

17 Autism During Adolescence: Rethinking the Development of Intersubjectivity

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Abstract. The goal of this chapter is to theoretically explore intersubjectivity when social development goes awry. More specifically, it will explore intersubjectivity and autism by combining work with infant intersubjectivity, anthropological dimensions of socialness, and sociocultural positions on mediated action and sense of self in order to conceptualize how social changes during adolescence might transfigure mutual engagement. A sociocultural framework that focuses on mediated action is outlined as one way that individual mental functioning and social phenomena come together. The idea that routines become cultural, symbolic tools and social others often function as animate tools that support late emerging intersubjectivity is developed within the paper. Case study material of one child with autism, as reported by the mother, is used to illustrate how intersubjectivity can be constructed by means of these tools after years of disruptive communication and social engagement.

Contents

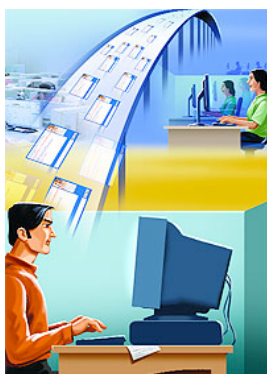
17.1	Introduction.....	251
17.2	Statement of the problem	252
17.3	Autism from the inside out	253
17.4	Intersubjectivity and autism	254
17.5	Socialness and mediated action.....	255
17.6	Cultural tools and the sense of self	257
17.7	Conclusions.....	259
17.8	References.....	260

17.1 Introduction

The importance of intersubjectivity for the development of communication has a long history in the social sciences. Those taking a developmental perspective often situate its beginnings in the biological substrates of humanness. For example, Bråten [1] used the notion of presentational immediacy to suggest that infants come prepared for mutual attunement, and Trevarthen [2] postulated that infants are equipped with primary intersubjectivity that allows them upon birth to enter into mutual engagement with social others. The goal of this chapter is to

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theoretically explore intersubjectivity when social development has gone awry by rethinking the manifestations of this during adolescence. Focusing on autism as a challenge for the development of intersubjectivity, case study material will be used in conjunction with theoretical contributions from the literatures on infant intersubjectivity, anthropological dimensions of socialness, and sociocultural positions on mediated action and sense of self to question and transfigure theoretical perspectives about changes in mutual engagement during adolescence.

17.2 Statement of the problem

It can be asked why fundamental positions on intersubjectivity are going to be revisited during the adolescent period using individuals with autism. There are several reasons. First, there is a long standing debate in the literature about whether children with autism develop theory of mind (ToM) [3]. Once accepted as part of the syndrome, scholars are increasingly making the argument that failure in ToM tasks are more about the tasks than about the thinking of the child. This claim and counter argument have been made by Trevarthen and Aiken [4] as well as Ochs et al. [5] and legitimizes perspectives on atypical development that differ from the prevailing 'deficit' literature. Second, regardless of the failure of children on ToM tasks and other measures of social understanding, parents continue to report that their children, even those who are severely autistic and non-verbal, intentionally communicate and convey a wide range of emotions during interactions. This signals a difference between the evidence of science, in the narrow sense, and lived experience. And finally, fundamental positions on intersubjectivity are being revisited because they provide the theoretical evidence for making decisions about life trajectories when development is atypical. Societal demands change during adolescence for parents and children as transition from formal schooling to life beyond this is planned. Therefore, adolescence becomes not just a biological reality but a social shift point. This necessitates rethinking what children with less than perfect neurophysiologic status can and do accomplish in order to interact with others. Acknowledging the forms that mutual engagement may take can enrich developmental theory and at the same time substantiate a push toward possible futures rather than relegate adolescents with autism to stagnant living situations.

The main points of this paper will be to raise questions about present notions of the development of intersubjectivity when mutual attunement seems not to exist (early on) for parent-child dyads; to theorize about the role of social others and cultural tools as mediators for constructing intersubjectivity; and to illustrate points of intersubjective achievement when cultural tools and social others as animate tools become the units of analysis [6]. In order to shed new light on the development of intersubjectivity, a sociocultural framework that focuses on mediated action [7, 8] will be outlined as one way that individual mental functioning and social phenomena come together. The idea that routines become cultural, symbolic tools and social others often function as animate tools that support late emerging intersubjectivity will be developed through case study material within the paper.

