Chapter 23

The Regulation Of Arousal In Intellectual Disability

Bruce W. Chenoweth

Introduction

Dysregulation of affect is commonly found in people with an intellectual disability, and in particular in those with autistic traits. This chapter emphasises the relevance of early experience in the establishment of the capacity to self-regulate emotions, and to highlight the importance of enduring and consistent good quality relationships in the maintenance of affective stability. This emphasis is not to be considered to be at the expense of the many other contributions to emotional instability found in this population (which are acknowledged) but to expand the field of enquiry when seeking to be helpful.

The Neurobiology Of Experience

When a baby is born the brain weighs about 400gm. By the time the infant is fifteen months old, the brain may have doubled or even trebled in weight. In that critical time, the process of neural generation and migration has been accompanied by a process of bundling and parcellation of neural networks, and through apoptosis, the planned pruning of redundant neurons (Schore, 1994). Thus functional processes, which have been useful at an earlier time become superseded and are replaced by processes and functions of a higher order of hierarchical complexity (Jackson, 1931).

Late maturing cortical areas of the brain are particularly sensitive to postnatal influences. Among the many functions established in this period of the first year of life, are the beginnings of the capacity for regulation of one's emotional world later in life. It is clear that the reciprocal dyadic process called 'empathic attunement' between mother (or primary carer) and infant over many hours, days, weeks and months is critical for the formation of these neural pathways. This attunement is the foundation of a lifelong

sense of security that one's needs will be met, and also establishes the mechanisms for affect regulation. Thus, there is a dyadic origin of the adaptive capacity to self-regulate affect. Conversely, the absence of well-modulated socioaffective stimulation leaves the infant unable to neurobiologically mediate self-regulatory functions (Schore, 1994).

This latter capacity for emotional regulation may not be fully apparent until mid adolescence or beyond. The lack of this ability may lead to increased vulnerability to traumatic events and even to psychiatric morbidity in the form of a Personality Disorder (Grotstein, 1987). People with an intellectual disability statistically are more vulnerable to experience serious abuse or traumatic events (Balogh, et al., 2001). They also may have an increased vulnerability to the long term consequences of that trauma if there is an unstable sense of self and a lack of internalised imagery or memories as a source of self-soothing.

Perhaps fear and apprehension, even panic that their needs may not be met may drive people in this population into unsafe or unwise situations in adolescence or later. This vulnerability may expose them to predatory exploitation. There is some good evidence that they are more prone to Complex Post Traumatic Stress Disorder (PTSD) than those more fortunate in their earlier secure attachments. Nijenhuis, Van der Hart and Steele (2004) label these people Emotional Personalities (EPs), whose vulnerability to trauma is different to 'Apparently Normal Personalities' (ANPs) in a wide number of neuro- and psycho-biological ways.

It is important to acknowledge at this point Winnicott's notion of the 'good-enough parent' (Winnicott, 1960). Most parents anxiously review their parenting skills wondering if they in fact had been empathically attuned enough, particularly during the more difficult moments of infancy. However, most parenting is deemed 'good enough'

for the purpose of establishing eventually a modicum of emotional regulation and an adequate sense of self.

In neurobiological terms, the modulation of unruly feelings comes from a well functioning orbito-frontal cortex, which is the thinking, anticipating, judging, and conscience-ridden higher centres of the brain. These regulatory mechanisms are slowly acquired over childhood and adolescence. The prefrontal cortex continues to develop this modulating and regulating function of behaviors until people are well into their twenties, earlier for women than for men (Schore,1996). Attachment is mediated intrinsically as a right hemisphere function. Lateralisation of hemispheric functions occurs much earlier than two years of age (Mento, Suppiej, & Bisiacchi, 2009).

What Can Go wrong?

