



*Journal of
Religion & Society*
Supplement Series

The Kripke Center

Supplement 12 (2015)

**Caring for Persons with Intellectual and
Developmental Disabilities**

Ethical and Religious Perspectives

Edited by Jos V. M. Welie, Creighton University

“Nothing about Us without Us”

**Understanding Mental Health and Mental Distress in Individuals with
Intellectual and Developmental Disabilities and Autism through their
Inclusion, Participation, and Unique Ways of Communicating**

Elsbeth Bradley, University of Toronto, Canada

Phoebe Caldwell, University of Bristol, UK

Marika Korossy, Toronto, Ontario

Abstract

Full inclusion and participation of people with intellectual and developmental disabilities in daily life in their own communities, is now recognized as their human right and is a stated goal in many countries. When people with intellectual and developmental disabilities experience mental distress, or their behaviors appear unusual, attending carefully to their

communication in whatever way this occurs is crucial, as their perspectives on what may be causing this distress (or unusual behaviors), may be different from what might be concluded based on traditional psychiatric diagnostic frameworks, e.g., *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and *The International Classification of Mental and Behavioral Disorders* (ICD). Learning the emotional and behavioral language of those who do not communicate in typical ways will ensure that all with intellectual and developmental disabilities contribute their voices to a better understanding of the mental distress they experience and should result in more effective interventions and optimal mental health and well-being.

Keywords: learning disabilities, developmental disabilities, intellectual disabilities, autism, profound and multiple disabilities, mental distress, psychiatric disorders, unusual behaviors, problem behaviors

Introduction

Throughout history, people with disabilities have been viewed as individuals who require societal protection and evoke sympathy rather than respect. The United Nations Convention on the Rights of Persons with Disabilities is described as a major step toward changing the perception of disability. It strives to ensure that societies recognize that all people must be provided with opportunities to live life to their fullest potential. This includes freedom from disability-based discrimination, respect for inherent dignity and individual autonomy, including the freedom to make one's own choices. In the context of this Convention "persons with disabilities" include those who have physical, mental, intellectual or sensory impairments that, in interaction with various barriers, may hinder their full and effective participation in their own communities on an equal basis with others (United Nations: Article 1).

In various countries, the history of care, specifically for people with intellectual and developmental disabilities, has included sending many to institutions at an early age. In the latter part of the twentieth century, concerns about this institutional care gave way to programs of deinstitutionalization with a focus on community integration and normalizing the conditions of their lives. While there has been much progress in these regards, efforts to integrate people with intellectual and developmental disabilities into mainstream activities have been criticized as a practice aimed at individuals rather than the social contexts in which they find themselves. Recently, a new vision about a life of dignity and citizenship through inclusion, participation and relationships has been proposed by the International Association of Social Educators (AIEJI).

Beyond a focus on the importance of inclusion, participation and relationships from a social rights perspective, we propose that this nature of social engagement is crucial in matters related to emotional wellbeing and the mental health of people with intellectual and developmental disabilities; in the absence of this engagement, the risk of making diagnostic errors and consequently providing inappropriate and even harmful treatments is greatly increased. We need to avoid imposing a perspective of mental ill-health that has developed solely from the population that has not experienced the challenges of living with developmental conditions. Inclusion of people with intellectual and developmental disabilities as active contributors, and not just as passive recipients, is central to a better understanding of their mental health and emotional concerns.

As a template for this understanding, the focus here is on autism, a lifelong neurodevelopmental condition that embraces all ages and all levels of capacity. This offers a unique situation where more able individuals can comment on what it is like to have autism and to describe the mental distress they experience and its origins. This is referred to as the Inside-Out (as opposed to the Outside-In) perspective, a term first coined by Donna Williams (1996), a well-known Australian writer, teacher, artist and musician diagnosed with autism as an adult. There are now numerous instructive autobiographical accounts by people with autism (Gerland; Grandin and Scariano; Jolliffe, Lansdown, and Robinson; Nazeer).

The Outside-In perspective is the view of mental health and mental disorders as we have come to understand these disorders in the general population (without autism) – this perspective is communicated in the two major diagnostic texts – the *Diagnostic and Statistical Manual of Mental Disorders: DSM-5* (DSM) (American Psychiatric Association and American Psychiatric Association. DSM-5 Task Force), used largely in North America, and *The International Classification of Mental and Behavioural Disorders* (ICD) (World Health Organization) used more globally. We propose that these frameworks of understanding mental ill-health are insufficient to explain the mental distress experienced by those with intellectual and developmental disabilities and with autism.