17.3 Autism from the inside out

The cause of autism as a result of insufficient maternal nurturing to a neurologically based developmental disorder changed in the latter half of the 20th century. Today it is considered one of the most severe behavior disorders of childhood and, regardless of causation, is manifested by social-communicative isolation [9]. Scientific investigations provide insights to autism as a disorder. Rather than a review of the extensive literature on autism, this paper uses parent description as the basis for rethinking development changes in intersubjectivity. Parent descriptions and stories provide insight about the everyday experience of living with autism as well as the ways that they recognize and guide their child as a person within the autistic experience. One such description comes from Donna (personal communication) when telling the story of her son Terry's emerging autism.

“Terry was a beautiful, healthy and happy baby. All this changed when he was about 2-1/2 years old. Rather than progressing, his development began to slide backwards. Within six months Terry lost all the words he had been speaking and no longer made attempts to get attention or interact with others. He began to bite and hit himself and began to use repetitive actions with little meaning. By age three Terry was diagnosed as severely autistic, and as a child who would never speak or be able to learn.”

Donna's story contains themes common to the stories many parents tell about their children with autism. Parents claim in the beginning, at birth and in the early months of infancy, they were in love with their babies and their babies were responsive, engaged and in love with them. Joy, laughter, smiles, gazing and touching were shared between mother and baby.¹ In other words, from the perspective of the mother, the baby was 'normal'. While there are variations among story tellers, sometime between the first and third year of life a change occurs. Some children become repetitive; some children don't talk; some children lose developed skills. These common stories of the beginnings of autism share a social-communicative theme. There is a communication breakdown that may or may not include specific language delay but does impact the social relation of the child within the routines of the family and, to even a greater extent, the relation of the child to the social world outside of the family.

For most parents the years that follow the onset of autism in their children are filled with struggles to understand the syndrome and at the same time interpret their child's unique ways of understanding and communicating to other family members, social service workers and teachers. Confronted with the medical advice to institutionalize her first child, Donna began to learn about autism and worked to keep her child not only at home but cared for within the health and educational systems. For her, as for many parents, living with and learning about autism plunged Donna into theories about development and hoped for changes in intersubjectivity that would settle questions about Terry's future. Would it be one lived with inadequate social skills and poor interpersonal communication or one shared with others?

¹ Mother will be used throughout this paper for ease of reading.

17.4 Intersubjectivity and autism

A functional definition of autism that can assist with thinking through issues of intersubjectivity may well be that it is at the same time both a neurodevelopment disorder and a social disorder [5]. As a neurodevelopmental disorder, sensory systems, language and symbolic systems, and cognitive systems are disrupted [10]. As a social disorder, both interpersonal communication and functioning in the social world are impacted. Ochs et al. [5] disembedded the concomitant social issues into two dimensions when conducting ethnographic research with family of children with high functioning autism or Asperger's. They purposed that 'social' can be understood as 1) interpersonal socialness and 2) socio-cultural socialness. The first describes communication that depends on the everyday shared use and interpretation of language. Children with autism vary in how much and how well they can use language, and even when they do use language, difficulty interpreting the messages of others can persist. This is often the focus of intervention and educational programs, since children with autism don't seem to 'get' what is said and often say the wrong or inappropriate things to others. The more interesting case made by Ochs et al. [5] is the parsing out of a second dimensions of socialness. They used Hymes' [11] notion of language as being context sensitive knowledge, as well as Lave and Wenger's [12] work on situated learning and legitimate peripheral participation to arrive at the notion of socio-cultural socialness. This is connected to expectations about knowing, perceiving and engaging in conduct appropriate to specific social practices. Recognizing two kinds of socialness allowed Ochs et al. [5] to describe the social interactiveness of children and families in ways that went beyond the skills of the individuals. Their position is particularly interesting with regard to intersubjectivity because, as they say, "Human beings are socialized to recognize and implement social practices, including their own and others expected roles, stances, and compomentment, all of which require socio-cultural perspective". Donna's stories about her work with Terry in early childhood illustrate this point. According to Donna,

"I kept Terry at home and began working with him in conjunction with home services. There was little change in Terry's language skills. He never learned to speak like he was before autism, but did learn to use a few basic pictures for communication. He never stopped biting himself (and on occasions others). He remained a picky eater, and he required assistance for even the most basic of personal needs, usually running or screaming when others tried to meet these. We, all of us at home, just kept being consistent, demanding that he take part in life around him and that he communicate."

As can be seen, Donna assigned social expectations and communicative roles to Terry and established a picture communication system as well as routines so he could participate in the everyday life of the home. These actions are consistent with the Ochs et al.'s [5] two dimensions of socialness.