In the more primitive areas of the brain, i.e., those areas more concerned about survival, lurk the vestigial remnants of the ‘fight,’ ‘flight,’ ‘rage,’ and immobilizing fear responses. Such areas are in the amygdaloid nuclei and periaquaductal grey matter, as well as in other limbic structures. These structures were from an evolutionary perspective extremely important when our small furry forebears were hopping around in some primeval forest, which also harboured sabre-toothed tigers! Life is now somewhat safer, and consequently the well-tempered prefrontal cortex has limited the necessity for, and the activity of, these survival functions. The hippocampus has the task of integrating memory and affect. It is extremely sensitive to the effects of stress of all kinds, a phenomenon that can be demonstrated anatomically by volumetric changes.

The Nature Of Dissociation

Dissociation is a psychological defense wherein the overwhelmed individual cannot take meaningful action or successful flight and so escapes by altering internal organisation (Kluft, 1985). Dissociation is described as a failure to synthesise and personify terrifying experiences (Kluft, 1985). From the perspective of evolutionary biology, and even evolutionary psychology, responses to extreme life-threatening events are varied and frequently specific to the species. Understanding of dissociative states has been clouded by the great disparity in the form of clinical presentation of dissociation between individuals, and even in an individual at different times, and in different circumstances.

Individuals with dissociative states can present with a spectrum of behaviors beginning with states of fugue or absence, a withdrawal and seeming oblivion to surroundings. A parallel could be drawn with a gazelle on the Serengeti being pulled down by a lion - glazed eyes, passively awaiting fate, immobilized and apparently unfeeling. Victims of sexual assault or other violence frequently describe such responses at the time and perhaps subsequently following the event. Frozen immobility is a variation of this with the preservation of appropriate affect.

A state of dissociative rage may be ascribed to a cornered animal, such as a Tasmanian Devil fighting blindly and indiscriminately, impervious to changes in circumstance. Clinically, people demonstrate this in some states of ‘episodic dyscontrol’ or ‘intermittent explosive disorder’. At some stage in the escalation of anger, a point can occur where the rage takes on a life of its own and efforts at distraction or diversion are ineffective. At such times the neural connections between the prefrontal cortex and these primitive structures are not functioning.

The chaotic and pointless panic and milling of a flock of sheep that have been attacked may have a survival advantage for the flock if not the individual. ‘Blind panic’ however has been easier to study in humans with elegant PET scans of Vietnam veterans with Complex PTSD who are suddenly exposed to the sound of the Bell Ranger helicopter. This can immediately cause a flurry of neural activity in the areas of the amygdaloid nuclei and related structures with an almost complete collapse of all prefrontal cortical activity (Shin, et al., 2004). At such times, the veterans were inaccessible to reason or reassurance. It was as if such reassurance was being given to a non-functioning part of the brain seemingly remote from the actual regions of activity. Likewise, ‘blind flight’ has a clinical correlate in the frantic efforts to escape crowds in supermarkets by someone suffering an acute panic.

Nijenhuis, Van der Hart, and Steele (2004) have contributed a neural model of dissociation based on ethological observations as described above. They suggest that all humans have these latent and vestigial behavioural capacities. Severe attachment traumas may establish a permanent reactivity in the limbic areas of the right brain thereby inhibiting its capacity to deal with future stress. This right-sided lateralization may account for the non-verbal encoding of traumatic memory in PTSD subjects (Schiffer, Teicher, & Papanicolau, 1995)

Post Traumatic Stress Disorder

Acute and chronic stress cause structural brain changes notably in the hippocampus and prefrontal cortex (Schiffer, Teicher, & Papanicolau, 1995). This is in response to increased glucocorticoid and noradrenalin exposure as well as to proinflammatory cytokines and other peptide regulators. There can be a loss of integrative hippocampal

volume and hence functional capacity. The ‘emotional person’ re-experiences unintegrated trauma as though it is happening now, and these ‘hallucinatory, solitary, and involuntary experiences consist of visual images, sensations, and motor actions, which engross the entire perceptual field’ (Nijenhuis, Van der Hart, & Steele, 2004, The Theory of Structural Dissociation of the Personality section, ¶ 2). Personality variables, personal vulnerabilities, and some genetic predispositions, all determine the form that dissociation takes given sufficient stress.

