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# **Autism and Affordances of Achievement Narrative Genres and Parenting Practices**

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The concept of achievement demands a narrative lens: achievement is durative and agentive and thus by its very nature it denotes a narrative of becoming. To capture a phenomenology of achievement, I propose to direct this narrative lens at autism, a developmental disability that disrupts normative expressions of sociality but that, as Murray (2008: 5) suggests, ‘contains its own logic and methods’ that command analytic attention. The view can be traced to Hans Asperger, who, writing in 1944 in Vienna about what is now known as ‘Asperger’s syndrome’, commented that in autism there is difficulty in learning in conventional ways; instead ‘the autistic individual needs to create everything out of his own thought and experience’ (Asperger 1991 [1944]: 56). This view, however important, suggests that the autistic individual’s pursuit of achievement is a solitary process and is consistent with clinical descriptions of autism as a disorder of intersubjectivity (Hobson 1993; Trevarthen 1996). It also implies a contrast with non-autistic processes of pursuing and experiencing achievement. I seek to problematise these distinctions related to autism and achievement in two ways: firstly, I examine certain kinds of ‘stories to be in’ (Mattingly 1998) that are constructed by parents, especially mothers, from published life stories of successful adults with Autism Spectrum Disorders (ASD), and from memoirs of other parents. When mothers craft these stories, they create, for their children and for themselves, courses of action toward desired subject positions and ways of being in the world that stand in contrast to other possible but undesirable futures, futures that these mothers strive to escape. Secondly, I identify certain kinds of experiences and occupations afforded by engagement in such narrative co-construction that may have profound and tangible effects on the achievement of children, youth and adults diagnosed with ASD.

The interplay of autism and achievement merits a discussion located at the intersections of the discursive and the embodied, the developmental and the socio-interactional, the individual and the collective, the relational and the solitary, the routine and the improvisational, the cross-cultural and the socio-

political, and the institutionally sanctioned and the institutionally prohibited. To move the discussion in such a multi-faceted analytic direction, I draw upon three kinds of narratives: firstly, interviews conducted with African American mothers who live in Los Angeles about their experiences of raising children diagnosed with autism; secondly, published first-person accounts of autism that are publicly recognised as stories of achievement; and thirdly, published parental memoirs of raising a child with autism who grows into a professionally successful adult. Within this chapter I am especially interested in the narrative framing of the experience of achievement in relation to the diagnosis of autism. Does achievement in these narratives happen in spite of autism or because of autism? Is achievement in these narratives always desirable and laudable?

My goal is to describe the 'expressive, storied dimensions' (Yanow 1999: 31) of autism and achievement and to identify narrative processes involved in making sense of autism as it relates to achievement, and achievement as it relates to autism, across the lifespan and from multiple perspectives. These narrative processes frame developmental differences and potentialities as visible, interpretable, ratifiable and contestable against the horizon of future-implicative social actions that permeate everyday life. To understand this narrative framing, I consider the three narrative sources with an eye for the everyday activities that afford individuals with autism experiences of achievement.

The concept of 'affordance' is complementary to this phenomenological, process-oriented view of achievement, and it denotes an engagement in an activity with others that enfolds over time. 'Affordances' are understood as opportunities for action provided by a particular object in the environment (Gibson 1977), and human perception of the self is directly linked with 'perceiving affordances for acting in the world' (Gibson 1993: 32). A critical part of the theory of affordances is the idea of 'fit' or 'scale', reflecting that the affordances have to be of the right scale to be perceived by the organism as relevant – that is, to fit the parameters of the organism, its anatomy and capacity for action. The concept of 'affordances of achievement' allows us to examine the processes by which parents and children make certain cultural and symbolic objects – such as a book or a movie based upon a life story of a successful person with autism – 'fit' their lives and make it relevant to their circumstances and challenges. These narrative texts of achievement are shared among parents of children with autism as a collective experience, engendering a sense of community, belonging and hope. Such uses of these narrative texts by parents illustrates, in a novel way, the Russian philosopher of language Mikhail Bakhtin's notion that 'the life of the text ... always develops at the boundary between two consciousnesses, two subjects' (Bakhtin 1986: 106). Parents, as the audience of these texts, become their co-authors, interpreting and re-crafting these narratives of achievement as relevant to their children's and families' lives.