The work of both Bråten and Trevarthen provide developmental links to the above position on socialness. Bråten [1] made the case for mutual attunement by suggesting that infants enter their social worlds at birth with a self-organizing system that allows for presentational immediacy that does not require or rely on linguistic modes of communication. This point is relevant for the later discussion

of adolescent intersubjectivity in the case of autism, as is Trevarthen's [12] stance that preverbal intuitive communication is fundamental to the development of thinking and talking in culturally specific ways. Here Trevarthen is elaborating on his long maintained position that infants at birth have primary intersubjectivity that result in shared emotions with adults and supports the development of secondary (socially mediated) intersubjectivity [4]. He argues that collective human understanding, and hence secondary intersubjectivity, results from emotional and sympathetic experiences with others that arise out of continuous communication and construction of meaning. His writing on child motives for engagement and his broadening of the criteria of intersubjectivity to include emotional empathy and coordinated communicative expressions, not necessarily linguistic in nature, are particularly pertinent for thinking through the ways intersubjectivity might change over the course of a life lived with autism [4,12].

The positions of Bråten and Trevarthen provide essential points that can support conclusions about intersubjectivity that may be 'real' to parents but not to the occasional professional when children have severe forms of autism. This could apply to Donna's perspective. She was steadfast in her view that Terry knew her, loved her, and was responsive to her. While outside observation might do little to support this, the theoretical positions of both Bråten and Trevarthen validate the possibility that Donna and Terry could share mutual attunement and emotions that might look very different to those outside the lived experience of autism. To outsiders Terry, according to Donna, simply looked very autistic and mentally deficient. This leads to the question, is there an additional theoretical perspective that can be used for analysis of Terry's situated actions that support intersubjectivity?

17.5 Socialness and mediated action

Ochs et al. [5] in part based their distinctions of socialness on the works of Vygotsky [14] and scholars aligned with the fundamentals of his theory. One such scholar, Wertsch [14,15], used Vygotsky's account of intermental and intramental functioning to differentiate between social as individuals interacting in an immediate context and social as the cultural, historical and institutional means by which an individual acts. He referred to this as mediated action since any action produced by an individual either in isolation or with others is inherently social because the material by which the action is accomplished is always a social and, thereby, a cultural derivative. Hagstrom [8] used Wertsch's mediated action as well as his discussion of cultural tools [16] to organize a functional individual system (FIS) framework for working with clinical populations, including autism. Three interdependent systems, the physical, cultural and social, are understood as continuously influencing each other during the developmental process. Thus rather than focus simply on the physical differences associated with autism, teachers, social service workers and parents can think about how things created and passed down by people to people (cultural) when appropriated via interactions with others (social) become the way that any individual, including a child with autism, acts in and on his everyday world. This action, regardless of biological/neurological determinates remains social and cultural. In other words, it remains in Wertsch's words, mediated action. Hagstrom [8], consistent with

Vygotskian and Wertschian theory, included three kinds of tools in the FIS framework: tangible, mental and animate. Tangible tools, as actual objects or artifacts, and mental tools, as symbolic, are widely discussed in the sociocultural literature. Animate tools have not received the same attention even though the notion that an individual might function as a tool for another person was considered by Vygotsky [17] and further elaborated by Zinchinko [18]. It is a particularly integral tool whose use is constrained by culture for children with various disabilities including autism.

Donna when talking about her approaches to working with Terry as a school age child provides an example of mediated action.

“Each summer I work with Terry to keep him going, building skills, and most of all to decrease his self-abuse. He knows about rewards because I use a counter that clicks. Each click means that he has stayed with an activity. These can be as simple as continuing to eat a new food to using his picture communication board to answer questions.”

Donna’s approach to working with her son reflected a cultural, historical and institutional paradigm that mediated her actions. Donna could not have used it nor could we as readers understand it outside of the cultural frame that organized her actions and expectations for responses.

A tools analysis [8] of the following excerpt makes it clear that routines upon which activities were based as well as the reward system reflect values of a particular world (cultural) view. The journal entry does not reflect the use of animate tools, probably not because this form of assistance was not used but rather because noting it was not part of the treatment paradigm that organized the sessions.

“This is a journal entry for one morning’s work: Used picture communication for requesting, 10 clicks; verbal imitation of basic vowels and consonants, 15 clicks; facial massage and blowing on party favors, 25 clicks. Used a five token card to go for a car ride.”

