



Part 2:
Expanding on understandings of autism

by Courtney Olinger



Courtney Olinger is a licensed marriage and family therapist in San Diego, California, who, along with many other passions, specialises in working with autistic individuals of all ages and abilities. Courtney completed a year-long intensive certificate in narrative therapy at Dulwich Centre in 2009 and a doctorate in psychology at Alliant International University in 2010, defending a participatory action research dissertation on autism. She has been honoured to support many children, adolescents, adults and families faced with challenges and concerns related to learning differences, school or work struggles, sensory processing differences, social or relational challenges and the process of developing an identity that one can be proud of. Courtney has worked alongside the autism and neurodevelopment community since 2000. She has worked in community mental health, public education settings and a neurology healthcare clinic in clinical, supervisory and administrative roles. Currently, Courtney maintains a private practice and consulting business and can be contacted at colingerpsyd@gmail.com courtneyolinger.com

Abstract

Autism, like many psychological diagnoses, has suffered some narrow interpretations and representations, particularly in the media. Modern definitions of autism are often heavily focused on impairment and deficit. This can significantly skew individuals' understanding of their own identities and how others come to understand the role of autism in their lives. This paper embarks on a deconstruction and expansion of understandings of autism, including voices of autistic individuals. This serves as an example of possible ways to thicken one's own identity when developing an understanding of autism. This is the second article in a three-part series exploring different concepts associated with working with autism. It builds on the focus on theory and engagement in Part 1.

Key words: *autism; Asperger's; neurodiversity; sensory processing; neurodevelopment; narrative practice*

What is autism?

I will start with what I believe is a very big question: *What is autism?* Historically and in the present, there are many different perspectives and understandings of autism. These can vary incredibly, depending on the profession or the position that the person takes when defining autism. Dr. Stephen Shore, an autism self-advocate and author, has a saying that has since been adopted by Autism Speaks: 'If you've met one individual with autism, you've met one individual with autism.' This accurately suggests that autism affects every individual differently, and that one cannot assume that any one presentation of autism will be shared by others affected by autism.

These definitions are social constructions; that is, they are agreed upon ideas in a given society or group of people. They have been developed to help better understand a phenomenon. These social constructions are also constructions of identity: they influence the identities of those living with or experiencing autism, most commonly through how others construct the identities of autistic individuals.¹ These constructions unfortunately do not represent autism in the greatest light. By understanding autism as a social construct, I do not mean to suggest that we dismiss the ideas that are out there. Rather, I suggest that we hold them lightly and consider the intentions behind them. I have met many narrative therapists over the years who have expressed scepticism about the diagnosis of autism. A prominent figure once said to me, 'oh, I hope you're working with real autism'. This statement baffled me. It was as if to suggest that a person's experience of autism may not be 'real' – a notion that to me seems dismissive. I have also met narrative therapists who have wanted to reject the diagnostic label – this is probably a more common stance. However, I would like to propose that, instead, we hold the multiplicity of ideas that are represented by different communities as means to understand different perspectives, and hold close to the understanding that different ideas are valid and valuable. In doing so, it is my hope that we can avoid representations of a person that fail to connect with what *they* connect with.

The disability rights movement, and more recently the neurodiversity movement, has adopted the motto 'nothing about us without us' (Charlton, 1998). In honour of this, I have constructed this paper around insights and quotes from people living with autism.

Autism diagnosis

It is my contention that knowing common characteristics and experiences of autism allows one to ask about these from a place of curiosity rather than a place of assumption. Research and, even more importantly, experience show that for many, there are certain characteristics present. However, we also know that these characteristics may present differently, may be experienced differently or may not be present at all. When we ask about these characteristics, we can learn more about the person's experience, becoming 'experience-near' (Mann, 2002) as a means to better support them.

The ideas that are accepted in a society have changed and will continue to change. Dominant ideas about autism have been developed over the years through research and attempts to categorise what has been observed in comparison to neurotypical development; that is, the way children who do not have autism typically develop. These categories have been collected and summarised in the *Diagnostic and Statistical Manual (DSM)*, in which the definition of autism has changed with each revision. The current version, DSM-5 (American Psychiatric Association, 2013), recognises autism as a neurodevelopmental disorder known as Autism Spectrum Disorder, encompassing two specific areas of challenge: social communication/interaction and behaviours. Behaviours are specifically described as restricted, repetitive, idiosyncratic or stereotypical movements rituals or routines. Within the DSM-5 description of autism, one can see some representations of common characteristics that are important to ask about and explore from a place of curiosity.