To consider these processes, I draw upon a data corpus collected for an ethnographic study conducted by an interdisciplinary team of researchers and clinicians at the University of Southern California.<sup>1</sup> The study examines African

American children's pathways to ASD diagnoses, interventions and services, and their parents' experiences and interactions with practitioners across multiple healthcare and educational systems. The study involves extensive clinical, home and community observations and video- and audio-recording of clinical encounters, ethnographic interviews with family members and practitioners, and narrative-based family group meetings. Twenty-three families living in Los Angeles, including twenty-two mothers and fourteen fathers and stepfathers, took part in the study. These participants represented a wide range of educational and income levels. The children's cohort consisted of twenty-two boys and three girls aged four to nine. In addition, medical practitioners and other professionals who served the children – paediatricians, neurologists, occupational therapists, physical therapists, speech therapists, nurses, teachers and service coordinators – also participated in the study.

Following Lawlor (2004), the chapter draws upon narrative, interpretive, phenomenological approaches to understand children's and families' experiences related to an autism diagnosis, and the implications of these experiences for children's achievement. The next section of the chapter addresses ways in which narrative genres construct certain subject positions for the children and their caregivers that can be transactionally pursued or resisted (Connolly 2000; McDermott 2006).

### **Autism and Achievement: The Narrative Genres**

From a constructionist perspective, 'achievement' is a kind of narrative, one that provides an interpretive framework for categorising certain kinds of people who carry out certain kind of actions (D'Andrade 1992). Narratives of 'achievement' can be described, following Yanow (1999: 31), as "an ensemble of texts" that display and enact cultural meanings and that the anthropologist seeks to read over the shoulders ... of those engaged in them'. An analysis of narrative genres illuminates the relation between narrative text and social action, or, as Hanks (1987: 670) writes, between 'the linguistic form of such texts and the broader social and cultural world in which they are produced'. The relation of the 'thematic, stylistic and compositional elements' of a text and the 'historically specific conventions and ideals according to which authors compose discourse and audiences receive it', makes visible the 'orienting frameworks, interpretive procedures, and sets of expectations' occasioned by these discourse genres (Hanks 1987: 670; see also Ochs and Capps 2001).

In the contemporary United States, children's 'achievement' has come to be associated with a certain kind of activity called 'learning'. The narratives of 'achievement' are constitutive of institutional constraints that organise learning, and even of institutions themselves. Arguing for a situated understanding of this process – that is, for a 'theory of situated genius' – Ray McDermott offers a powerful critique of theories of learning, knowledge and accomplishment that put

learning and achievement in individual heads far from conditions of its use. This way, individuals and groups can be celebrated for learning more than enough, degraded for not learning enough, and, the key to the system, destroyed for learning too much ... A theory of situated genius ... demands that conditions of practice become the focus of any ascription of learning. (McDermott 2006: 299)

In McDermott's view, it follows that procedures for ascribing genius should be problematised, as the ascription can do 'more harm than good' (ibid.: 299).

Some adults diagnosed with ASD later in life may agree. Consider the recollections of Tim Page, a Pulitzer Prize-winning classical music critic and a university professor diagnosed with Asperger's syndrome in late adulthood, about his childhood experience with the ascription of 'genius':

From early childhood, my memory was so acute and my wit so bleak that I was described a genius – by my parents, by my neighbors, and even, on occasion, by the same teachers who handed me failing marks. I wrapped myself in this mantle, of course, as a poetic justification for behavior that might otherwise have been judged unhinged, and I did my best to believe in it. But the explanation made no sense. A genius at *what?* Were other 'geniuses' so oblivious that they needed mnemonic devices to tell right from left, and idly wet their pants into adolescence? What accounted for my rages and frustrations, for the imperious contempt I showed to people who were in a position to do me harm? (Page 2009: 3)

Page's unique account is a peering back through memory, with the hindsight of post-diagnosis and the self-understanding and self-forgiveness that it brought, to the childhood and youth fraught with, as he writes, 'an excruciating awareness of my own strangeness', and a relentless pursuit of 'something around which to construct a life' (ibid.: 4, 6). Besides the challenges of self- and other-understanding that have become a familiar theme in personal accounts of the high-functioning autism experience, and the story of achievement 'perhaps not *despite* Asperger's but *because* of it' (as the anonymous writer of the text on the cover of Page's book put it), the other important part of Page's narrative of achievement is his family. His 'patrician mother' saved everything that originated from her son's penmanship beginning from the time he held a crayon in his hand, creating an archive that became the material for his book. She took the twelve-year-old Page to the original New York Metropolitan Opera House to hear *Madama Butterfly* before the building was demolished, an event that Page remembers as a transformative experience of his childhood. This trip, and his mother's keen attentiveness to Page's infatuation with classical music, made it possible for him to 'visit the place where so much musical history had been made' (ibid.: 44), and to recognise what that musical history meant for him. Page remembers his father being similarly involved. He served as a patient and understanding scribe who typed the 'doom-laden narratives' Page wrote as a child, as well as Page's advocate and defender who protested his school suspension in a four-thousand-word letter to the school principal. The prodigious classical music record collection the family had at home became

Page's personal, passionately experienced, life-world, something around which he did 'construct a life'.