In support of this proposition, we highlight two individuals in greater detail: Tito Mukhopadhyay, diagnosed as a child with autism and mental retardation,¹ and Donna Williams, mentioned above, both of whom have written extensively about their autism experiences. Their autobiographies and poetry provide fascinating insights into the world of autism and explain behaviors that at first may seem bizarre to people who do not have autism. But the adaptive nature of these behaviors becomes more understandable when we consider autism from the Inside-Out point of view.

The second half of this article is devoted to individuals with profound and multiple intellectual and developmental disabilities, many of whom also have autism.

Understanding Mental Distress in Autism

In answer to the question “what can be learned about mental distress and mental ill-health from those with autism?” we introduce Tito Mukhopadhyay as seen on *60 Minutes* and *YouTube* (Mabry), engaging in repetitive, ritualistic behaviors that interfere with his daily activities and, one presumes, his learning.

Such repetitive behaviors have been extensively described in people with autism; some may engage so intensely, they cause injury to themselves – this is frequently referred to as self-injurious behavior. If care providers interrupt, some individuals will lash out aggressively and may hurt others or destroy property. Because these behaviors are often seen by care providers as embarrassing or inappropriate, they frequently lead to referral to mental health services. If the behaviors result in aggression or self-injury, care providers and services may feel obliged to intervene with physical restraint or medication (Emerson and Einfeld).

¹ Different diagnostic criteria are described in the IACB Consensus Statement. DSM-5 diagnostic criteria adopt the term intellectual disability (intellectual developmental disorder)

Fortunately, Tito is able to tell us why he is engaging in these behaviors and offers us the opportunity for more empathically aligned and effective intervention.

I am calming myself. My senses are so disconnected, I lose my body. So I flap (my hands). If I don't do this, I feel scattered and anxious . . . I hardly realized I had a body . . . I needed constant movement, which made me get the feeling of my body . . . I need to move constantly to be aware that I am alive and my name is Tito (Mabry).

Tito is telling us he needs the sensory input he is creating by flapping, in order to know who he is. He is seeking deep pressure and proprioceptive input from his muscles and joints to appreciate and validate his sense of self; he is low on this input – and is boosting this himself – this is part of the autism condition for many (Caldwell and Horwood; Donnellan, Hill, and Leary).

From a variety of sensory receptors located in our tissues, we get continuous feedback about the state of our bodies. We process these incoming sensory perceptions mostly unconsciously, but some can be brought to consciousness: reflect next time when standing or sitting with others and bring to awareness what you feel in your feet, your legs, your torso, working upwards towards your arms and then neck and head; if you now move your hand you will see your hand move and you will feel your hand moving, you may see your neighbor's hand move but you will know exactly which movements are yours and which are your neighbor's. Imagine if the visual and proprioceptive feedback you get is scrambled (an experience described by those writing about their autism) and you have difficulty matching the two different visual images with what are your movements and what are your neighbor's movements – you will become confused as to who you are and may even panic. Our experience of ourselves, through our senses, is fundamental to how we manage our emotions (for more examples of these processing difficulties and sensory confusions experienced by people with autism, see Box 1).

Box 1: Examples of Sensory Confusions and Processing Difficulties Described by People with Autism

1. Temple Grandin tells us that autistic people “get visual cues mixed up with aural ones.” She writes, “When autistics are listening to sound cues, their visual cortices remained more active than neurotypicals. If this is the case, then even while they are straining to process aural cues, they're being distracted and confused by visual ones.” (Grandin and Panek: 91).
2. Donna Williams (to whom we owe so much of what is known about what it feels like to be autistic) tells us that she can hear better if she is wearing her colored lenses – suggesting that the actual capacities to process auditory and visual stimuli appear to intermingle, with consequent interference and distortions (Caldwell 2014a).
3. Donna Williams also comments, “The underlying causes of hypersensitive reactions may have nothing to do with the perception of pitch or volume but rather are the results of information processing problems.” As Williams points out, the problem is not with the sounds themselves but the stress involved in

trying to interpret the overloaded system, in making meaning from what has been heard (or seen, in the case of visual distortion) (Williams 1996). Recent research suggests that impaired audition stems from complex neural deficits rather than outer ear dysfunction (Davis and Steigler)

