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Introduction

Autism is a neurodevelopmental condition defined clinically by impairments in social interaction and communication, accompanied by restricted, repetitive and stereotyped patterns of behaviour, interests and activities (American Psychiatric Association, 2000). It is a syndrome diagnosis underscored by different aetiologies, the latter contributing to multifaceted clinical presentations throughout the life span. The proposed fifth edition of the American Psychiatric Association's diagnostic criteria (DSM-5; scheduled for 2013) combines the social and communication criteria into a single criterion along with restricted behaviour (American Psychiatric & DSM-5 Development, 2011). The current category of pervasive developmental disorders (PDD) that includes autism, Asperger syndrome, atypical autism and PDD-NOS is to be replaced by a single category: autism spectrum disorder (ASD).

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Clinical manifestations of ASD (hereafter autism) overlap with those of other conditions such as attention deficit hyperactivity disorder (ADHD), intellectual disabilities (ID) and fragile X syndrome (the most common identifiable inherited cause of ID and autism; Turk, 2011). Autism is associated with a high prevalence of coexisting medical conditions such as gastrointestinal problems (Buie, Campbell, et al., 2010; Buie, Fuchs, et al., 2010; Ibrahim, Voigt, Katusic, Weaver, & Barbaresi, 2009), sleep disturbances (Malow & McGrew, 2008) and epilepsy (Turk et al., 2009). Recent evidence has raised the possibility that autism and epilepsy may even represent a different syndrome from autism alone (Turk et al., 2009). These medical comorbidities contribute further to different developmental challenges and adult outcomes. Autism is more common in males but this may in part be related to females showing a different autism phenotype (Kopp, Kelly, & Gillberg, 2010).

Overlapping clinical presentations, difficulties in reliably identifying different autism subgroups and other evidence have led to the proposal that there may be different autism spectra (Wing, Gould, & Gillberg, 2011) with the most appropriate term for the whole group of disorders inferred here being the 'autisms' (Coleman & Gillberg, 2011; Wing et al., 2011).

Autism is not a psychiatric disorder. However biological, psychological, social, educational, work and other circumstances associated with autism predispose those with autism to greater

risk for mental health problems (National Institute for Health and Clinical Excellence, 2011, 2012). In this chapter we focus on psychopathology (psychiatric symptomatology as described in DSM/ICD; World Health Organization, 1993) that arises when autism and ID are coexisting conditions. Noting a discrepancy between clinical descriptions of psychopathology in autism and the experience of people on the spectrum, we also compare these clinical descriptions with the (often very moving) accounts of individuals with autism. We have adopted the terminology proposed by Donna Williams, herself with autism, ‘Outside-In’ and ‘Inside-Out’ (Williams, 1996). We explore whether an Inside-Out perspective may contribute to our understanding of psychopathology observed in those with autism. An improved understanding can be anticipated to have implications for treatment and prevention of such psychopathology that may arise.

Determining whether the addition of autism adds to the risk of mental ill health in those with ID has implications for care and service provision. In the UK, with the Autism Act (2009), and subsequent government initiatives (Department of Health, 2010a, 2010b; National Audit Office, 2009, 2010), there is increasing support for those with autism in the general population but there remain concerns that the needs of those within ID services are still not being recognised.

Finally, drawing on evidence from clinical research and narratives from people with autism, we make suggestions for future research to shed light on the complex interplay of circumstances that contribute to mental health and psychopathology in those with both autism and ID.

Prevalence of Autism in the General Population

Prevalence estimates for autism range from 0.72 to 1.57 % for child populations (less than 16 years old; Baird et al., 2006; Barbaresi, Colligan, Weaver, & Katusic, 2009; Baron-Cohen et al., 2009; Centers for Disease Control and Prevention, 2009; Posserud, Lundervold, Lie, & Gillberg, 2010) and 0.55 to 1.4 % for adult populations (16 years plus; Brugha et al., 2011; Chang et al., 2003; Cimeria &

Cowan, 2009; Nylander & Gillberg, 2001). The most commonly quoted rate is 1 %. The rate of unrecognised autism has been found to be as high as 40 % for children (Baron-Cohen et al., 2009) and 91 % for adults (Nylander & Gillberg, 2001).

Rates of ID in autism have been reported in two of these studies of children: estimated prevalences were 55 % (Baird et al., 2006) and 41 % (Centers for Disease Control and Prevention, 2009), respectively. Earlier reviews of ID in children with autism reported estimates of up to 88 % (Table 1 in Bryson, Bradley, Thompson, & Wainwright, 2008). More recent rates of ID are lower likely because they include a wider range of individuals on the autism spectrum and because of improved recognition and therefore higher rates of high-functioning autism.

Prevalence of Autism in ID

Diagnosing autism can be particularly uncertain where there are:

- A lack of information about early life
- Complex coexisting mental health disorders (e.g. ADHD, conduct disorder or attachment disorder)
- Sensory impairment (e.g. blindness or deafness) or motor disorder such as cerebral palsy
- Mental age less than 18 months equivalent (National Institute for Health and Clinical Excellence, 2011)

Autism screening (Charman et al., 2007) and assessment tools (National Institute for Health and Clinical Excellence, 2011) generally have greater efficacy when used with individuals who do not have significant other disabilities. The Diagnostic Interview for Social and Communication Disorders (DISCO; Leekam, Libby, Wing, Gould, & Taylor, 2002; Wing, Leekam, Libby, Gould, & Larcombe, 2002) assessment of autism is unique in that it identifies autism across the range of functioning including mild to profound ID. The ability of other gold standard assessment tools such as the Autism Diagnostic Interview (ADI; Lord, Rutter, & Le Couteur, 1994) and the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) to differentiate autism among individuals with

Table 16.1 Studies of psychopathology comparing individuals who have intellectual disabilities (ID) with and without autism (ASD)

Study		Rating on criteria		Population and identification/assessment of ASD		N ASD		Measure of psychopathology	Results for ASD+ID vs. ID
A	B	C	D	+ID	ID	+ID	ID		
<i>I: Population-based studies</i>									
1	3	1	3	Adolescents with severe ID (mean age 16, IQ<40). Matched on age, gender and non-verbal IQ. ASD identified using ADI-R		12	12	Diagnostic assessment for the severely handicapped (DASH-II)	Reaching 'clinical significance': anxiety (42 % vs. 0 %), mania (67 % vs. 8 %), depression (50 % vs. 8 %; all $p<0.05$). Mean of 5.3 'clinically significant disorders' vs. 1.3 for those with no ASD. Higher mean total score (44.8 vs. 16.2) and higher scores on anxiety, mania and depression scales (all $p<0.05$)
1	3	2	3	Adolescents with ID (aged 14–20, IQ<75). Matched on gender, age and non-verbal IQ. ASD identified using ADI-R		36	36	Clinical diagnosis using SAPP, ICD-10, research diagnostic criteria (RDC)	Greater history of ≥ 1 episode of psychiatric disorder, 47 % vs. 17 %; higher mean total number of episodes, 0.89 vs. 0.23 (both $p<0.05$). Most frequent diagnoses: depression (22 % vs. 8 %), adjustment (22 % vs. 5 %), mixed (11 % vs. 1 %) and bipolar disorder (5 % vs. 0 %) (these differences were not significant)
1	3	2	3	See Bradley and Bolton (2006)		31	31	See Bradley and Bolton (2006). ICD-10 symptoms of inattention, hyperactivity and impulsivity (IHI)	More likely to have ≥ 1 symptom of I, H and I or any one of IHI (55 % vs. 23 %); more likely to meet criteria for hyperactivity, impulsivity or any one of IHI (52 % vs. 19 %) (all $p<0.05$). Not significantly more likely to reach full criteria for ADHD (23 % vs. 7 %, $p=0.07$) or hyperkinetic syndrome (1.3 % vs. 3 %, $p=0.2$)
1	3	2	3	See Bradley and Bolton (2006)		36	36	See Bradley and Bolton (2006). Compulsive behaviour checklist, tic checklist, stereotypy checklist, self-injury and self-restraint checklist	Higher mean number of conditions (3.4 vs. 1.8; $p<0.001$). Higher number of fears and phobias, compulsions, stereotypies and observed anxiety symptoms ($p<0.05$). No difference in number of tics, self-injurious or self-restraining behaviours. No difference in number meeting criteria for anxiety (25 % vs. 17 %), phobic disorder (19 % vs. 11 %) or Tourette syndrome (6 % vs. 3 %)

