

Autism and Systemic Family Therapy

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A shop in Singapore.¹

A 14-year-old Chinese boy barges me out of the way. Before I realize what is happening I say, “Rude boy!” loud enough for the boy to hear. A man runs in behind me. “Sorry!” he says panting to catch up with the boy who is wandering around the shop. “Sorry, he’s autistic.” He catches up with his son and slows to the boy’s pace, holds his hand and says, “You need to be more careful. You knocked that lady. Come, we need to go.” And he leads his son past me out of the shop.

I am mortified. As they pass I smile and say as casually as I can, “I’m sorry I was cross” and he says, “It’s alright.” I can see he feels he should appear genial to compensate for his child’s insensitivity but I realize I am making another demand on him by apologizing for my crossness. And it’s my need to do this, not his need to have the recognition. They leave and I am humbled and startled as I imagine the task he faces each day of keeping his boy safe and at ease in such a busy city.

For many families, having a child with autism can be a long-term worry and involvement. Parents worry how their children will cope beyond the family home and they worry about the impact on their siblings. For parents, siblings, partners and children of people with an Autism Spectrum Condition, there are challenges which can impact on their own wellbeing. Exhaustion, stress, worry and the misunderstandings of others are some of the main issues for both autistic people and their families. Health and social care professionals are often undereducated in the impact of autism in people’s lives and this affects whether and how people with autism and their

families feel about approaching services. Because autism is a hidden disability, you can't always tell if someone is autistic. People with autism and their families are often subject to stigma and discrimination, misunderstanding and criticism.

Family therapists have a great deal to bring to the world of autism. We specialize in communication, coordination, working with people's strengths and interests. We work collaboratively with family members to find new ways of going on in our everyday relationships and co-construct a safe reflective space that can lead to change without compromising people's identities and values.

In this chapter, we argue the case for systemic family therapy to be included in the resources offered to autistic people and their families. First, we offer some background information on autism. We discuss trends in autism theory, diagnosis, research and treatment methods and look at how autism can impact on people's lives. Then, we introduce new systemic theory and practice for working with the impact of autism in families through sharing examples illustrating how systemic family therapy improves communication. Finally, we highlight areas for developing systemic family therapy training, practice and research on autism.

Autism

The question of what counts as autism or an autism spectrum condition is complex and evolving. What a person must demonstrate in order to acquire an autism diagnosis changes with each diagnostic manual. The increasing prevalence rates of diagnosis has led to some concern that there is an "autism epidemic" (Timimi, 2011). With ongoing debate about what has caused the increase, is there "more" autism, greater knowledge or a widening of criteria (Timimi & McCabe, 2016; Timimi, Gardner, & McCabe, 2011; Mallett & Runswick-Cole, 2016; Hassall, 2016; Mollay & Vasil, 2002; Grandin & Panek, 2014).

What is Autism?

Autism is a wide-ranging umbrella term and one of a number of neurodiverse conditions. Autism Spectrum Conditions are understood within mainstream psychology and psychiatry as a form of pathology occurring in an individual. Key characteristics of autistic individuals include difficulties communicating, connecting, increased sensory sensitivities, need for “sameness” and coordinating with others. Many (not all) autistic people find eye contact difficult and may use limited non-verbal communication. Some people find metaphors perplexing and plain speaking easier to understand. Some don’t like physical contact, others want more physical contact than is usual.

These experiences of the world affect relationships with partners, parents, siblings, other family members, teachers, colleagues and members of the wider public. Differences can vary widely with many autistic people functioning in everyday life, holding responsible positions while managing or hiding their social challenges. At the other end of the spectrum some autism people have no spoken language and cannot care for themselves. This prompts a caution in using the term autism as it can refer to such a wide group of people and potentially obfuscate the significant differences in needs and challenges.

The word “autism” comes from the Greek word *autos*, which means *self*. It describes conditions in which a person apparently removes their self or selves from social interaction. In other words, the person with autism is understood as an “isolated self.” This belief wrongly orientates professionals and others to assume that all people diagnosed with an Autism Spectrum Condition are antisocial.

Mohammed, a young man with autism, shares his experience of how knowledge of his autism shows up the assumptions of others. “The moment people hear I have an

autism diagnosis, they start saying 'It's fine if you need time out' or 'We didn't ask you to come with us as you looked deep in thought.' That makes me sad. I love being invited out and going new places. When they don't ask me out, it makes me feel like a freak - and lonely."

The challenge then for family therapists is to appreciate that the word "autism" is a starting point for finding out the specifics of each person, their family and social network. It is important to remember that people with autism are not only people with autism. Autistic people come from all class and economic backgrounds, are members of different ethnic communities, exist all around the world, have different genders and sexual orientations, are people of all ages, and can be found in every profession. People with a diagnosis of autism are all different from each other, not the same as each other. Research highlights the variety of needs and abilities across the autism spectrum, supporting the saying, "If you've met one autistic child you have met one autistic child."

While many of the issues associated with an Autism Spectrum Condition can be worrying and a struggle, some may be helpful, enjoyable and are to be celebrated. In his book on the history of autism, Silberman highlights how the world would be a much poorer place, in all kinds of ways, had people who think differently not achieved what they have (Silberman, 2015).

History of Autism

Ideas as to what autism is have changed greatly since the term autism was introduced in the 1940s and it continues to change. There are descriptions of people who would have fulfilled current diagnostic criteria for autism dating back hundreds of years (Silberman, 2015).

In 1943, Leo Kanner introduced the concept of "Childhood Autism" (Kanner, 1943). The diagnosis of autism was later defined by Kanner and Eisenburg in 1953 (Robison, 2016). Hans

Asperger was also developing theories about children who struggled with social participation in the 1930s and 1940s (Volkmar, 2011). In 1981, Lorna Wing applied the phrase “Asperger Syndrome” to describe a group of people who has social difficulties but could participate to a high degree in everyday life (Wing, 1981). Theories were developed by the medical profession without the collaborative involvement of the people being diagnosed as having autism.