4. Apart from processing problems of sensory stimuli, Chris [quoted in the *The Anger Box*] talks about her relationship to her body, how she has “out of body” experiences when she is looking down on herself, observing herself from above, and having no relationship with her body. Chris comments, “my head and body seem to separate” . . . “I don’t know which bits are me; who I am and who everyone else is, is not clear – the edges between us seem to soften, sometimes they include everyone else rather than just me, I can’t be separate.” Or “I find myself being fragments of other people” . . . “But sometimes my body is too tight” . . . “I can’t see all of myself at the same time. Until I look in the mirror, I have no idea what I look like, who I am.” (Caldwell 2014a: 89-94)
5. A loss of (physical) boundaries is also described by others with autism. For example, Richard says, “I have a poor sense of my body and where it is. The bicycle provides a framework to fit my body with five contact points, I feel connected on a bicycle, there is a lovely warm comfortable sense I am an embodied being. I get messages from my body, I don’t feel like I am floating somewhere nearby watching my body from a distance. It’s good to feel like a flesh and blood human being . . . and know where I am and what size I am.” (Maguire: 86)
6. Because of the sensory distortions Chris experiences, she says that when faced with a situation, her first question now is always, “is this real or not real?” “Bits of me seem to have to be on the backburner so I can function at all,” she says, “When I have lost my boundaries, the first puff of a cigarette [a physical sensation] brings everything back.” (Caldwell 2014a: 89-94)
7. In addition to all of the above, there is “emotional overload” (used in the sense which the authors understand that Donna uses it – a bodily flooding of sometimes disconnected feelings, pure sensation without a home, the word “emotion” not connecting with affective warmth; an internal effect rather than cause). This emotional overload does not seem to be related to anything and is rather a floating time-bomb, activating without warning. “Sometimes you know what you want to do but just can’t do it: I will want to read but just sit crying, the page is just a string of words.” Her ability to attend and put things together has gone (Williams 1996).

Autism is associated with unique neurobiology. Significant differences in brain structures and neurobiological functioning have now been found that underpin different perceptual and psychological experiences described by Tito and others (Baron et al.; Kushki et al.; Minshew et al.: 632-60; Parellada et al.: 11-19). This has led some individuals with autism to refer to themselves as “Neuro-Atypical,” compared to those who do not have autism, to whom they refer to as “Neuro-Typical.”

These different experiences are well documented in self-narratives by people with autism – including those by Tito and Donna already mentioned. These neuropsychological differences include being over-sensitive or under-sensitive to sounds, lights, smells, tastes, as well as problems with filtering and processing incoming information, especially verbal information such as normal conversation. Table 1 shows two examples of these differences in brain processing alongside behaviors of distress that we might observe as a result of these differences. For example, if a person covers his ears or eyes with his hands, this could be an indication that surrounding sound or light is too intense or uncomfortable. If a person experiences difficulty filtering out unimportant information so that there is more information coming in than the individual can handle, giving rise to sensory overload, the brain “crashes” in its ability to cope and the individual may show a variety of behaviors indicating his/her distress.

Table 1. Two Examples of How Unique Neurobiological Functioning in Autism can Lead to Distress and Unusual Behaviors²

Differences in brain processing associated with:	The following distress behaviors may alert to the presence of these differences:
1. a. Hypersensitivities to sensory input b. Sensory distortions	<ul style="list-style-type: none">• squinting eyes, hiding eyes, hands over ears,• squirms to touch, avoids touch, gags to tastes, textures and smells;• difficulties focusing and concentrating• avoidance of the offending places or people• outbursts where this is not possible.
2. Inability to filter out unimportant incoming stimuli so their processing system is swamped by surplus detail.	<ul style="list-style-type: none">• Stalling and freezing in movements; behavioral outbursts; meltdowns and temper tantrums.

This experience of overload and resultant distress behaviors are vividly described in a video simulation created by a woman with autism to help those without autism understand how powerful, dramatic, and debilitating this experience is.

. . . I process information at a slower pace than average. My brain is like a dial-up modem versus a cable modem. Non-autistic brains are like cable modems that take in several data packets at a time. My brain doesn't work that way. If you try to send it more data than it can handle, it crashes . . . [when this happens] I hear everything four times louder than a non-autistic person . . . if I don't remove myself from the situation I immediately go into

² Examples 1 and 2 taken and adapted from Table 1 in Bradley and Caldwell: 15.

sensory overload. To someone watching, I appear to cop an attitude or fly into a rage . . . When I'm in overload I'm in a fight or flight response. Acting angry is a defense mechanism . . . once I am in full overload there is nothing I can do but ride the meltdown until I've expelled all my emotional energy. I just kinda lose my head and explode and then I'm fine (WeirdGirlCyndi).