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Table 16.1 (continued)

Study		Population and identification/assessment of ASD		N ASD		Measure of psychopathology	Results for ASD+ID vs. ID
A	B C D	+ID	N	ID	N		
<i>II: ID register-based studies</i>							
Melville et al. (2008)							
0	1 2 3		77	154		Clinical diagnosis (DC-LD, ICD-10 and DSM criteria)	No significant differences on the number with mental ill health: excluding problem behaviours (21 % vs. 23 %) and including problem behaviours (48 % vs. 40 %); incidence of mental ill health over 2 years (16 % vs. 19 %) or recovery from mental ill health over 2 years (36 % vs. 48 %) (all $p > 0.05$). Those with ASD and problem behaviours less likely to recover over a 2-year period (6 % vs. 38 %)
Morgan et al. (2003)							
1	1 2 0		164	400		Clinical diagnosis based on ICD-10	41 % had a psychiatric disorder (65 % of those with mild ID, 35 % of mod ID and 40 % of severe ID). Higher rates of depression (20 % vs. 3 %) and bipolar disorder (11 % vs. 2 %), both $p < 0.05$, no difference in prevalence of schizophrenia
<i>III: ID service-based studies</i>							
Hill and Furniss (2006)							
1	0 1 0		69	13		Aberrant behaviour checklist, DASH-II	Higher number met criteria on DASH-II for anxiety (77 % vs. 39 %), mania (77 % vs. 39 %), mood disorder (64 % vs. 46 %) and schizophrenia (30 % vs. 8 %) (all $p < 0.05$). Higher scores on organic, anxiety, stereotypes and mania subscales ($p < 0.05$). No significant differences on ABC irritability, lethargy, stereotypy or hyperactivity scores
Totsika et al. (2010)							
0	0 1 1		87	195		PIMRA or PAS-ADD, aberrant behaviour checklist	No difference in number meeting criteria for psychiatric caseness in unmatched sample (32 % vs. 23 %, $p = 0.09$) or matched sample (37 % ($N = 65$) vs. 27 %, $p = 0.11$), higher ABC score for unmatched group only (38 vs. 19, $p < 0.01$)

LoVullo and Matson (2009)	0	1	0	0	1	84	42	Autism spectrum disorders-comorbidity for adults (ASD-CA)	Higher scores for ASD + ID vs. ID on total (10 vs. 4), anxiety (0.8 vs. 0.05), irritability (3 vs. 1.4), hyperactivity (2.4 vs. 1.2) and depression (0.7 vs. 0.3) scores (all $p < 0.05$). Significantly higher scores for ASD + ID + psychopathology vs. ID on total (8), anxiety (0.4), irritability (2.6) and hyperactivity (2.6) (all $p < 0.05$). No significant differences for ASD + ID vs. ASD + ID + psychopathology groups	
Matson, Rivet, Fodstad, Dempsey, and Boisjoli (2009)	0	1	2	1	287	90	287	Clinical diagnosis (DSM-IV-TR), Vineland ABS	Higher number with an additional axis I diagnosis (33 % vs. 13 %). Significantly lower adaptive skills for those with ASD and axis I diagnosis compared to those with ASD and no-axis I diagnosis and those with ID alone	
Smith and Matson (2010)	0	1	0	3	50	50	50	ASD-CA	Higher scores on anxiety and hyperactivity subscales for ASD + ID + epilepsy vs. ID + epilepsy. Higher scores on irritability, hyperactivity and depressive subscales for ASD + ID + epilepsy vs. ID (both $p < 0.05$). Higher scores on irritability subscale for ASD + ID vs. ID	
<i>IV: ASD service-based studies</i>										
Bakken et al. (2010)	0	1	1	0	132	62	132	Psychopathology in autism checklist (PAC)	Overall higher rates of any psychiatric disorder (53 % vs. 17 %), psychosis (25 % vs. 9 %), depression (37 % vs. 15 %), anxiety (34 % vs. 9 %) and OCD (13 % vs. 3 %), all ($p < 0.05$). No differences among those with a psychiatric disorder for depression (70 % vs. 87 %), OCD (24 % vs. 17 %) or anxiety (64 % vs. 52 %). Mean no. of disorders in those with a psychiatric diagnosis = 2.1 for each group	

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Table 16.1 (continued)

Study		Rating on criteria		Population and identification/ assessment of ASD		N ASD N		Measure of psychopathology		Results for ASD+ID vs. ID
A	B	C	D	+ID	ID	+ID	ID			
0	1	0	1	367	550	Children and adolescents (aged 4–18). 86 % of ASD group had ID (ASD confirmed using ABC, CARS and DSM-IV structured clinical interview)		Developmental behaviour checklist-parent version (DBC-P)	Higher mean total (61 vs. 43), disruptive (13 vs. 11), self-absorbed (15 vs. 9), communication disturbance (5 vs. 4), anxiety (9 vs. 7), ADHD (7 vs. 5) and depression (5 vs. 4) scores; all $p < 0.001$ for MANCOVAs controlling for age, gender and ID	
<i>V. Mental health service-based studies</i>										
0	1	1	2	13	40	Adult inpatients with depression. Matched on age/gender/ID severity. Included those with an existing clinical diagnosis of ASD according to DSM-IV		Mood and anxiety semi-structured interview for patients with ID (MASS)	Prevalence of comorbid anxiety: 62 % vs. 38 %. Higher mean number of symptoms: 12 vs. 10, $p = 0.05$. No differences on individual symptoms or clusters, except for decreased sleep ($p = 0.05$)	
0	1	2	1	23	23	Adult mainstream mental health patients. Matched on gender and inpatient/outpatient status. Included those with an existing clinical diagnosis of ASD		Clinical diagnosis using ICD-9	Lower rate of psychosis (26 % vs. 78 %, $p < 0.01$). No significant difference on other disorders. Lower rate of psychosis compared with 23 mental health patients with no ASD or ID (83 %, $p < 0.01$)	
0	1	2	1	124	562	Adult from a specialist mental health in intellectual disability service. Included those with an existing clinical diagnosis of ASD according to ICD-10 criteria		Clinical diagnosis using ICD-10, challenging behaviour (CB, according to DAS-B)	More likely to have CB (88 % vs. 62 %, $p < 0.01$). For those with CB, lower rates of schizophrenia (10 % vs. 19 %) or any psychiatric disorder (29 % vs. 52 %) for those with ASD ($p < 0.05$). For those without CB higher rates of schizophrenia, 40 % vs. 16 %, $p < 0.05$. After controlling for the level of ID, gender and age, there was no association between comorbid psychopathology and presence of CB	