Kamran Nazeer, a policy advisor to the British government who was diagnosed with autism as a child, also reflects on the ascription of 'genius' in his memoir *Send in the Idiots: Stories from the Other Side of Autism*, providing a counter-argument to Asperger's ([1944] 1991: 56) observation that 'the autistic individual needs to create everything out of his own thought and experience':

Sometimes our use of the term 'genius' implies that we believe that there is a group of people with some fantastic natural capability to produce thoughts and objects out of thin air ... Genius has to work hard too. Our conception of the privileges of genius is a false one ... The term 'genius' may be one element of our broader view in which progress relies on the series of daring leaps made by great individual minds. However, this view neglects to consider how it is that great individual minds come to the point at which they can make a leap, and the extent to which other people and institutions are involved in that. (Nazeer 2006: 83–84)

Such writings of adults with ASD have altered the landscape of possibilities for children diagnosed with this condition and their families. Perhaps to a lesser degree, these writings have also altered the language of science used to describe ASD. Far from taxonomies of deficits or deficit-related savant abilities, these first-person accounts described a way of being, a world as perceived and experienced, the people and other important actors – some animate, some not – with whom the world was shared, and the opportunities for action that engagement with these existential companions offered. Most importantly, these narratives plotted 'stories to be in' (Mattingly 1998), pathways to achievement that, at least in imagination, others with ASD and their families could travel as well.

These narrative accounts also set precedents for autism and achievement co-existing, contradictorily and often unfathomably, in the lives of real people. Achievement may have uniquely personal, multifaceted and yet ordinary meanings for these authors with ASD, from marriage and parenthood to education and professional success (e.g., Prince-Hughes 2004, 2005; Prince 2010; Perner 2012). This is an important development because until recently autism and achievement have been a relatively rare and unlikely pairing in the social science and education research. Examining autism and achievement together may have appeared questionable: autism is a life-long pervasive developmental disorder that is highly heterogeneous, which makes developmental trajectories difficult to predict (e.g., Lord and Spence 2006). Nevertheless, autism often presents a barrier to the achievement of adult autonomy, let alone to the achievement of financial independence through participation in a market-based economy.<sup>2</sup> With the exception of hypothetical, after-the-fact diagnoses of famous, usually deceased, scientists, musicians and others (Fitzgerald 2004; James 2005), and the assignment of autistic cognitive profiles to the 'extreme male brain' (Baron-Cohen 2003, 2004) or other cognitive differences (Happé and Frith 2009; Happé and Vital 2009), autism and achievement are usually not

discussed as relevant to each other. Public figures who have an autism diagnosis are often portrayed ambivalently in the media, as anomalies whose achievement exists in spite of, but possibly also because of, autism.

Such ambivalence has not always been the case. In his original article 'Autistic Psychopathy in Childhood', Hans Asperger, who first described what is now called 'Asperger's disorder' (APA 2000), writes:

To our own amazement, we have seen that autistic individuals, as long as they are intellectually intact, can almost always achieve professional success, usually in highly specialized academic professions, often in very high positions, with a preference for abstract content ... The superficially surprising fact that such difficult and abnormal children can achieve a tolerable, or even excellent, degree of social integration can be explained if one considers it a little further. A good professional attitude involves single-mindedness as well as the decision to give up a large number of other interests ... With collected energy and obvious confidence, and yes, with a blinkered attitude towards life's rich rewards, they go their own way, the way to which their talents have directed them from childhood. Thus, the truth of the old adage is proved again: good and bad in every character are just two sides of the same coin. It is simply not possible to separate them, to opt for the positive and get rid of the negative. (Asperger [1944] 1991: 89)

This hopeful view has since been considered more as an oddity – there is an opinion that Asperger himself was 'on the spectrum' – than as a call to action. Notably, some individuals, such as artists Jessica Park and Stephen Wiltshire, who would not have been considered 'high-functioning' or 'intellectually intact' by Asperger, have nevertheless achieved a high level of professional success. Missing in Asperger's account is what Kamran Nazeer emphasises in the above quote: the transactional nature of achievement and the role of other people and institutions in autistic individuals' professional success. This is conveyed by Clara Claiborne Park who writes about her daughter Jessica in an interview-format chapter co-authored by them both and titled 'Living with Autism: A Collaboration', "It is something more than a joke when I say that Jessie is the lowest-functioning high-functioning person with autism I have ever seen" (Park and Park 2006: 83).