As can also be seen, documentation of social interaction between the participants or between the participants and the surrounding social world is missing from this activity description. The importance of social others in acquiring and using cultural tools is not part of the mind set used to organize these tasks or important to the documented results.

The point being made here about cultural tools and mediated action becomes clearer by contrast. Six months after the journal entry above, Donna attended a workshop that stressed social interaction when working with children with autism. This is her first journal entry for Terry, now 14 years of age, following that workshop.

“Sunday will be six weeks that I’ve been working with social interaction. It has been a blast rather than a struggle! He gets my undivided time for thirty minutes every night. What ever he is doing, I join in with. I don’t make him do anything for that thirty minutes. In return, I enjoy my son and he gets a hug, a kiss and no struggle about going to bed.”

This journal entry describes the general technique, which has as its goal recognizing the person with autism as first and foremost a person and then joining that person's activity rather than imposing a pre-established objective on the activity. This thirty minutes of interaction comes with a cultural history of therapeutic use that is far different from the earlier representation of parental intervention. The description of Terry's activities this time focus on social interactional skills, again reflecting how the perception of what is important has been shifted by the cultural (historical and institutional) frames of meaning.

“Here are some things we see Terry doing that are definitely a change (and all with no rewards or clicks). He is doing all kinds of different things at the park instead of just swinging. And he's approaching other kids. Maybe giving them a big fat kiss is an awkward way to say hello, but the fact that he is noticing other children is awesome! He sat on the front porch, just sat there, for 30 whole minutes, just relaxing without getting up or running away. He is starting to show jealousy of things his sister gets to do. For example, she sleeps with me and last night he arrived at my bedroom door with his blanket and pillow. He communicated the unfairness by bringing symbols of bedtime downstairs! It was a first, but did we ever let him try to communicate his way, using things his way?”

Considering cultural tools as the means by which individuals move through everyday life helps us better understand the needs and challenges of persons with disruptive communication, such as that associated with autism. First, understanding the tools used (i.e., tangible, symbolic, animate) allows for the adjustment of communication. Second, describing a person's use of the tools for social as interpersonal action and /or social as socio-cultural situated action reveals the network of meanings (i.e., cultural dimension) that are being deployed by participants in situated learning. And lastly, the selection, manipulation and social negotiation of communication via tools allow others to “see” the agency of a thinking self in action.

17.6 Cultural tools and the sense of self

Tools are important in the everyday life as ways to attune to others. This can include what the individual brings to the communicative interchange as knowledge and skills as well as what is made available within such interactions by means of materials and the participants' manipulations of these, which may well involve assistance of others.

To be a thinking self in a particular ‘moment’ is to act in that moment with an array of tools identifiable to at least one other person involved in the action. These tools are acquired from/within culture, and for the child and family with autism, within what over time has emerged as the working culture of the home. The identifiable commonalities are recognized as the home culture, which involves ongoing, dynamic interpersonal creation. As new tools are created in the service of shared engagement, culture at the local level changes. As culture changes, new tools are needed. As a result of this change, the ‘tool kits’ of the individual may have similar kinds of tools (consistent with the notion of culture resulting from the

actions of people living and working in groups/communities) yet the kit has the possibility for constant expansion.

Therefore, it can be said that one's own sense of self as well as the sense that others have of the individual as a self emerges out of communicative consistencies that are interpersonally woven together over time via action mediated by cultural tools. [19] This results in a persistent sense of self for the individual, even an individual with autism, as well as for those around him. This sense of self is an expectation frame for how a person will act with others or in a given situation. So it is important to do two things. One, theoretically recognize that the thinking of one's self or others as selves is a mediated construction which need not be linguistic. Two, and at the same time, accept that individuals achieve a pervasive sense of this self that guides actions and participation with others in everyday life, even when both interpersonal and socio-cultural situated socialness is violated.

The notion of a sensed self is pivotal to the discussion of intersubjectivity and is fundamental to socialness. Specifically, because tools are vital to the ways we each negotiate everyday life, culture reflected in and through the use of tools is fundamental to the social perception of an individual as a persistent self. The forms (or tools) used by individuals during social interpersonal action permit others to sense the self behind the act even when this socialness in the course of a socio-cultural situation violates conventions and expectations of comportment. This self action, need not be symbolic but can rather be mediated by cultural tools such as the enactment of shared routines or the negotiation of space or time via animate tools. Such forms of tool use for interpersonal action would be consistent with Bråten's [1] mutual attunement and Trevarthen's [4,12] broadened position on intersubjectivity. The appropriation of routines and the rhythm of the interactions associated with this becomes a communicative tool for individuals with disruptive communication and for the social others with whom they are communicatively engaged. In the course of typical development for a child who is neurodevelopmentally atypical, the building of predictable social interpersonal action depends on mutual attunement. This mutual attunement, which according to so many of the mothers of children with autism, is present at birth and during the early months of the infant's life. Perhaps it is this that they use and build on to interpret, as animate tools, the actions and communications of their children to others as the children attempt to negotiate Ochs et al.'s [5] second dimension of socialness.

