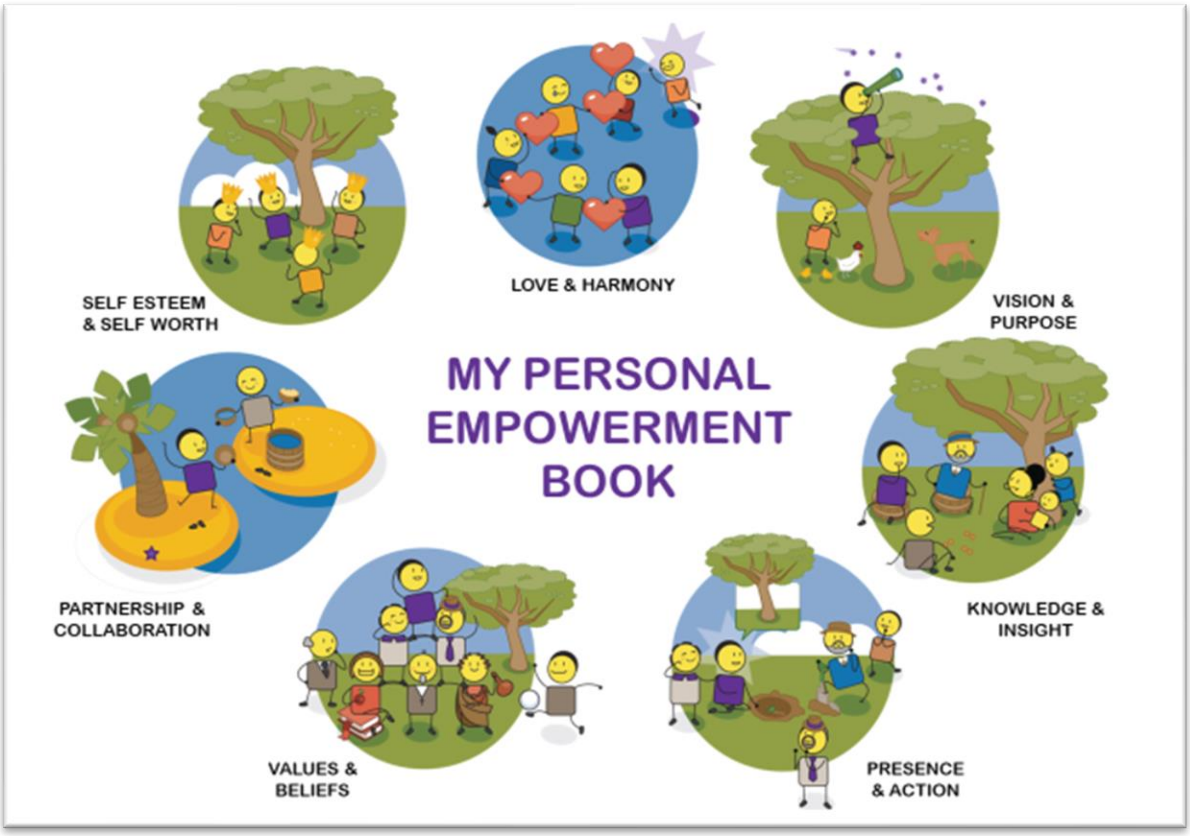
DISCUSSION GUIDE FOR TEACHER OR THERAPIST

Please note, these interviews will be less in-depth as they serve as support to the primary story that has been told by the person diagnosed.

1. Introduce yourself and describe your area of expertise?
2. Why did X get referred to you?
3. What is your first memory of X?
4. How would you describe X's difficulties?
5. What do you think caused X's difficulties?
6. How do these difficulties show up on a day to day basis?
7. What impact do these difficulties have on X?
8. What therapies have you implemented or recommended to X and his/her family? Why did you recommend these therapies? (I will explore each of these therapies in-depth).
9. How do you think these therapies have worked for X?
10. How will you continue to help X moving forward? (ie will the therapies change over time or stop after certain milestones have been achieved).
11. What advice do you have for parents who have children like X?
12. What advice do you have for X as he/she grows up/gets older?
13. Do you think more or less children are struggling with difficulties like X?
14. How do you think education and therapeutic support is evolving to support children like X?

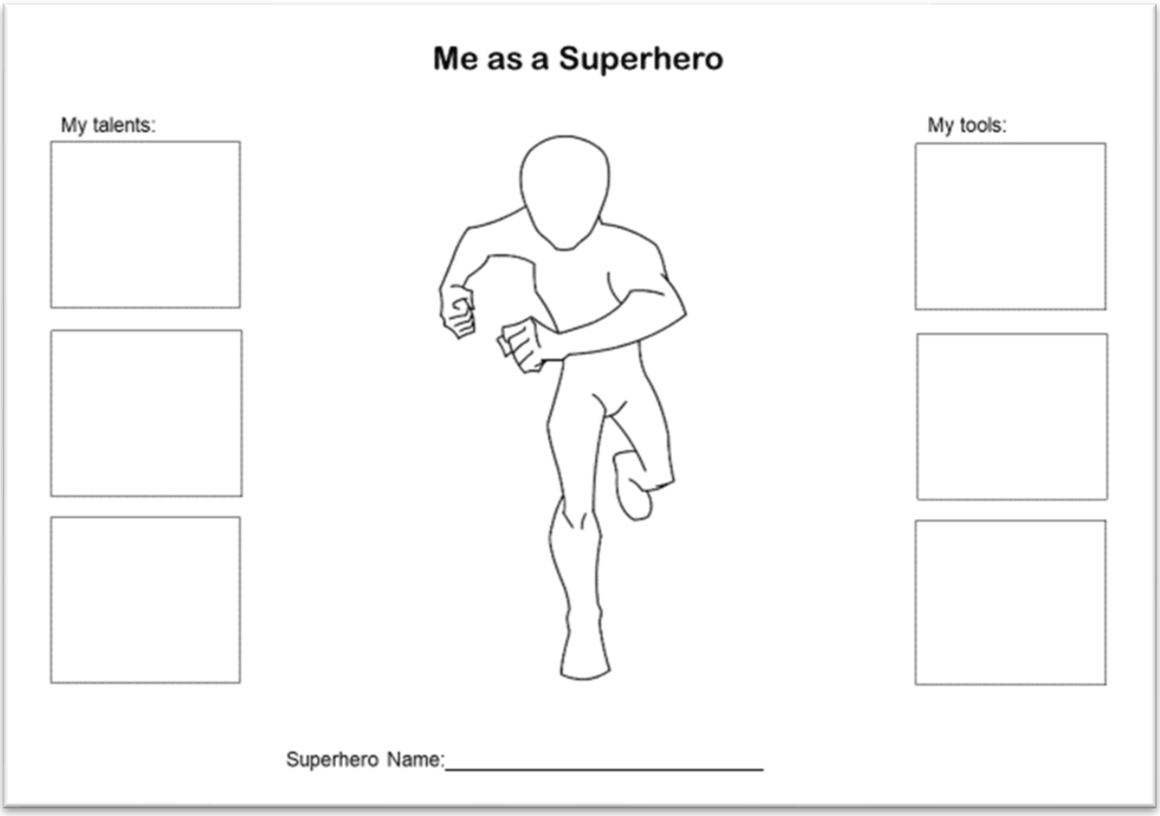
APPENDIX D

PERSONAL EMPOWERMENT WORKBOOK AND INSTRUCTIONS



Instructions:

- This book has been created as a personal workbook for children considered to be atypical.
- Its purpose is to explore their world from their perspective.