Common characteristics and experiences

Expanding on the DSM's definition, I have adopted the practice of asking about the common experiences of autism that autistic children, adolescents and adults have shared with me. These include experiences related to communication, socialisation, sensory-motor processing, learning and focus. Here are some of the ways that those living with autism describe these common experiences.

Communication

'My biggest frustration was not being able to communicate with others around me.' (Erik)

'I have everything I want to say in my head. I just can't get it out.' (David)

Socialisation

'Well, another thing that I've also had to learn is facial and body language. I have to be able to pick up on if they're starting to look bored. Then I've got to change the subject ... Sometimes I just get so far off on a tangent that sometimes I don't pick it up right away.' (Erik)

Sensory-motor processing

I have very sensitive senses ... My ear doctor says I can hear the grass grow. It could be soft or loud sounds that bother my ears so I might plug my ears with my fingers ... It doesn't necessarily mean they do not like you. It may be that certain sounds overwhelm them [like humming and whistling] ... I am hyper-visual. I see brighter and more intense colours than most of you. This is why it is hard for me to look into the eyes of other people ... If I am trying to pay attention to what they are saying, I need to look away so my brain can focus on their words so I will not be overwhelmed by their facial features or expressions. My skin is sensitive to touch. When someone touches my skin, it sometimes feels painful or prickly. It is hard to be in a crowd of people. I worry that someone will bump into me or touch me. When any of my senses are overwhelmed it is hard for me to concentrate and learn. That is why it is important for people to be patient with me. (Joel)

Learning and focus

'The good effects of autism are my memorisation skills that I use to recite comedy and make people laugh. I guess a negative would be I sometimes get so occupied with a task that it's hard to switch activities.' (Erik)

'I have different ways to learn things.' (Joel)

Common challenges and concerns

Along with these common characteristics and experiences, I ask about some of the common challenges and concerns that I have heard about over the years. One way that I have explored these common challenges and concerns is to review a list of different expressions of social communication and behavioural challenges that a group of parents helped me devise years ago. This list was created after a group of parents shared that one of the most overwhelming parts of receiving the diagnosis was that the ways the provider spoke of autism were very clinical and hard to understand. These parents felt strongly that it would have helped to have the challenges described in lay terms. Now, when I am working with a family, I will pull out this list and express that I understand that autism is very challenging to understand, and that even more confusing is that it shows up in many different forms, making it hard for families and individuals to understand what autism looks like for them. I explain that I have a list of common challenges and concerns that I hear about, some that might fit and others that will not. I ask if it would be helpful to go through the list and see what does or does not fit so we can have a better understanding of *that* individual's autism profile. I work diligently to allow my clients to affirm or reject any of the challenges named. When they do affirm any challenges or concerns, I then have an opportunity to ask more questions, to get closer to experience-near descriptions and to learn more about the ways autism shows up in their story.

ASD-related challenges and concerns

Typically, there are challenges associated with sensory processing, social understanding and abilities, communication (understanding and use), and behaviours (often characterised by repetitive behaviours, extreme behaviours or limited scope of interest).

Social challenges

- new or unknown people, places or activities
- group play and work
- team sports and teamwork
- personal space
- making new friends OR keeping friendships

- reading body language and nonverbal cues
- understanding another's perspectives, likes/dislikes, interests or emotions (limited interest)
- understanding non-literal language, idioms, jokes, sarcasm or inferences
- maintaining conversation, especially with same-aged peers
 - trouble with back and forth or leaving room for others to talk
 - limited topics of interest (few but often strong, focused interests)
 - frequently talking off topic, talking in tangents or frequent segues, or persisting about a few particular topics
 - limited referencing of others (with eyes or comments) to keep the conversation going or give an indication that they are still involved in (listening to) the conversation; may sometimes state that eye contact is uncomfortable, painful, hard or disrupts the ability to pay attention
 - giving a great deal of detail even if others don't seem interested or don't need the detail ('data dump')
- keeping hygiene (can be related to sensory challenges)
- speaking patterns— volume, affect, emotion or monotone speech patterns (little or odd fluctuation or intonation while speaking)
- socially awkward (uses strange words/phrases; very intellectually based language) or inappropriate (says what they think without considering niceties or based on misunderstanding a social rule)
- extremely sensitive to criticism, others laughing, losing or getting something 'wrong'.
- difficulty shifting from one activity to another, one place to another or starting with new/unknown situations or places
- is 'rule-bound' (may have difficulty with unspoken rules or taking a 'rule' too literally)
- finds facts and reasoning of most interest (while emotions, opinions and exceptions to the rule seem confusing)
- finds sports difficult or has poor coordination
- overly sensitive to light, sounds, textures, smells, tastes, touch, etc.
- May be exceptionally good at some tasks and exceptionally poor at others.

