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## Are Difficult Behaviours Described in Intellectual and Developmental Disabilities and Autism Actually Adaptive Responses to Feeling Unsafe?

Les comportements problématiques décrits dans les troubles du développement, la déficience intellectuelle et l'autisme sont-ils des réponses adaptatives à un sentiment d'insécurité ?

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#### Abstract

*People with intellectual and developmental disabilities* (IDD) and autism are often marginalized and further traumatized because of behaviours that are difficult (challenging) for care providers and services to manage. These behaviours are similar in many ways to responses of our autonomic nervous system when triggered by danger and life threat – namely fightflight-freeze (FFF) and shutdown survival responses. This discussion paper, drawing on polyvagal theory understanding, explores these similarities further from Outside-In (i.e., as observed and reported by others such as carers and clinicians) and Inside-Out perspectives (i.e., as described by people with IDD and autism engaging in these behaviours). Polyvagal theory, developed by Dr. Stephen Porges, explains how the sympathetic nervous system and the dorsal branches of the vagus nerve are involved in FFF and shutdown survival responses; the ventral branches of the vagus nerve are involved in the capacity for social engagement and in the experience of feeling safe. In our paper, the experience of feeling safe is investigated and triggers that alert the nervous system to danger and threat are identified. Being safe and feeling safe diminishes autonomic nervous system reactivity and automatic survival responses. We conclude that imbuing a safe experience for people with IDD and autism (from their perspective), through optimal health and supportive emotional and physical environments adapted to unique needs, will diminish

autonomic nervous system reactivity and dysregulation, which in turn will diminish consequent distress behaviours that services and care providers find difficult. Being safe and feeling safe, are key to both treatment and prevention of emotional and behavioural distress and difficult behaviours.

#### Résumé

Les personnes ayant une déficience intellectuelle (DI), un trouble du développement (TD) ou le trouble du spectre de l'autisme (TSA) sont souvent marginalisées et davantage traumatisées en raison de comportements qui sont difficiles (comportements problématiques) à gérer pour les prestataires de soins et les services. Ces comportements sont similaires à bien des égards aux réponses de notre système nerveux autonome lorsqu'elles sont déclenchées par un danger et une menace pour la vie - soit les réponses nommées lutte-fuite-inhibition (en anglais : fight-flightfreeze) et des réponses d'effondrement de survie. Ce document de travail prend appui sur la théorie polyvagale, explore davantage ces similitudes depuis des perspectives extérieur-intérieur (c.-à-d. telles qu'observées et rapportées par d'autres comme les soignants et les cliniciens) et intérieur-extérieur (c.-à-d. telles que décrites par les personnes ayant une DI, un TD ou un TSA utilisant ces comportements). La théorie polyvagale, développée par le Dr Stephen Porges, explique comment le système nerveux sympathique et les branches dorsales du nerf vague sont impliqués dans la lutte-fuite-inhibition et réponses d'effondrement de survie; les branches ventrales du nerf vague sont impliquées dans la capacité d'engagement social et dans l'expérience de se sentir en sécurité. Cette étude cherche à investiguer l'expérience de se sentir en sécurité et identifier les déclencheurs qui alertent le système nerveux d'un danger ou d'une menace. Être en sécurité et se sentir en sécurité diminuent la réactivité du système nerveux autonome et des réponses automatiques de survie. Nous concluons que créer pour les personnes ayant une DI, un TD ou un TSA une expérience sûre (de leur point de vue), grâce à une santé optimale et à des environnements émotionnels et physiques soutenants et adaptés à leurs besoins uniques, diminuera la réactivité et la dérégulation du système nerveux autonome, ce qui à son tour diminuera les comportements de détresse qui en résultent et que les services et les donneurs de soins trouvent difficiles. Être en sécurité et se sentir en sécurité sont la clé à la fois du traitement et de la prévention de la détresse émotionnelle et comportementale et des comportements problématiques.

Mots-clés : DI, TD, autisme, comportements problématiques, trauma, polyvagal

#### Introduction

In this article, we address the question as to whether difficult to manage behaviours (otherwise known as challenging behaviours or behaviours that challenge) displayed by some individuals with intellectual and developmental disabilities (IDD) and/or autism, represent survival responses of their autonomic nervous system (ANS) consequent to their nervous system

detection of danger and life threat in their everyday living environments. We draw on neurobiological and behavioural research over the past several decades that attempts to integrate brain and sympathovagal homeostatic regulation with feelings, emotions and behaviours (e.g., Damasio, 2003. 2017; Craig, 2016, 2002, 2009). In particular we draw on new insights provided by Dr. Stephen Porges into the adaptive reactions of the autonomic nervous system in response to danger and life threat (polyvagal theory; 2009, 2011, 2017). The subjective experience of this nervous system detection of danger and life threat (Craig, 2002, 2009) we refer to as feeling unsafe; the triggered autonomic nervous system responses we propose are the difficult to manage behaviours.

We deal sequentially with the following topics:

- 1. what are challenging behaviours,
- 2. some specific examples and causes of challenging behaviours from Inside-Out and Outside-In perspectives,
- 3. involvement of the autonomic nervous system in behaviours that are difficult to manage, including the neuroception of danger and life threat and how we feel,
- 4. (a) emerging understanding of the ANS and feeling safe, and (b) interventions from a polyvagal perspective including the principles of *co-regulation* (the reciprocal sending and receiving of signals of safety and danger between two people) and creating environments that feel safe when supporting people with autism and IDD. These topics are followed by summary and conclusion sections, and are supported by the inclusion at the end of the article of one figure describing the ANS from the polyvagal perspective and a series of boxes containing relevant information about specific topics. In brief, the information and arguments in this article support the notion that creating environments for people with IDD and/or autism that are perceived by them as safe, are a necessary part of any treatment plan.

#### **Discussion Topics**

#### **Challenging and Difficult Behaviours**

This section explains why it is preferable to refer to challenging behaviours as difficult behaviours. Emotional and behavioural distress is common in people with IDD, as evidenced by greater rates of psychiatric diagnoses documented in those with IDD compared to those without (Buckles et al., 2013; Cooper et al., 2007; Cooper et al., 2022; Smiley, 2005). When IDD coexists with other conditions that contribute further communication barriers such as autism, hearing or movement difficulties such as cerebral palsy, individuals so affected may be unable to communicate their distress in words or gestures. Instead, mental and emotional distress, bodily discomforts, medical conditions and pain, are communicated through their behaviours. These behaviours may be misunderstood for what they represent, they can be difficult for care providers and services to manage, and as such are often referred to as *challenging behaviours*, or *behaviours that challenge* (Banks et al., 2007; 2016; Bowring et al., 2019), the latter term perhaps better reflecting the co-constructed nature between an individual and the environment in which he/she is supported. Unfortunately *behaviours that challenge* set a tone of confrontation

unhelpful in supporting the patient and carers: in this article we refer instead to behaviours that are difficult to manage or *difficult behaviours*.