Early theories suggested that autism was “caused” by mothers who were emotionally distant and cold nature (Bettelheim, 1967; Kanner, 1944) or the result of dysfunctional families and poor parent-child relationships (Estrada & Pinsof, 1995). Such theories were later rejected by the scientific community as unsubstantiated with evidence pointing to caring and attentive parenting. Parent support interventions which did not judge the parents or subscribe to any idea of causality were successful and popular (Attwood, 1998) focusing on support for families in promoting their children’s development. Another widely held view is that there is a multifactorial basis to autism which includes a polygenetic, neurobiological and developmental basis (Minshew & Williams, 2007). Influenced by Bronfenbrenner’s social ecological model (Bronfenbrenner, 1979) and neuroscientific literature (Celano, 2013), some propose that social and environmental factors exacerbate or suppress the expression of those genetic and neurobiological factors which give rise to the features of autism.

While opinions differ as to whether the cause of autism is organic, genetic or environmental, theories and practices about autism are currently dominated by the medical hypothesis which proposes that autism is hard-wired in the biology of the individual (Ha et al., 2015). Many large-scale research studies explore the possible organic basis for Autism Spectrum Conditions but there has been no evidence to date which conclusively supports this thesis (Cozolino, 2014). Timimi & McCabe (2016) argue that physical structures in the brain can and

do change for many reasons to do with environmental stimulation and for unknown reasons. Nevertheless, the hypothetical narrative of organic causality influences trends in research funding, in how professionals theorize human development and change and hence the treatment methods they develop.

Current Debates

The contemporary Neurodiversity Movement led by autistic people promotes a view of autism as part of human diversity, as a neurodivergence, subject to the same social dynamics as other forms of diversity (Walker, 2016). It criticizes medical and psychiatric approaches to autism as reflecting cultural prejudice and reproducing oppression through relying on the construction of normative developmental theories (Walker, 2016).

Critical Autism Studies treat autism as a socially and culturally produced phenomenon (Runswick, Mallett & Timimi, 2016). Chown (2016) posits that there are no autistic behaviors - just behaviors that can be found across the wider population, but which are seen more frequently in autistic people than non-autistic people. The Critical Autism Network challenges dominant understandings of autism as a neurological deficit, instead focusing on autism as an identity that is discursively produced within diverse socio-cultural contexts (O'Dell et al., 2018).

Contemporary literature on autism analyses historical narratives (Donvan & Zucker, 2016; Silberman, 2015) with an accepted respect for *neurodiversity* which opens up possibilities of looking at autism in new ways. Silberman suggests that “we can consider that conditions like autism, dyslexia, and attention-deficit/hyperactivity disorder (ADHD) should be regarded as naturally occurring cognitive variations with distinctive strengths that have contributed to the evolution of technology and culture rather than mere checklists of deficits and dysfunctions” (2015, p. 16).

Awareness of autism has greatly increased since the introduction of autism policies and rights in some countries such as the Autism Act in the United Kingdom in 2009. This impacts on public and private institutional resourcing. The primary complaint of young autistic people is that they feel bullied in school. Only 16% of autistic adults in the United Kingdom gain and retain employment, and remain poorer in the United Kingdom than in other European countries (National Autistic Society 2018). Across Europe, a number of organizations specifically employ autistic people and focus on creating the right environment, such as “Specialisterne” in Denmark, “Passwerk” in Belgium and “Auticon” in Germany. Autistic people with a diagnosis are protected by disability legislation in the European Union, with a right to *reasonable adjustments* at school and work. This creates a binary view of autistic and non-autistic students and employees. By introducing systemic thinking and postmodern theory to open up new meanings and possibilities through dialogical reflective inquiry and narratives, we can influence school and workplace policy and practice that maximizes the talents of neurodiverse school populations and workforce (Vlam, 2016).

An increasingly important component of the spectrum of epistemologies of autism is the voice of those living with an autism spectrum condition. Autism rights movements describe autism as a way of being in the world that is not possible to separate from the person. The tragedy “is not that we’re here, but that your world has no place for us to be” (Sinclair, 1993, p. 3).

Historically, autism has been researched, (like homosexuality before it which was de-categorized as a mental health condition in DSM in 1973), by outsider professionals who created theories which subjected people which had the effect of “othering” people with autism. Expertise *about* autistic people has been created by and situated in non-autistic professionals. In service

provision and research, this has begun to change with an investment in seeking stakeholder views and more participatory action research studies (Frazier et al., 2018). Research organizations such as Autistica include autistic people in research about autism and support research undertaken by autistic people. While some people with autism are articulate and vocal, others cannot communicate and need advocates, especially people described as having autism and learning disability. Some people, with or without autism, refuse to cooperate with some streams of autism research as they are concerned that the predominant focus on researching the *cause* of autism will lead to a fascistic program to eradicate people with autism as indeed is now believed to be the case with Hans Asperger (Sheffer 2018).

Autism as a Fluid and Changing Diagnostic Concept

For some people and their families, partners and friends, the diagnosis of autism helps to make sense of their lives and it can facilitate access to support. People can feel relieved and empowered through having an explanation of their experience and struggles and find support from other experts by experience or from professionals. But people can also feel the diagnosis implies personal inadequacy which can reinforce a sense of dissonance between the idea that there is something wrong with them without reference to the challenges society, families, workplaces or cultures pose for people. In some countries, having a diagnosis of autism is the only way they can access resources such as educational support or social care. In other countries, there is no concept of autism and little infrastructure to support people with special needs.

The diagnostic practice of pattern-spotting often distracts therapists from seeing the whole and unique person, their abilities, strengths and the relational contexts in which they live, love, communicate, work, travel and play.

Autism as a diagnosis is now established in two commonly used diagnostic manuals: the International Classification of Diseases, known as ICD-11, a diagnostic manual produced by the World Health Organization (2011), and the United States created Diagnostic and Statistical Manual of Mental Disorders, known as DSM-V (American Psychiatric Association, 2013). In both manuals autism is described as a “disorder” and there are lists of “impairments” that need to be evidenced in order to receive a diagnosis. There has been some concern that ICD-11 has imported the U.S. centered criteria of DSM-V for its international manual, however, ICD-11 has made changes to take cultural difference into account such as by putting less emphasis on type of play when assessing for autism as it acknowledges that what counts as play varies across cultures.

DSM-V describes autism as a *dyad* of impairments with difficulties with social interaction and communication combined. DSM-V removed previous subcategories such as Asperger Syndrome and PDD-NOS (Pervasive Developmental Disorder - not otherwise specified) with all diagnoses under the umbrella term “Autism Spectrum Disorder.” The British Royal College of Psychiatrists (2017) defines autism as a central condition in the group of difficulties known as Autism Spectrum Disorders (ASD) or Autism Spectrum Conditions (ASC) which are understood as developmental disorders *likely* to be “caused by abnormalities in the way the brain develops and works.”