### **Temple Grandin's Story: A Meta-Narrative of Autism and Achievement**

Temple Grandin's story is a particularly important narrative of becoming because it has turned into a meta-narrative of autism and achievement. After Grandin was already a well-known animal science researcher in the U.S., a public speaker and an author of several books, some of which were national bestsellers, her life story was recently made into an HBO film (Jackson 2010). The film, with much publicity, received seventeen Emmy awards, and many families of children with autism saw both the film and the Emmy award

ceremony where Grandin's life was celebrated. Grandin's mother, Eustacia Cutler, was in the audience. During the ceremony, the film's executive producer, Emily Gerson Saines, whose son has autism, held high one of the Emmys and said, 'Temple Grandin, you are our hero, and Eustacia Cutler [Grandin gave Saines a long embrace] – and Eustacia Cutler, you are our inspiration.' Grandin then pointed to her mother in the audience, and demanded that she stand up. Cutler, author of the memoir *A Thorn in My Pocket* (2004), which documented Grandin's childhood, did just that. This was an emotional, and very public, moment: Cutler's role in her daughter's achievement was publicly recognised at a televised event viewed by millions. It was perhaps even more significant that Grandin herself initiated her mother's public recognition. This scene brought tears to the eyes of many people in the audience, as well as those watching it on their television screens, and was especially memorable for parents of children with autism.

Behind this moment was a life story that could have gone very differently. Temple Grandin was diagnosed with autism during the time when the psychogenic theory of this disorder was widely accepted; and her mother, like most mothers during that time, was blamed for her autism. A noteworthy detail of Grandin's narrative of becoming is that her parents were advised by the diagnosing physician to place Temple in a 'foster home', a euphemism for an institution. Grandin's mother firmly resisted this advice (Cutler 2004) and Grandin herself reflects on this choice: 'I owe my success to my mother, who defied the professionals who told her that I belonged in a school for the retarded' (Grandin 2005: 1276). This narrowly escaped possibility is very much on Grandin's mind when she writes:

Many people ask me: 'What was the big breakthrough that enabled you to lead a successful life?' There was no such single breakthrough. My development was a gradual evolution that had many small but important steps. If I had fallen off any of these steps, I would have ended up in a school for the retarded or at a job that would have been below my abilities. (ibid.: 1276)

Grandin's life story, perhaps because of its traumatic beginnings and consequent success, and its wide coverage in the media, presents a powerful cultural resource of hope for families of children with ASD. Consider this excerpt from an interview with Stephanie whose eight-year-old daughter Tina was diagnosed with ASD.<sup>3</sup> Stephanie, Tina and several members of their extended family participated in the 'Autism in Urban Context' project. In this interview, Stephanie describes ways in which the film *Temple Grandin* had changed how she thought about Tina's abilities and interests, and how she organised Tina's everyday activities.

STEPHANIE: I've been trying to work things out a little bit more, um, to find out what she likes. And last week, I want to say two weeks ago, there was a movie, um, I don't know if you've seen it, uh – *Temple Grandin*?

INTERVIEWER: Oh yeah. I've seen it.

STEPHANIE: I saw that movie. And, um, I wanted to watch it because, um, a friend of mine was saying that there was this movie on TV that you have to see. It's about an autistic girl – she grows up, she does so and so and such and such and I saw it and I been trying to tell people about the movie as it relates to real life, you know ... But it – it kind of gives you hope that – it's a movie, still. So you can tell that it's a movie. But, it kind of gives you the hope that something can really happen, and with little kids like this you see the foreshadowing, and Tina, that if Tina had these skills that she could, like, cultivate and, and when she becomes a certain age if she sticks to it and her mind is going to go towards being productive and that, then, you never know what she could do with that talent, and that was the reason why I wanted to watch the movie.

Stephanie describes a sense of collectivity and belonging that this movie created. She explains how she learned about it from a friend who insisted that she had to see it; she also describes what she has done with this experience: she has been telling other people about it. She struggles with her experience of having hope engendered by something that 'is a movie, still', that 'you can tell it's a movie'. Nevertheless, the movie affords a narrative foreshadowing of a desired future (Bernstein 1994; Morson 1994): that if Tina 'cultivates' her skills and 'sticks to it', then 'you never know what she could do with that talent'.

STEPHANIE: Plus I really think it's what the child devotes themselves to. Whether it be art or music or agriculture, in Temple Grandin's case, whatever it is, I believe that, that's what kind of struck me to take this next two weeks as a project on myself to try to see what she's really interested, that way I'm able to, um, give her a focus. Because what hit me the – the most is that these kids need focus. They can really be productive members of society. Temple Grandin is now a doctor, you know what I mean? And she's teaching other people and whatever, and she's gotten her doctorate – from a person who didn't even learn to talk till they were four.