#### Behaviours that are Difficult to Manage

#### Those that Threaten Quality of Life and/or Physical Safety of Others

Behaviours can be described as difficult to manage when they are of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others. These behaviours may include physical or verbal aggression (e.g., hitting, spitting or swearing at other people), self-injury (e.g., hitting or pinching self, eye poking), destruction (e.g., throwing furniture, breaking equipment) and other behaviours such as running away, smearing feces, screaming or shouting, inappropriate sexual behaviours, self-induced vomiting, eating non-edible items (pica) and stereotyped behaviours (such as rocking). About 15% of people with IDD show some form of difficult behaviour; those with more severe IDD, poorer communication skills and co existing autism spectrum disorder or autistic-like behaviours, are more at risk (Murphy et al., 2015). These behaviours can result in separation of individuals from their families and communities, exclusion from access to ordinary community facilities or participating in social activities and can lead to responses from services that are restrictive and traumatizing.

Best practices recommend evaluations of these behaviours by considering both the individual and the environment in which they are supported (Bradley & Korossy, 2016; Murphy et al., 2015). However, in many jurisdictions, such multi-disciplinary, comprehensive evaluations are unavailable. What evaluations are possible, tend to take on more limited perspectives that typically focus on managing the concerning behaviours with restrictive behavioural interventions and medications, rather than clearly identifying underlying cause(s) and contributory circumstances. Difficult behaviours can be managed for years with such behavioural (including physical restraint) and pharmacological interventions, rather than treating the underlying conditions (e.g., pain and medical conditions) or attending to the contributing circumstances (such as emotional distress from past or current adversity or trauma) from which they have arisen. The inappropriate use of psychotropic medication for managing difficult behaviours and the harmful long term side effects from these medications, have been recognized, for example, STOMP (Royal College of Psychiatrists, 2021) and SPECTROM (Deb et al., 2022). Behavioural approaches are also changing, moving away from *shaping* behaviour with rewards and punishments towards understanding the function of these behaviours and promoting proactive and preventive strategies to avert crises and keep people safe (e.g., positive behaviour supports; The Challenging Behaviour Foundation, 2022).

#### **Outside-In and Inside-Out Perspectives**

While such shifts in medication usage and behavioural approaches are welcome, these interventions are still very much led by *Outside-In* perspectives (i.e., perceptions of the observer, such as a clinician or care provider based on the observer's lived experience). *Inside-Out* perspectives (Williams, 1996), that come from the lived realities, perceptions and sensory experiences of those with IDD, autism, or experiencing other communication barriers, are less often invited, included, or even considered. To note here, Inside-Out perspectives may be

available to Outside-In observers in ways that may not easily or immediately be recognized by them, such as Owen Suskind (Suskind, 2014; Williams, 2016) who shares his experience of the world through cartoon characters and Naoki Higashida (2013) who uses an alphabet grid to painstakingly construct words, sentences and thoughts that he is unable to speak out loud. Caldwell has eloquently described, and demonstrated, how individuals without verbal or symbolic language, express their inner experience through their body language (Caldwell, 2006, 2012, 2014, 2018; Caldwell et al., 2009; Delafield-Butt et al., 2020; Hoghton & Mytton, 2009). These Inside-Out perspectives become available to us when we make space and time for authentic engagement, mutually sharing curiosity and creativity to find shared meaning and understanding in whatever ways our bodies are responding each to the other.

People with autism are now sharing with the wider world their lived experience and ways of responding, providing their Inside-Out autism perspective (Box 1). They describe suffering sensory overload, being terrified, confused, and losing all sense of self in everyday living. Sometimes being so overwhelmed they are *tipped* into *meltdowns* and *shutdowns*. The behaviours they describe in these states are reminiscent of those described in people with IDD as difficult or challenging (Box 2).

These Inside-Out autism perspectives can perhaps inform us as we try to imagine the world of those with IDD who, because of greater severity of IDD or with other co-existing conditions, are unable to share with us verbal or written accounts about their daily experience, and what may have triggered their similar difficult-to-manage behaviours.

Psychiatric assessment of these behaviours is guided by international classificatory systems of psychiatric disorders such as DSM-5 (American Psychiatric Association, 2013) and ICD 11 (World Health Organization, 2022), and is based on observations of the patient (behaviours or *signs*) and an account from the patient of their inner experiences (*symptoms*). If the patient has difficulty communicating inner experiences, such as occurs when the patient has IDD, autism or other communicative difficulties, the examination relies on observations and reports from others about the patient's behaviour (i.e., predominantly an Outside-In perspective). These behaviours reported by others have sometimes been considered *behavioural equivalents* of psychiatric disorders (Allen, 2008; Eaton et al., 2021). However, people with autism engaging in these "behavioural equivalents" have different explanations for their behaviours that point to adaptive responses of their nervous system (rather than pathology) to circumstances that have been triggering to them. Examples of behaviours that can be mistaken for criteria for psychiatric disorder are provided in Box 3.

Associated with Outside-In perspectives is the misattribution of intentional states, such as *non-compliance, attention seeking, deliberate*, even *malingering*. Rather than being intentionally planned by the individual, this misattribution by care providers, occurs because of failure to recognize that these behaviours have arisen in the context of physical or emotional distress manifesting *atypically* because of the developmental disabilities and co existing conditions.

Outside-In perspectives can lead to problematic interventions and treatments. Not recognizing or ignoring the underlying cause(s) and contributors to the behaviours can result in their escalation, while restrictive behavioural approaches that use control regimes can add further to sensory overload, for example in autism, and to meltdowns. This in turn can lead to even more intrusive interventions by the care system including inappropriate use of psychotropic medications and

behavioural approaches that ignore context, unique meaning and the communicative function of the behaviours, leaving underlying conditions untreated and underlying issues unresolved.