While the diagnostic label used by the DSM-V is “Autism Spectrum Disorder,” the term “Autism Spectrum Condition (ASC),” is the term coined by Baron-Cohen (2009) to reflect the notion that not all symptoms of the condition reflect *disorder*. Disorder implies the “natural order has gone awry but when we examine the cognition and biology of autism, arguably what we see is not evidence of dysfunction but rather evidence of difference” (Lai, Lombardo, & Baron-

Cohen, 2014). Timimi, Gardner, and McCabe (2011) and Hassall (2016) argue autism is not a “disorder” at all. Others see Asperger Syndrome as just a “neurological difference that has been constructed as a disorder” (Mollay & Vasil, 2002). One could argue that if our worlds are socially constructed through language and communication, difficulties with social communication are perhaps the most disabling of all impairments (Evans, 2017).

The autism spectrum has been understood as being a way of speaking to degree of difficulty but is more of a cluster of diagnostic criteria. This spectrum is often conceived of as a single axis, a slider along which people are expected to sit like at a fixed centile or within a diagnostic range. However, it is in keeping with systemic social construction to think of people as moving along and between many spectra. This *multi-spectra living* (Urbistondo Cano & Simon, 2019) demands that we slide around many different spectra: agency, eating, mobility, socializing, technological living, creativity, communication, nature, shopping, rigor, for example. You can see that they immediately start to overlap, to connect. In fact, this is a way of mapping complexity in our daily lives but not as a static map nor one which is finalizable. It is constantly - *we* are constantly - in movement in contexts we are moving through. The speed and ease of movement, our abilities and struggles are all affected by these contexts, the cultural expectations of a family or community for example all coming together for a celebratory meal, by public transport culture, by the means and rules we have for buying goods or communicating with others) and impact on our story of ourselves.

The Journey Through Diagnosis

Diagnosis is a significant part of the autism journey. Where there is state provision, people wait up to two or more years to be offered a diagnostic assessment as is the case in many parts of the United Kingdom. Diagnosis can often come as a relief to parents, to have a name for

something but diagnosis also creates an expectation of help. While in some communities people experience excellent advice and support, in some less resourced countries parents (mostly mothers) walk tens of miles or take long car or public transport journeys to take their child with complex needs for an assessment. In many cases, this might be conducted in incomprehensible ways by professionals of another social class, culture and possibly language only to set off on the return trip to their village or town without any follow up or advice and perhaps simply the diagnosis. The impact of diagnosis varies widely. In Hong Kong and China shame on families has been reported to increase stigma for parents but also has an associated risk for the diagnosed child, with higher reported incidents of abandonment, abuse and neglect (Tait et al., 2015). In some cultures, people with autism are seen as having special abilities and accorded status in communities or as being possessed requiring local rituals to rid the person of spirits.

Systemic therapist, Haydon-Laurelut (2016) encourages a need for *critical systemic therapy*. He claims that to focus as a culture on the primary provision of diagnosis risks creating therapeutic violence as a person's experience is appraised in relation to an external hegemonic norm, colonizing it rather than seeking to understand it in local terms. Whilst for some, the diagnosis may bring a welcome understanding of their child's needs and challenges, Mallett and Runswick Cole (2016) suggest that for some autism is a "promise that is never fulfilled" with parents being left "high and dry," that they experience a "loss of satisfaction" when autism diagnosis does not materialize into something of value such as additional support.

Terminology

Across the world, and across most local autism teams, there is little agreement on terminology for autism. Each of the contributors to this chapter has their preferred term-for-now. One of us uses the phrase *a neurodiverse person*. Another says *autistic person*. A third prefers *a*

person living with autism. A fourth says *a person described as having autism*. The fifth uses the expression *a person with an Autistic Spectrum Condition (ASC)*. The term “disorder” is often used in medical discourse. None of these terms are innocent descriptions. For many autistic people and their families, these terms are political and ethical punctuations. Each phrase belies a different understanding of autism which in turn informs what kind of therapeutic response we might privilege as a systemic practitioner. This chapter then reflects the unfinalized and unfolding discourses of autism in people’s lives and in professional theories. It is always best to ask people what term they use for themselves or their partner, child or friend and understand how they understand autism, so you can decide how to coordinate with their beliefs and politics.

Prevalence

According to the World Health Organization (2017), 1 in 160 children worldwide has an “autism spectrum disorder.” The figure reflects countries who diagnose for autism and countries which do not. Consequently, the figure is likely to be higher. The number of people being diagnosed with autism started to increase significantly in the 1980s and 1990s from .5 in 1000 to 1% - 2% (Newschaffer et al., 2013). A study of children in South Korea reports the highest incidence in the world with 1 in 38 children being diagnosed as having autism despite high stigma about autism in the country (Kim et al., 2011). A study of children in Sweden found a prevalence rate of 1.5 in every 100 which is very similar to results of similar studies across Europe (Idring et al., 2012). A report on the United States found 1 in 59 (CDC, 2018) people has autism. In some countries, such as Somalia, there is no word for autism and therefore no autism diagnostic practice. In a study of Somalian families, Decoteau found that families of children diagnosed in America believed that autism was “brought about” by Western medicine and pollutants (2017) with a return to Somalia believed to be the cure.

People with autism have a range of intellectual ability. About 10% of people with autism have “some special skills and abilities” and “many often have intense interests such as train timetables, buses or dinosaurs” (The Royal College of Psychiatrists, 2017). Between 44% - 52% of ‘diagnosed’ autistic people have a learning disability (Fombonne et al., 2011; Emerson & Baines, 2010). Brugha and colleagues (2011) find that between 30 – 35% of people with learning disabilities have a diagnosis of autism.

Fombonne and colleagues’ review of studies (2011) find that 5.5 males are diagnosed with autism compared to one female in the United Kingdom and United States whereas Baird and colleagues (2006) suggest it is closer to 3.3 males to every female diagnosed. There is now a growing body of research to suggest that the difference is not due to a prevalence of autism in boys, but due to society’s differing expectations of men’s and women’s social skills, and a male bias in the identification, assessment, diagnosis and understanding of autism itself (Attwood, 2007; Dean et al., 2017; Duvoket et al., 2017; Gould, 2017; Loomes et al., 2017; Mandy et al., 2012; Shefcyk, 2015).