Me as a Superhero

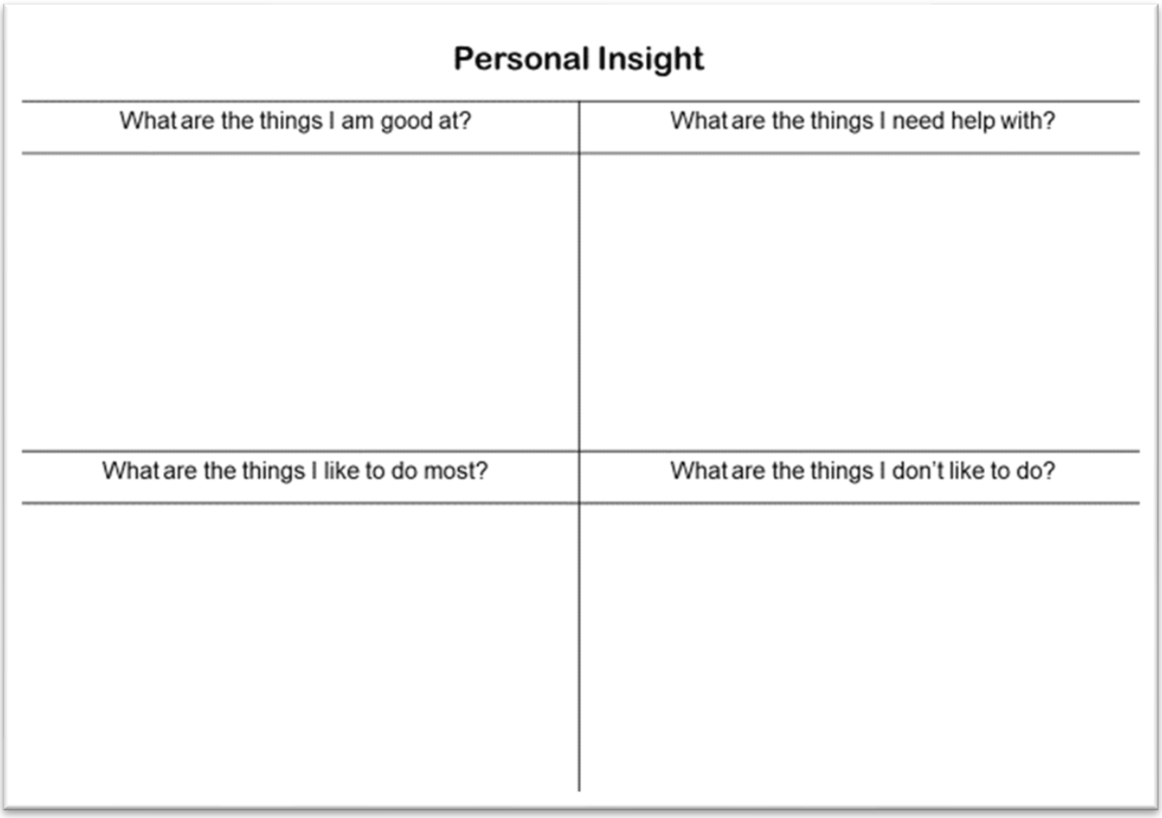
My talents:

My tools:

Superhero Name:__________________________

Instructions:

- Use the template to draw yourself as a superhero.
- Give yourself a superhero name.
- Use the blocks provided to describe your superhero talents and tools (you can draw or write these).

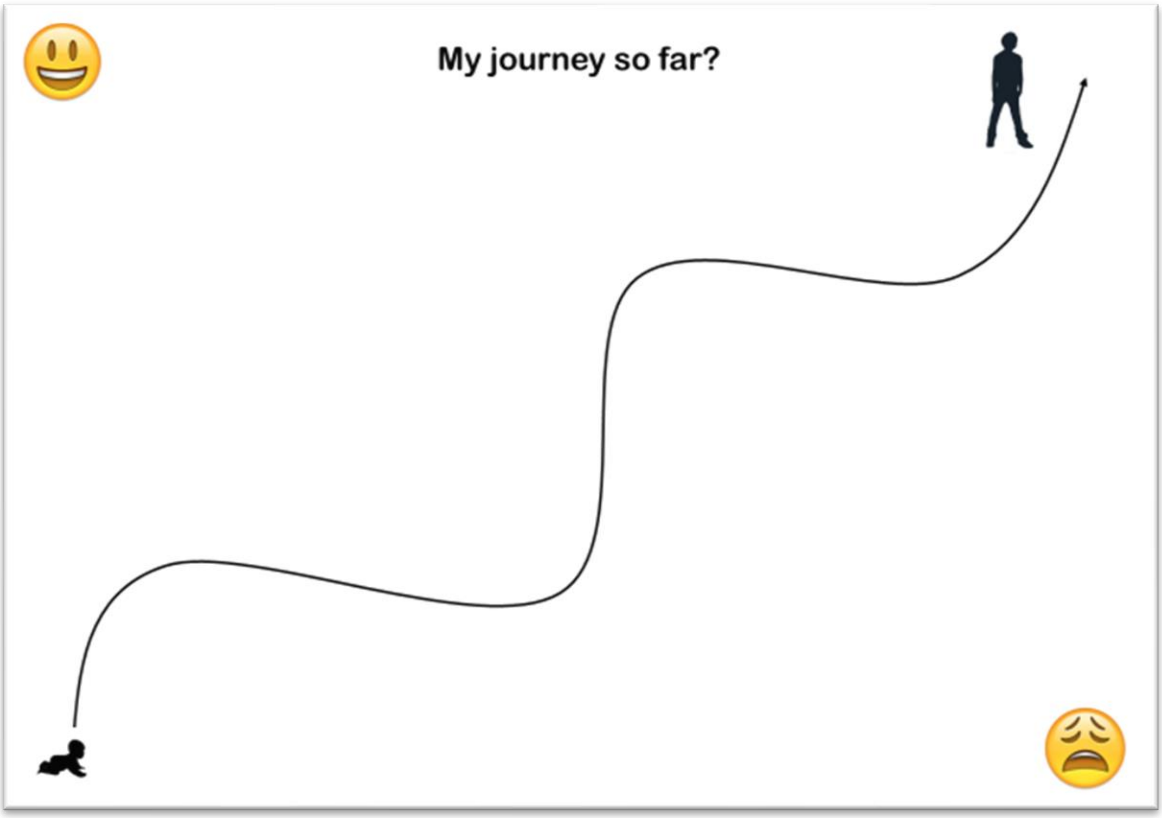


Personal Insight

What are the things I am good at?	What are the things I need help with?
What are the things I like to do most?	What are the things I don’t like to do?

Instructions:

- Fill in this template as honestly as possible.
- If the child cannot write, this can be a discussion with the facilitator or a creative drawing exercise.



Instructions:

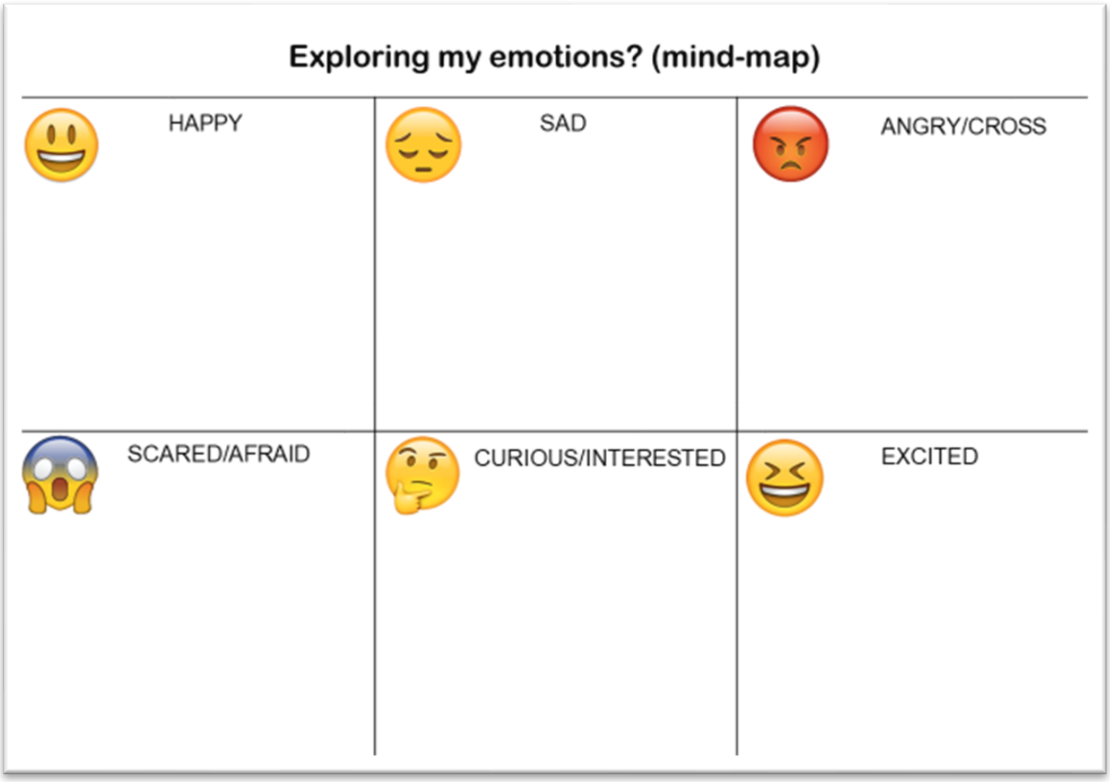
- Draw or write the highlights and lowlights in your life so far.
- You do not have to remember everything just the things that were important or had an impact on you.

My best vs worst day?

My best day?	My worst day?

Instructions:

- Describe your best vs your worst day.
- This can be an actual day or a ‘made-up’ day.

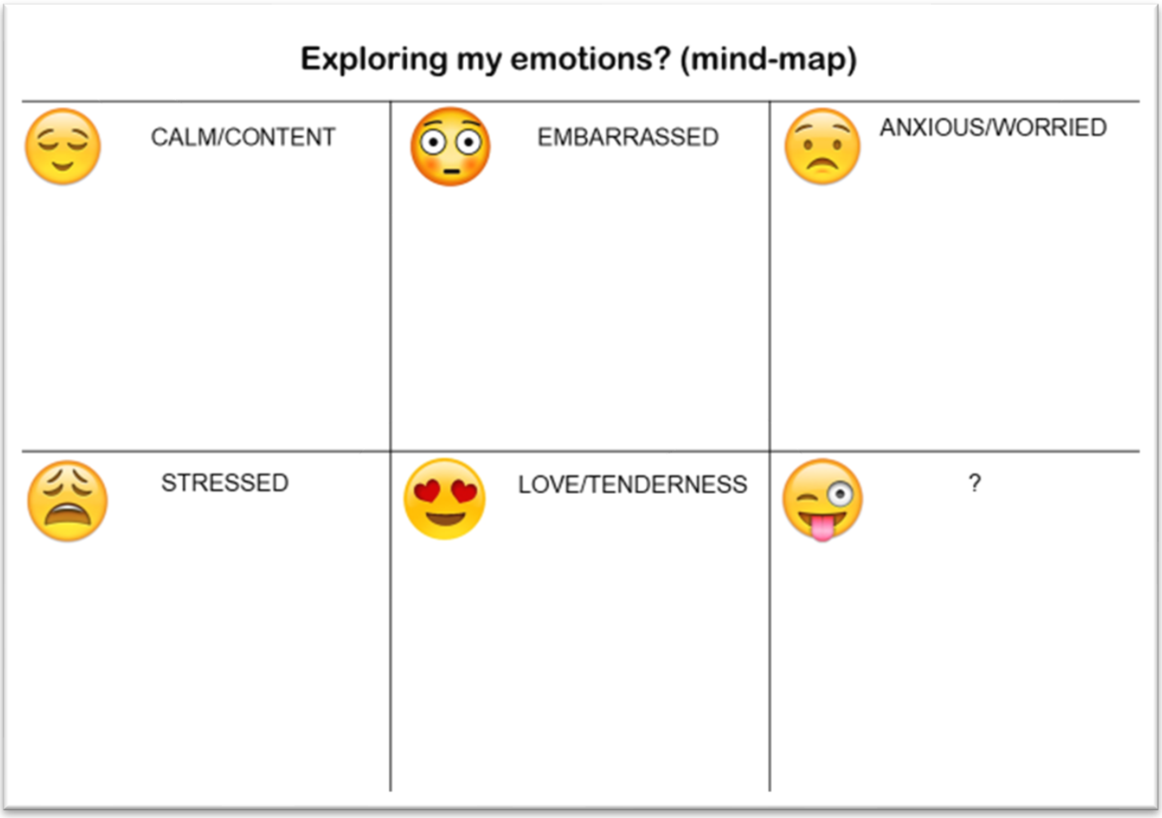


Exploring my emotions? (mind-map)

😃 HAPPY	😔 SAD	😡 ANGRY/CROSS
😱 SCARED/AFRAID	🤔 CURIOUS/INTERESTED	😆 EXCITED

Instructions:

- Explore each of your emotions as a mind map.
- Ask: What makes you happy? When do you feel happy? Who makes you happy? Where do you feel happy in your body? (etc. for each emotion)

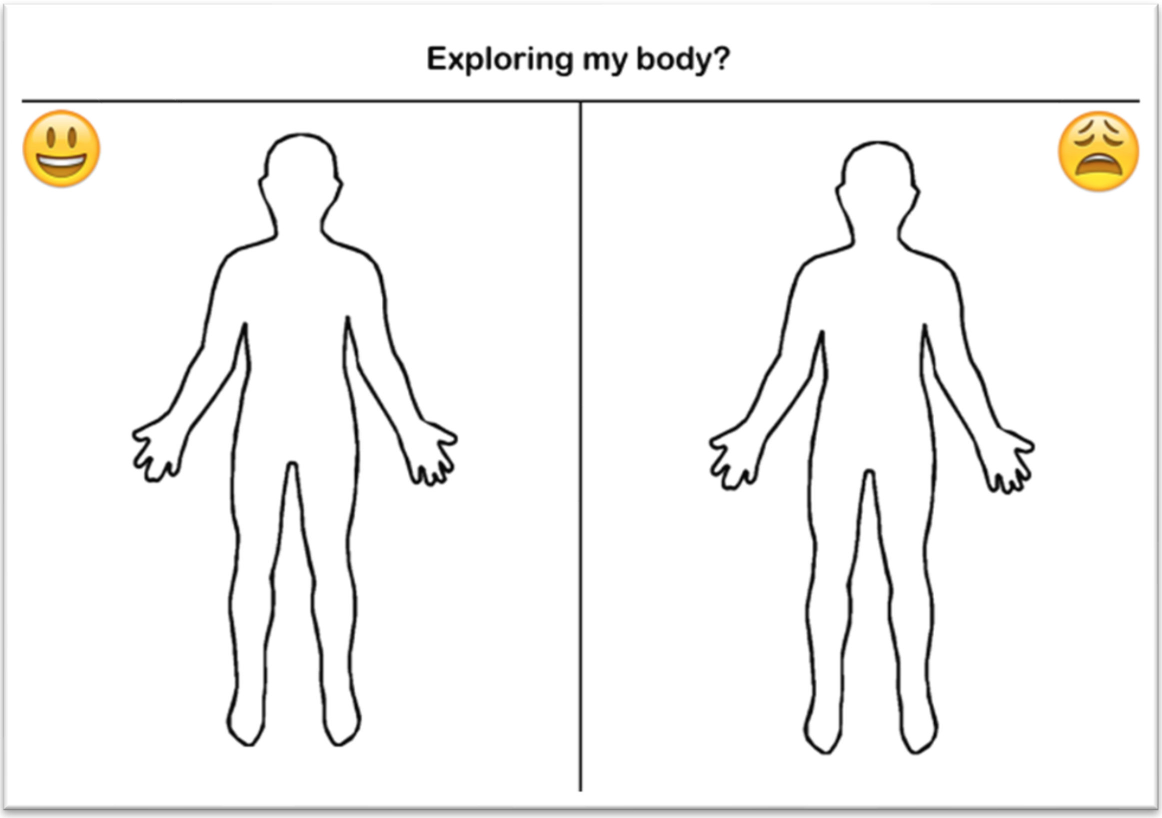


Exploring my emotions? (mind-map)

CALM/CONTENT	EMBARRASSED	ANXIOUS/WORRIED
STRESSED	LOVE/TENDERNESS	?