#### Box 1

Narratives of People with Autism with and without Intellectual Disabilities

#### 1: Sense of self in a terrifying world

"I used to repeat the same words over again as this made me feel safer...reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seem to be no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything. Set routines, times, particular routes, and rituals all help to get order into an unbearable chaotic life." (Jolliffe, et al., 1992, pp. 12-19)

"I [Tito Mukhopadhyay] 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." (Blakeslee, 2002, p. 83, 86 print version)

"Autistics are captivated by movements and inner rhythms ... these provide a stabilizing action that grounds the child ... they focus upon some point of themselves to help calm them especially when they are threatened." (O'Neill, 1998, p. 74)

#### 2: Sensory overload

"Tantrums occurred when I became tired or stressed out by too much noise ... my behaviour was like a tripping a circuit breaker. One minute I was fine, the next minute I was on the floor kicking and screaming like a crazed wildcat." (Grandin, 2006, p. 44)

"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, 1994, p. 9)

#### 3: Fear, confusion, frustration

"Trying to keep everything the same reduces some of the terrible fear. Fear has dominated my life. Even when things are not directly frightening I tend to fear that something horrible might happen, because I cannot make sense of what I see. Life is bewildering, a confusing, interacting mass of people, events, places and things with no boundaries" ... (Joliffe et al., 1992, p.16)

".... confusion that results from not being able to understand the world around me ... I think causes all the fear ...... fear then brings a need to withdraw. Anything which helps reduce the confusion ........... has the effect of reducing the fear and ultimately reduces the isolation and despair"... (Joliffe et al., 1992, p. 16)

".... what is often called difficult behaviour, is in fact a direct response to the difficulties (fear and frustration) of life and that these difficulties stem from a very imperfect ability to understand sounds, sights and demands, of which human beings are the most complex"... (Jolliffe et al., 1992, p. 18)

## Box 2

Meltdowns (a) and Shutdowns (b) Described by People with Autism Self-Advocates (Inside-Out Perspective) and Noted by Clinicians (Outside-In Perspective)

### (a) Meltdowns and Pending Meltdowns – Behaviours and Feelings Reported by Self-Advocates

## Meltdown behaviours include:

- Self-injury (head banging, scalp picking, skin picking, digging fingernails into palms), agitated repetitive behaviours, running, stomping, screaming, growling, uncontrollable crying
- Aggression towards others perceived to be the trigger
- Agitation, pacing and aggression, particularly in response to being contained or restrained **Feelings described:** 
  - Being overwhelmed
  - Head pressure and intense urge to head bang. Self-advocates report sometimes being aware that their self-injurious behaviours are dangerous but are unable to resist the relief provided by these behaviours.
  - Some describe the self-injury as trying to head off the *tipping point*; behaviours to prevent going into meltdown include: pacing, toe wiggling, rocking, finger biting, finger tapping, moving in certain patterns including hopping.
  - Meltdowns are described as needing to run their course, typically lasting 5–10 min [but may last much longer (hours) for non-verbal individuals]. Typically, self-advocates report feeling better afterwards, provided the source of the build-up and trigger(s) have been removed
  - Lipsky, author and self-advocate (2011), differentiates between *catastrophic reactions* and *meltdowns*. She describes catastrophic reactions as "*explosive immediate involuntary reactions to something gone off script or not according to plan*" (p. 113) and meltdowns as "*involuntary responses from prolonged exposure to sensory triggers or cognitive overload without any chance to get away from the overwhelming stimulation*" (p. 112).

## (b) Shutdowns

## Behaviours and feelings reported by self-advocates include:

- Withdrawal, zoning out, staring into space, curling up into a ball
- Self-advocates describe shutdowns as not being accompanied by the same feeling of relief as occurs from meltdowns

## **Observations reported by clinicians:**

- 1: Loos Miller and Loos (2004, p. 1) describe a female child with autism who ... "In academic settings when pressured by an adult to perform tasks that were difficult, she became unresponsive, sleepy, immobile, and limp to the touch for several minutes and then fell asleep in a chair for as briefly as 10 min. and up to 2 hours. These 'shutdown' (SD) states were always triggered by social stress of a certain kind and they became more severe and frequent over a period of about a year."
- 2: Prolonged shutdowns, and autism-related catatonic-like deterioration are rare but may be life-threatening as the individual is no longer independently able to meet basic needs (e.g., related to nutrition and safety (Shah, 2019, pp. 23-24).

Adapted from Bradley, 2019

#### Box 3

*Explanations Provided by People with Autism Engaging in Unusual or Difficult Behaviours (Inside-Out Perspective) that Might be Mistaken as Criteria for Psychiatric Disorder (Outside-In Perspective)* 

Obsessive-compulsive disorder – obsessive thoughts and compulsive behaviours

"My attention was firmly set on my desire to lose myself in spots and I'd ignore the garble"; "I learned eventually to lose myself in anything I desired, the patterns on the wallpaper or the carpet, the sound of something over and over again, the repetitive hollow sound I would get from tapping my chi." (Williams, 1992, pp. 3-4)

"The tendency of some autistic people to constantly touch themselves and objects around them may be an attempt to stabilize body and environmental boundaries" (Grandin, 2000a)

Repetitive speech or echolalia: "I used to repeat the same words over again as this made me feel safer." (Jolliffe et al., 1992, pp. 12-19)

"Echolalia or the constant disconnected use of a particular word or phrase ... described as the desire for local coherence, the preference that autistic people frequently demonstrate for a limited though immediate form of order' as a protection against complexity or confusion ..." (Nazeer, 2006, p. 3)

Oppositional defiant disorder – refusal to engage or doing the opposite of what was requested

"If you were being FOREVER forced (at times none too patiently) to do upsetting functions or at times acutely painful ones, just because everyone else does it with no discomfort, AND expects you to be the same; would that make you outgoing, and a party personality? Or would you turn away from your tormentors, acting as if you were uncomfortable or afraid or possibly frustrated with them." (Bogdashina, 2010, p. 61)

Stereotypies - repetitive or ritualistic movements, postures, or utterances.