Tsakaniikos et al. (2006)	See McCarthy et al. (2010)	147	605	Clinical diagnosis using ICD-10, DAS-B	Lower rates of psychiatric disorder (36 % vs. 55 %) and personality disorder (PD; 3 % vs. 9 %, both $p < 0.01$). No significant differences for anxiety (4 % vs. 8 %), depression (6 % vs. 9 %) or psychosis (16 % vs. 19 %). Significant association between ASD and PD when age, gender and severity of ID were accounted for
0 1 2 1					
Underwood et al. (2012)	See McCarthy et al. (2010), Diagnosis of ASD/no ASD confirmed using ADOS	53	48	Clinical diagnosis using ICD-10, DBC-adult version (DBC-A)	Lower rates of psychiatric disorder: 46 % vs. 85 %, more likely to reach cut-off for psychiatric caseness on DBC-A (total score >50): 60 % vs. 11 %. Presence of ASD significantly predicted a higher total DBC-A score and greater likelihood of score >50 when age, gender and severity of ID were accounted for
0 3 2 1					

Studies are grouped together according to the way in which they identified their samples:

I: Population-based studies that identified all (or all in a specific age range) with ID in a geographical area (including those with previously undiagnosed ID)

II: Studies that identified all with an existing diagnosis of ID in a geographical area (e.g. sourced from an ID register)

III: Studies that sourced participants from an ID service (e.g. a residential placement for individuals with ID)

IV: Studies that sourced participants with ASD from an ASD service

V: Studies that sourced participants from a mental health service

Criterion A: Screening for ASD 0=Method with a high threshold/lower level of potential identification (e.g. existing clinical diagnoses). 1=Method with a low threshold/higher level of potential identification (e.g. standardised ASD screening tool)

Criterion B: Confirmation/diagnosis of ASD 0=Did not use any standardised *diagnostic* assessment for ASD. 1=Used a clinical diagnostic assessment for ASD according to standardised clinical criteria (DSM/ICD/RDC). 2=Used a gold standard ASD diagnostic assessment (e.g. ADI) but there was no face-to-face contact with participant. 3=Used a gold standard ASD diagnostic assessment (e.g. ADI, ADOS, DISCO) that included face-to-face contact with participants

Criterion C: Assessment of psychopathology 0=Compared scores on a psychiatric symptom tool rather than presence/absence of a psychiatric disorder/diagnosis. 1=Used a psychiatric symptom tool with cut-off scores for psychiatric caseness or specific diagnoses. 2=Carried out a comprehensive psychiatric assessment using standardised clinical diagnostic criteria (DSM/ICD/RDC)

Criterion D: Matching of participants with and without ASD 0=No matching or attempt to account for (a) severity of ID/IQ/standardised measure of functioning or (b) age or (c) gender. 1=Data analysis took into account all three of a, b and c or participants were matched on at least one of a, b or c. 2=Group matching on all three of a, b and c or groups were compared and no differences found for a, b or c. 3=Case-by-case matching on all three of a, b and c

ABC autism behaviour checklist, *ADI* autism diagnostic interview, *ADOS* autism diagnostic observation schedule, *CARS* childhood autism rating scale, *DAS* disability assessment scale, *MANCOVA* multivariate analysis of covariance, *PAS-ADD* psychiatric assessment schedule for adults with developmental disorders, *PDD-MRS* pervasive developmental disorder in mental retardation scale, *PIMRA* psychopathology instrument for mental retarded adults, *SAPPA* schedule for the assessment of psychiatric problems associated with autism (and other developmental disorders)

the most severe intellectual disability remains challenging. Care has to be taken that for each individual, the items considered are developmentally or otherwise appropriate (Bryson et al., 2008). Increasing severity of ID is associated with other disabilities such as sensory and motor impairments that will further complicate the developmental history and manifestations of possible autism. Autism assessments conducted by clinicians and researchers experienced in autism and ID, together with the opportunity for discussion to develop consensus around complex cases, seem likely to offer the most accurate assessment available at the present time.

A review of earlier studies spanning from 1978 to 2005 (Table 2 in Bryson et al., 2008) showed prevalence rates of autistic disorder in ID populations of between 19.8 and 40 % when the broader spectrum of the triad of autistic impairments were included. Of the further eight studies subsequently available for review, six reported on adults (Bouras, Cowley, Holt, Newton, & Sturmey, 2003; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; La Malfa, Lassi, Bertelli, Salvini, & Placidi, 2004; Morgan et al., 2002; Saemundsen et al., 2010; Totsika, Felce, Kerr, & Hastings, 2010), one on adolescents only (14–20 years; Bryson et al., 2008) and one reported on children and adolescents (4–18 years; de Bildt, Sytema, Kraijer, & Minderaa, 2005). Prevalence estimates for autism ranged from 7.5 to 39.2 % for adults, 28.2 % for adolescents and 17.7 % for children. Diagnosis of autism prior to the study identification tended to be low: less than half of the adolescents had been previously diagnosed. Pre- and post rates reported in two of the adult studies (La Malfa et al., 2004; Saemundsen et al., 2010) were 7.8 and 9 % (pre) to 39.2 % and 21 % (post), respectively. Two studies reported greater rates of autism with greater severity of ID (de Bildt et al., 2005; Morgan et al., 2002) and one reported that autism prevalence decreased with age (Morgan et al., 2002). Recent evidence (Underwood, 2011) indicates there may be significant numbers of people with autism in adult clinical populations with ID who have remained undiagnosed; these individuals tend to be in older age groups for whom it can be anticipated getting an early history

may be problematic. Such findings may account in part for the lower estimated rate of autism found in one study (Melville et al., 2008).

These research studies support the view that unless specifically looked for and systematically assessed, autism may not be identified in the general population or in populations with ID (Emerson & Baines, 2010; National Institute for Health and Clinical Excellence, 2012). Where such robust identification occurs, autism can be calculated to be up to 24 (children) and 28 (adults) times greater in the population with ID than in the general population.

Psychopathology in ID and in Autism

There is good evidence for greater mental ill health in populations with ID compared to general populations (children: Emerson & Hatton, 2007); (adults: Cooper et al., 2007; Cooper & van der Speck, 2009). Multicentre studies of children with autism indicate that psychiatric disorders are common and frequently multiple; high levels of anxiety, mood, disruptive disorders and ADHD are reported (Leyfer et al., 2006; Simonoff et al., 2008).