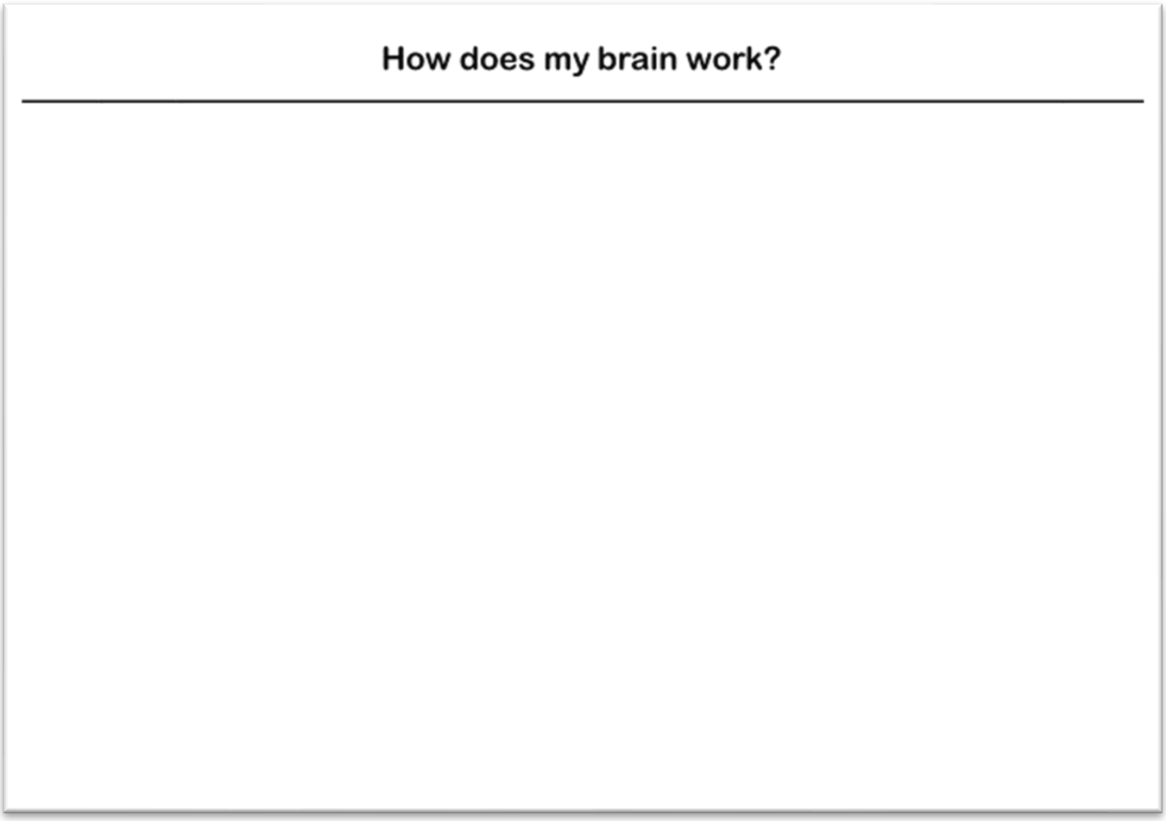
Instructions:

- Explore each of your emotions as a mind map.
- Ask: What makes you happy? When do you feel happy? Who makes you happy? Where do you feel happy in your body? (etc. for each emotion)



Instructions:

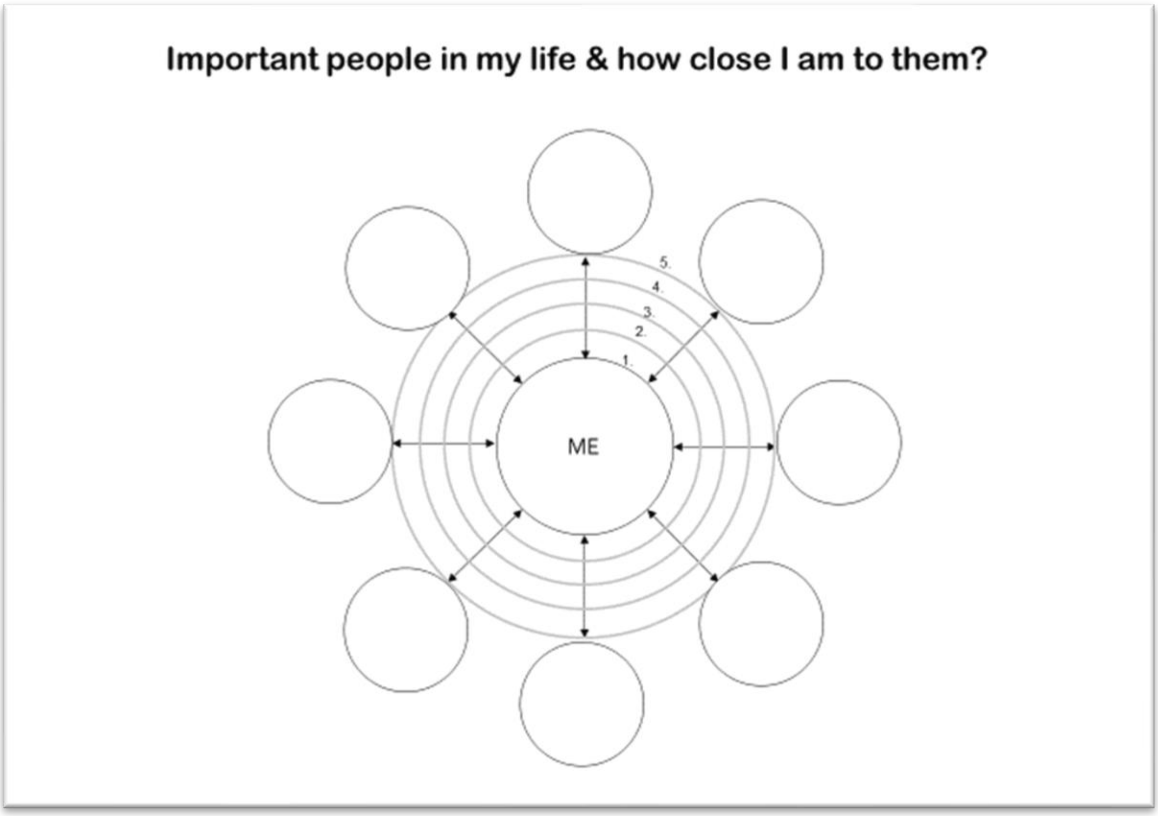
- Draw what you think is happening inside your body when it feels happy and when it feels sad.
- You do not have to keep inside the lines if this is not how your body feels.
- Remember to use colours, shapes, and colouring techniques to bring this exercise to life.



How does my brain work?