"Rocking and spinning were other ways to shut out the world when I became overloaded with too much noise." (Grandin, 2006, p.44)

Phobias – avoidance of people and places

"I always hated to be touched. I wanted to experience the feelings of being hugged but it was just too overwhelming ... like a great overwhelming tidal wave of stimulation I reacted like a wild animal ... loud noises were also a problem, often feeling like a dentist's drill hitting a nerve." (Grandin, 2006, p.62)

#### Behaviours that are Difficult to Manage and the Autonomic Nervous System

The autonomic nervous system (ANS) (Figure 1) is part of the peripheral nervous system and regulates the internal organs of the body to maintain homeostasis and to prepare the body for action. The ANS acts largely unconsciously (outside of awareness) regulating bodily functions, such as heart rate, digestion, respiratory rate, pupillary response, urination and sexual arousal. Homeostasis is a self-regulating process by which biological systems tend to maintain stability while adjusting to conditions that are optimal for survival. In response to the detection of a perceived harmful event, attack or threat to survival, the ANS is triggered into a physiological reaction referred to as fight-flight-freeze (FFF); also sometimes referred to as hyperarousal or acute stress response. This reflexive activity of the ANS occurs through *neuroception*, a term coined by Porges to describe neural detection without explicit awareness of the provocative cues (Dana, 2018; Porges, 2001, 2009, 2017; Porges & Dana, 2018). The sympathetic nervous system (SNS), a branch of the ANS, is primarily responsible for this mobilization of our bodies in response to threat or danger while the parasympathetic branch of the ANS (the vagus nerve) has the opposite effect, moving from its usual *rest and repair* function, to shutting down these

restorative activities. Changes in body state consequent to these triggered survival responses, are part of a felt sense of how we feel (Craig, 2002, 2009; Damasio, 2003). How we feel determines our subsequent perceptions and behaviour (Porges, 2004) (Box 4).

#### Box 4

Survival Responses, Emotions, Feelings and Behaviours

Our biological imperative is to survive. *Neuroception*, a term coined by Porges (2004) is the constant scanning by our nervous system, without our explicit awareness, of the environment inside and outside our body, for cues of danger and life threat. Detection of danger and life threat involves a shifting of the nervous system, into response survival mode, resulting in pre-programmed actions for rapid response – fight-flight-freeze (FFF) – shutdown (Porges, 2004). Feelings are mental experiences related to the body's sensory detection and physiology. They are the portrayal of our physiological state when we are having an emotion (Damasio & Damasio, 2017). Emotions are action programs, such as FFF and can therefore be observed, whereas feelings can only be described by the person having the feelings.

Craig (2002; 2009) describes two types of feelings:

- Feelings that come from our bodies (e.g., my fingers feel cold), and
- Affective feelings that relate to our moods (e.g., I feel anxious, I do not feel safe).

Both bodily feelings and affective feelings are a direct reflection of the physiological state of our bodies; expression of our feelings is not just emotional (or verbal) but it is also an expression of how our body feels and reacts. In people unable to express their emotions in words we can tap into their emotional state (their affect) by attending closely to what we observe going on in their bodies - their body language, body posture, breathing pattern, facial expression, tone of voice, how they move and respond when we try to engage. The emotional tone of these behaviours (e.g., agitated, impulsive, unpredictable, restless, SIB, hypervigilant, withdrawn), will resonate in ourselves as observers: one nervous system influencing the other.

The neuroception of danger and threat is a uniquely personal experience associated with individual, neurobiology and life experiences. What is dangerous and threatening to one person may not be experienced as such by another. Those with IDD have greater exposure to adversity, trauma and negative life experiences, all of which will impact subsequent detection of and responses to danger and life threat. Spending time with the non-verbal individual, observing their reactions to people and the world around, taking time to learn about their life experience and developmental needs, help to better understand the meaning and intention of their nonverbal communications and help prevent us from making false inferences based only on our personal life perspective.

There are clearly similarities between the descriptions of people with autism tipped into meltdowns and shutdowns and survival responses of the ANS, triggered when our nervous system feels threat or danger (Box 5). We might ask therefore, "Are the difficult behaviours seen in people with IDD and autism in essence adaptive/survival responses of their nervous system to neuroception of danger and threat?" In this case we should be asking "What gives rise to these experiences of danger and threat?" and "What are the implications for daily supports, intervention and prevention?"

These questions are explored further below: firstly, by reviewing emerging insights into the functioning of our ANS (Section 4a below) and secondly, by considering the implications for intervention and treatment of 'difficult' behaviours (Section 4b below).

## Box 5

Situations (cues) Giving Rise to the Detection, without Awareness (Neuroception), of Danger and Life Th	ireat
(Column 1): ANS Survival Responses (Column 2) and Concomitant Behaviours (Column 3 - See also Box	c I)

Examples of cues that may trigger	Autonomic Nervous System	Behaviours described as difficult or
the neuroception of danger	response to danger and life threat	challenging in people with IDD and how
the neuroception of dunger	1: Sympathetic nervous system	these behaviours may be interpreted by
	(SNS)	care providers
	mobilizing responses to danger	
	and life threat	
1: INSIDE: Arising from within	Fight	Fight
(the body)	<ul> <li>Aggression directed towards</li> </ul>	• Aggression, physical or verbal (e.g.,
Physical status and health related	the perceived danger resulting	hitting, spitting or swearing at other
Medical condition	in damage to self, others and in	people)
• Pain	the outside world	• Self-injury (e.g., hitting own head, eye
• Disability		poking)
Psychological and emotional		• Destruction (e.g., throwing furniture,
• Any change or loss in physical or		smashing equipment)
mental functioning		• Screaming and shouting
• Any change in or loss of personal		• Other difficult behaviours include:
sense of agency and capacity to		smearing teces, inappropriate sexual
Traumatic momenties		eating non-edible items (nice) and
• I raumatic memories Nota Being in a chronic state of		stereotyped behaviours. Some of these
survival impacts negatively on the		behaviours may in part be attempts to
physiological functioning of the		self-regulate a dysregulated nervous
body: a body out of homeostasis		system.
represents an internal threat.		• Meltdowns – which may be
1		misinterpreted as attention-seeking
2: OUTSIDE: Arising in the	 Flight	Flight
outside world	• Running away from the danger	• Running off, restless
• Life events particularly in the	or threat	• Not engaged
absence of agency or skills to		• Autistic masking (to avoid standing out,
manage or avoid		harassment or bullying)
Unpredictable circumstances		• These difficult behaviours may be
• Lack of structure in daily living		interpretated as non-compliance, task
<ul> <li>Inconsistent supports</li> </ul>		avoidance, malingering.
• Expectations that exceed the	Freeze	Freeze
individual's emotional,	• Cessation of movement in a	• Stuck behaviours – seemingly unable to
psychological or physical	maintained posture – <i>tonic</i>	move, <i>frozen</i> in action
Global events or disasters that	<i>immobility</i> (a hybrid of SNS	• May be misinterpreted as non-
• Global events of disasters that	and dorsal vagal activity)	compliance, avoidance, evasive, lying
supports	Unable to light of field in     response to danger or threat	
• Exposure to external risk injury	May be cognitive freezing	Not able to think confusion
peril	way be <i>cognitive</i> freezing	ivot able to think, confusion
Environmental triggers associated     with previous trauma		
• Sensory hyper and hypo		
sensitivities		