Across the lifespan, people with Autism Spectrum Conditions are more likely than those without Autism Spectrum Conditions to experience a range of psychological or mental health difficulties and to seek access to psychological wellbeing or mental health services (Simonoff et al., 2008) as they struggle more in daily negotiations with the social world. For example, 40% of autistic people have symptoms of at least one anxiety disorder at any time, compared with up to 15% in the general population (Galanopoulos et al., 2014).

General Family Interventions for Change

Different theories of autism give rise to different treatment theories with their internal coherence for rolling out treatment methods. Most family-oriented interventions are behavioral

and psychoeducational and focus on parental guidance and behavioral interventions that change or manage “problem” behaviors and promote compliance and conformity with a view to promoting easier family communication and reducing stress for all family members. *Parent support programs* aim to support the parent as caregiver and increase their parental knowledge of Autism Spectrum Conditions. They usually involve care coordination planning and psychoeducation. Parents report increased parental knowledge, enhanced competence in advocating for the child, decreased parental stress and a reduced sense of isolation (Attwood, 1998; Daley et al., 2013). *Parent Mediated Interventions (PMI)* (Bearss et al., 2011) are technique oriented in which the parent is the person who introduces change to the child or partner. Parents learn together in groups or therapists coach the parent-child dyad in their feeding, play or communications (Oona et al., 2011). In some PMI programs the focus is on core symptoms such as communication, participating in and adjusting to everyday routines. There are specialist Parent Mediated Interventions for disruptive behaviors such as social behavior, sleeping, eating and toileting. Parent Training Programs appear to be more effective than Parent Education Programs for disruptive behaviors (Bearss et al., 2015).

Self-help resources such as Volkmar and Weisner’s (2009) book *A Practical Guide to Autism: What Every Parent, Family Member, and Teacher Needs to Know* and the many online websites and participant forums have been reported by families and individuals as beneficial especially where there is no or only restricted access to local resources.

Autism Research on Family Therapy

There is very little research into systemic family therapy and autism. There are no large randomized controlled trials that have explored and evaluated whether and how family therapy works with autistic people and their families (Helps, 2016) The Cochrane Review (Spain et al.,

2017) into the clinical and cost effectiveness of family therapy for individuals with Autism Spectrum Disorders was inconclusive as there were insufficient studies meeting the criteria to be included in their review. Goepfert et al. (2015) suggest that families where one or more members of the family are autistic can benefit from family therapy to improve relationships, and strength the family system by creating a context for hope and empowerment. Anecdotal evidence from families is that they find it helpful to expand the type of dialogue they have about relationships with a particular focus on communications, understanding and decision making (for example, Simon, 2016).

Systemic Theory and Practice with Autistic People and Their Families

Dad I felt like suddenly we were all people again.

Mum The family therapist was really interested in him - as a whole person. She asked him some questions, but they were different to what he had been asked before by the psychs as part of the diagnosis.

Dad Yeah, for a change it wasn't us having to give information about our son.

Mum And he wasn't being tested. Though it took him a while to realize that. Instead he was allowed to speak about things he enjoyed.

Dad And we could all hear his passion. And his knowledge!

Mum Yes we could. She wanted to know, she wanted to learn about his interests. He's got this thing about street lighting! I found myself quite shocked actually to realize that this was the first time his dad and I had seen him as an interesting person since we started the process of diagnosis. I'd, um... sorry...

Dad It's okay love.

Mum I'd got used to just noticing his symptoms...

Dad We didn't realize how much he knew about how street lights communicate with each other! It was fascinating to hear actually, wasn't it? We learned a lot! He knows a lot about how things communicate with each other!

Mum And the family therapist helped him – well more us really - to use his knowledge about how things communicate with what happens at home when we all communicate.

Dad We felt more optimistic about some change when we left. In the car, even his sister said she didn't hate him as much. It was like we felt more love for each other. We felt hope for him.

Mum And hope for us as a family.

In this section we offer guidance for systemic family therapists and provide examples of some innovative systemic practice to use with autistic people and their families. We have found that methods which arise out of a collaborative and appreciative approach to systemic practice, out of an assumption that people with autism and their families come with a great deal of context specific knowledge are in a position to help us learn how to help them. Such systemic approaches require the therapist to take a position of inquiry, to relinquish some of their “knowing about” expertise so as to be open to what works and to be ready to learn and hear new information that will be given agentive space to be allowed to make a difference.

Whatever the origin or nature of Autism, there are limits to the benefits for families and partners of therapeutic approaches which conceptualize the single individual as the primary focus for diagnosis and treatment. Family therapists are most useful in understanding communication issues in families and finding ways of collaborating with all participants to find more satisfying ways of being in relationships. The belief that the individual is the organic site of any social or

developmental difficulty has resulted in the exclusion of considering how systemic family therapists could help in the opportunistic social space between people with autism, their families, partners and colleagues.

What Parents Want Help With

The problems that parents of autistic children want help with occur almost exclusively in the context of relationships. Communication difficulties are the most common presenting concern in therapy. Parents want to talk about how to keep their child safe, how to manage mealtimes, changes of routine, about arguments between family members and friends, co-parenting communications, dealing with frequent worrying feedback from school and other “Now What?” episodes.

Systemic Knowledge

Family therapy has a long history of understanding and working with communicating systems to enhance everyone’s potential to become better communicators and participants in an increasingly complex and challenging social world.

Systemic therapists understand human systems as communicating systems involving not only those with whom we live but also involving those people and systems which look after our children, involving our workplaces, our health care services and political systems. Systemic family therapists understand people as not simply embodied entities but as participants in socially constructed and physically resourced worlds. As systemic family therapists we are not invested in questions of *why* people are autistic so much as *how* autism as both a condition and as a label impacts on social communication and coordination between a person and others in their life. There are many people within the neurodiverse community who find the focus in research on cause and cure to logistically imply the eventual erasure of an entire population group

(Robison 2014)². A growing lobby by many neurodiverse and neurotypical people calls for the acceptance of neurodiversity in society alongside the acceptance of other forms of social diversity. This fits with the commitment within family therapy to social equality and social justice for all sections of the community.