Difficulties with any of the above may result in explosive behaviours, extreme anger or shut down.

Understanding common characteristics does not constitute a comprehensive assessment, but rather provides me with a richer understanding of the experiences that the person I am working with has had that may be associated with autism. These characteristics and stories give a snapshot of experiences that may relate to autism if there is also a developmental history of common challenges and concerns; that is, a presence of a constellation of neurodivergence evident in early childhood, up to about age six.

Gathering a variety of understandings

Throughout my career, I have gathered parents' and individuals' experiences, knowledges and understandings to become better prepared to support the people who I work with. One really valuable piece of work started with a project (Olinger, 2010a) in which I brought some parents together to explore their local knowledges. From this project, a collective document was developed. This document since has been used at the beginning of successive parent groups to share the knowledges of parents and express that we know how valuable parent knowledges are. At the end of each group, we invite parents to add to the document.

Behaviours

- has interests (activities, objects, topics) that are all consuming
- engages in routines, repetitive behaviours and/or rituals that don't necessarily serve a functional purpose
- repetitive behaviours may be seen in movements of body or with objects, such as rocking, pacing, spinning, pushing buttons over and over, lining objects up or saying the same words or phrases over and over

This was also the focus of my dissertation (Olinger, 2010b), in which I explored first-hand knowledges of family members of children with autism², including mothers, fathers, extended family members and an adult with autism. I have also had the fortune of working with parents in support group settings. Through my dissertation, I was fortunate to learn about some of the knowledges that parents and family members hold. This work paved the way for all that I have done since. The parent knowledges that I have held close include judgement as a common theme, different understandings of autism and different experiences.

Judgement as a common theme

Throughout the years, I have heard countless stories of autistic individuals and their parents and family members facing judgement. Because of this, I make it a point to ask about judgement early on in my work with parents. Often parents respond with a sense of relief. A young man with autism, Erik, shared a story of judgement: 'My mom has stories about when we were in the grocery store and persons gave us weird looks whenever I would have a tantrum, like, "oh, she must not be parenting right", or it's a kid acting up but that really wasn't it at all.'

Understandings of autism

In my work, I am curious about how each person in the family understands autism and in what ways they would like to develop their understandings. In my first session, I ask the client if they know the term 'diagnosis' and whether or not they have heard anyone use any words or phrases to describe any of their challenges, concerns, difficulties or problems. I do this, not to share what I think their diagnosis is or what I have heard it is, but rather to find out what ideas these individuals already have regarding diagnosis. More often than not, even if the person does not know the term diagnosis, they have heard some sort of diagnostic or psychological term and, more often than not, they have made up some ideas about their difficulties or what others think about their difficulties, often in ways that are not very helpful. Children are not the only ones who are influenced by unhelpful ideas about their challenges or what they say about them. Parents are also often under the influence of social ideas that are quite problematic. It becomes important to find ways to separate the person from the problem. One mother of a child with autism expressed this: 'there's an understanding of autism and then there's an understanding of [my child], and it's a huge difference, right?'

Parent experiences

Parent experiences vary based on a wide range of factors. There are many points throughout a parent's experience where their story can change or where problems can take over the story. It has been helpful to recognise that parent experiences do not have to be overrun by what narrative therapy refers to as 'problem-saturated' stories. When working with parents, we need to be on the lookout for the ways in which their story shifts when not overrun by the problem. Two parents shared experiences that speak to more than just problems:

Autism to me is like walking on a long path by yourself. No other autistic kid is like yours, but there are people who are on that same path with you. They don't know exactly how you feel, but they kind of understand. So as I walk on that journey, if I look to the sides, I'll see people there who are just an arm's reach away. (Father of a child with autism)

I feel like autism has let me know what a strong person I can be. I have learnt about life and love because of [my son] and his special view. (Mother of a child with autism)

Local knowledges of those living with autism

Some of the most valuable learnings I have gathered over time have come from the work I have done with autistic adults, both individually and through groups, and even more so in the work I have been privileged to do working alongside autistic children in all kinds of settings. The children, adolescents and adults have taught me more than I could have ever imagined, and I continue to learn every day.