<ul> <li>3: IN-BETWEEN: Arising between the individual and others on whom the individual is dependent</li> <li>Bullying, stigma, exclusion, préjudice, attitudes, exploitation</li> <li>Abuse of power in services and systems giving rise to shame, humiliation, exploitation</li> <li>Any expression (verbal or non- verbal) of intent by another to injure or punish or a suggestion that something unpleasant or violent will happen especially if a particular action or order is not followed.</li> <li>Any sort of abuse (emotional. physical sexual) or neglect</li> </ul>		
Examples of cues that may trigger neuroception of life threat	2: Parasympathetic nervous system (dorsal vagal activity), immobilizing responses	Behaviours described as difficult or challenging and how these behaviours may be interpreted
The same as above except the neuroceptive experience is of immediate risk to life or limb or abject fear or terror from which there is no escape	<b>Shutdown</b> – immobilized, behavioural collapse, fainting, urination, defecation, dissociation and being detached from physical and emotional experiences – a trauma response likened to <i>feigning</i> <i>death</i> seen in other mammals	<ul> <li>Withdrawal, zoning out, staring into space, curling up into a ball</li> <li>No interest in food</li> <li>Unresponsive, sleepy, immobile, limp, falling asleep</li> <li>Incontinence</li> <li>May be diagnosed as psychogenic, mood or psychotic disorder without recognizing the triggers / trauma</li> </ul>

#### Emerging Understanding of the Autonomic Nervous System (ANS)

Historically, the human autonomic nervous system has been considered to consist of two parts: the sympathetic nervous system (SNS) and parasympathetic nervous system, the latter primarily involving the vagus nerve. Porges (2017) proposes a third pathway that involves the ventral part of the vagus nerve along with several other cranial nerves that supply the muscles to the head and neck involved in communication with others (ears, eyes, face, larynx, pharynx). This pathway has evolved, allowing mammals to use social engagement as a first line of defense against threat and danger, which he refers to as the *social engagement system* (Figure 1). Through this third pathway, mammals, and especially humans, are able to draw on each other to manage stress, anxiety and feel safe with each other and resilient to outside threats; in humans this involves both verbal and non-verbal ways of social-emotional engagement. Whether or not we develop symbolic language using pictures or words, or struggle with verbal communication, the capacity for non-verbal social-emotional connection is present at birth (indeed this is our first *language*) and continues during our lifetime. Those with IDD and co-existing autism clearly demonstrate their capacity for emotional connection, even without words, when we reach out to them in ways that have meaning for them (Caldwell, 2013a; Delafield-Butt et al., 2020). This

capacity of the human mammalian nervous system to engage socially with or without words is therefore an important emotional conduit through which communication and meaningful connection can occur regardless of the linguistic abilities of the communicating partner. As such, understanding this neural pathway offers the potential, through social-emotional engagement when verbal exchange is not possible or meaningful, for intervening and supporting individuals showing emotional and behavioural distress. However, crucial to this third pathway, and any possibility of meaningful social-emotional engagement through body language, is the importance of feeling safe.

#### Figure 1

#### Activities and Responses of the Autonomic Nervous system from a Polyvagal Theory Perspective

The Autonomic Nervous System – Parasympathetic & Sympathetic Nerve Pathways & Function



**Legend:** The autonomic nervous system showing ventral vagal (green fibres), dorsal vagal (red fibres) and sympathetic (orange fibres) pathways, their involvement in everyday activities (under subtitles in green font) and when dange and life threat are present (under subtitles highlighted in yellow)

#### Polyvagal Theory and Feeling Safe

The vagus nerve is the largest nerve of the autonomic nervous system and is also the longest of the twelve cranial nerves (Figure 1). Porges' polyvagal theory provides a cohesive account of autonomic nervous system and vagal nerve activation, helpful in understanding neurobiological underpinnings of feeling safe and what happens when this felt sense is threatened.

Porges describes two vagal nerve distributions: the ventral vagal (top and left in Figure 1) and the dorsal vagal (on the right in Figure 1).

- 1. The dorsal vagal complex (unmyelinated slower conduction) primarily supplies organs below the diaphragm (e.g., stomach, pancreas, gut), and is ordinarily involved in body maintenance, repair and regulation, e.g., digestion and elimination.
- 2. The ventral vagal (myelinated faster conduction) supplies organs above the diaphragm (e.g., heart, lungs). Importantly, the ventral vagal is part of the cranial nerve complex (involving cranial nerves V (trigeminal), VII (facial), IX (glossopharyngeal), X (vagus) regulating the smooth muscles of the heart and bronchi through visceromotor pathways (myelinated). It also serves the striated muscles of mastication, middle ear, face, larynx, pharynx and neck through special visceral efferent pathways (myelinated) (Porges, 2011). These cranial nerves together regulate social engagement through facial expression, eye lid movement, preparedness for listening and vocalizations, turning of the head and neck to orientate to people and the surroundings; additionally, the ventral vagus innervates the heart and bronchi resulting in preparatory changes in heart rate and breathing when the SNS is activated. The ventral vagal system is thus involved specifically in supporting social interaction with others and in regulation of the individual with the outside world.

Porges has identified separate ventral and dorsal vagal activation in response to our sensory system detecting danger and life threat. He introduced the concept of *neuroception* to describe the automatic process by which the nervous system and brain areas evaluate risk such as safety, danger and life threat, without explicit awareness. Once detected, body physiology adjusts to optimize survival (homeostasis) (Porges, 2004).

Ventral vagal activation is associated with the social engagement system. When in this state, we are grounded, resourceful, curious, interactive, participating, able to think clearly, explore and learn. If danger or threat is detected while in this ventral vagal social engagement state, the sympathetic nervous system is activated, firstly mobilizing social behaviours that attempt to reduce, avoid or avert the threat, (e.g., smiling, vocalization, listening, negotiating). If this does not work then we fall back on phylogenetically earlier ways to respond to physical and psychological threat which involves activation of the sympathetic nervous system into mobilized states of: *fight* (we fight off the perceived threat); *flight* (we run away); *freeze* (we stop still in our tracks being less likely to draw attention).