While there is a lack of epidemiological research on adults with autism (Brugha et al., 2009, 2011), two robust clinical longitudinal studies of mental health in adults with autism are reported: (1) 122 adults with 'possible childhood onset neuropsychiatric disabilities' and normal IQ were found to have high rates of mood (53 %), anxiety (50 %), especially obsessive-compulsive disorder (OCD; 20 %), chronic tic disorder (20 %), psychotic disorders (12 %) and ADHD (43 %; Hofvander et al., 2009); (2) a follow-up study of 135 adults referred for evaluation of autism as children showed that 16 % had developed new onset disorders (and a further 8 % uncertain new onset disorder), with these disorders falling into two main groups: OCD (some with catatonia) and affective disorders (Hutton, Goode, Murphy, Le Couteur, & Rutter, 2008). An increase in rates of anxiety and depression is also described in adults with Asperger's syndrome (see review by Woodbury-Smith & Volkmar, 2009).

Table 16.2 Different perspectives in understanding distress behaviours and psychopathology in autism

<p>Outside-In perspective: DSM, ICD and other clinical diagnoses based on behaviours of concern</p>	<p>Examples of behaviours of concern</p>	<p>Inside-out perspective: people with autism: first person autobiographical accounts when engaging in these behaviours of concern</p>	<p>Comments on the behaviours of concern by those with autism and those supporting people with autism</p>
<p>Obsessive-compulsive disorder (OCD) (for similarities and differences of repetitive behaviour between OCD and autism, see Zandt, Prior, & Kyrios, 2007)</p>	<p>Repeating the same behaviours over and over (such as opening or closing doors, putting items back in place, arranging things in certain order) may or may not be upset if interrupted but will seek to return to this behaviour</p> <p>Obsessional rituals—rocking, rhythmic head banging, spinning objects, perimeter hugging, needing to touch everything in the room before settling down</p>	<p>‘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, Lansdown, & Robinson, 1992)</p> <p>‘if you start feeling reality slipping away you want to focus on something – pain or flicking a light switch on or off’ I like sameness, need to know what’s coming next, things are more coherent, under pressure things tend to fragment’ (Weeks, Undated)</p>	<p>Focusing on something in order to avoid overload (and the ‘autonomic storm’; see text page 8)</p> <p>Obsessional rituals may reflect (1) the autistic individual’s construction of the world by means of a very different set of sensory information (as seen in visually impaired children) ‘using her eyes as much as her ears, using her hands as much as her eyes’ and (2) checking up on a distorted sensory perception with an alternative sense, e.g. touch on distorted vision (Albano, 2003; Bogdashina, <i>Date unknown</i>)</p>
<p>Obsessive and unusual interests (such as in parts of objects)</p>	<p>‘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 chin’ (Williams, 1992)</p>	<p>‘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)</p>	
<p>Repetitive speech or echolalia</p>	<p>‘I used to repeat the same words over again as this made me feel safer’</p>	<p>Nazeer, a person with autism, writes about his school friends with autism and their search for coherence (Nazeer, 2006)</p>	

(continued)

Table 16.2 (continued)

Outside-In perspective: DSM, ICD and other clinical diagnoses based on behaviours of concern	Examples of behaviours of concern	Inside-out perspective: people with autism: first person autobiographical accounts when engaging in these behaviours of concern	Comments on the behaviours of concern by those with autism and those supporting people with autism
		<p>‘Trying to keep everything the same reduces some of the terrible fear’ (Jolliffe et al., 1992)</p>	<p>‘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> <p>‘... Earlier I mentioned the way that autistic people regularly seek local coherence.... I rarely go out without a crocodile clip in my pocket although recently my cell phone has begun to substitute for it’ (Nazeer, 2006)</p> <p>‘The rule probably tended to work. It achieved local coherence. We could make sense of it’ (Nazeer, 2006)</p> <p>‘Andre tries to reach local coherence to protect himself by putting more complex things in the background and focusing instead on tapping a pen or liming up empty glasses’ (Nazeer, 2006)</p>
Stereotypies	<p>Repetitive movements or vocal sequences that appear to be invariant in form without any obvious eliciting stimulus or adaptive function, e.g. body rocking, mouthing and complex hand and finger movements (Baron et al., 2006)</p>	<p>‘rocking and spinning were other ways to shut out the world when I became overloaded with too much noise’ (Grandin, 2006)</p>	<p>Coping mechanism to attain homeostasis and calm (functional relationship between stereotypies and arousal (HR) has been found) (Baron et al., 2006)</p>

<p>‘what other people call odd hand movements and what people refer to as grimaces are not meant to be annoying, they too give a sense of control, safety and perhaps pleasure’ (Jolliffe et al., 1992) and</p> <p>... ‘The search for coherence: other coherentizing behaviours include ‘whirling on own initiative, running to and fro, bouncing, walking on toes, mouthing and licking things’ (Nazeer, 2006)</p>	<p>‘Many autistic adults deal with discomfoting events by returning to a regime – it may be as simple as rocking ... or involve multiplying three digit prime numbers’ ...</p>
<p>‘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> <p>‘many of my fixations had a sensory basis’ (Grandin, 1992a, 1992b). ‘fixations can be tremendous motivators’ (Grandin, 1992a, 1992b)</p> <p>‘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>	<p>‘from the moment I get in (to the supermarket) there’s all the sounds, movements, smells, shapes, colours, shadow and shine from all directions all hitting me at once ... my mind get flooded with this array of contrasts at a pace that’s much too fast for my conscious mind to process’ (Williams, 1995)</p>
<p>Anxiety disorders including panic, fears and phobias</p>	<p>Responses to sensory hypersensitivities and distortions</p>
<p>Low threshold startle response, constant high levels of anxiety, agitation, hyper vigilance, and avoidance of objects and situations; may (or may not) show physiological signs of anxiety and may have rapid pulse in the absence of other physiological signs of anxiety</p>	<p>(continued)</p>

Table 16.2 (continued)

<p>Outside-In perspective: DSM, ICD and other clinical diagnoses based on behaviours of concern</p>	<p>Examples of behaviours of concern</p>	<p>Inside-out perspective: people with autism: first person autobiographical accounts when engaging in these behaviours of concern</p>	<p>Comments on the behaviours of concern by those with autism and those supporting people with autism</p>
<p>‘Behaviour problems’—with behavioural judgments (such as ‘refusal’, ‘manipulative’, ‘attention seeking’, ‘deliberate’) based on the clinicians’ sensory experience of reality, and not on that of the person with autism</p>	<p>Withdrawal into own activities</p>	<p>‘Life is bewildering, a confusing, interacting mass of people, events, places and things with no boundaries.’ (Jolliffe et al., 1992)</p> <p>‘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> <p>‘All things coming from the outside must be gentle, sometimes devoid of emotion, so as not to overwhelm.’ (O’Neill, 1998)</p>	<p>One adult with autism interviewed by Cesaroni and Garber (1991) theorises that certain frightening sounds can act as a trigger for disorganisation of processing similar to epileptic seizures triggered by a flashing light</p> <p>‘A ‘side effect’ of [visual] perception in bits, is a sense of fear that is not specifically related to objects but is originated in the fact that the first encounter with a physical object is a particle one’ (Van Dalen, 1995)</p> <p>VanDalen compares this with a confrontation with a silhouette in the dark: ‘one knows that something is there but it is not altogether immediately clear what it is’ (Bogdashina, Date unknown)</p>
<p>As overload intensifies, increasing difficulty filtering and prioritising information occurs and the body’s self-defences system (ANS) is triggered to ‘flight’, ‘fight’ and ‘freeze’ (reactive behaviours) and eventually to an autonomic storm (a massive increase in sympathetic nervous activity—a hyperstress response; Parady, 2011)</p>	<p>‘I would sit for hours watching and dribbling sand between my fingers ... I went into a trance which cut me off from the sights and sounds around me’ (Grandin, 2006)</p>	<p>‘Flight’ responses</p>	<p>‘Flight’ responses</p>