The Dunedin Study (Nada Raja, McGee, & Stanton, 1992) which has followed a large cohort of children for over thirty years, has recently highlighted individual vulnerabilities, which may contribute to an ongoing underlying substrate of anxiety or depression. Importantly, poor attachment, deprivation or trauma has been associated with lower serotonin levels as mediated by serotonin transporter gene variation, deficits of which may predict subsequent suicidality and poor response to antidepressants. Conversely, early good attachments are protective; contribute to the formation of an ‘apparently normal personality’ with the concomitant neuroprotective structures

Affect Regulation And Intellectual Disability

Intellectual disability is rarely a simple deficit of ability or capacity. There may be some major disruption of neural architecture that predisposes the individual to perceptual, communicative, emotional, or behavioural difficulties. Sometimes these difficulties or challenging behaviours are somewhat predictable as in the case of a specific behavioral phenotype associated with a known genetic syndrome. For example, those behaviours typically associated with Prada Willi or the Fragile X Syndromes are well known. Also, despite some limitations to this approach, it is often useful to start with, and apply, what

we know about the responses of the more neurotypical populations in attempting to understand some of the more distressing and challenging behaviours of those with an intellectual disability.

Empathic Attunement And Intellectual disability

All experience is encoded architecturally in our brain in some form. Attunement is such an experience and occurs, not as a one-way street but depends on dyadic reciprocity over time. Changes occur in the brain of both mother/carer and infant and in a sense, the mother *is*, metaphorically speaking, the prefrontal cortex for the infant for many years until her influence becomes embedded in the child's cortical function. In the situation where the infant has an intellectual disability and the mother receives little response from the infant, or if the infant is dysmorphic or autistic, empathic attunement may be very difficult to establish. Maternal depression, marriage failure, cultural alienation, excessive demands of a sick or very demanding child, all can take their toll on the process of reciprocal attachment. So many parents are devoted to the disabled child but exhausted by the task of caring for that child.

In a previous era, many disabled children went into care at a very young age and remained in care all of their lives. Many of these are now adults who may have had several primary caregivers each year of their lives. Their parents and families were encouraged to give them into care and to forget them in that less enlightened time. Many of these people have demonstrated a lifetime of emotional dysregulation, poor sense of self, fears of abandonment, self-harming behaviour, and other symptoms of attachment failure. The natural development of mechanisms regulating emotional responses through bonding and secure attachments may not have occurred.

Clinical Presentation: What Do We See?

Firstly, a high level of Generalized Anxiety can prevail for many reasons in those with intellectual disability. For this population, the world can be a harsh, an uncomprehended and uncomprehending place with real and perceived threat. As the child with disability develops, parents can no longer interpret their world for them. The child becomes aware of 'differentness'. Relationships can be tortured and tortuous. Depression and anxiety may follow.

Autism

The state of autism confers a particular level of dismay, frustration, mistrust, and generalized anxiety with recurrent episodes of panic. People with autism may lack the flexibility to rapidly switch their focus of attention. Allen, Buxton, Wong and Courchesne (1997) regard this partly as a consequence of cerebellar dysfunction.

Transitions of all types are therefore difficult for people with autism. This may include transitions from one activity to another, e.g.; from bed to bath, from home to school, from class to playground, from primary to secondary school, and to work placement. All of these transitions may need slow and adequate preparation if anxious protest is to be averted. Gualtieri (2002) noted that 'no anxiety state is quite as dramatic in all of psychiatry as that of an autistic child whose routine is changed or whose environment is disrupted' (p. 244). Likewise, people with autism can be overwhelmed by complex simultaneous stimuli or by crises of intimacy when emotional demands are excessive. Sensory hypersensitivity, particularly auditory hyperacusis, can create intolerable anxiety in people with autism.