A common challenge for family therapists is to avoid getting tangled up into the medical preoccupation with diagnostic activity. We have to work at blocking out symptom spotting in order to develop relational curiosity and encourage collaborative, inquiry led ways of conversing between autistic people and others in their networks. It is surprising how easily we can bring forth evidence that *autistic people have unique and useful expertise which plays a part in resolving social difficulties and improving communication between those in their networks*. But we need to create the conditions to immerse ourselves in dialogue with people and their social and professional networks using our systemic ways of thinking, talking and playing to find what works with each family we encounter.

We have found that people in the autistic person's social and professional networks often need support in moving from a rhetorical and echolalic position reproduced from diagnostic ways of speaking. In the professional network, colleagues from modernist discourses value systemic ways of seeing and talking. In the social and familial network, people value help relinquishing the sense of personal failure, frustration and anger at their child/partner/playmate/student/colleague.

In the case examples that follow, we demonstrate the use of systemic social constructionist ways of talking and thinking which expand the possibilities for conversational partners to find renewed energy and joy and develop more self and relational reflexivity,

benevolent curiosity about the person with an autism spectrum condition and about their own pre-suppositions.

A Systemic View of “Mind”

A governing idea in the psychiatric and psychological fields of autism is something called “Theory of Mind” (Baron-Cohen et al., 1985). This theory plays a central part in explaining and diagnosing autistic spectrum conditions and dominates professional thinking but offers a limited set of assumptions about what “mind” can be. “Theory of mind” centers individual cognition at the heart of its hypothesis and relies on an idea that it is the individual who has the problem *in them*. It proposes a deficit model of human beings and omits to draw out evidence of resourcefulness in people. Furthermore, by not focusing on people’s relational world, the model does not consider exploring relational possibilities in a person’s social networks. Brownlow and O’Dell (2009) critically review the literature on Theory of Mind and conclude that as the research has been carried out by outsiders, it makes fundamental assumptions about neurotypicality which undermine new knowledge emerging about ability and the whole person.

McGuire and Michalko situate autism within a relational system. “Rather than conceiving of autism as an individual medical problem, we understand autism as a complex interactional process. We treat autism as belonging squarely in the realm of the social and not in the realm of the individual” (McGuire & Michalko, 2011, p. 164). They go on to explain, “Nor do we treat Theory of Mind as a ‘thing-in-the-brain’. Instead, we understand intentionality, shared and otherwise, as a method whereby people, all people, attribute motives to one another as a way to make sense of human interaction” (McGuire & Michalko, 2011, p. 173).

Systemic professionals have long-since critiqued the concept of mind belonging solely in an individual to understanding *mind* as co-constructed with others in relational contexts (Bateson, 1979). *Mind*, from a systemic view, is a fluid and evolving process between people in response to social situations allowing us to check we are not restricting opportunities to find new parts of each other which our prejudices may obscure.

By foregrounding dialogue over diagnosis, and by acknowledging that the diagnosis and experience of autism can mean different things to different people, family therapists can experiment with ways of talking *suited to each person with autism and their family* to provide opportunities for symptoms and features of autism to be understood as meaningful communications and not only as diagnostic criteria. In this way, the “disabled” person is experienced as able and enabling. The individualized account of the person having been diagnosed as having an Autism Spectrum “Condition,” “Disorder” or “Disease” is exchanged for descriptions of an interacting social system.

Systemic relationship therapist, Ann Jinks, (2016) shows a kind of collective mind when as parents, she and her partner drive half a day to see their teenage son who has severe autism and lives in a residential facility. The best way to visit Liam is to take him out for a drive in the car. It involves quite a team effort to get him dressed, safely out of the building and into the car. He is in a hurry to go. He loves being driven around with them listening to music by The Beatles – and they have learned how to make this a special day that works for them all. Ann is struck by words in the song, *Got to get you into my life*: “Another road where maybe I /Could see another kind of mind there /Ooh, then I suddenly see you...” (Beatles 1966).

“We have learned not to talk. We just want to be with him. Liam’s dad has compared the visit with being in love or having a new baby; it’s enough to just to see

*him, to look at him, and be in his company. [...] To Liam, the lyrics are probably irrelevant, incomprehensible, but to me they seem unusually apt. We are **on** The Long and Winding Road, we **are** Let(ting) it Be, and we have **always** Got to Get You Into My Life. These are probably not the songs other teenagers would be listening to in 2015, but Liam enjoys them just the same. He rocks. He smiles. We're happy.” (Jinks, 2016, p. 5)³*

Deconstruction and Reframing of the “Oughtistic Spectrum”

Systemic autism specialist Evans (2018) has noticed that people with autism and their families coming for therapy are often carrying the wounds of pejorative narratives of professionals and others. She has developed a form of family therapy which deconstructs medical and societal beliefs about autism and family relationships and explores how families can be supported to develop narratives that are enabling and useful for them. She encourages systemic therapists to

- be confident and irreverent in challenging the medical language of autism with the focus on cause and prevalence;
- be curious about what is created for families by autism narratives before, during and after the process of diagnosis; and
- listen out for how generalizing or deterministic stories work to limit narratives about people.

Evans shows how *autism* is made up of layers of *oughtism*. Left unexplored, Evans says such narratives reinforce a culture of *oughtism*. Evans’ definition of “ought” combines several common meanings: a duty or correctness, typically when criticizing someone’s actions; as something that is probable; as how something *should be*; an “ism”; a distinctive practice, system, or philosophy, typically a political ideology or an artistic movement. “Oughtism” therefore refers

to the practice of telling others how they should or shouldn't be, of criticizing others, of questioning their actions or beliefs. Applied to oneself, it is a feeling that one "ought" to act a certain way in order to gain something or avoid criticism. Evans (2018) has noticed this is typically experienced by autistic people and their families. She notes that the diagnostic process is fraught with *oughtisms* about parental expectations: *Should we have asked for a diagnosis sooner? Ought we have pushed the school to support our child more? Should we care more about whether our partner is diagnosed or not? Should I be worried about my diagnosis? Ought I be able to cope with my child's needs better?*

Systemic therapy can help to reveal these worries and explore the relationship between stories lived and stories told (Pearce, 1999). In her work with families and professionals, Evans (2018) identifies numerous *oughtistic* responses that have informed them either in how they see others or feel they are seen by others.

"You ought to leave him with me for a week and I'd sort him out."

"She doesn't look like she has autism."