<p>Oppositional defiant disorder (ODD)</p>	<p>Refusing to engage or doing the opposite of what was requested</p>	<p>‘Auditory and tactile input often overwhelmed me. Loud noise hurt my ears. When noise and sensory stimulation became too intense I was able to shut off my hearing and retreat into my own world’ (see Grandin, 2000a, 2000b)</p> <p>Grabbing and Clinging: ‘The din made the ground under my feet disappear and I could neither see nor feel the world round me. Up and down were suddenly in the same place and I had no idea where my feet were. So as not to fall over or explode from inside, I had to grab the fence where I was standing, pressing myself against it and holding on hard. I had to feel something that stood still, something anchored in a world that had become totally unpredictable.’ (Gerland, 2003; page 130)</p>	<p>Looking for coherence and a point of reference when in overload</p>
<p>Avoidance of places and situations</p>	<p>Grabs or clings onto others; ‘No’ may intensify this unwanted behaviour</p>	<p>‘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; page 61)</p>	
<p>A criterion for autism</p>	<p>Avoidance of eye contact</p>	<p>‘someone looking directly into my eyes felt like an attack’ (Nony, 1993)</p> <p>‘People have no idea how unbearably painful it is for me to have to make eye contact.’ (Jolliffe et al., 1992) ‘Agony’ (Grandin, 2006)</p>	<p>Avoidance of direct perception helps to avoid sensory overload and pain</p>
<p>Conduct disorder including aggression and property destruction</p>	<p>Suddenly lashes out (aggression); this may appear unprovoked and out of the blue or in response to certain triggers</p>	<p>‘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>	<p>‘Fight’ responses and behaviours of an autonomic storm</p>

(continued)

Table 16.2 (continued)

<p>Outside-In perspective: DSM, ICD and other clinical diagnoses based on behaviours of concern</p>	<p>Examples of behaviours of concern</p>	<p>Inside-out perspective: people with autism: first person autobiographical accounts when engaging in these behaviours of concern</p>	<p>Comments on the behaviours of concern by those with autism and those supporting people with autism</p>
<p>Intermittent explosive disorder</p>			
<p>Self injurious behaviour</p>	<p>More severe and sustained aggression directed towards self; others or the environment; hits, pinches and bits self</p>	<p>‘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 realising 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, 1995)</p> <p>‘... you’re going to run out into the street where the traffic is, or run full tilt into a brick wall, anything to stop it [the panic]. I’d much rather have pain – pain is one over-riding sensation rather than getting a whole lot of jumbles’ (Weeks, Undated)</p>	<p>Some of these behaviours may represent flashbacks to previous trauma and or abuse</p> <p>‘Fight’ responses and behaviours associated with an autonomic storm</p>
<p>Disruptive behaviour and impulse control disorders</p>			
<p>‘Challenging Behaviours’</p>			
<p>Autism-related catatonia</p>	<p>I: New onset posturing (freezing), stereotypes, alteration in level of activity</p>	<p>‘if I get a lot of sensory overload, I just shut down, become catatonic. I get what’s known as fragmentation ... like being turned into forty channels at once ... if you get this when you are four, the result is total panic’ (Weeks, Undated)</p>	<p>ANS response of ‘Freeze’—resulting in catatonic-like states (Dhossche, Shah, & Wing, 2006; Fink, Taylor, & Ghaziuddin, 2006; Loos Miller & Loos, 2004; Loos & Loos Miller, 2004; Wing & Shah, 2000) sometimes referred to as ‘meltdown’ or ‘shutdown’ states</p>

Catatonia associated with schizophrenia or mood disorder

<p>2: Slowed down, unusual motor patterns and gait, especially in response to requests; may show normal motor movements in self initiated activities and in some environments compared to others</p>	<p>'like having 4 drill sergeants screaming conflicting orders at you at once and if you don't do everything right away you will be in big trouble and you don't know what to do first so you stand there being yelled at'. (see list by Loos) (Loos Miller & Loos, 2004)</p>	<p>Shyness and being on the more passive end of interaction on the ASD spectrum may increase vulnerability to these shutdown and catatonic (Loos Miller & Loos, 2004; Wing & Shah, 2000) withdrawing being characteristic rather than acting aggressively in response to distress</p>
<p>3: Increased slowness also affecting speech</p>	<p>What makes the shut down better? '... time, sleep, rhythmic rocking, spinning, "stimming", working puzzles and spending quiet time alone ...' (Loos Miller & Loos, 2004)</p>	<p>'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 h. These "shutdown" 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' (Loos & Loos Miller, 2004)</p>
<p>4: Difficulties initiating and completing actions with increased reliance of physical and verbal prompts by others</p>	<p>Williams recalls as a child she was afraid of 'the big black nothingness coming to get me'. As an adult she recognised the syndrome as 'sensory flooding triggering such a degree of overload as to cause an epilepsy-like total shut down on the processing of incoming information' (Williams, 2003)</p>	
<p>5: Increased passivity and lacking in motivation (Wing & Shah, 2000)</p>	<p>'I can't take the fire alarm. I go completely stiff. If it goes off and the house was burning round me, I should have to be physically removed from the room.' (speaker with autism—National Autistic Society Conference Cardiff, 2011)</p>	

Psychopathology When Autism and ID Coexist

Given the evidence cited it might be hypothesised that the presence of autism would add to the risk for psychopathology in those with ID. Current evidence indicates that the interplay of autism and ID on psychopathology is complex. In a review of 24 studies published during 2006 and 2007, McCarthy (2007) concluded that children with ID and autism have a higher prevalence of ADHD, mood disorders, catatonia and repetitive behaviours compared to children without autism. However, in a subsequent review of the literature spanning from 2003 to 2010 concerning adults with ID with and without autism, methodological challenges were more apparent and conclusions less certain (Underwood, McCarthy, & Tsakanikos, 2010). The authors commented on (1) the difficulties of assessing psychopathology in adults; (2) the need to ensure that autism is attributed accurately; (3) the importance that studies match groups on age, gender and severity of ID; and (4) the need to collect data on a broader range of measures including health, social functioning and service users experiences of mental health services. In one population-based study, apparent differences in mental ill health between ID groups with and without autism were accounted for by factors other than autism, including ability level and Down syndrome (Melville et al., 2008). A more recent series of studies including mental health clinic-based matched groups found participants with ID and autism were less likely to have a psychiatric disorder but had significantly lower health and social functioning than those without no autism (Underwood et al., 2012; Underwood, 2012). The group with autism and ID were also more likely to exceed the cut-off score for 'psychiatric caseness' on the Developmental Behaviour Checklist for Adults (DBC-A; Mohr, Tonge, Einfeld, & Gray, 2004). These latter studies taken together point to the important difference between (a) clinical evaluation of psychiatric disorder and (b) psychopathology as measured by screening tools and checklists; the former embeds symptoms and behaviours in a psychiatric

diagnostic formulation while the latter do not differentiate between behaviours that may underpin psychiatric disorder from those related to other aetiologies (such as autism, ID or unrecognised medical conditions).