Flight responses are associated with that part of our nervous system, the autonomic nervous system (ANS), that activates when we come face to face with danger such as a predator; we may stand and fight the predator, or run away, or we may find ourselves rooted to the spot with fear. These same responses occur in people with intellectual and developmental disabilities and autism when overwhelmed in daily life (e.g., associated with processing difficulties) with what is going on around them. They have been described both by parents and care providers (Caldwell 2014a: chap. 6) and observed in clinical practice (Dhossche et al.; Loos and Loos Miller; Mazzone et al.; Wing and Shah). Fight responses are seen in aggressive behaviors (and may be misinterpreted as psychosis); *flight* responses include running away or withdrawing (and may be misinterpreted as depression), and *freeze* behaviors are slowed movements and posturing, sometimes referred to as catatonia.

We can imagine these behaviors in ourselves when faced with a situation where we feel in mortal danger. When on a routine flight we hear the engine starting to fail and the pilot instructs us to take emergency action, some people on the flight will show their fear by screaming, some will want to get up and do something, some will freeze, unable to move at all, some may actually faint from fear while others may engage in behaviors that are familiar and reassuring, such as prayer.

Others (in addition to WierdGirlCyndi) with autism have also written about their experiences when they become overwhelmed and unable to process all that is going on around them. For example Donna Williams recalls engaging in self-injury as a child:

There was a rip through the centre of my soul. Self-abuse was the outward sign of an earthquake nobody saw. I was like an appliance during a power surge. As I blew fuses my hands pulled out my hair and slapped my face. My teeth bit my flesh like an animal bites the bars of its cage, not realizing the cage was my own body. My legs ran round in manic circles, as though they could outrun the body they were attached to. My head hit whatever was next to it, like someone trying to crack open a nut that had grown too large for its shell. There was an overwhelming feeling of inner deafness – deafness to self that would consume all that was left in a fever pitch of silent screaming (Williams 1995b: 9).

Essentially, Donna's response to feeling overwhelmed is the fight response – and the need for action.

In her movie "Jam Jar," Donna poignantly describes her experience of two worlds: "their world" or "the world," and "my world." The distinction speaks to her experience of being different and her resulting anguish.

The definition of autism is a love hate relationship with yourself – and that's me and my brother [looking at photographs in an album] but this is like

permanent smile [pointing to her face in the photograph] that's just stuck on not connected inside . . . and that's different to when they make me in their world and they take all my patterns out and just want this . . . [gesture] – then it's not connected . . .

That's me and Paul and we are touching feet and making the ground [gesture of walking on the ground with squelching sound] . . . cause I was before just me in my world and now together with somebody else I can be like my world but with someone else . . . and not always just have the choice of tear up your real self and then be in the world with the world people

There are many components to autism. Autism not just one thing. It is an emotional hypersensitivity problem . . . it can be an information processing problem . . . it can be total withdrawal into yourself where the whole world is replaced and made redundant and you have every relationship with your own self that you could have with people in the world and they don't matter anymore (Williams: 1995a).

The experience of anxiety is part of our human consciousness and our evaluation of risk – it is protective and keeps us safe (Bateson, Brilot, and Nettle). But anxiety is more prevalent and more severe in people with autism and intellectual and developmental disabilities (Helverschou and Martinsen; White et al.). Feedback from people with autism through their words and through their behaviors is informing us that we need to consider both “neuro-typical” anxiety (anxiety experienced in the general population without autism) and the anxiety experienced in autism which we can refer to as autism-associated anxiety. Self advocates with autism write about their autism associated distress and anxiety as follows:

I used to repeat the same words over again as this made me feel safer (Jolliffe, Landsdown, and Robinson).

Trying to keep everything the same reduces some of the terrible fear (Jolliffe, Landsdown, and Robinson).

Someone looking directly into my eyes felt like an attack (Nony: 1).

Treatment of Mental Distress

Evidence based practice for the treatment of anxiety disorders includes medication and psychological therapies (National Institute for Health and Care Excellence). The same approach is also used to treat anxiety conditions in people with autism and other developmental disabilities, but often with less effect. Not surprising, as the aetiology of the distress giving rise to anxiety behaviors is often different. Table 2 shows contributors to anxiety behaviors in individuals with autism along with interventions to reduce or prevent this distress. For example, if the individual is hypersensitive to light and pattern, instead of resorting to anxiolytics we can change the lighting source, color, and intensity, or take away the brightly colored patterned material that is causing distress. In response to proprioceptive deficits and vestibular distortions, we can offer pressure, physical activities, and sensory integration therapy (Table 2).