"You ought to discipline him more, that would sort things out."

"You shouldn't seek to label your child."

"An autistic child ought not to be sociable or use eye contact."

"You ought to say child with autism, not autistic child."

A counter list by autistic activists includes:

"You ought to accept autistic people."

"You ought to celebrate autisms strengths."

"You ought to celebrate diversity."

"You ought not to see Autistic people as less."

An Example of Living With Oughtism

Mother: “Meal times are the worst.”

Father: “Really bad. And I’m not always there to help. But when I get home, she’s really stressed and exhausted. Sometimes I wonder if it’s worth trying to get him to eat...”

Mother: “And so we end up arguing – on top of everything else.”

Family therapist: “And what’s Joni doing while all this is going on?”

Mother: cries. “That’s the worst of it. She’s being such a good girl. And we just ignore her because we focus on Sammy.”

Therapist: How come you all eat at the same time?”

Father: “It’s how we were brought up. It was family time. You know, we joked and chatted, and it felt good.”

Mother: “They say the family that eats together, stays together.”

Therapist: “And so does this ritual help you feel together or are you just going through the motions to be together physically?”

Father: “Well, we aren’t even physically together as Sammy often kicks off, hits his sister for making a noise while she’s eating, and then he storms out.”

Mother: “I suppose I was hoping he might learn from her, to behave well, to eat more foods... I worry he isn’t getting a balanced diet. What kind of parent am I if I can’t even get him to eat fruit or vegetables?!”

The parents have a strong belief that not eating together was “bad” and so they persevere with strategies that are not working for their family in the belief they “ought” to be like “other” families or their own family of origin. Over the next few sessions, the therapist and parents

- explored how Sammy experienced mealtimes and what they could do to help him given his high level of sensory sensitivity and dislike of certain tastes, textures and background noises.
- explored the narrative “a family that eats together stays together.” The parents worked through any loyalty to their own families’ ways of doing family togetherness. Instead, they re-invented key family rituals to suit everyone’s needs. Mealtimes were arranged differently.
- reframed Sammy eating separately so they didn’t see it as parental failure but as a positive parenting strategy.
- framed times that they could connect as a family as a shared activity and looked at how they could be still be close whilst doing things apart or in sub-groups.
- constructed new family scripts about how they could still be a family “that stays together” but one which also responds to the individual needs of each of their children.
- strategized how they might respond if professionals supporting their family saw them as “bad” parents if they did not widen their son’s diet.
- explored ways of communicating with the wider family about the individual needs of their children.
- supported critical thinking about *oughtistic* narratives so liberating the parents from any personal sense of failure and stories of normal family.
- invited them to celebrate their differences as a family and as individual family members.

Using systemic ways of understanding, questioning, deconstruction and reframing, we can see how the parents start to feel more respect for their own ideas and less subservient to the professional discourse. They refocus on what is most important immediately to them - to work

on respecting the unique characters of their children and co-ordinate their lives together in ways that are valued and more relaxed.

Using Communicating Systems in an Area of Special Interest

Maturana suggests that every family member is a “scientist” – in as much as people generate explanations for behavior (Maturana, 1989). He speaks of the *passion* in human beings to attempt to understand, relate parts of a system but points out that we can only generate explanations (descriptions) of workings within the limits of our area of structural determinism (Maturana, 1991). This means that professionals, autistic people and other family members form living systems and are part of other living systems which are determined by culturally generated, linguistic structures.

Systemic lines of enquiry have been successful if an autistic person has an area of special interest as this can often be used as a resource (Simon, 2004, 2014). This interest or *area of expertise* may be the most likely topic of meaningful conversation for some people (Frith, 1991). The talk may appear repetitious and monotonous to listeners, especially tired parents and siblings. But when one listens, really engages with the topic, it has the potential to develop and show extensive understanding of communicating systems, both mechanical and social systems and how they work or break down. If we, as systemic therapists, reduce an area of real interest to simply a diagnostic evidence of autism, if we become seduced by obsessive symptom-spotting behaviors of diagnostic culture, then we lose our relational know-how and we will miss invaluable opportunities to hear about relational functioning within that area of interest. We risk overlooking a person’s vast body of knowledge of how things work together in the world.

Simon (2004) designed a six-session systemic intervention for parents or carers and children with a diagnosis of autism. This systemic approach generates additional strategies for

and alternative meanings about communication, connection and co-ordination *between* family members.

Exploration of the area of interest of a person with autism can bring forth a description of a meaningful, communication system. By understanding the area of interest as a communicating system, the therapist and family can be invited to communicate at times with each other through the metaphor of the area of interest. The system in an area of special interest can be useful in generating a language to describe the workings of that family and which all family members can use. This facilitates and helps to understand processes of communication, of change and learning what makes a difference. This can generate knowledge and expertise about the moving parts of a communicating, interactive system within a feedback loop. The narrative describes a relationally responsive system (train, driver, fireman, signalman, signals, pedestrians, passengers, fuel, water, air) in which all the component parts/people are cooperative and sensitive to communications. Within these cybernetic systems are feedback loops, mechanisms for managing cyclical or unusual events, rule-bound *and* rule-creating ways of being.

Simon noted how families reported that the sessions had made a positive difference to family relationships and school-based behavior. This was often accompanied by request for further sessions to explore parenting and parental relationships following the diagnosis of autism.

The Eco-Chaotic Conversational Approach

Ecology is sometimes used in everyday systemic practice as an alternative punctuation of the word “system.” Families are complex and moving practical, emotional and linguistic systems made up of different people, places and things, each with their own often invisible movements, influences and dependencies. A system which has subsystems interacting in such a way as to produce very intricate dynamics. But families are rarely highly ordered or predictable so

Urbistondo Cano (2017) has found it useful to consider the concept of chaotic system when working with families and carers where autism is present. The word “chaos” refers to the generation in systems of complicated and random behavior and complexity which generates rich, collective dynamic behavior from simple interactions between large numbers of subunits in systems (Bertuglia & Vaio, 2005). Chaos and complexity theory has its origins in mathematics and meteorology (Gleick, 1987; Parker et al., 2003) and intends to demonstrate the discontinuous, dynamic, unpredictable and nonlinear forces in many life domains (Cambel, 1993).