When working with families of individuals living with or experiencing autism, I have found it helpful to situate the diagnosis as a social construct. I work with families and the individual to better understand and articulate their experience-near descriptions and re-discover the knowledges they hold. Along the way, I find it useful to share others' understandings as a way to locate autism as an ever-evolving construct. Below are some of the experience-near descriptions of autism that I share.

My brain just works differently. (David)

Although it can be a problem, I wouldn't swap my autism for anything. It makes me who I am. I just wouldn't be the same without it. For instance, I think it gives me my imagination. It also gives me my incredible skill at remembering hundreds of impressive facts. Some people might call my obsession with facts a bit boring. I call it focus. (Rosie King in CBBC Newsround, 2011)

I have Asperger's and that means I'm sometimes a bit different from the norm. And – given the right circumstances – being different is a superpower. #aspiepower. (Greta Thunberg, 2019)

Many of the quotes I have included in this article are quotes I share with others as we explore autism. Because social constructs concerning autism are largely focused on deficit, impairment or dysfunction, it is uncommon for a person to learn about autism and immediately view it from a place of preference. I create space to expand on understandings of autism and present understandings that are not constructed as solely problematic or 'all bad'. I am also cautious in my offerings of other constructions as I have an understanding that these statements have been developed often after a great deal of support to identify preferences.

Another document that has been helpful in my practices is 'The discovery of "Aspie" criteria' by Tony Attwood and Carol Gray (1999), two prominent figures in the autism field who were dismayed by hearing autism portrayed as only consisting of deficits and dysfunction. In this document, Attwood and Gray respond to the DSM-IV (American Psychiatric Association, 1994) diagnostic criteria for Asperger's Syndrome by highlighting the many positive qualities that can be associated with those living with Asperger's (which was subsumed under Autism Spectrum Disorder in DSM-5). I often share this document with parents, family members and/or the autistic individual as a way to start to shift perspectives away from deficit, impairment and dysfunction and allow for other possibilities and perspectives.

What if the 'problem' isn't even a problem?

In the narrative therapy world, we are all familiar with the saying, 'The problem is the problem; the person is

not the problem' (White & Epston, 1990). This is a beautiful and simple saying that encourages us to view people as separate from the problems they experience. In this way, we can avoid constructing a person's identity as the problems they live with because we know that people are much more than the problems they face. However, when it comes to autism (and many medical concerns), this has often been applied in ways that situate autism as the problem. If we view autism as solely problematic, we may miss the ways autism can be supportive or protective of one's experience.

I once heard the mother of a 19-year-old man with autism speak at a conference. She spoke of how her son had been blissfully naïve prior to the interventions he had received, and how as he went through his interventions and gained a greater awareness of the world around him and the world's expectations of him, he lost this naivety and developed more anxieties.

If we view autism through a lens of deficit, dysfunction and impairment, we run the risk of being dismissive of parts of autism that the person appreciates or values. I was very honoured to meet Valerie Paradiz, a woman with autism who is an author and has developed a self-advocacy curriculum (Paradiz, 2009). She introduced me to the term 'focused interest', which I have since adopted. When I was working in the behavioural world, repetitive behaviours and all-consuming interests in subjects, movements or objects were referred to as 'perseverations'. This carried a negative connotation and implied that these behaviours needed to be stopped. I never felt quite right about this idea and the way we languaged this phenomenon. It seemed to me that there was a reason why these behaviours were happening and that they served a purpose in that person's life, often one that seemed regulating and calming. When I met Valerie, she referred to these same behaviours as 'focused interests', ones that were to be honoured, nurtured and cultivated. She believed that when we could do so, the person might very well thrive. I have since met several individuals with autism who have done just this. I knew a young man whose focused interest was Audi cars. After years of going by the Audi dealership, he was hired. Another young man I know, whose focused interests were in aerospace and politics, was the youngest docent ever at a local aerospace museum, and now lives in our nation's capital making the most of his interests and knowledge about politics and history. A view of autism as solely problematic may have limited these young men's lives and opportunities.

Social constructionist and poststructuralist ideas position the ways that others construct these individuals' identities and problems as what is actually problematic. If my view is that autism is a devastation or all bad, I am more likely to create experiences, environments and 'interventions' that lead to an experience for that person that is riddled with discomfort and confusion. I also risk missing what skills, knowledges and abilities this person has that they or others associate with autism. If my view is that autism can be a part of an identity that one can be proud of, and that autistic people are capable of a great deal (that we might not yet know about), I can find all sorts of sparkling moments or moments of brilliance.

In order to see autism as more than just problems, we also need to view behaviours from a more expansive lens. When we understand that behaviours serve a purpose, we can resist viewing the person, or even their autism, as having behaviours that need to be mitigated. Instead, we can find ways to support the person to expand their skills and recognise many possibilities. Their view of the world may expand mine.