Two studies, subsequent to the literature reviews above, reported further on psychopathology in individuals who have ID, with and without autism. Using a Psychopathology in Autism Checklist (PAC), greater rates were reported of 'any psychiatric disorder', psychosis, depression, anxiety and OCD in an autism-ID group ($N=62$) compared to an ID only ($N=132$) group of adolescents and adults (all $p<0.05$; Bakken et al., 2010). In a population-based sample of 36 individually matched adolescent ID and autism-ID groups, using a standardised semi-structured clinical evaluation of psychiatric disorder, significant differences were reported in compulsive behaviours ($p<0.001$), stereotypies ($p<0.001$), anxiety ($p<0.001$) and fears and phobias ($p<0.05$) (Bradley, Ames, & Bolton, 2011). These background (non-episodic) behaviours were independent from significant differences in episodic disorders (e.g. depressive, adjustment; Bradley & Bolton, 2006) and clinically significant inattentive, hyperactive, impulsive behaviours and ADHD (Bradley & Isaacs, 2006) in the same matched groups. This population-based study specifically distinguished relapsing and remitting psychiatric illness (e.g. adjustment disorder, depression, bipolar affective disorder) that tended to occur for the first time in adolescence, from disorders that may appear more insidiously during childhood and continue into adolescence but are not specifically episodic although may escalate during episodic illness (e.g. ADHD). This study and others (Cooper et al., 2007; Howlin & Moss, 2012; Hutton et al., 2008; Mouridsen, Rich, Isager, & Nedergaard, 2008) demonstrate the complexity of presenting psychopathology, coexisting diagnoses and the need to take into account individual historical patterns of mental distress.

Additionally there is emerging evidence that circumstances external to the individual such as staff attitudes (Rose, 2011), life events (Hulbert-Williams & Hastings, 2008), traumatic experiences

(Martorell et al., 2009) and other supports (Allen, 2008; Cooper et al., 2007; Smiley et al., 2007) need to be taken into account when studying psychopathology in ID.

As briefly noted above, the concept of psychopathology covers a broad range of mental distress—from clearly identifiable psychiatric disorders to behaviours and symptoms that are inferred to be psychiatric in origin but may be difficult to confirm definitively because of the limited cognitive and communication capacities of the individual with ID and autism. Some behaviours that appear to be mental distress have been shown to be a medical condition, e.g. GI related (Buie, Campbell, et al., 2010; Buie, Fuchs, et al., 2010). Alternatively psychiatric distress may be correctly identified but its origins not fully recognised, e.g. early trauma and other life events (Bradley, Sinclair, & Greenbaum, 2012). These diagnostic issues become more problematic with increasing severity of ID (and autism) and require comprehensive biopsychosocial longitudinal evaluation to unravel the aetiological complexities of the presenting symptoms (Bradley & Hollins, 2010).

From the evidence reviewed above, it is apparent that robust determination as to whether autism, when coexisting with ID, contributes further mental distress, requires, at a minimum, the following methodological criteria to be met:

- (a) All in the autism group have been correctly identified with autism and none in the ID group have autism (Criteria A and B: see Table 16.1).
- (b) Psychiatric disorder is correctly identified (Criteria C, Table 16.1) as well as aetiological factors wherever possible.
- (c) Groups with and without autism are carefully matched on gender, age and level of functioning (Criteria D, Table 16.1).

Details of studies designed specifically to compare psychopathology in individuals who have ID with and without autism are shown in Table 16.1. Each study has been evaluated according to the criteria above. As can be seen there is great variation in the extent to which these criteria are met for each study adding uncertainty to the interpretation of the findings.

However, apart from these methodological challenges there is another circumstance that is becoming more apparent when comparing autism and non-autism groups: that is, the continued practice of considering psychopathology in autism only through the lens crafted for understanding psychopathology in the general population. This limited perspective and its implications are explored in the next section.

Mental Distress Associated with the Condition of Autism

People with autism describe a different experience of the world we share, some referring to themselves as neuro-atypicals (Autism Network International, Williams and Jim Sinclair (http://www.autreat.com/History_of_ANI.html; <http://www.autreat.com/>)) compared to those without autism (neurotypicals). Significant differences in brain structures and neurobiological functioning in autism have been found (Baron, Groden, Groden, & Lipsitt, 2006; Courchesne, Webb, & Schuman, 2011; Minshew, Scherf, Behrmann, & Humphreys, 2011) that underpin these different perceptual and psychological experiences (Baron et al., 2006; Bogdashina, 2003, 2010). It can be anticipated that mental health disturbances in those with atypical neuro-functioning may be both different as well as similar to those with typical neuro-functioning. Understanding how people with autism experience the world differently from the general population may illuminate more accurately the nature of the mental health disturbances they experience, the extent to which these overlap and are different from the general population, as well as provide opportunities for more targeted interventions and treatment.

Processing differences and difficulties in social and communication domains, particularly where verbally mediated content is concerned (e.g. speech), are well documented (Groen & Buitelaar, 2011; Tager-Flusberg, Edelson, & Luyster, 2011). Not so well documented in mental health research in autism, are the specific hyper- and hyposensitivities to sensory input (e.g., touch, taste, smell, hearing and vision;

Bogdashina, 2003; Caldwell & Horwood, 2008; Grandin, 2006; O'Neill, 1998; Williams, 1999a). These different sensory sensitivities have been found to be pervasive, multimodal and persistent across age and ability in children and adults with autism (Billstedt, Carina Gillberg, & Gillberg, 2007; Leekam, Nieto, Libby, Wing, & Gould, 2007). Included in these sensory differences are hyposensitivities to proprioception, making it difficult for the individual to know what he/she is doing and hence to atypical motor patterns such as rocking, climbing, swinging, banging and walking on toes, to help restore a sense of body boundaries (Ayres, 1972; Ayres & Robbins, 2005; Caldwell & Horwood, 2007). Some individuals with autism meet criteria for sensory processing disorder (SPD), a proposed new disorder in DSM-5, characterised by persistent atypical over- or under-responsivity to neutral sensation (Sensory Processing Disorder (SPD) Scientific Work Group (SWG), 2007, Appendix A; 2008, Appendix B). Added to these different sensory experiences, there are autism-specific difficulties with regard to regulating behavioural responses to contingencies in the outside world: change, transition and choice being especially problematic in these regards (Caldwell, 2006; Caldwell & Horwood, 2007; Grandin, 1992a, 1992b; O'Neill, 1998; Robinson, 2011; Williams, 1996), as well as difficulties in regulating emotional responses to internal contingencies such as embarrassment and any form of emotional warmth (Caldwell, 2006; Caldwell & Horwood, 2007; O'Neill, 1998).

Inside-Out Experience in Autism

The inability of the brain to keep up with filtering and processing incoming sensory stimuli (including proprioceptive, emotional and cognitive perceptions) is described by those on the spectrum as 'overload'. When the resulting confusion becomes too overwhelming, the brain 'crashes', in what is termed the 'autonomic storm'. This experience and resultant behaviours are vividly described in a video simulation created by a woman with autism to help 'neurotypicals'

understand how powerful, dramatic and debilitating this experience is [<http://www.youtube.com/watch?v=BPDTEuotHe0>]. As such, it draws attention to 'ordinary' environments and circumstances that are intolerable for many with autism; without this understanding their behaviour may be misinterpreted as to its aetiology and intent:

...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..... I hear everything four times louder than a non-autistic person ... if I don't remove myself from the situation I immediately go into sensory overload.¹ 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 ...