The story of Temple Grandin's life, with its difficult beginning and a long path to achievement – 'Temple Grandin is now a doctor ... she is teaching other people ... she's gotten her doctorate – from a person who didn't even learn to talk till they were four' – is perceived by Stephanie as an affordance that she can use to make a story she wants to be 'in' with her daughter. This story-making is carried out through practical engagement with Tina in activities that allow Stephanie to see what Tina is 'really interested in, that way I'm able to, um, give her a focus', because 'these kids need focus' to be 'productive members of society'.

STEPHANIE: That was the other scene that got to me there was the mother who was sitting on the steps, and she says well the doctor says, 'your child will probably never speak'. And – and Temple is like gazing at this like chandelier and – as her mom tries to teach her to talk, and her hair is like tousled and she's like about to cry and Temple is just staring off into space at the chandelier and she keeps turning her head back and trying to get her to talk but the child is absolutely just like, enthralled in this like structure over here because in her mind she's seeing the shape of the chandelier, she's probably thinking how many crystals does it have,



she's looking at the colour of the crystals, you never know, like they inte- – she intensely thinks about things, even Tina nowadays, when we were playing Wii last week, and I don't know if it's my turn, or her turn, she says to me, she says, 'Well, you could tell it's your turn because the background is white'. And which is something that, you know she didn't see the names, she didn't see the pictures. Her mind goes to different things that are way too detailed for us to pick up on some times. She's like – 'well the background is white. When it's white it's your turn, when it's blue it's my turn'.

As Stephanie recalls a scene from the movie, she engages in intersubjective imagining of her daughter's perceptual world, a world where Tina has an advantage over her mother because she can see 'different things that are way too detailed for us to pick up on sometimes.' Stephanie uses this understanding to newly interpret a specific recent event: Tina and Stephanie playing a video game on their Nintendo Wii.

STEPHANIE: You know, because I guess people don't see these kids for what they are. To me, if you can get past having all the fits, and you can get past to what, whatever it is that their emotional lack is, what their emotional lack is, the kids are genius [...] Tina has said so many things, she has done so many things, created so many things, that makes us think that she is just way advanced in certain things, and may- – she's not, um – I don't know – who she is yet? She's only eight. There's so many possibilities.

Stephanie laments that 'these kids are not seen for what they are,' with all their potentialities and unique challenges ('if you can get past all the fits and whatever it is their emotional lack is'). Implicit in this lament is the realisation that more should be done for them to develop their talents because 'these kids are genius.' Like any genius, as McDermott argues, Tina's is situated in an environment created at home by her mother and other family members, and at school by her teachers and other professionals, that not only enhances certain kinds of learning but also allows her to grow into a certain kind of person, one who has already achieved 'many things' and one that has many possibilities in the future. Stephanie also voices the ontological uncertainty, open-endedness and promise of Tina's life story: 'I don't know – who she is yet? She is only eight. There's so many possibilities.'

At a practical level, Stephanie uses Temple Grandin's story as a guide and an existential roadmap to choose and orchestrate activities for her eight-year-old daughter. Echoing Asperger's observations quoted above, Stephanie reflects on ways in which the film affected her understanding of her daughter and her daughter's autism. She describes how she deliberately structures Tina's everyday activities to support a certain kind of development. Temple Grandin's story of achievement, both in spite of autism and because of autism, affords a narrative landscape against which Stephanie and Tina can improvise their own life stories and their own narratives of becoming.

Such narrative processes, however, are often complicated by portrayals of autism and achievement characterised by ambivalence and contradictions. The narrative genres of ‘achievement because of autism’ and ‘achievement in spite of autism’ are not easily reconcilable, perhaps because they each could successfully generate a narrative of achievement but do not easily fit together in one narrative plot. An example of such ambivalence can be seen in an article posted on the U.S. TV station MSNBC’s website – titled ‘Can Animals You Eat Be Treated Humanely?’ – where Temple Grandin’s career in animal science is discussed:

An Associate Professor of Animal Science at Colorado State University, Grandin can take more credit than almost anyone for trying to make modern slaughterhouses efficient and humane. Once considered curious, if eccentric, her audits and remodeling of processing plants have set new standards in the meat industry, which has come to embrace her message: Give the animals you eat a decent life and a humane death. ‘They just walk up there in a quiet line, and they walk up the conveyor and they’re shot, and it’s over before they know what’s happened’, she says. ‘It’s almost hard for me to believe it works’.