Considering difficult behaviours from this neurobiological perspective, fight may be manifested as self-injurious behaviours, or hitting out at others or obstacles that happen to be in the way; flight may be manifested as running, trying to get away, or masking/camouflaging as described in autism (Cook et al., 2021) and freeze or stuck behaviour seen as brief cessation of movement, not infrequently in a maintained posture - *tonic immobility* (Box 5: columns 2 and 3). When the neuroception of threat is perceived as life threatening, the body defaults to an even earlier phylogenetic survival strategy – that of feigning death (immobilization) – a dorsal vagal activity involving the parasympathetic nervous system.

Our human response to safety, danger and life threat is thus hierarchical, occurring in a predictable sequence depending on the perceived level of safety, danger and life threat: from being socially engaged (ventral vagal, social engagement circuitry), to mobilization of fight-flight-freeze in response to danger (sympathetic nervous system), to immobilization and shutdown/collapse (dorsal vagal circuitry) if the danger is perceived as overwhelming and life threatening.

These autonomic nervous system behaviours are not chosen or planned – rather they are biologically triggered. The threshold to their triggering is associated with the perceived degree of danger and threat, prior trauma experiences, coping capacities and other physiological states of the body that may compromise resilience and coping, such as physical illness and pain. People with autism have eloquently described their behaviours and felt sense when overwhelmed and triggered into meltdowns (Box 2).

Porges describes *feeling safe* as an important moderator influencing the effectiveness of many medical procedures, psychological interventions and psychoeducation. Activating the social engagement system supports health, growth and restoration of body function; in this state the autonomic nervous system is not easily triggered into the defensive responses of mobilizing fight, flight, freeze, or immobilizing shutdown and collapse. He promotes the principle of feeling safe as a precursor to treatment and advises vetting of treatment environments for safety cues. For example, in autism, these might be related to specific sensory sensitivities, as eliminating these (sensory triggers) can prevent neuroceptive triggering of defensive states of the ANS, which in turn can be anticipated to interfere with engaging with others, learning and the effectiveness of any intervention.

Polyvagal theory also predicts that being in a chronic state of survival, hijacks the parasympathetic system away from its rest and restorative function giving rise to dysfunction of visceral organs (e.g., gastrointestinal (GI) problems, ANS dysfunction affecting heart rate and blood pressure, and medically unexplained symptoms). Increased prevalence of medical conditions especially GI related, are reported in people with IDD and autism (Chaidez et al., 2014; Madra et al., 2020). Concerns about difficult behaviours being related to pain are often hard to evaluate when individuals are unable to provide direct feedback about their pain and do not understand the need for investigations or unable to cooperate with needed investigations. It is possible that some difficult behaviours represent medically unidentified symptoms (Edwards, 2021) which in turn may be associated with a chronically dysregulated ANS due to stress (Kolacz & Porges, 2018; Ruschil et al., 2021; Zalewski et al., 2018).

Porges describes our *tuned-in* capacity to derive the state and intentions of others from the tone of their voices, their facial expressions, their gestures and postures and respiratory patterns (Porges, 2004). It is through this tuned-in capacity that we detect cues of safety and danger in others. Some existing effective interventions for difficult behaviours such as *responsive communication* (Caldwell, 2018) and *intensive interaction* (Caldwell, 2006) implicitly recognize and optimize this tuned-in capacity between individuals with IDD and autism and their care providers. Responsive communication and *low arousal* (McDonnell, 2010; Woodcock & Page, 2010) approaches also implicitly recognize cues of danger in some environments such as from sensory hypersensitivities. Caldwell describes those with autism and sensory hypersensitivities as living in *red alert*, not just about what is happening in their present environment but also the anticipation of how that may change and what is going to happen (Caldwell, 2012).

Meaningful social connection and predictable environments also help our nervous system selfregulate and with that comes an embodied felt sense of safety. Withdrawal or absence of social support, or loss of predictability are sufficient to trigger post-traumatic stress disorder (PTSD; Charuvastra & Cloitre, 2008; Porges, 2017).

In summary, from a polyvagal perspective, our biological imperative is towards survival; in this context through neuroception, our nervous system is constantly monitoring the environment for

cues of safety and cues of danger. Neuroception shifts the autonomic nervous system into three broad states: safety (social engagement system), danger (fight-flight-freeze, meltdown) and life threat (immobilization – complete shutdown/collapse). These three different states influence our perceptions and drive our behaviours (Dana, 2020; Porges, 2017).

## **Interventions From a Polyvagal Perspective**

## **Co-Regulation**

The third principle of polyvagal theory after (1) hierarchy of response to danger and life threat and (2) neuroception, is (3) co-regulation (Dana, 2018, 2020; Porges, 2017). *Co-regulation* is the reciprocal sending and receiving of signals of safety (and danger) between two people, where two nervous systems are connected, each regulating and nourishing the other. This nervous system to nervous system connection is through verbal and non-verbal cues from each communicating partner (often below the level of awareness) and is experienced as a felt sense of safety (or danger) being in the presence of the other. Because co-regulation is engraved into our evolutionary past, this is not a desire, but a need – one developed to facilitate survival. We are wired to seek interpersonal connection which has meaning (Siegel et al., 2021); *meaning* for the person with IDD and autism involves our being sensitive to their particular forms of personal communication (e.g., to their body language, articulations and themes of interest; Boxes 4 and 6).

Through co-regulation, an individual is assisted to move out of mobilizing sympathetic and immobilizing shutdown states into ventral vagal social engagement; in this latter state we are able to learn and are more in charge of our lives. Experienced therapists are essentially safe co-regulators. With repeated experiences of safe co-regulation, a nervous system that is in chronic autonomic hyper- or hypo-arousal state, or easily triggered into these, can be *retuned* to more easily return to the safety of a socially engaged state. Over time co-regulation may be embodied into self-regulation (Dana, 2020; Dana, 2021).