Table 2. Contributors to Stress and Anxious Behaviors in Autism ³

Contributors to stress and anxious behaviors	Strategies to reduce stress and resultant anxiety from this cause
<p>A. Painful incoming stimuli caused by sensory hyper-sensitivities to external stimuli such as:</p> <ul style="list-style-type: none"> • light and pattern 	<ul style="list-style-type: none"> • Use diffuse soft lighting, remove fluorescent lighting; • Where appropriate, provide colored light or lens. • Use dimmer switches. • Offer sunglasses. • Avoid brightly colored patterned materials.
<p>B. Deficits in the proprioceptive system and distortions in the vestibular systems</p>	<ul style="list-style-type: none"> • Provide pressure to body parts: e.g., using sports pressure clothing, weights, back packs, bean bag presses • Use outdoors activities: e.g., swing, seesaws, roundabouts, climbing walls, trampoline vibration to increase body awareness. • Use visual clues for start, stop etc. • Sensory Integration Therapy.

These interventions may seem small but can be huge in their implications for those with autism who have these sensory sensitivities, proprioceptive deficits, and perceptual distortions; it is the difference between being able and not able and the difference between being calm or in a highly anxious dysregulated emotional state. In the assessment and treatment of anxiety in autism there is, therefore, need to consider both typical anxiety as well as autism-related anxiety; the latter is about appreciating the unique neurobiology of autism and consequent differences in brain processing and sensory and perceptual experiences. Autism related distress and anxiety can be identified by attending to the verbal and written accounts offered by those with autism. In addition or when such accounts are unavailable, empathic observations of behaviors and engagement with individuals in distress through approaches such as Intensive Interaction will be informative (see Box 2; Caldwell and Horwood).

Box 2. Intensive Interaction

Intensive Interaction uses the child's or the adult's personal body language to develop emotional engagement. This includes responding to (rather than mimicking) their sounds, movements, rhythms, interests, and behaviors

³ Examples A and B taken and adapted from Table 2 in Bradley and Caldwell: 16.

(including repetitive behaviors), using these as a language with which to build up a reciprocal conversation. It is not just about what individuals do but also how they do it. Intimate attention allows us to tune into how they are feeling and align ourselves to their affective states. Intensive Interaction is at its most effective when combined with attention to sensory deficits such as hyper- and hypo-sensitivities (not only of vision, sound and touch, but also their emotional sensitivities), and awareness of physical pain (Caldwell 2014a).

Inclusion and Participation of People with Autism and Intellectual and Developmental Disabilities in Health Related Matters

This is not just about taking away barriers that exclude people with autism and intellectual and developmental disabilities, either directly (e.g., in some countries general psychiatric services may specifically exclude those with intellectual and developmental disabilities or autism arguing that these services do not have the necessary resources or expertise) or indirectly (e.g., because the patient with intellectual and developmental disability or autism may not be able to remain still for an X-ray or other such investigation, their medical condition may not be adequately investigated) from services. Inclusion and participation means actively reaching out and building the necessary bridges, appreciating that individuals with autism may have a different experience of the world from our own, and making any necessary accommodations so that they are comfortable in their surroundings and then able to participate fully and actively. These bridges will include finding the best way of communicating with each person. Many people with intellectual and developmental disabilities including autism find pictures easier to understand than words (Boardman, Bernal, and Hollins).

Individuals with profound and multiple developmental disabilities are completely unable to use verbal language to participate in their own health care and service planning. While not able to articulate their experience directly to us, they can, however, tell us when they are happy and content through their non-verbal responses in the context of empathetic and supportive relationships developed over time. This is exquisitely demonstrated in the film “If you listen you will hear us” (see Box 3).

Box 3. Transcript from “If You Listen You will Hear Us”⁴

Narrator: When we talk to each other we are expressing our feelings, talking about our opinions and needs, our likes and dislikes. We take for granted usually we can easily understand those around us and make ourselves understood. But not everyone finds communicating in this way easy. People with profound and multiple learning difficulties (PWPMLD) can communicate but not usually with words. Most will mainly express themselves through non-verbal gestures and through their day to day behaviors. Their communication is personal to them and hard to interpret for people who do not know them well. They will have severely limited

⁴ We gratefully acknowledge Leicestershire and Leicester Learning Disability Partnership Boards, UK, who commissioned this movie and Bill Newsinger, filmmaker, for allowing us to make a transcript from listening to the movie clip and including it in this publication.