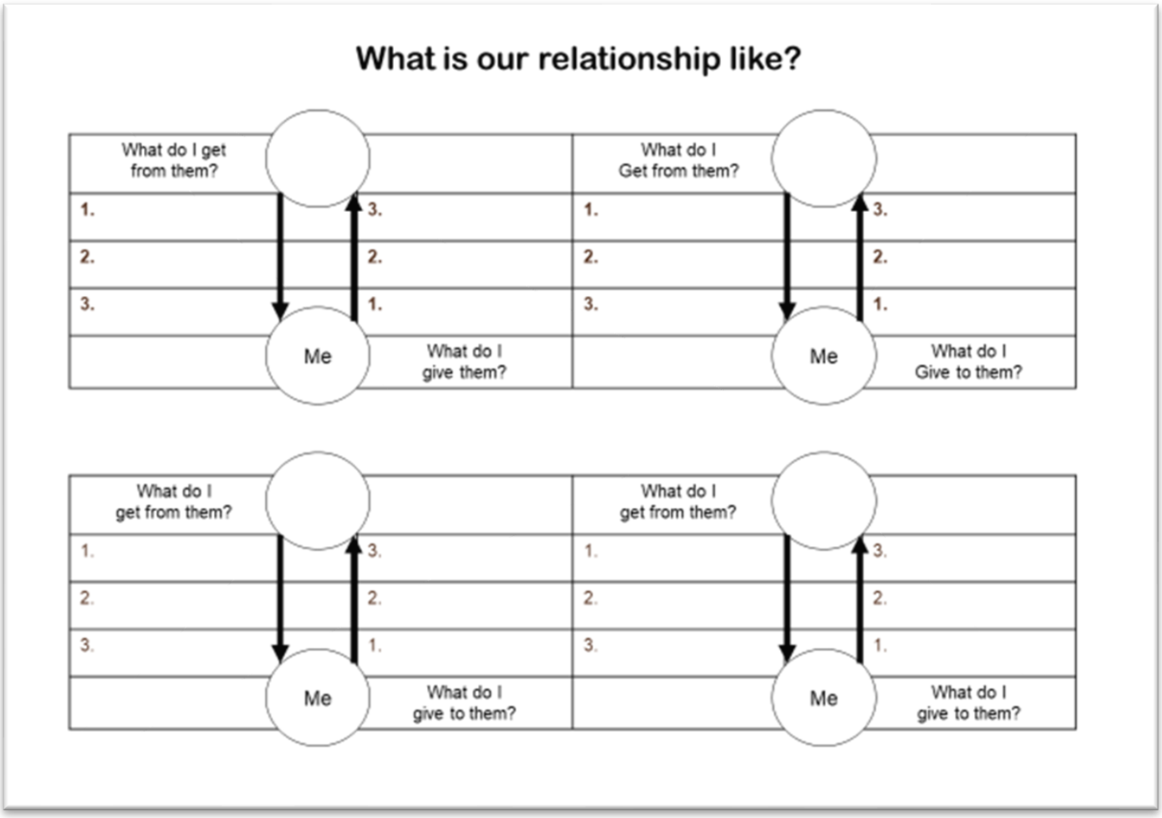
Instructions:

- Draw how you think your brain works.
- You do not have to draw an actual brain, but rather a picture that describes how you think your brain works.



Instructions:

- Who are the most important people in your life and how close are you to them? (1 = very close and 5 = not that close)



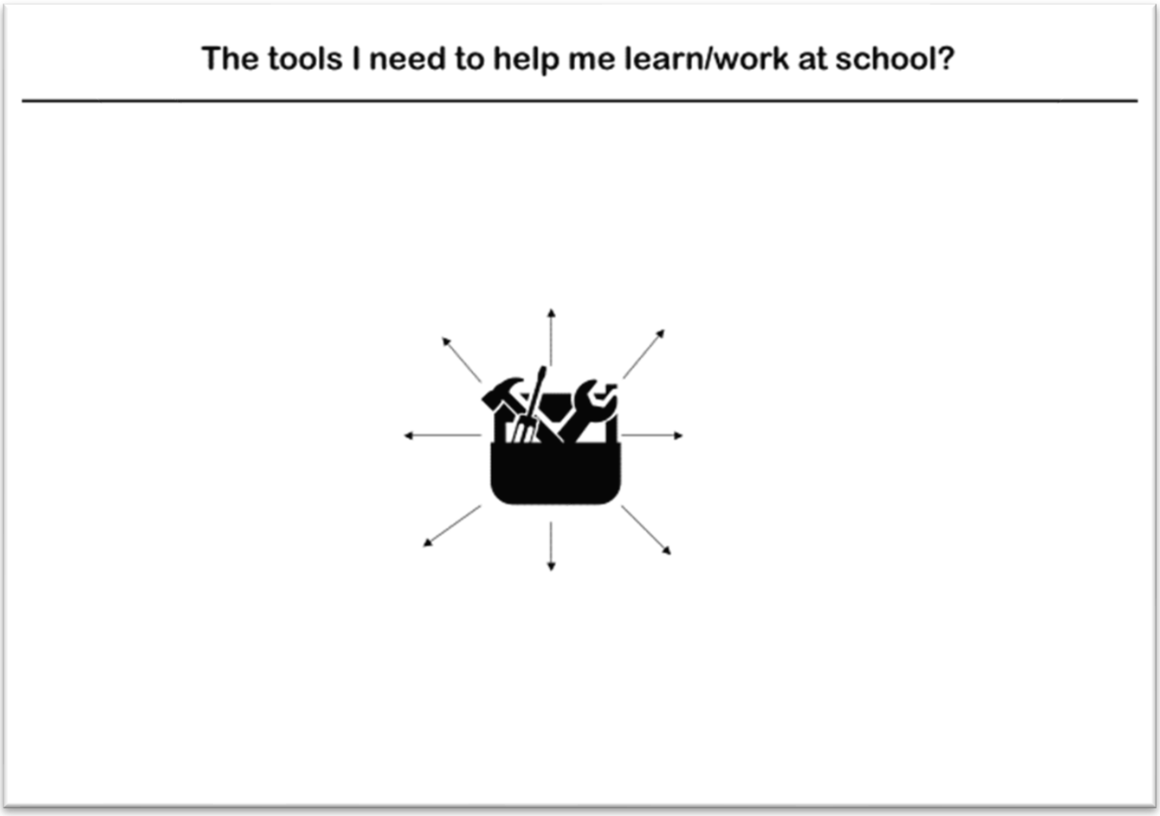
Instructions:

- Explore your relationship with all of the important people in your life.
- Think about what you get from them (physically, emotionally, socially) and what you give them (physically, emotionally, socially).

My perfect learning environment/school?

Instructions:

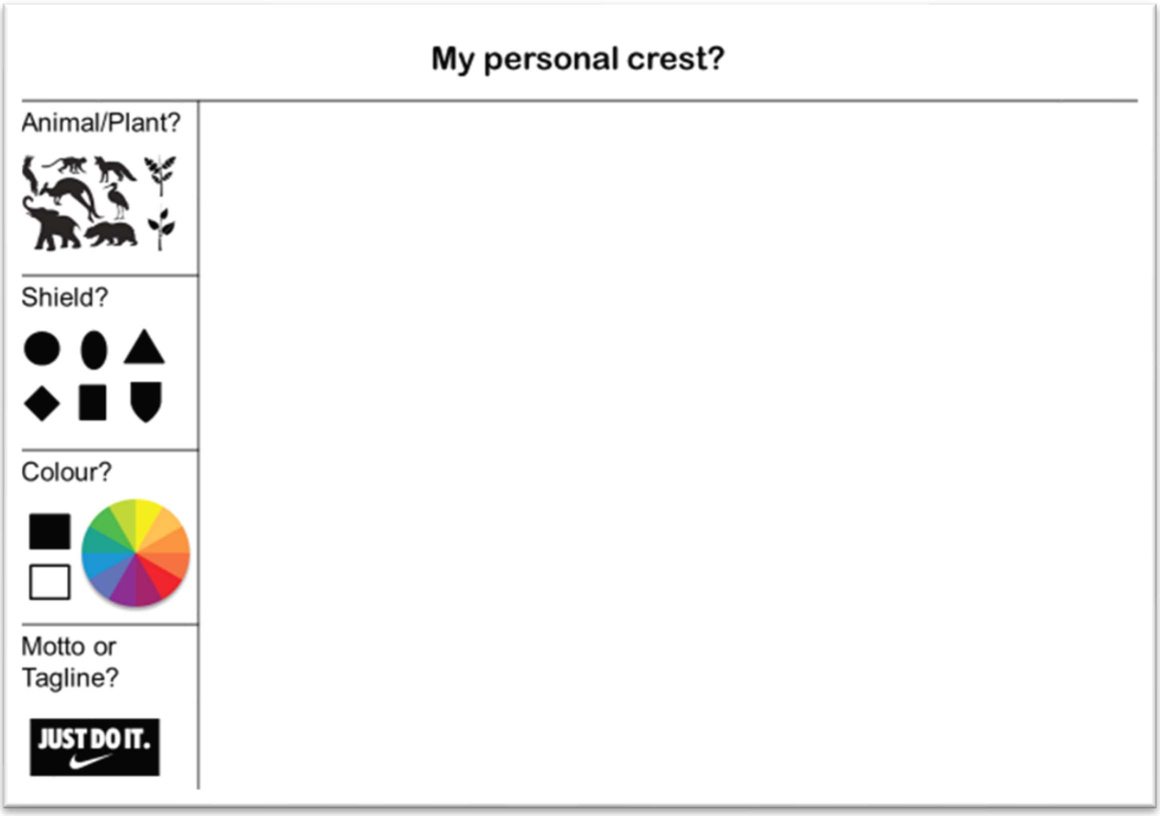
- Design and draw your perfect learning environment.
- This does not have to be your existing school, but rather a space that you think you learn best in.
- Try to be as creative as possible.



The tools I need to help me learn/work at school?

Instructions:

- What are the tools that you use, or think you should use to help you learn and work better at school?
- These can be strategies, certain kinds of people, medication, diet, really anything that you think helps you learn and work better?



My personal crest?

Animal/Plant?

Shield?

Colour?

Motto or Tagline?

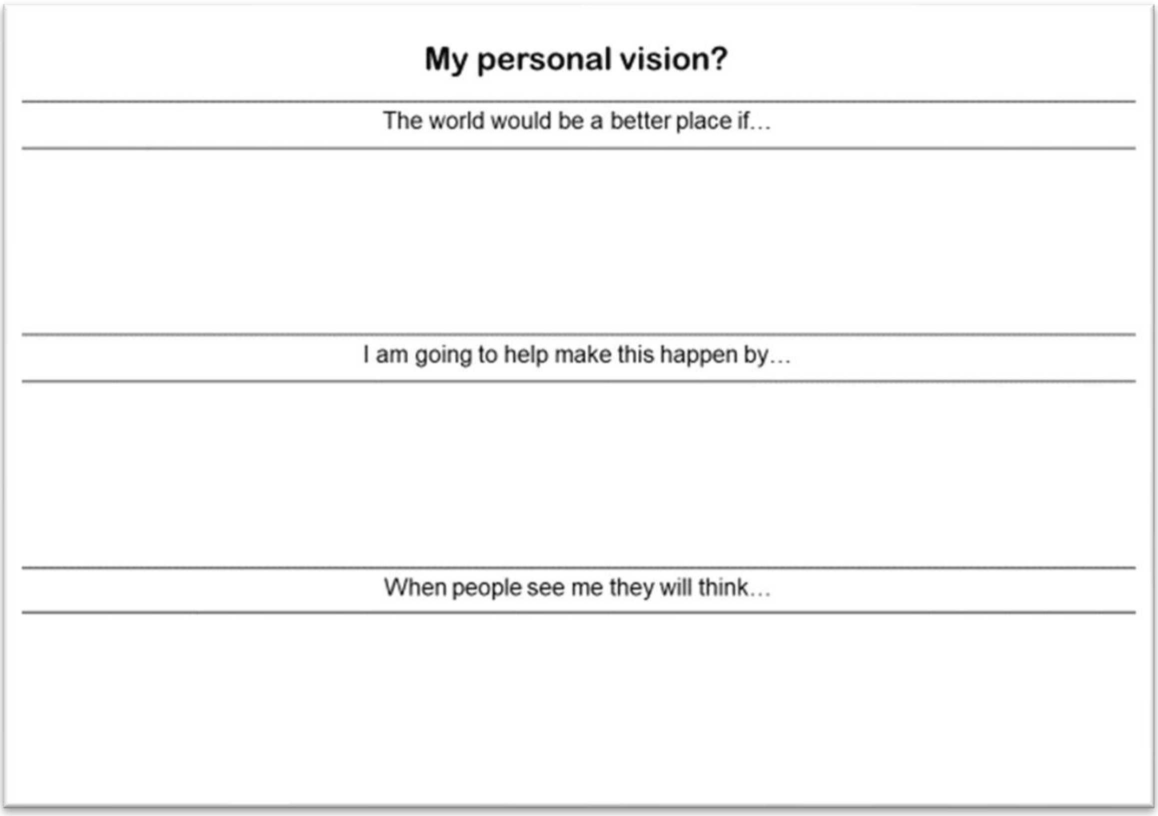
Instructions:

- Design your own personal crest, like your school crest (explore this if there is confusion).
- You will need to choose an animal that you think represents who you are and/or who you would like to become, a shield shape, your favourite colour (you can choose more than one) and a motto or tagline that inspires you and who you want to become.

My Future Dream World?

Instructions:

- Draw a picture or create a collage of your future dream world.
- This is the world that you would like to create for yourself to live in when you grow up.



My personal vision?

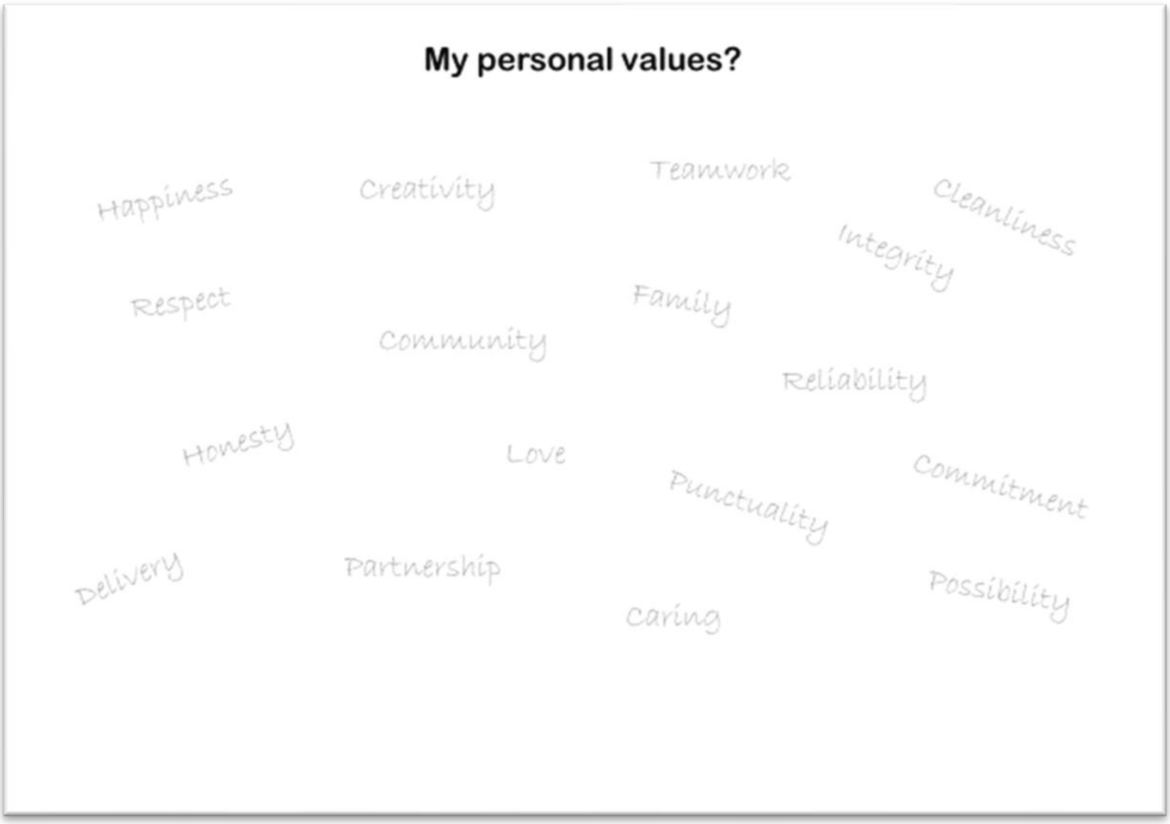
The world would be a better place if…

I am going to help make this happen by…

When people see me they will think…

Instructions:

- Finish each of these sentences to create your own personal vision.

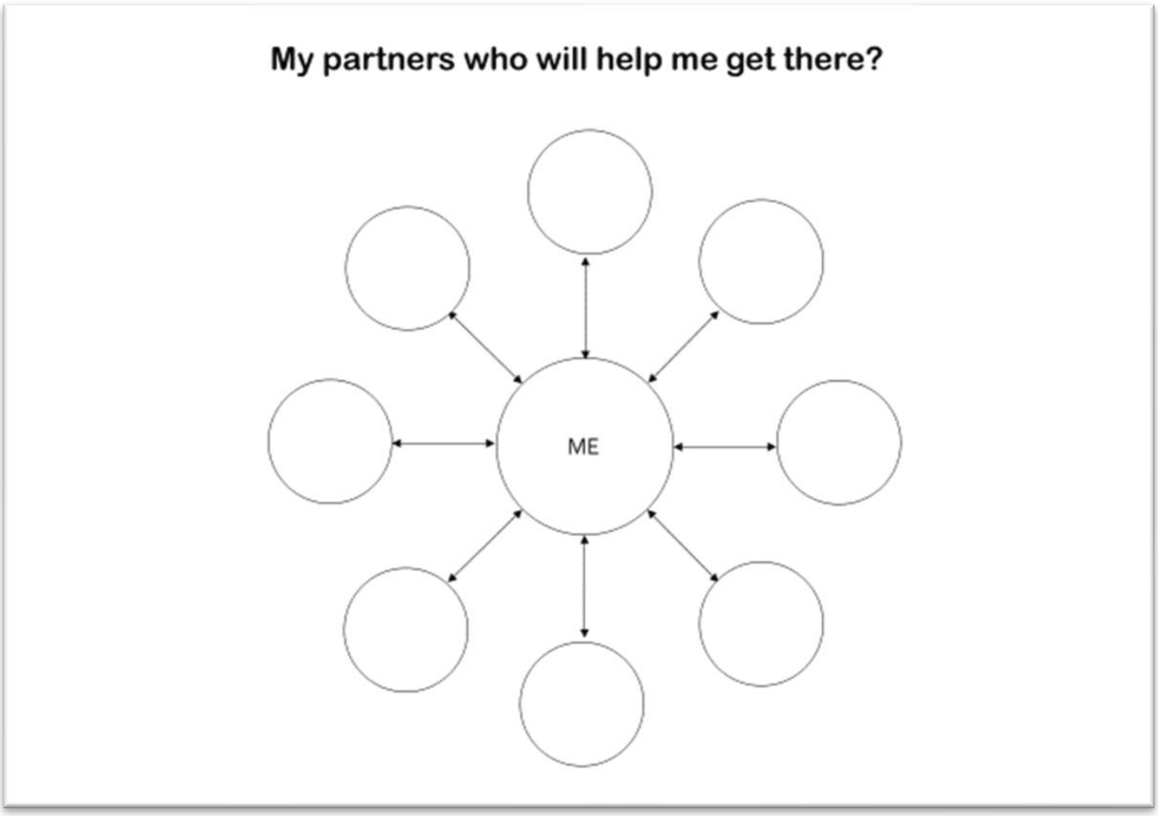


My personal values?

Happiness
Creativity
Teamwork
Cleanliness
Integrity
Respect
Family
Community
Reliability
Honesty
Love
Commitment
Punctuality
Delivery
Partnership
Possibility
Caring

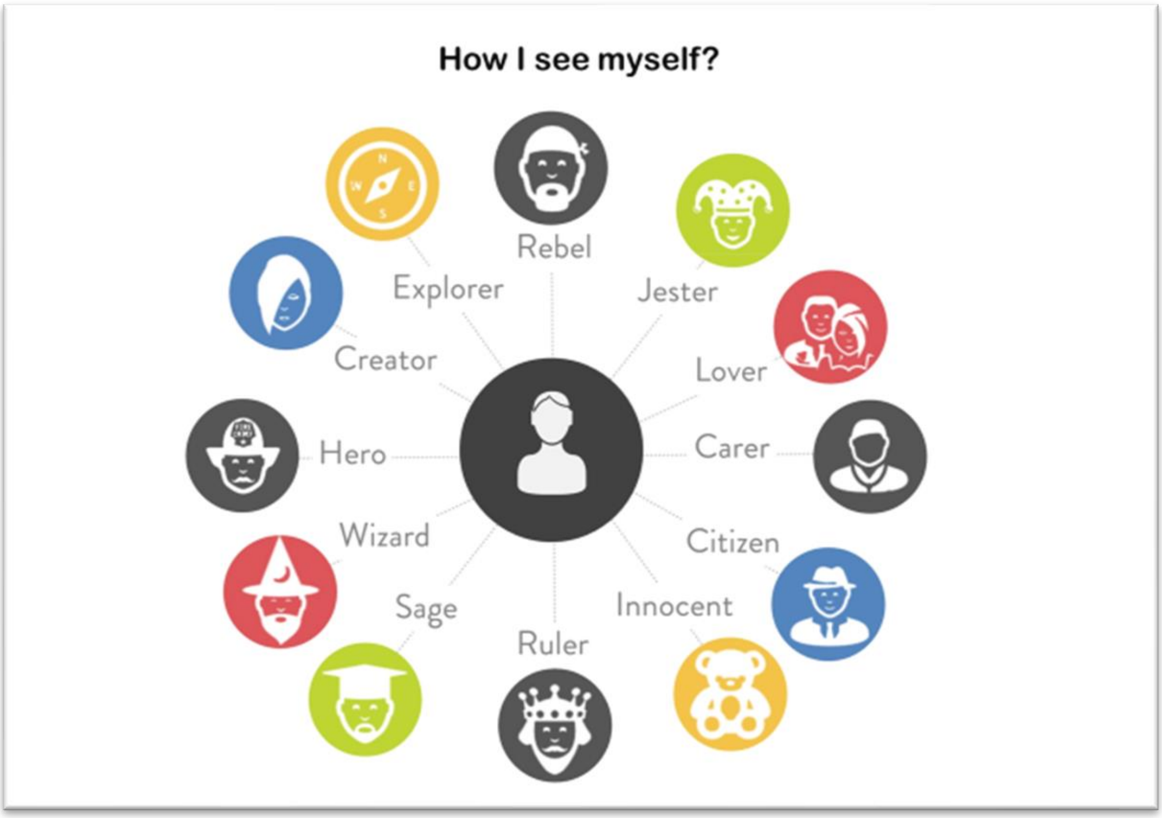
Instructions:

- Think about what is most important to you in your life, your values.
- Values are the things that are most important to you and often guide how you act or behave on a day to day basis.
- There are a few examples on the page that you can circle, or you can write your own in your own language.
- Try to pick the 4 or 5 most important values that represent what is most important to you.