She says this while cutting into a thick steak following an afternoon spent among cows. For Grandin, eating meat requires accepting where it comes from and what’s needed to put burger to bun. (MSNBC 2004)

The argument is often made that, because of her autism, Grandin has a unique ability to see the world from a cow’s point of view (e.g., Dolgert 2009: 235).<sup>4</sup> This understanding enables Grandin to design slaughterhouses in a way that takes this view into account, a practical and unsentimental expression of empathy directed towards reducing animal suffering. Yet there is considerable ambivalence about this kind of empathy as reflected in the MSNBC journalist’s musing that Grandin describes slaughterhouse operation while ‘cutting into a thick steak following an afternoon spent among cows’, or Dolgert’s assessment that: ‘Grandin designs humane slaughterhouses using, among other things, her insights into animal cognition based in her experiences as an autistic human. This is objectionable not only because of the insipid definition of humane which she operates, but also because of the implicit hierarchical way of viewing animals as cognitively-deficient humans’ (ibid.: 235).

In the face of such ambivalence, the analytic vocabulary to describe the relationship between autism and achievement, its subjunctive, socially co-constructed nature, and the socio-cultural practices and processes that afford it, has not been well developed. Beyond the cognitive psychological accounts of savant abilities that are assumed to result in extraordinary, super-human skills (see Mottron and Burack 2001; Mottron et al. 2006, 2009; cf. Treffert 1989), such notions as ‘motivation’, ‘desire’, ‘activity’, ‘practice’, ‘mastery’, ‘expertise’ and ‘imagination’ are not often applied to understanding the achievement of individuals diagnosed with autism.<sup>5</sup> It does not mean, however, that because such a vocabulary does not exist to describe it, children, youths and adults with autism do not pursue or experience achievement, or that they are not members of communities of practice where what is called ‘achievement’ takes place. They

do, often to the researchers' surprise, and in spite of numerous challenges imposed on them by ASD, as well as the prevailing assumptions about the degree and scope of their limitations.

### **Narratives of Autism and Achievement that Leads to Trouble**

Sometimes the success of individuals with ASD comes in unexpected forms and goes against the norms of socio-culturally sanctioned, and even legal, conduct. A third narrative genre that captures such successes by linking autism and achievement is 'achievement that leads to trouble'. This narrative genre makes it possible to tell stories about a type of activity such as computer hacking, especially when national security-sensitive data are involved.

Three autistic hackers – Gary McKinnon, Viacheslav Berkovich and Adrian Lamo – have particularly attracted the attention of the media. Their stories are all of the genre 'narrative of achievement that leads to trouble', demonstrating the development of high-level expertise while simultaneously showing significant disregard of and resistance to structures of power. Unlike 'neurotypical' hackers who often pursue financial gains accessing credit-card data bases, autistic hackers so far have been unmotivated by the possibility of accessing information for these reasons. Their heightened proclivities in pattern recognition and hyper-focused attention to details have turned into idiosyncratic, determined pursuits of information. For example, between 2001 and 2002, Gary McKinnon, a 35-year-old man born in Glasgow and diagnosed with Asperger's syndrome, broke into the NASA and U.S. Department of Defense computer systems and tried to download a photograph of what he thought was a UFO. When the U.S. government demanded his extradition to the United States so that he could stand trial, the National Autism Society in the United Kingdom intervened on McKinnon's behalf, arguing that, because of his ASD diagnosis, he would psychologically deteriorate if he was moved away from home and jailed in a high-security prison. Although the extradition order was passed, it was eventually blocked in 2012 by Britain's Office of Home Affairs. This unprecedented move, which took place in spite of the U.S.-British extradition treaty, was based on McKinnon's mental health problems and his ASD diagnosis. British prosecutors, however, may still consider the possibility of trying McKinnon in Britain. The fact that McKinnon's achievement of high-level computer skills and his interest in UFOs led to 'trouble' is at once tragic for him and his family, and revelatory of how ideologically structured notions of 'legitimate achievement' are, even for those diagnosed with developmental disabilities.

Ideologies of autism and achievement come into focus even more vividly when narratives of 'achievement that leads to trouble' are contrasted with narratives of achievement of creative artists on the autism spectrum. A case in point is Clara Claiborne Park's memoir *The Siege* (1967), about raising her

daughter, Jessica Park, now an artist with a gallery in New York. Jessica's life story can be characterised as achievement both in spite of autism and because of autism, but perhaps even more importantly – as the feminist scholar Jane Taylor McDonnell (1991) has highlighted – as the consequence of a distinctive form of mothering that Park's memoir not only describes but serves to promote amongst its readership. Like Nora in Ibsen's *A Doll's House*, mothers have to seize their own interpretations of their children, their potentialities and the horizons of their relationships, and 'record reality which perhaps has never been recorded before' (ibid.: 60).