## **Co-Regulation Supporting People with IDD and Autism**

In the same way adults without sight or hearing are particularly attuned to other sensory input, we might consider that people with IDD and autism who rely on body language to communicate, have finely tuned skills in reading body language, especially refocusing on recognizable rhythms and picking up attitudes and intentions below awareness of those whose communication is primarily verbal. Neuroception of danger (e.g., resulting from stigma, negative attitudes, rejection, or not taking the time to truly listen) may thus be perceived in these interpersonal and social exchanges (Box 5). In our support and care of people with IDD and autism, *how we are*, will be as relevant as *what we do* because as care providers we (our nervous systems) are also implicitly co-regulators; as such, our emotional state, even when outside our own awareness, will impact that of our non-verbal communicating partner.

## Creating Safety

Box 6 expands on the neuroception of safety and outlines sources for cues of safety for people with IDD and autism, experienced from inside the body, from the environment outside and from interpersonal relationships.

#### Box 6

Cues of Safety and Behaviours of Feeling Safe

Evidence of a felt sense of safety in non-verbal individuals will be seen in their behaviours (engaged, interested, curious) and felt in ourselves from the affect and emotion that radiates from their face, their articulations, breathing pattern, body movements and postures, when we spend time with them. In polyvagal terms the individual is in ventral vagal state where the social engagement system is activated (Porges, 2017; Porges & Dana, 2018; Box 2, Non-Verbal Affective Care link) – *Safety is treatment*.

A felt sense of safety (neuroception of safety) comes from within the individual, from the world outside and from the interaction of the individual with others in the world outside (Dana, 2020). Cues of safety from Inside, Outside and In-between are outlined below.

*Note.* Focusing on how to ensure people with IDD and autism feel safe where they live, work and spend time, will prevent difficult behaviours from arising and provide effective intervention when these arise from the perception of danger and life threat (see box 5).

#### INSIDE: Physical and mental well-being as cues of safety

- Good health, with opportunities for physical activities and access to the outdoors especially nature
- Attention to communication needs
- Absence of pain
- Care provider recognition and understanding of specific sensory hyper- and hypo-sensitivities
- Identification of hearing, vision and motor difficulties with provision of aides and necessary adaptations of the environment
- Attention to emotional well-being with opportunities for emotional connection and a meaningful life
- Appropriate expectations given individual emotional and psychological profile
- Attention to loneliness; recognition of the impact on physical and mental health
- Opportunities for self-regulations, e.g., exercise and walking, singing, connection with nature, sensory room / sensory aids

*Note.* Living with unrecognized neurological differences (such as sensory sensitivities in autism), hearing, vision or motor difficulties in environments without necessary accommodations, represent a threat – a cue of danger – which for some may trigger the nervous system into a chronic state of defensiveness.

#### OUTSIDE: Environment and support issues as cues of safety

- Needed environmental adaptations to support inclusion and participation
- Consistencies in care provision,
- Careful preparation for any anticipated changes in routine,
- Recognition of and preparation for unexpected events
- Proactive strategies to minimize the negative impact of negative life events (e.g., meaningful emotional support, pictures narratives, social stories)

- Appropriate expectations: attention to the match between developmental and emotional needs and provided supports
- Care providers recognize community and global life events (e.g., the *threat* of the COVID pandemic Porges, 2020) and proactively respond to the anticipated direct and indirect impact on the individual.

*Note.* A polyvagal informed approach shifts the focus from events to the individual's nervous system response and feelings associated with the event; focusing on events may dismiss the impact of events that are traumatic to the person but not to others

## **IN-BETWEEN:** Relationships as cues of safety and opportunities for co-regulation are fostered by

- Opportunities for emotional connection (e.g., intensive interaction approach; Caldwell, 2006) as well as practical support in everyday living skills; a focus on *being with* rather than *doing to*
- Care providers being able to promote positive interactions with the individual by making any necessary accommodations to facilitate communication
- Care providers understanding the impact of losses of family or friends, from changes in staff, routines, activities and places: emotional support can be provided even in the absence of words (e.g., Non Verbal Affective Care, Box 7).
- Care providers being trauma informed and supported in providing trauma informed care; in particular attention to choice, invitational language, non-coercion, in addition to providing supports that are experienced as safe
- An appreciation of power dynamics in service settings supporting vulnerable individuals
- Care providers understanding the way trauma can influence emotions and therefore behaviour
- Care providers recognizing their role as co regulators to individuals in distress

*Note.* In the same way that difficult behaviours are co constructed, understanding these behaviours from a nervous system perspective, shifts the focus of intervention to co regulation between one nervous system (the care provider) safely grounded in ventral vagal social engagement state and the activated autonomic nervous system of the individual. Through such coregulation comes the perception of safety which brings a dysregulated nervous system in defensive state back into a ventral vagal social engagement state that permits full engagement with others, the world around and a greater grounded felt sense of who we are. This in turn *promotes better health*.

*Listening with all our senses*: Neuroception of safety is a personally felt experience; therefore, supporting a safe environment and safe supports for an individual with IDD/ASD involves understanding the lived experience of that individual and their daily challenges. Often family and paid care providers who know the individual well, have an intuitive sense of what contributes to their family member/client capacity for social engagement, curiosity and play. They will also have a sense of what triggers the individual into more defensive states. Identifying cues of safety and cues of danger for that individual comes from listening carefully to these informants as well as being with, and observing first-hand, the individual's responses towards ourselves, as well as their responses towards others, their supports and environments where they are living and spending time.

#### **Summary and Implications**

• Greater understanding of the autonomic nervous system as provided through the lens of polyvagal theory, identifies the crucial role of the neuroception of safety and danger, in regulating our perceptions and behaviours. In other words, the felt sense of feeling safe (or not) determines how we engage socially and emotionally with others, learn new skills and are fulfilled in our life's journey. Chronic perception of danger and life-threat keeps

us in chronic autonomic reactivity which is associated with emotional and behavioural distress and poor health. Chronic mental distress and ill health are not compatible with optimal emotional, psychological and social well-being, ability to listen and learn effectively and engage fully in the world.