Mechanisms For Coping With Anxiety By Those With Intellectual Disability

Intellectually disabled people use many and varied attempted strategies for coping with anxiety, some are helpful and some not. Some behaviour could be interpreted as anxiety- relieving strategies or can be interpreted in less helpful ways. Descriptive terms such as 'attention-seeking behaviour' are often best replaced by the description, 'care-eliciting behaviour'. Some of these anxiety reducing strategies include: school refusal, ritualistic behaviour, some compulsions, self-stimulating behaviour, relentless and remorseless verbal onslaughts, stereotypic behaviour, oppositional and defiant behaviour, somatic preoccupation, self-injurious behaviour, masturbation, and hyperphagia, etc. The list is long. These behaviours may also occur for other reasons, which could be explored through a detailed Functional Analysis of Behaviour by a skilled Psychologist. However, the clinician can do well to initially regard aroused or challenging behaviour as anxiety-driven once physical causation has been eliminated.

Episodes of heightened arousal or challenging behaviours may be seen as an indication that the individual still retains some sense of agency or has some executive or imperative functionality, in relating to their circumstances. That is, they retain the capacity for hippocampal integration of past experience with the present stress (Nijenhuis, Van der Hart, & Steele, 2004). When this sense of agency evaporates, dissociative episodes may occur. Unreachable rage, panic, or flight may occur with the episode itself taking on a life of its own and during which there can be great risk to persons and property. In the past, a diagnosis of psychosis was frequently made. Gualtieri (2002) noted 'no skills are available for self-reflection or to describe an inner

state for the clinician to utilize' (p. 170-171). More often now, a diagnosis of an anxiety disorder will be made.

Assessment Of Challenging Behaviour

Physical Causes And Pain

Discussion here will be limited to the obvious medical causes of emotional dysregulation or challenging behaviours. Beange, McElduff, and Baker (1995) documented the most common medical causes of distress in those with an intellectual disability. Some of these included dental pain, otitis media, constipation, chest infections, urinary tract infections, gastro-oesophageal reflux, arthralgias, and headaches.

Domiciliary Dynamics And Relational Issues: The Right To Enduring Quality Relationships

Most people have some degree of choice about with whom they live. For those in group homes and residential care this is not the case. Not only can they be accommodated in situations of misfit, with disparate persons with disparate abilities and with less than complimentary behavioural patterns and demands, but they have to accept instability of staffing placements with many changes of attachment figures. It is curious that in the statements outlining Vision, Purpose, Values, Client- Focus, Equity, Integrity, and Performance, government departments and agencies charged with the care of those with disabilities make no mention of an individual's right to enduring, sustained, consistent, and rewarding relationships.

Conversely!

After a lifetime of failed attachments, sometimes of abuse or neglect, people with intellectual disabilities might find themselves in a caring, professional setting. All may go well for a 'honeymoon period'. However once a bond with a carer or significant level of trust develops, the relationship could predictably be tested often to a degree where the placement breaks down.

It is paradoxical that extremely challenging behaviour may in fact be a milestone of success in the establishment of a trusting relationship and that the behaviour may reflect some crisis of intimacy, or perhaps an expectation at a non-conscious level of further abandonment. Any attachment could lead to an innate sense of immanence of threat or loss. It is encouraging that in some jurisdictions and agencies, there is now an emphasis on consistent and stable staffing for children entrusted to care. The policy of moving carers at regular intervals to avoid entrenched practices is being questioned.

Functional Analysis Of Behaviour

In situations where the origin of distress and emotional dysregulation is puzzling, a trained psychologist may be engaged to tease out the relevant causal elements as part of a comprehensive functional analysis of those behaviours. This investigation would usually emphasise basic needs such as physiological comfort, security within the residential setting, issues of communication, and the presence or absence of sociopsychological satisfaction (see Figure 23.1).