He teaches me all the time. He'll surprise me. When I think he's not going to enjoy something, but then I put him through it anyways, and, oh, he really loved it, I'll file that away and next time I have some preconceived notion about how he's going to react to a scenario – going somewhere or doing something, trying to get him to do the simplest thing, come walk outside, or let's get in the car or whatever – you've got to keep trying, because what else are you going to do? (Father of a child with autism)

I think I kind of treated him that way at the beginning – talked to him very simple and I used to talk to him and not realise that he was even understanding what I said. And now, I'm like he understands everything. (Grandparent of a child with autism)

Engaging thicker understandings

One of the ways I work diligently to avoid viewing autism as all problematic is to ask effects questions. These questions get at that which may be problematic and also the ways that autism may affect the person or others apart from problems. In doing so, I am engaging my clients in exploring understandings that are more expansive than what might be offered in the DSM.

These questions seek to thicken understandings; that is, to further develop parts of the autism story or the experience of autism that might otherwise be overlooked. These questions might include:

- Can you describe how autism is part of your life (or family)? What would you want me to understand about your experience of autism?
- Are there any effects or influences of autism that you like or find interesting?
- What kind of influence does autism have on [client, family, relationships, communication]? Are there any that have supported relationships or growth?
- Have there been influences or experiences of judgement directed at [you, your child, your parenting]? In what ways would you rather be judged?

These questions are often new and even sometimes difficult, but tend to be empowering. These questions are designed to help clients consider that there is more to the story than that of deficit, dysfunction or impairment.

Summary

My work has been most significantly informed by what I have learnt from autistic individuals, and in this paper I have shared some of their voices as a way to expand on understandings of autism, which when only framed by diagnostic terminology can be limiting. When we focus on deficit and impairment, we risk contributing to constructions of an individual's identity in problematic ways. I have offered some possible ways to stay committed to engaging autistic clients in their own identity constructions: by asking about common characteristics and experiences (with communication, sensory-motor processing, learning and focus) and common challenges and concerns (with social communication and behaviours), while holding close to local knowledges and remaining critical of pathologising constructs.

In Part 1, I shared some possible strategies for making therapy more accessible to individuals who have different communication challenges. In Part 2, I laid some groundwork for considering autism in more expansive and experience-near ways. This sets the stage for Part 3 in which there is further exploration of identity work in practice.

Acknowledgments

Thank you to Erik Weber (contact: autism4dads@yahoo.com) and Joel Anderson (www.joelandersonartist.com) for sharing your experiences.

Notes

- ¹ There is some debate about the use of person-first language (individual with autism) versus identity-first language (autistic individual). Some autism self-advocates and those active in the neurodiversity movement advocate for identity-first language. I have chosen to mostly use identity-first language, except in cases in which a person had expressed a preference for person-first language (see Part 1).
- ² Person-first language was preferred by participants at the time the dissertation was written (2009–2010).

References

- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
- American Psychiatric Association. (2013). Neurodevelopmental disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). <https://doi.org/10.1176/appi.books.9780890425596.dsm05>
- Attwood, T., & Gray, C. (1999). *The discovery of "Aspie" criteria*. Retrieved from <http://www.tonyattwood.com.au/books-by-tony-m/archived-papers/79-the-discovery-of-aspie-criteria>
- CBBC Newsround. (2011, November 12). *My autism and me* [Video file]. Retrieved from <https://www.bbc.co.uk/newsround/15655232>
- Charlton, J. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley: University of California Press.
- Mann, S. (2002). Part I: Statement of position map. *International Journal of Narrative Therapy and Community Work*, (3), 5–6.
- Olinger, C. (2010a). Privileging insider-knowledges in the world of autism. *International Journal of Narrative Therapy and Community Work*, (2), 37–50.
- Olinger, C. (2010b). *Working toward agency among the autism community: A participatory action research study* (Doctoral dissertation). Available from ProQuest dissertations and Theses database (UMI No. 3451908).
- Paradiz, V. (2009). *The integrated self-advocacy ISA curriculum: A program for emerging self-advocates with Autism Spectrum and other conditions*. Shawnee Mission, KS: Autism Asperger.
- Thunberg, G. (2019, September 1). When haters go after your looks and differences, it means they have nowhere left to go [Tweet]. Retrieved from <https://twitter.com/gretathunberg/status/1167916177927991296?lang=en>
- White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. New York, NY: Norton.