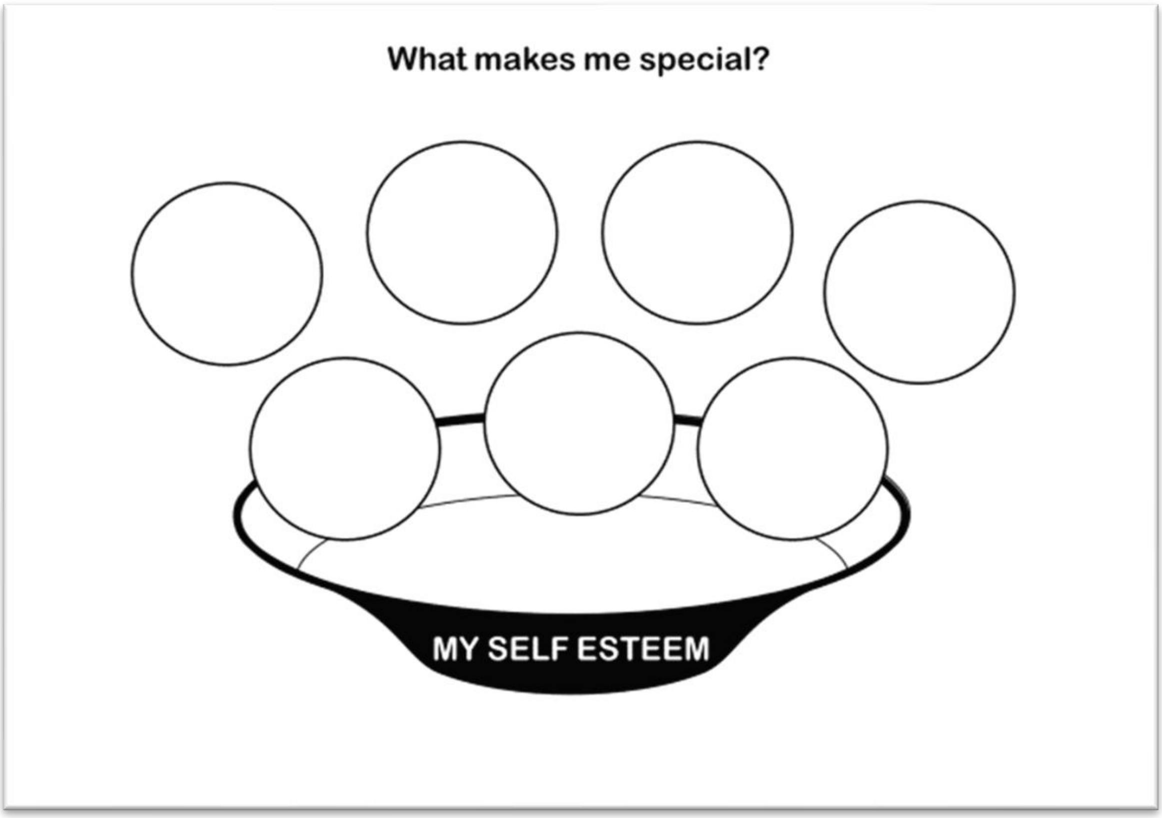
Instructions:

- Who are the people that you think will help you achieve your dream world.
- These may not be the same people that you are close to, but rather the people who can help you achieve your vision for yourself.



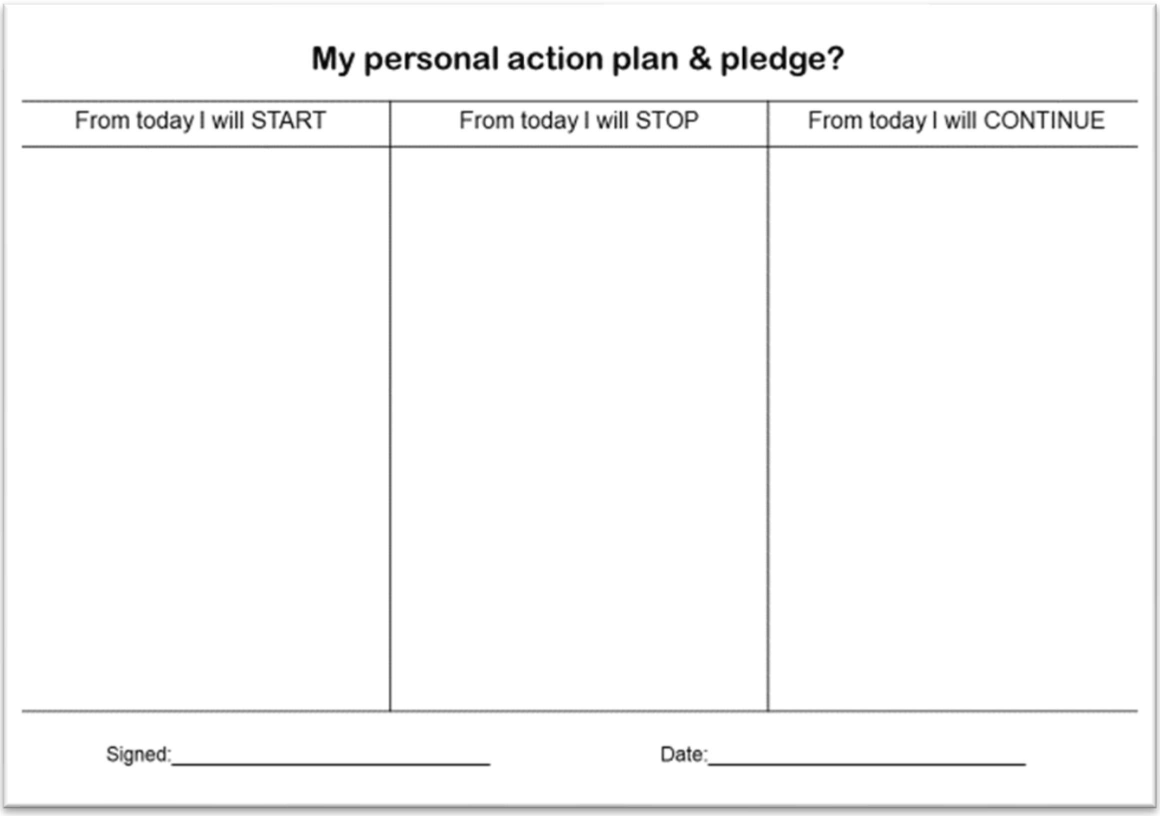
Instructions:

- Choose a first, second and possibly a third personality type that you think describes who you are.
- The first choice is the most important character trait, followed by the second and possibly a third.
- Discuss why you have chosen your personality types.



Instructions:

- Think about this bowl as representing your own self-esteem, or how you feel about yourself.
- Think about all the things that people say to you that makes you feel special about yourself.
- Now think about all the things that people say you that make you feel sad or unhappy about yourself.
- Remember, if you allow other people to fill your self-esteem bowl, you also allow them to empty the bowl!
- Try to think about all the things that you think make you special and unique, the things that no-one can take out of your self-esteem bowl.
- Now write these things into the circles above the bowl.



My personal action plan & pledge?

From today I will START	From today I will STOP	From today I will CONTINUE

Signed:__________________________ Date:__________________________

Instructions:

- It’s time to make an action plan.
- Thinking about all the things that you have written in this book, what will your action plan be from today.
- Think about all the things that you need to start doing to achieve your vision.
- Now think about all the things that you are doing at the moment that don’t support your vision or dream for yourself, these are the things that you need to stop doing.
- Finally, think about the things that you are already doing that support your vision or dream for yourself, these are the things that you need to continue doing.
- Sign this action plan and put a date on it, to make sure that you follow through on building your own personal vision.