Urbistondo Cano (2017, 2018) understands systemic therapy sessions with carers of people with autism and learning disability as a “chaotic” conversation with an internal ecology. The person with autism is called a service user, a patient or a client and is described as having a “presentation” of behaviors by potentially different professional discourses, for instance in education, psychology, social care, nursing, etc. and different responsibilities and bodies of knowledge. Carers, for instance, might express as a problem not understanding the behaviors and emotions that the person with autism is presenting, often described as random or challenging behaviors (Challenging Behaviour Foundation, 2014). In this line, the idea of an “ecology” speaks to the relationships in this chaos and complexity. A systemic conceptual umbrella called *Eco-Chaotic Conversational Approach* (Urbistondo Cano, 2017, 2018) intends to generate new meanings by including the flux, the movement, the ever-changing life of the therapeutic process through the following ideas:

- A therapeutic context can be co-created between professionals and service users or clients and their support network around something called a “problem,” which constitutes an ecology of ideas and a meaning system (Anderson, Goolishian, & Winderman, 1986).

- That context embraces the chaos and the complexity of ideas that can be understood as part of an ecology of ideas (Hoffman, 1993) in which some ideas are more relevant and have more resonance than others.
- The therapist takes on a collaborative, dialogical stance in relation to what counts as knowledge and power and how it is produced (Anderson, 1997).
- During the therapeutic conversation, autism is understood as a social construction, as a fluid term which can mean many things depending on the context and who is involved in the dialogue.

The therapeutic context could be described then as a process of social construction (McNamee & Gergen 1992; Gergen, 2009) that happens in a conversation and in a relationship, in which different discourses from psychiatry, psychology, education or social work for instance, are understood as ways of thinking or perspectives around what is called “autism.”

In terms of co-creation of the collaborative and dialogical process (Anderson, 2007) the therapeutic encounter becomes a dance and a co-action (Gergen, 2009). If the person with autism does not communicate through verbal language then body language (Watzlawick et al., 1967) becomes more relevant: self-awareness in relation to feelings and sensations, reactions to other person's movements, expressions in the face, sounds and utterances and the way people look or don't look at each other. If the person with autism communicates through verbal language Urbistondo Cano (2017) gives an example of how to engage with questions around culture and bodily coordination:

So while I tend to look at the person that I am communicating with using intensive eye contact, I might ask my clients: “Is it okay if we look at each other while talking or you prefer that we don't look at each other now?” I might explain that I come originally from

Argentina, a country where people tend to look at each other a lot and sometimes I don't know if that is fine in this culture (England) and for some people. I prefer to ask and meta-communicate about the way we communicate than making the assumption that all people with autism always struggle with eye contact, which is not necessarily always the case. (p. 24)

Finally, Shotter (2012) proposes that “people are not objects, they are not machines, they are living beings – and as such, live in relations the others and othernesses in their surroundings. The task is to make sense of reality as it is rather than as we think it should be” (p. 4).

Using Systemic Ideas to Support Parents and Carers

Parents of children with a high level of care needs, may well face the need for their child to have home-based support from carers and/or eventually move to a specialist residential care home. The transition to residential care can be very traumatic for parents who often feel they have failed their children when handing over their care to others (Jinks, 2016). In addition, they also have to find scarce energy and confidence to enter into a long battle with health or insurance authorities to secure appropriate care for their children. This can be as a result of changes in policy, budget cuts, inadequate resources, or a lack of knowledge about that particular person and their condition. This makes for depleted, isolated, worried and angry parents and children who are at risk while there are delays in securing suitable placements. Jinks (2011, p. 73) shows the isolation and potential difficulties for both parents and carers.

We too were feeling more isolated as time passed by. Our son, now ten years old, was becoming bigger and stronger and we his parents, and his twelve years old sister, were finding life with Liam more and more stressful. Sleep was often interrupted, our social life almost non-existent and our home a fortress with doors, cupboards and fridge

locked to stop Liam eating everything or escaping (he has no sense of danger). He was often bored, having no language or play skills and would often become distressed. He would lash out and sometimes bite, scratch or throw things. He would target his sister in particular and pull her hair. Countless agency carers were sent to support us, latterly in pairs for safety reasons. Some were heroically committed, reliable and helpful, others would come once and would never be seen again. Each time a new worker came there was a lot of information about Liam's disability and possible dangers to be discussed before they spent time with Liam on their own.

Systemic therapist Urbistondo Cano (2018) proposes that if autistic people cannot participate in the conversation through language, it can be useful to invite their carers and support workers to participate in an “as if” activity (Anderson, 1997) by asking them to answer *as if* they are the person whom they are taking care of (Urbistondo Cano, 2018): “Now, let’s imagine that you are her. What do you think could be her answer to this question?” Urbistondo Cano shows how the therapist can use themselves to add other perspectives and generate empathy in care workers:

“OK, now I am her. I think that.... I feel that....” and then I start to engage in the conversation as if I were my client. I find it a useful way of engaging the support team in finding an empathic point of view in relation to the person with whom they are working.

Other Systemic Family Therapy Interventions

Stoddart (1999) describes clinical work combining of individual and family therapy primarily within a structural frame where the aim of the work was to clarify and establish relational hierarchies, boundaries and subsystems to enable the family to complete their developmental tasks. Tilsen et al. (2005) describe a narrative approach of externalizing and

appreciation of how autistic people think. Cashin et al. (2013) report positive outcomes from a study of brief narrative therapy with ten autistic young people of five sessions over ten weeks. Sessions involved getting to know the person away from the problem, identifying a preferred reality, externalizing the problem and doing experiments to create new meanings and relationships to the problem.

In a further description of group work this time with parents, Olinger (2010) uses outsider witness approaches with parents telling their stories to an audience who listen out for what resonates with them and the connections with their own experience. This led to greater collaboration in the play group that she ran for parents of autistic children through the involvement of these parents and culminated in a document written by parents for other parents of a child with autism. A study by Ramisch (2013) concludes that a ten-week Emotion Focused Therapy home-based intervention could be of use to families as a way to “move beyond negative interaction cycles and place their responses within a more emotionally supportive frame” (p. 386).

Helps (2016) describes how she adapted core systemic practices in working with young autistic women and their families. Adaptations involved using psycho-educative conversations, changing the pace of the work and going slowly to catch, understand and process emotion and meaning in what is being communicated. Interests and behaviors were used as a starting point from which to explore increased flexibility of interests and actions. Solomon and Cheung (2012) show how using action, meaning and emotion in family therapy is useful to families where someone has autism.