The 'siege' that Park mounts takes the form of minute, momentary approaches that end up constituting interventions directed at such seemingly mundane activities as turning on a water tap, using a cup or turning on a light. The recording of these mothering practices in exhaustive detail is accompanied by Park's description of her own mental processes. McDonnell observes that Park is able to tolerate a high level of 'ontological insecurity': she does not know her daughter, is wise enough not to understand her, does not engage in the 'terrible arrogance' of forcing her daughter into the human social world, which allows Park to avoid inflicting the kind of violence of interpretation and intervention that the forcibly separated twins John and Michael, the numerical savants described by Oliver Sacks (1970), were obliged to endure (see Solomon 2010).

There is, however, a recognition that each of Jessica's 'special interests', an existential aspect of autism that is considered a 'symptom' and not a positive attribute of a person – numbers, radio dials, record players, railway crossings, electric blanket controls, quartz heaters – were intensely meaningful, compelling and a major organising principle of Jessica's reality, 'something around which to construct a life', as Page writes (2009: 6). Interestingly, Stephen Wiltshire, an artist with autism living in the U.K. known for his project *Floating Cities* (Wiltshire 1991), also had a progression of specific kinds of objects he liked to draw, moving from animals to London buses and finally to architectural landscapes.

These autistic artists' life stories combine both experiences of challenges and limitations, and of remarkable success and achievement, both because of and in spite of autism. Their distinct experience of the world as an aesthetic endeavour, and the works of art they created, highlight another important aspect of achievement in autism – that is, a lack of concern for ratified and familiar ways of engaging in the practice of art, exactly the same impulse that underpins the claim that autism leads to trouble. Stephen Wiltshire, for example, takes helicopter rides over cities he plans to draw so as to visually access his material in minute detail. Both Jessica Park and Stephen Wiltshire possess a highly focused and disciplined attention to detail and paint almost photographic images from memory. Their process of creation appears to be almost effortless and full of aesthetic pleasure derived from portraying quintessential qualities of buildings and other material objects (see Figure 6.1).

It seems fortunate that Jessica Park and Stephen Wiltshire escaped the fate of John and Michael, the twins described by Sacks (1970) who were evicted from



**Figure 6.1** Jessica Park, *St. Paul's and St. Andrew's Methodist Church #2, with Migraine Lightning and the Elves* (1997). Acrylic on paper. Courtesy of Pure Vision Arts.

their numeral universe by well-meaning professionals: no one has told these artists that their way of practicing art was somehow deficient and unhealthy, and therefore should be abandoned. Thus they each developed successful, albeit unorthodox, careers as creative artists based upon what was a disability but also an asset. About the special interests of those with autism, McDonnell notes: 'none of us has ever seen before such narrowness of focus, such total concentration and dedication to task – or such oddity of interest in a child' (McDonnell 1991: 65). McDonnell quotes Ruddick (1980) in arguing that mothering is a very normative activity, the central challenge of which is raising the child to become an acceptable adult through shaping his or her interests into a culturally normative form. This is reminiscent of what Lareau (2003) calls 'concerted cultivation' with one important difference – 'concerted cultivation' is a familiar practice of 'intensive' parenting (Hayes 1996; Wall 2010); in parenting a child with autism, parents often have to engage in what Daniel (1998) has termed 'fugitive practices', improvised parenting practices in the face of crisis.

This is a success story, McDonnell writes, in many ways: Jessica Park now has a successful artistic career, a remarkable gift that her mother helped her develop. Her mother re-invented motherhood as a ‘social activist position, turning her personal pain into the wisdom and courage to help others’ (McDonnell 1991: 73). But Clara Claiborne Park may have given her daughter another gift: by writing two books about Jessica’s childhood – *The Siege* (1967) and *Exiting Nirvana* (2001) – Park has attracted attention to Jessica’s art, which may have contributed to her achievement as an artist. In this sense, Jessica has experienced multiple affordances of achievement, including the appreciative public attention possibly generated by her mother’s memoirs.

Diane Savage’s (2003) story about her son Matthew Savage, an accomplished young jazz musician and a founder of the Matt Savage Trio, is a more recent narrative of becoming, and illustrates how the narrative genres of achievement because of autism and achievement in spite of autism may collide in one story. Matthew was diagnosed with a Pervasive Developmental Disorder Not-Otherwise Specified (PDD-NOS) at age three and has been called a ‘musical savant’ by specialists who, as the term suggests, attributed his musical talent to savant skills. A young person with a similar extraordinary musical talent but without a clinical diagnosis would have been called a ‘musical prodigy’. A leader of a jazz trio, an accomplished jazz pianist and a prolific composer with many music CDs to his credit, Matt Savage has performed with Dave Brubeck, Wynton Marsalis and other world-famous jazz musicians in well-known locations including the Lincoln Center in New York (Solomon 2009).