- Direct reports from people with autism across the spectrum of abilities describe their constant fear in the world, particularly related to sensory sensitivities, sensory processing and not understanding what is going on.
- Examination of behaviours that are difficult to manage (challenging), suggest that many of these behaviours represent a triggered autonomic nervous system. Such triggered neural activity is not intentional it is an automatic survival response to real or perceived danger and life threat.
- People living with disability are exposed to greater adversity and negative life events such as biological (health issues), psychological (difficulties understanding, communicating needs, dependence on others, less personal agency), social (stigma, embarrassment, humiliation, abuse, hate crimes), compared to those without; they have fewer coping skills to manage and a more fragile sense of self to fall back on (Caldwell, 2013b). Any of these inequalities and disadvantages may be a source of distress and triggering, especially if unrecognized, unacknowledged, not understood or attended to. Unrecognized and not understood, these difficult-to-manage behaviours in turn trigger automatic autonomic survival responses in caregivers that render them unable to provide the co-regulation that the individual needs (Sweeney et al., 2018).
- It follows that intervention for these survival responses includes promoting environments and social supports that are experienced as physically, psychologically and emotionally safe and includes care providers able to provide safe co-regulation.
- Decreasing cues of danger and increasing cues of safety will be healing feeling safe is treatment.
- Feeling unsafe is a subjective experience manifested in neural activity involved in the detection of danger and life threat (neuroception). Self-reports of people with autism feeling unsafe and distressed are described in Box 1. Such verbal self-reports are impossible from those with IDD (and autism); instead, we have to rely on observations of their behaviour and body language to detect physical and emotional distress. However neurophysiological ways to study behaviours, emotions, feelings, body states below awareness and behavioural responses to internal and external triggers, that rely less on verbal feedback, are developing (e.g., Picard, 2009, Manning et al., 2019, Van Hoorn, et al., 2019). Some of these neurophysiological studies have focussed specifically on those with autism and individuals who have experienced trauma. These studies are validating reactive ANS triggered behavioural responses to triggers in everyday environments and felt uncomfortable body states.

Box 7 Useful Websites
1. INTELLECTUAL DISABILITY AND AUTISM SPECTRUM DISORDER Learning Disability Today https://www.learningdisabilitytoday.co.uk/ Non-Verbal Affective Care (NAC) https://www.nacwellbeing.org/
<ul> <li>2. BEHAVIOURS THAT ARE DIFFICULT TO MANAGE         The Challenging Behaviour Foundation             https://www.challengingbehaviour.org.uk/         The Cerebra Centre for Neurodevelopmental Disorders School of Psychology University of Birmingham -             Key topics             https://www.findresources.co.uk/common-issues     </li> </ul>
<ul> <li>3. POSITIVE BEHAVIOUR SUPPORTS (PBS)         Challenging Behaviour Foundation – Key messages about Positive Behaviour Supports             https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/02/pbskeymessagesapril2017.pdf             https://www.challengingbehaviour.org.uk/information-and-guidance/positive-behaviour-support/             University of South Florida - The National Center for Pyramid Model Innovations (NCPMI) – Behavior             intervention and PBS             https://challengingbehavior.cbcs.usf.edu/Pyramid/pbs/index.html         </li> </ul>
<ul> <li>4. LONELINESS &amp; SOCIAL PRESCRIBING         <ul> <li>A Connected Society: A Strategy for Tackling Loneliness             <ul></ul></li></ul></li></ul>

#### Conclusion

Being unable to communicate in words or gestures because of IDD, autism, hearing and motor difficulties such as cerebral palsy, predisposes to social isolation, loneliness, emotional disconnection and absence of voice and agency in everyday living (Box 7 - UK Government policy on loneliness). Individuals so affected are totally reliant on others in navigating and understanding what is going on around them, and reliant on the structures and predictability of their daily environments and supports to contain anxieties and fears. The world is a particularly scary place when it is difficult to comprehend what is going on, when agency and empowerment to avoid personal threat and danger is limited and where there is no one around to imbue a sense of safety through relationships, emotional connection and meaningful communication. Nonverbal human distress is manifested through observable changes in our body (breathing, sweating, colour, trembling), facial expression (nervousness, anxiety, fear, rage, distress), behaviours (restlessness, threatening, defensive and hitting out) and vocal utterances (which through prosody further expresses the tone of our distress). Difficult (challenging) behaviours can be understood in term of this expression of human distress. The latter is a consequence of the

human autonomic nervous system responding to the detection, without explicit awareness, (neuroception - Box 4) of danger and life threat (physical, psychological, emotional, interpersonal) and the felt sense of not feeling safe.

It follows that optimizing opportunities for people with intellectual and developmental disabilities, or other communication difficulties, to feel safe (from their perspective) will both prevent and provide effective intervention for behaviours that are triggered ANS survival responses to their experience of danger and life threat: their need to feel safe in body (good health), safe where they spend time (environmental supports) and safe in their relationships with care providers, and others in their lives.

In recent years reflective practice which involves care providers analyzing personal experience in day-to-day work situations and social prescribing (Box 7), with its focus on promoting for patients/clients' social connection, inclusion, participation and healthy lifestyles, have gained momentum as key components for successful outcomes in the provision of health and social care. These approaches are essentially ways for both care providers and clients to experience cues of safety which in turn prevent escalation into triggered autonomic nervous system survival responses. Such approaches can be anticipated to reduce the incidence of difficult behaviours as well as reduce the current tendency for reactive prescriptions of psychotropic medication and restrictive support programs to suppress these communications of distress, when they occur.

#### **Key Messages From This Article**

**People with Disabilities**. You are entitled to good health and to feel safe where you live, work and spend time.

**Professionals.** Feeling unsafe activates the autonomic nervous system, causing disruption in body homeostasis and consequent physical ill health and mental suffering. Feeling safe promotes health. Ensuring people with disabilities feel safe is treatment.

**Policymakers.** A statement of intent and plan of action that positions safety, and in particular the felt sense of being safe, as key guiding service principles will enhance quality of life for all people with intellectual disabilities and autism and prevent difficult and challenging behaviours from arising. Safety is a basic human need – and enshrined in the Universal Declaration of Human Rights.

#### Messages clés de cet article

**Personnes ayant une incapacité.** Vous avez droit à une bonne santé et de vous sentir en sécurité là où vous vivez, travaillez et passez du temps.

**Professionnels**. Le sentiment d'insécurité active le système nerveux autonome, provoquant une perturbation de l'homéostasie corporelle et, par conséquent, une mauvaise santé physique et des souffrances psychologiques. Le sentiment de sécurité favorise la santé. S'assurer que les personnes ayant une incapacité se sentent en sécurité constitue un traitement. **Décideurs.** Une déclaration d'intention et un plan d'action qui placent la sécurité, en particulier le sentiment de sécurité ressenti, en tant que principes directeurs clés des services, amélioreront la qualité de vie de toutes les personnes ayant une DI, un TD et un TSA et préviendront que les comportements défis surviennent. La sécurité est un besoin humain de base et inscrit dans la Déclaration universelle des droits de l'homme.

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