understanding due to their learning disability and additional disabilities that may include impairment of their vision, hearing and movement, as well as other disabilities like epilepsy, autism and mental-ill health. Many people in this group are unable to walk unaided and may have complex health care needs which require specialist support such as physiotherapy and gastric feeding. These difficulties, especially in relation to communication, mean that traditional methods of engagement used by services do not work even when we make them more accessible. This has left this group of people with no voice in decisions in relation to things that have a major impact on their day to day life and no way of commenting on the services they receive. Although parents and families are skilled at advocating, their voice is not always heard and we have no mechanism of using the personal every-day information that we gather to monitor and plan services. It is not surprising that PWPMLD are the most difficult people to involve in consultation and decision making. We must remember that this group of people do have the same rights as you and I.

Jo Canham – Community opportunity officer: I provide sensory story telling sessions at the day center. This allows individuals to play an active part within the stories. These activities are a great way of detecting how someone is actually feeling . . . it has taken several years for me to get to know Hemma (an individual shown in the film) this closely (when she is happy and sad and how to cheer her up) and our relationship means I can interpret how Hemma is feeling. Consistency means relationships can be formed, and relationships enable people to communicate. In order to help PWPMLD they need to have access to a wide variety of activities and approaches. This then enables us to understand how they can communicate.

Narrator: PMLD will have unique ways of communicating. These ways will be known by close family and carers. Their preferences will be expressed mainly through day to day behaviors. Skilled support staff, including parents and family carers, can interpret and record these preferences. This information can then be documented in each individual's person centered plan and communication passport.

Avril Croft – Support staff: One of the most important documents and resources we have to work with in this work is something called Communication Passports (Millar and Aitken). This is a document that is put together for each individual by carers, by parents, by professionals. Everyone who has been involved with the person throughout their whole lives will put in information onto this document so that the rest of us when we come across this person can look at this document and it gives us a really good guide as to how we are going to work with this person.

Lyn Spence – Mother of Charles: This is Charles' person centered plan (Millar and Aitken) and the communication passport is an integral, and to my mind, the most vital aspect of it. If anyone is really wanting to get to understand what Charles is saying to them and to listen to him well, they need to read this and to read it thoroughly and carefully. It has taken me about 30 years to be able, and be fluent, in speaking Charles, but anyone else can do the same if they read and ponder this really carefully. The information contained in a communication passport is vital not

only to Charles but it is actually very important for those who are planning services for him. Those who are commissioning services need to be able to take on board the importance of the information contained in a communication passport. It really does tell them everything they need to know to get it absolutely right.

Narrator: It can take a long time to identify how someone expresses their choices and needs, but the outcomes are immeasurable to that individual. To do this effectively it is really important to have consistent staff who need to be trained in reading the subtleties of behaviors. The key to purchasing and planning meaningful services for people is to treat each person as unique and recognize they will have a personalized way of communicating. This ensures that we meet more than people's personal care needs.

Khairun Maden – Support worker: I think it is very important for PWPMLD to experience a while range of different activities and it is through these activities that they are able to show their preferences.

Narrator: Intensive Interaction (see Box 2), music therapy, aroma therapy, sensory stories, hydro therapy, sensory rooms and gardens, all of these can provide us with a gateway for communication and interaction.

Joy Gravestock – Music therapist: Music therapy is a very special way of being able to communicate with severely disabled clients. And music is a different mode of communicating – it uses music so there is no need for words and clients can express feelings in a sound, in a note, in a vocalization or an utterance. Using something small as a change of color in someone's face could indicate a change in emotion. So as a music therapist I need to be trained to focus very intensely on the micro communication in a client's face, or the smallest gesture, the smallest blink of an eye, or movement of a finger could communicate quite a lot to me. Being a musician and a music therapist is not about playing with clients or playing to clients, but it is about allowing clients to express themselves with me in a relationship. That relationship is crucial to what we do. As such I have very long term relationships with many of my clients. It takes a long time to build relationships with these clients when their communications are often so small and take time to understand.

Narrator: In March, 2008 the joint committee on human rights issued a report "A life like any other" highlighting in particular the human rights of adults with LD (intellectual and developmental disabilities) (House of Lords and House of Commons Joint Committee on Human Rights). This provides a legal framework for service providers to work towards. All of these personal views on services, how people want and need to live their lives, all of this valuable information that is provided by parents and carers, the use of therapists and other professionals that work with this client group, all of this information needs to be pulled together to help with the evaluation and improvement of services. We all have a responsibility to enable PWPMLD to reach their potential and to be treated with dignity and respect (Leicestershire Partnership NHS Trust).