A last entry authored by Donna on an email distribution list is a fitting example of the public emergence of sense of self. Terry's reported acts reflect the social engagement he has had with his family and the use of social routines and actions as a tool. His situated action demonstrates attunement and mutual engagement with a 'new' other that is reflective of continued changes in mediated intersubjectivity as an adolescence.

"Last night, here at my house, two of my amazing colleagues and I hosted our first "Supper Club with Autism". It's for teens with autism who use augmentative communication. Goal: socialization, attention, functional communication, cooking, serving, and cleaning skills, etc. It was scary because we weren't sure how the kids would take it. I was fairly certain Terry, my 15 year old with autism and who uses a Dynavox and some speech, would be alright...just a little hyper probably. But we were pretty uncertain about the other teen who this summer began learning to use

the Picture Exchange Communication System (PECS). This was a brand new experience for him, and we just wanted him to know how welcome he was and how much we wanted him there. But that wasn't going to be easy due to the nature of the disorder.

Well, he was pretty scared when his mother first left, and he was escalating with sounds and signs of potential abusive behavior towards anyone who came near him. So we adults sat down and got quiet to minimize sensory stimulation while this kiddo soaked it all in. We hoped he'd modulate. He was still squealing pretty hard and you could tell he was stressed out. I don't know what the other adults were thinking...but at that moment I was thinking something like... "UUgh, Donna...you and your stupid ideas! This is awful!"

And then a miracle appeared in the form of two autistic boys. Terry, who had been off in his own world until that point, suddenly came out of nowhere and plopped himself down right beside (and slightly on top) of this other guy who was so upset. Terry put his arm around him and patted his head and face. He was trying to tell him it would all be okay!!! He was reaching out to comfort another human being! And he KNEW what it was like to feel scared when something is different from the 'routine'. It was precious and it answered so many questions life poses. We all held our breath, wondering how the other teen, who can be prone to violent outbursts, would take Terry's physical gestures. And here is the beautiful part.... he seemed a little shocked, but then he appeared to understand and he calmed down and even smiled.

It was no small wonder friends. If you know anything about autism you will realize that both boys climbed a giant mountain, one in the giving and one in the receiving of comfort."

17.7 Conclusions

Certainly the goal of early and persistent education of children with autism is to maximize the possibility for them to have possible futures rather than stagnant lives. But because assessments and interventions are permeated with developmental perspectives that index specific child behaviors as representative of social engagement, other evidence of intersubjectivity may be over looked by decision making professionals. Therefore, understanding the essence of intersubjectivity rather than discrete behavioral manifestation becomes critical within the literature so a person-centered view will over time infiltrate scientific and cultural perspectives.

The main points of this paper was to raise questions about present notions of the development of intersubjectivity when mutual attunement seems to disappear or be nonexistent; to theorize about the role of social others and cultural tools as mediators for constructing intersubjectivity; and to illustrate points of intersubjective achievement when cultural tools and social others as animate tools become the units of analysis [6, 8]. The work of the parent and the child when viewed from this perspective may shed light not only on differences inherent to the individual reaching to achieve socialness when their atypical development is typical (in a lived sense for them), but also on the necessity of mutual reaching for communication and willingness to be an animate tool in order to achieve intersubjectivity.

The mother who fights institutionally situated socio-cultural action by maintaining that her child is a thinking, feeling individual can present little in the way of empirical data to support her position. And her fight is on two borders: interpersonally to push the child's continued development and social situationally to push for recognition of educational viability when few or none of the rules of comportment are realities for the child. Part of the claim in this paper is that intersubjectivity may be experienced differently by those involved in everyday situations and may not be observable if static ways of looking at intersubjectivity are imposed on the novelty of living with autism. Focusing on socialness from Ochs et al's [5] two dimensions, the mutuality of emotional and communication engagement between mothers and their children [12], and the use of cultural tools as mediated action [8,14] can assist in examining intersubjectivity as a life-long journey for those with autism.

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