Guidance for Therapists Speaking with Autistic Children, Young People, Adults and Their Families

Before Starting Work With People Who Are Autistic and Their Families

- Before we start work with anyone with autism, it is really helpful to read books by people with autism or family members with an autistic relative. This is going to be a more useful orientation than simply reading a professional text. Try immersing yourself in the interests of the person with autism. Imagine the world through their eyes as well as those of their family members.
- As therapists, we need to re-position ourselves as learners. We must listen and ask always *as if for the first time*, with an openness and almost no anticipation. Such repositioning by the therapist makes space for the autistic person and their family to bring forth their pre-existing and useful knowledge and expertise.
- The practice of diagnostic symptom-spotting is highly contagious. Not only does it transfer to other professions such as our own, but also to the parents and other family members who simply emulate what the professionals consider to be good practice in their quest to be better parents etc. So, we must avoid questions which try to bring forth evidence of the presence of autism. We are not diagnosing.
- Meeting parents beforehand on their own is helpful as you understand more about the needs of the person with autism and can understand what kind of talk or conditions they will find accessible or not. You might even decide you could just work with the parents on their own.

The Sessions

- We need to be very clear in explaining the rules of the family therapy game. That means we need a clear and honest way of saying who we are, what our job is with them and what it is not compared to a teacher or psychiatrist. We need to explain how we talk, where the choices are about how we talk and how long we will meet for. Allow time for follow up questions. Be prepared to show everyone round the video suite if using video. Offer choice about ways of using technology and conducting the session. Having an autistic person in the conversation can enhance our standards of good practice.
- Rather than rush to a position of expert knowing, we need to create a culture of collaborative learning and sharing expertise in family therapy. Learning happens from within the living moment of interaction *with* people and not through theorizing without them or about them.
- We need to help other participants in the conversation (family and co-professionals) to recalibrate their expectations and learn to let go of their expectation of hearing repetitive, decontextualized facts so they can be receptive to noticing abilities and characteristics which contradict evidence of diagnostic criteria, and engage with the narrative of a system at work in an area of interest or other knowledge of communicating systems.
- We need to appreciate that the knowledge and expertise of a person with autism is not simply a list of decontextualized facts though it might sound like that at first. With more exploration, many autistic people can demonstrate both contextualized knowledge and hypothesizing abilities. A coherent narrative is made visible through having an interested enquirer.

- It is important not to assume that reflexivity, empathy, flexibility, emotions, understanding etc. are either present *or* absent in an autistic person. It may be that they are expressed or experienced differently. We need to appreciate that we are handicapped as systemic therapists by our expectations of usual ways of talking and that can limit our empathy and imagination.
- Experiment with and negotiate different ways of speaking or playing with people with autism and their families and find out what kind of talk makes a positive difference to them. Don't assume having parents in the room is going to make things easier. It may or it may not.
- Find a new or different conversational focus in an individual's life or their family life so they can each feel more engaged in setting an agenda for the therapy and be more inclined to break out of being good diagnostic patients.

Future Directions

- We need to avoid “aboutness” research and involve people with autism and their families in experimenting, developing and research systemic practice.
- The systemic profession needs to experiment collaboratively with families to develop ways of working which families find useful and sensitive to their specific needs.
- Further research is needed to explore what family therapists are already doing that families find helpful for their child with autism.
- We need research to explore the use of different systemic techniques such as the use of therapeutic letters, video review with families and children, one-way screens or the reflecting teams, the therapeutic alliance, with different kinds of play, spoken language, or embodied, non-verbal aspects of systemic practice.

- Systemic family therapists need to invest in developing therapeutic process research in order to be able to eventually produce an evidence base which is robust. working systemically in the contexts of different cultures, languages, ages, levels of cognition, with different learning disabilities.
- We need research into how we use systemic consultation with non-systemic colleagues in psychiatry, psychology, social work, health and education to understand children and young people with autism and their families.
- We need to help the systemic profession become inclusive of colleagues with autism and resist pathologizing discourses which “other” people.

Conclusion

Family therapists are well placed to work with families where relationships and patterns of communication are difficult - whatever the cause. Autism is not owned as a subject by any one professional discourse such as psychiatry or psychology. People with autism should always be offered the choice of working on relational issues with their significant others. Isolating individuals with autism by seeing them as the site for treatment deprives people of the potential to improve relationships and feel understood. Systemic family therapy should therefore be available to families where a child has autism.

Based on the published literature, this chapter covers the small but important body of practice-based evidence about what works in working with families where there is a child or young person with an Autism Spectrum Condition. The literature shows how systemic family therapists are experimenting in developing ways of working with families where autism is present, innovating new systemic theory and understanding.

The field of systemic family therapy with families where autism is present is at a very early stage of development. The field of systemic family therapy cannot, and perhaps should not, provide one fluid and coherent story of what family therapy looks like where autism is present. Nor do we espouse a single story of autism. Rather, we invite our colleagues to be inspired to collaborate with families using some of the ideas in this chapter to see what works for them and to develop systemic creativity and sensitivity in this field of work and not rush to generate or follow any prescribed manualized practices which could further marginalize a very diverse group of people. Systemic approaches can help families where a person has an Autism Spectrum Condition and challenge other theoretical models to move beyond the notion of internalized pathology to see human systems as knowledgeable and able participants in communicating systems. Systemic family therapists can make a useful and important contribution in supporting families and consulting to colleagues through using creative and playful communications to ensure diagnostic culture does not limit our cognitive abilities as practitioners working with complex systems and multi-agency contexts. Systemic conversation is not understood as collecting knowledge so much as a means of collaboratively understanding and generating knowledge.

The profession of systemic family therapy needs to learn from each and every family, and from each and every therapist to be appreciative not only of neurodiversity but of methodological diversity.

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Endnotes

¹ This example is based on more than one family and highlights commonly encountered themes of “oughtisms.” Names and comments have been changed to protect anonymity except where real names came from a quote in another publication as was the case with Liam (reproduced here with his parents’ permission).

² Indeed, this has already happened. It has been shown how Hans Asperger handed over details of children and young people with autism to the Nazis who then systematically murdered them in the holocaust (Sheffer 2018).

³ We remember Liam Jinks who provided much joy and learning for his family, care workers and many others like us.