Others with autism have also written about their experiences of the sometimes sliding scale between overload and the autonomic storm. Williams (1995), for example, describes floating images in her brain and 'running, running, running' to try and keep up. Gerland (2003) describes how as a child she experienced 'a constant shudder down my spine It was like the sound of screeching chalk on a blackboard turned into a silent concentration of feeling, then placed in the back of my neck. From there, so metallic, the feeling radiated out into my arms, clipped itself into my elbows but never came to an end, never ever came to an end'. For Williams (1999a), sensations that began in the spine radiated even further, to her feet, 'like cracks in an earthquake'. She describes being in terror, 'it felt like death coming to get me... surprising how many times a

¹There is some confusion in the exact use of the term 'overload'. Weird Girl Cindi is using it to refer to the condition that other authors refer to as 'Fragmentation', 'Meltdown', and more recently, in the light of increasing understanding of what is happening in the brain, 'The Autonomic Storm' (see Table 16.2 for further descriptions of this condition and experience of those with autism, pp. 245–251).

day I could be dying and still alive'. Descriptions by children include reference to 'my head running away', 'being in a car crusher' (see Table 16.2, for further descriptions of the experience of overload, pp. 245–251).

These experiences of fragmentation and sensory chaos accord well with the proposal by Ramachandran (2011) of a distorted salience landscape, involving overreaction by the autonomic nervous system (ANS) to (what may appear to a non-autistic person as) apparently 'trivial' incoming stimuli, triggering an autonomic storm accompanied by an increase in sweating and other responses of the body's self-defence system. The salience theory has been tested by measuring the Galvanic Skin Response (GSR) which showed a heightened response to a wide range of stimuli in children with autism compared with children not on the spectrum (Ramachandran, 2011).

Autism-specific differences in autonomic functioning and anxiety have been extensively investigated by Groden and colleagues (finding differences in attention, habituation, general arousal and cardiovascular response; Baron et al., 2006; Goodwin et al., 2006; Goodwin, Groden, Velicer, & Diller, 2007) and inferred in clinical descriptions of individuals who 'shut down' (Loos Miller & Loos, 2004; Loos & Loos Miller, 2004) or become catatonic (Dhossche et al., 2006; Fink et al., 2006; Wing & Shah, 2000) seemingly in response to life events they experience as overwhelming.

Some people on the autism spectrum describe their autonomic storm as initiated by an unusual or fizzy sensation in the back of the neck (Gerland, 2003; Williams, 1999b). They use words such as 'confusing', 'painful' and 'agonising' to describe its onset (further descriptions by authors with autism in Table 16.2, pp. 245–251). One man described the pain triggered by his hypersensitivity to light as 8–9 out of 10 compared to 4–5 caused by kidney stones (Caldwell; personal communication). Weeks (Undated) says of the autonomic storm, 'I would do anything to stop it, crash my head against the wall, run in front of a car'. Such symptoms, not infrequently described in metaphors that focus on immediate

sensory experiences and visual imagery, run the risk of being misinterpreted as psychotic if these unique ways of communicating distress are not recognised (Howlin, 2004, Chap. 10; Palucka, Bradley, & Lunsy, 2008).

Barron and Barron (1992); Gerland (2003); Grandin and Scariano (1986); Jolliffe et al. (1992); Nazeer (2006); and Williams (1999a) also provide accounts of their response to these painful effects of sensory overload. Grandin (1992a, 1992b) reports 'By focusing on the spinning coin I could cut out other sounds'. When Gerland (2003) heard the sound of a scooter revving up she would lose all sense of where up and down were and had no idea where her feet were. She would seek proprioceptive reassurance, clinging to the railings in order to have a physical point of reference.

Nazeer (2006) describes how, when it became noisy in the pub, his friend Andre would spill some beer on the bar and doodle in it. Focusing on this activity enabled his friend to shut out the overloading chatter. Barron describes how, when he switched the lights on and off, it gave him a wonderful sense of security (Barron & Barron, 1992). He knew what he was doing and it was exactly the same each time. These repetitive patterns and clinging grabbing behaviours in those with autism should be seen as coping strategies against the potential threat of being overwhelmed. In the absence of being able to cut out the overloading sensory clutter, they essentially attempt to find coherence in a world marked by altered and distorted sensory and proprioceptive inputs (Nazeer, 2006; see also Table 16.2 for further descriptions of repetitive behaviours and stereotypies functioning as coping strategies, pp. 245–251).

The instinct of the non-autistic world is to try to limit these repetitive behaviours. However, if the individual is stopped from engaging with their point of focus, they run the risk of becoming overloaded by incoming sensory stimuli (Gillingham, 1998). Levels of agitation and distress rise. Misattribution of intentional states may occur if the non-autistic perspective fails to recognise that these are attempts by the individual to cope with their sensory distress in whatever way he/she can; behaviours otherwise considered as

inappropriate or even provocative, deliberate, aggressive and ‘challenging’ (e.g. increased grabbing and squeezing directed towards others in a desperate attempt to reestablish perception of body boundaries) can result. As the perceived threat increases, sensory distortions become more urgent (see the video simulation previously mentioned) and the repetitive behaviours become more agitated. Other defensive strategies employed either contingently or in sequence, if previous attempts to reduce overload have failed, are those of the body’s self-defence ANS response appearing as:

- Flight: avoidance such as shutting eyes, pulling clothes over head and turning or running away
- Fight: aggression towards the perceived offending circumstance such as others or objects in the environment or against self, the individual being unable to distinguish between what is or is not their own body
- Freeze: shutdown of everyday functions—either partial or verging towards catatonic-like states

These coping strategies overlap and the triggers are not always simple. For example, in terms of eye contact, eyes may be screwed up (1) to avoid light that is too intense and therefore painful; (2) to shut out patterns or colours that set off the zooming, swirls and breakup of visual intake; or (3) when the individual is with another person, where eye avoidance occurs associated with the severe pain that can be caused by hypersensitivity to the body’s emotional responses (‘emotional overload’). Jolliffe et al. (1992) write, ‘people have absolutely no idea how painful it is for me to look at them’. Williams (1999a) simply calls it ‘agony’.

As the brain shuts down on some of its functions, Williams (1996) describes how at times she could either see or feel or vice versa but not both at once. So she could either see her hand but not feel it as part of her or feel it but not see it. As far as she was concerned, it was just a thing floating in front of her and she kept trying to push it away. The experience of the brain shutting down completely is described by one child as how sometimes he can hear his teacher but sometimes everything disappears and he has no idea what is happening. He says his teacher does not believe him (Caldwell, personal communication).

Finally, the whole body may simply refuse to move resulting in ‘shutdown’ (Loos Miller & Loos, 2004; Loos & Loos Miller, 2004) and catatonic-like states (Wing & Shah, 2000).