We have to learn how to speak “Charles” (as described by Lyn Spence, mother of Charles described above); Charles and others with profound and multiple developmental disabilities are unique communicators – we can learn about their mental distress and needs from their behaviors. Consistent, mutual, and supportive relationships over time provide the context within which people with profound and multiple learning difficulties (PWPMLD) communicate their needs and preferences and the context within which care providers can learn their communicative language. As with the narratives of self-advocates with autism, appreciating that experiences and perspectives may be very different from our own will enhance this learning opportunity.

Conclusion

“Nothing about us without us,” a quote from disability rights groups in the early 1980s, takes on a particular poignancy when we consider mental distress and ill-health in people with autism and intellectual and developmental disabilities. However this is not just a rights issue. Inclusion and active participation of Charles and others with intellectual and developmental disabilities or with autism are essential as we try to understand the mental distress they experience, develop appropriate and responsive services, and seek feedback from them about our efforts in these regards. This is also ethical and good clinical practice.

The Convention on the Rights of Persons with Disabilities (United Nations) notes, “There are no people without language since all human actions can be ascribed meaning.” This quote speaks to the importance of removing the barriers we create by assuming all communication is verbal, thereby excluding those not using words. In learning the unique body language of our communicating partner with intellectual and developmental disabilities or autism, we find ways to engage with and better understand the inner experience of that person. In the absence of being equal partners in the communication dialogue we are at risk of doing harm, albeit unintentional.

Bibliography

- American Psychiatric Association and American Psychiatric Association
2013 *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*. Fifth edition. Washington, D.C.: American Psychiatric Association.
- Baron, M. G., J. Groden, G. Groden, and L. P. Lipsitt
2006 *Stress and Coping in Autism*. Oxford: Oxford University Press.
- Bateson, M., B. Brilot, and D. Nettle
2011 “Anxiety: An Evolutionary Approach.” *The Canadian Journal of Psychiatry* 56, 12: 707-15.
- Boardman, E., J. Bernal, and S. Hollins
2014 “Communicating with People with Intellectual Disabilities: A Guide for General Psychiatrists.” *Advances in Psychiatric Treatment* 20: 27-36.
- Bradley, E. and P. Caldwell
2013 “Mental Health and Autism: Promoting Autism FaVourable Environments (PAVE).” *Journal on Developmental Disabilities* 19, 1: 8-23. Available online from

http://www.oadd.org/docs/41015_JoDD_19-1_8-23_Bradley_and_Caldwell.pdf.

Caldwell, P.

2014a *The Anger Box: Sensory Turmoil and Pain in Autism*. Hove: Pavilion Publishing and Media.

2014b "Autism and Intensive Interaction." Available online at <http://www.phoebecaldwell.co.uk/>.

Caldwell, P. and J. Horwood

2008 *Using Intensive Interaction and Sensory Integration: A Handbook for those Who Support People with Severe Autistic Spectrum Disorder*. London: Jessica Kingsley.

Davis, R., and L. N. Steigler

2005 "Toward More Effective Audiological Assessment of Children with Autistic Spectrum Disorder." *Seminars in Hearing* 26, 4: 241-52.

Dhossche, D., L. Wing, M. Ohta, and K.J. Neumärker, Editors

2006 *Catatonia in Autism Spectrum Disorders*. International Review of Neurobiology 72. San Diego: Academic.

Donnellan, A. M., D. A. Hill, and M. R. Leary

2013 "Rethinking Autism: Implications of Sensory and Movement Differences for Understanding and Support." *Frontiers in Integrative Neuroscience* 6, art. 124: 1-11. Available online from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3556589/pdf/fnint-06-00124.pdf>.

Emerson, E., and S. L. Einfeld

2011 *Challenging Behaviour*. Third edition. Cambridge: Cambridge University Press.

Gerland, G.

2003 *A Real Person: Life on the Outside*. London: Souvenir.

Grandin, T., and R. Panek

2013 *The Autistic Brain: Thinking Across the Spectrum*. Boston: Houghton Mifflin Harcourt.

Grandin, T. and M. Scariano

1986 *Emergence, Labeled Autistic*. Novato: Arena.

Helverschou, S. B., and H. Martinsen

2011 "Anxiety in People Diagnosed with Autism and Intellectual Disability: Recognition and Phenomenology." *Research in Autism Spectrum Disorders* 5, 1: 377-87.