Diane’s experience of Matthew’s infancy and childhood is reminiscent of other parental stories of autism: a colicky, inconsolable baby, a sensory defensive child unable to ride in a car seat, to be near a vacuum cleaner or a popcorn maker. Highly perseverative and hyperlexic,<sup>6</sup> Matthew was also highly intelligent. He started playing a toy piano at age six and soon was taking classical piano lessons, improvising and playing music when the music sheet was turned upside down. His main challenge in music is ‘making mistakes’: he is terrified of not being able to play a piece perfectly. Diane Savage writes about Matthew’s challenges and his achievement in spite of autism:

Don’t misunderstand me. There are many, many difficulties with which Matthew copes everyday. He still shows signs of his autism. People immediately notice him in a group! He still has inappropriate behaviors and regresses in new situations. But he is making progress. We focus on how many things he has been able to accomplish, not on the things with which he will always struggle. (Savage 2003: 290)

As with Jessica Park’s and Stephen Wiltshire’s stories, Matt Savage’s narrative of achievement could be seen as portraying his success as both because of autism and in spite of autism. The ontological uncertainty of his musical talent is best left alone: it would be difficult, and perhaps unnecessary, to determine whether he is a talented jazz musician who happens to be autistic, or if there is something about his music, or the way that he engages in his creative process,

that reflects his autism. As Asperger ([1944] 1991: 89) wrote, 'It is simply not possible to separate them, to opt for the positive and get rid of the negative.'

## Conclusion

The three narrative genres – achievement because of autism, achievement in spite of autism, and achievement that leads to trouble – may occur simultaneously, occasionally producing contradictory accounts. These narrative genres may also guide parents in their work of structuring experiences and occupations for their children, thus creating opportunities for action and affordances of achievement. Such work of narrative imagination (Mattingly 2010) can be well understood from an occupational science perspective that places analytic focus on everyday activities, engagement and participation as related to human health and well-being.

Related to the discussion of autism and achievement, Christenson argues:

occupations are key not just to being a person, but to being a *particular* person, and thus creating and maintaining an identity. Occupations come together within the contexts of our relationships with others to provide us with a sense of purpose and structure over time in our day-to-day activities. When we build our identities through occupations, we provide ourselves with the contexts necessary for creating meaningful lives, and life meaning helps us to be well. (Christenson 1999: 547)

There is nothing inevitable about the ways in which autism and achievement manifest themselves in children's and families' lives. As I have shown, narrative genres create certain subject positions for children and their families as desirable and possible, and as potentially leading to achievement. Achievement is transactional and is afforded by the children's and their mothers' engagement with one another in seemingly mundane but significant activities in their life-worlds. It is in the context of this engagement that the children are afforded the freedom to develop their relationships with the world they inhabit and to be 'at home' in this world (Reilly 1962: 2). Finally, I would suggest that granting children with ASD the freedom to be in the world in a certain way rests upon an acceptance of an ontological uncertainty of those children's development and achievement, a difficult and precarious parenting task.

I would like to end this chapter by stressing the role of collective, relational, interactional and imaginary work in the achievement of people with ASD. I see the work of families as the organising force that creates environments in which children, youths and adults with ASD engage with 'something around which to construct a life' (Page 2009: 6). Returning to McDermott's theory of situated genius, the case of autism and achievement suggests that achievement is better conceptualised as an attribute of learning environments rather than of individual cognition: 'The locus is people organizing collective problems well defined enough for a solution to be advanced and noticed ... Genius in a situational

analysis is *ordinary* in the best sense of the term: people doing what has to be done with the materials at hand' (McDermott 2006: 294). For children with ASD and their families, 'the materials at hand' are stories about others who experienced autism before them: narratives of achievement with which they can craft their own stories of life with autism.

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## Notes

1. This study was entitled 'Autism in Urban Context: Linking Heterogeneity with Health and Service Disparities', and funded by the National Institute of Mental Health (R01 MH089474, 2009–2012) with myself as principal investigator.
2. The importance of being a 'productive' and market-value-producing member of society is not lost on McDermott who laments that, 'Genius ... became worth money, and conceptions of genius have delivered their object ... to be measured, quantified, bet on, and bought and sold as a unit of exchange and capital investment ... Its current packaging displays our own situation and illustrates the cultural demands we place on theories of intelligence, learning and achievement' (McDermott 2006: 287).
3. All names used are pseudonyms.
4. Grandin describes her experiences of understanding animals in Grandin and Johnson (2005, 2010).
5. But see Kasari et al. (1993).
6. Perseveration is engagement in repetitive behaviour: repeating others' utterances or stretches of talk from movies, or motor behaviour such as hand flapping. Hyperlexia is a spontaneous and precocious mastery of single-word reading emerging ahead of the development of comprehension.



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