In people with autism these coping strategies in response to environments that are experienced as overwhelming, result in clinical presentations (e.g. repetitive behaviours) that overlap with behaviours (e.g. OCD) characteristic of psychiatric disorders seen in the general population (Table 16.2). Evidence from electrodermal studies of children with autism has highlighted the use of self-stimulation activities in order to calm hyperresponsive activity of the sympathetic (‘fight or flight’) branch of the ANS (Hirstein, Iversen, & Ramachandran, 2001). In order to ensure accurate psychiatric diagnosis (and hence appropriate targeted treatment), it is important to differentiate between symptoms that herald psychiatric disorder and autism-specific distortions resulting from sensory sensitivities and differences in brain processing and ANS system functioning. These two perspectives focusing on repetitive behaviours, stereotypies, anxiety disorders and behaviours associated with the flight, fight and freeze responses of the ANS are further elucidated in Table 16.2.

While these personal accounts are from more articulate people on the autism spectrum, similar repetitive compulsive behaviours and anxiety behaviours are common in those less articulate and lower functioning. Additionally, clinical interventions aimed at reducing overstimulating environments, attending to sensory issues and increasing coherence (e.g. familiar, predictable environments, planning around transitions, care providers using Intensive Interaction and Sensory Integration approaches), result in reduction of these behaviours in lower functioning individuals as they do for the more able on the spectrum (Caldwell & Horwood, 2008).

Summary

In this chapter our focus has been on (1) understanding psychopathology in autism and (2) determining whether the prevalence of

psychopathology in those with autism and ID is greater than those with ID alone.

1. Psychopathology in Autism

We have identified two different perspectives in understanding mental distress in autism—perspectives that touch directly on our understanding of clinical presentations, aetiology and consequently on treatment and prevention of mental health disturbances that arise. We refer to these two perspectives as (a) the ‘Outside-In’ approach, essentially applying DSM/ICD criteria to presenting symptoms and behaviours to make psychiatric diagnoses, and (b) the ‘Inside-Out’ approach, poignant descriptions by people who describe what it is like to live with sensory hypersensitivities, sensory integration deficits, brain processing problems and ANS dysregulation.

Importantly the Outside-In perspective infers psychopathology for some behaviours that people with autism actually describe as helping them to cope with sensory perceptual distortions and overload consequent to these autism-specific neurobiological differences in brain function. The Outside-In perspective derives from an evidence base of psychiatric disorder as this presents in the general population. Guidelines (also evidence based) as to how to treat these disorders have been developed from this perspective. However, if applied inappropriately to people with autism, treatments will be offered that may be inappropriate and indeed have serious outcomes (Esbensen, Greenberg, Seltzer, & Aman, 2009; Propper & Orlik, 2009).

The alternative Inside-Out perspective from people with autism is that the world picture (associated with neurobiological differences in autism) is totally chaotic. In an attempt to cut down on unfiltered sensory overload—and so make sense of their situation—the individual may (1) focus on a particular object or theme, idea or script (repetitive behaviour), (2) hide their eyes or run away (avoidance), (3) shut down the processing of one or more of the senses or freeze (catatonia) or (4) attack self or others (aggression). Underlying these behaviours is a desperate search for coherence (Table 16.2).

This Inside-Out perspective also has implications for the identification of those with autism who may (or may not) have ID. Many of these self-advocate authors describe difficulties at school and mistaken functioning and academic abilities which come to light only when their sensory needs are accommodated.

It is hard for those without autism and without the physical and psychological impacts of these hypersensitivities, sensory integration deficits and ANS dysregulation to understand the profound impact these have on all aspects of daily life; difficulties in perspective taking between those with and without autism may be more mutual than currently acknowledged. In relation to catatonia seen in autism, Hare and Malone (2004) report that existing labels may obscure an expression of the underlying autism condition, one which warrants a more in depth understanding of the individual’s sensory, perceptual and neurocognitive functioning.

2. Psychopathology and the Impact of Autism Coexisting with ID

While separate studies of children and adult populations with ID (of which up to a third may have autism) and populations with autism (across functioning levels but mostly reported for those without ID) have shown increased psychopathology compared to the general population without these disabilities, it remains unclear whether autism coexisting with ID gives rise to greater psychopathology than ID alone. We have identified the need for (1) robust identification of autism and matching of autism and non-autism groups on variables known to impact on psychopathology and (2) careful identification of mental health disturbances that considers longitudinal understanding of patterns, as well as aetiology, of these disturbances. When these criteria are met, the evidence is pointing to greater psychopathology in children and adolescents where ID and autism are coexisting.

Meeting these research criteria for adults is more difficult and the picture is less clear. This may relate in part to less robust identification of autism in adult populations and therefore less accuracy in identifying ID groups with and without autism for comparison.

However, it is noteworthy that to date comparison studies of psychopathology in ID, with and without autism, have not considered the autism-specific differences we have described in this chapter, differences that would be anticipated to impact significantly on behaviour in everyday settings: for example, when reporting anxiety behaviours noting whether there are any autism-specific hypersensitivities and whether accommodations have been made to reduce exposure to distressing and sometimes painful ‘everyday’ sensory events.

Implications for Future Research on Psychopathology in ID with and Without Autism

Population-based studies, controlling for relevant variables and using robust screening and assessment tools, will determine whether there are differences in behaviours related to mental health between those who have ID with and without autism. Relevant variables already acknowledged in current matching studies (see Table 16.1 Criteria) include chronological age, gender and level of functioning (acknowledging that those with autism may function differently depending on whether verbal or non-verbal skills are being tested). Syndrome diagnosis is increasingly being recognised as relevant to specific types of mental ill health (Society for the Study of Behavioural Phenotypes (SSBP), 2011) and matching on these is recommended, though difficult in practice given the relatively low prevalence of these syndromes.

As noted, understanding the aetiology of any differences found between autism and non-autism groups is likely to be restricted if these behaviours are viewed only through the lens of our current understanding of mental health disorders (DSM criteria) in the general population. Assessment tools developed to measure autism-specific behaviours across the life span and across levels of functioning will more accurately identify those behaviours that are associated with autism and those that represent the onset of psychiatric disorder. The DISCO is one such tool; the use of this diagnostic approach resulted in the first systematic identification of (a) atypical sensory responses

and found these to be present in over 90 % of those with autism (Billstedt et al., 2007; Leekam et al., 2007) and (b) autism-associated catatonia present in 17 % individuals (Wing & Shah, 2000). Neither of these conditions had been previously identified using tools developed from DSM criteria. We recommend that these neurobiological differences in autism (e.g. hypersensitivities) and consequent autism-specific vulnerabilities in ‘ordinary’ environments are taken into account when studying psychopathology in autism.

Clinical practice attests to effective outcomes in reducing anxiety, repetitive behaviours and catatonia when environments and supports that are offered acknowledge these autism-specific vulnerabilities and needs; in our clinical practice we refer to these environments as ‘autism friendly’. Future research might evaluate the impact on mental health of implementing such autism-friendly environments and supports. Using an analogy to reading ability, the latter can only be accurately evaluated when the person who requires glasses to see the script is provided with glasses; likewise differences in ‘psychopathology’ (DSM, ICD criteria) may only be evident when the individual with autism is provided with appropriate supports and does not have to struggle so hard to make sense of their world and retreat into repetitive behaviours and fight, flight and freeze responses when these are not offered.

Finally, more formal involvement of self-advocates with autism in future mental health-related research might ensure that conceptualisation of mental health disorders in autism is not biased in favour of the non-autism perspective. This should include more efforts to understand the experiences of individuals with ID, not just those with high-functioning autism.

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