House of Lords and House of Commons Joint Committee on Human Rights

2008 *A Life Like any Other? Human Rights of Adults with Learning Disabilities*. London: Stationery Office Limited. Available online at <http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf>.

- International Association of Social Educators [AIEJI]
- n.d. "Working with Persons with Developmental Disabilities – the Role of the Social Educator." Available online at <http://aieji.net/wp-content/uploads/2010/12/Working-with-persons-with-developmental-disabilities.pdf>.
- Jolliffe, T., R. Lansdown, and C. Robinson
- 1992 "Autism: A Personal Account." *Communication* 6, 3: 12-19.
- Kushki, A., E. Drumm, M. Pla Mobarak, N. Tanel, A. Dupuis, T. Chau, and E. Anagnostou
- 2013 "Investigating the Autonomic Nervous System Response to Anxiety in Children with Autism Spectrum Disorders." *PloS One* 8, 4: e59730. Available online at <http://www.plosone.org/article/fetchObject.action?uri=info%3Adoi%2F10.1371%2Fjournal.pone.0059730&representation=PDF>.
- Leicestershire Partnership NHS Trust
- 2013 "If You Listen, You Will Hear Us." By Bill Newsinger. Available online at <http://vimeo.com/49957264>.
- Loos, H. G. and I. M. Loos Miller
- n.d. "Shutdown States and Stress Instability in Autism." Available online at <http://www.ingridloosmiller.com/files/SI-SDinAutism.pdf>.
- Mabry, V., narrator
- 2003 "Breaking the Silence: One Woman's Drive to Teach Her Autistic Son." *CBS 60 Minutes*. Available online at <http://www.youtube.com/watch?v=Nfiap3a7Tuo>.
- Maguire, R
- 2014 *I Dream in Autism*. Buckinghamshire: A Penn PR.
- Mazzone, L., V. Postorino, G. Valeri, and S. Vicari
- 2014 "Catatonia in Patients with Autism: Prevalence and Management." *CNS Drugs* 28, 3: 205-15.
- Millar, S., and S. Aitken
- n.d. "Personal Communication Passports: Guidelines for Good Practice." Available online at <http://www.communicationpassports.org.uk/Home/>.
- Minshew, N. J., K. S. Scherf, M. Behrmann, and K. Humphreys
- 2011 "Autism as a Developmental Neurobiological Disorder: New Insights from Functional Neuroimaging." Pp. 632-50 in *Autism Spectrum Disorders*. Edited by D. Amaral, G. Dawson, and D. H. Geschwind. New York: Oxford University Press.
- National Institute for Health and Care Excellence
- n.d. "Generalized Anxiety Disorder and Panic Disorder (with or without Agoraphobia) in Adults Management in Primary, Secondary and Community Care." Available online at <http://publications.nice.org.uk/generalised->

- anxiety-disorder-and-panic-disorder-with-or-without-agoraphobia-in-adults-cg113.
- Nazeer, K.
2006 *Send in the Idiots: Stories from the Other Side of Autism*. New York: Bloomsbury.
- Nony
1993 "Speculation on Light Sensitivity." *Our Voice* 3: 1.
- Parellada, M., M. J. Penzol, L. Pina, C. Moreno, E. Gonzalez-Vioque, G. Zalsman, and C. Arango
2014 "The Neurobiology of Autism Spectrum Disorders." *European Psychiatry: The Journal of the Association of European Psychiatrists* 29, 1: 11-19.
- United Nations
n.d. "Convention on the Rights of Persons with Disabilities." Available online at <http://www.un.org/disabilities/convention/about.shtml>.
- WeirdGirlCyndi
n.d. "Sensory Overload Simulation." Available online at <http://www.youtube.com/watch?v=BPDTEuotHe0>.
- White, S. W., D. Oswald, T. Ollendick, and L. Scahill
2009 "Anxiety in Children and Adolescents with Autism Spectrum Disorders." *Clinical Psychology Review* 29, 3: 216-29.
- Williams, D.
1996 *Autism, an Inside-Out Approach: An Innovative Look at the Mechanics of "Autism" and Its Developmental "Cousins."* London: Jessica Kingsley.
1995a *Jam Jar*. Directed by Simon Everson. Channel 4 TV in association with Fresh Film UK.
1995b *Somebody Somewhere: Breaking Free from the World of Autism*. Toronto: Doubleday Canada.
- Wing, L., and A. Shah
2000 "Catatonia in Autistic Spectrum Disorders." *The British Journal of Psychiatry* 176: 357-62.
- World Health Organization
1993 *The ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research*. Geneva: World Health Organization.