[Insert Figure 23.1. here]

Exploration too, may focus on obtaining a profile of sensory functions and an assessment of thresholds of distress for a number of sensory stimuli. Hypersensitivity to multiple intercurrent sensations may overwhelm an individual. Conversely, other high threshold inputs, which are better tolerated, may offer alternative modalities of contact, communication and reassurance. Recourse to a multiaxial psychiatric diagnostic formulation could then follow according to the protocol of the text revision of the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV TR, APA, 2000). There are many useful tools to elucidate functional capacity as well as assist in psychiatric diagnosis. Of these, the Developmental Behavioural Checklist (DBC, Einfeld & Tonge, 1995) is perhaps one of the most useful in terms of assessing the presence of psychopathology.

A Behavioural Intervention Strategy or set of protocols can be developed from such a comprehensive analysis. Appropriate training of parents or staff should follow to assist them to better understand the child/client and to sensitise them to specific and required needs. Careful analysis, if done well, may lead to the empowerment of staff, the avoidance of pejorative judgments, and renewed enthusiasm for an albeit difficult management task.

What Of DSM IV?

By its nature, much of DSM-IV TR (APA, 2000) is a set of descriptors, which tend to cluster together on multivariate factor analysis into predictable diagnostic groupings. These are useful tools to utilise in people with mild to upper moderate disability but of limited value for those with moderate to severe and profound disability.

Medication

Increasingly in intellectual disability, there is a move to identify the underlying neurobiology of behaviour. The pathways and receptor sites subserving emotional states are rapidly declaring themselves. Multiaxial DSM-IV TR (APA, 2000) formulations can assist in decision-making about the place of medication in the redressing of supposed up-regulated or down-regulated neural activity. Limbic and mesocortical over-activity can be regulated, prefrontal underachievement can be stimulated, amygdaloid and periaqueductal grey matter arousal can be modulated, and more efficiency can be extracted from the nucleus accumbens and other association nuclei, and so on.

The crude hypothesis is that anxiety and depression have, as a final common pathway, some paucity of serotonergic activity. Conceptualising anxiety and depression in this narrow and over simplified manner can initially be a productive way of achieving an entry point in dealing with a very complex problem. selective serotonin reuptake inhibitors (SSRIs) may have a place in the management of these conditions and should be used within the broader contexts discussed above. Caution is required in prescribing their use in children especially in those with intellectual disability due to the exquisite sensitivity to side effects often encountered in this population.

The Repair Of Affect Dysregulation

The mechanism of affect regulation is of intense interest to researchers and clinicians across a converging range of disciplines. These disciplines include medical, biological, psychological, and social sciences as well as clinicians in psychiatry, psychology, and social work. The emphasis in these endeavors has progressively shifted from the study of conscious to non-conscious processes.

The model of down-regulating affect through conscious effort or through the imposition of strategies is the central theme of cognitive psychology. However, most affective responses occur intuitively, spontaneously, and instantaneously, are nonverbal and preconscious. Efforts are now being focused on nonverbal, noninterpretive components, i.e., responses mediated through the right prefrontal cortex. This area is dominant in dealing with the stress and uncertainty of life. This part of the cortex is also engaged in the interpretation of facial, prosodic, and bodily communication, in the recognition and maintenance of empathy, and the response to stress. Homeostatic mechanisms occur here that maintain a coherent, continuous, implicit sense of self. Bowlby (1969) held to the centrality of a nonconscious internal working model for which good early attachment was essential.

As the psychotherapeutic alliance reflects the infant-mother dyad, so too does the benign respectful and enduring relationship between carer/parent and the disabled child work its magic in altering the internal structural brain systems that nonconsciously and consciously process and regulate external and internal information. (Schore, 2003). As in a therapeutic alliance, the prime variables affecting positive change can be independent of the theoretical model employed. Similarly, the stability of relationships for those with intellectual disability is a critical factor in alleviating anxiety and dissociative episodes. The brain responds architecturally to all input.

Summary

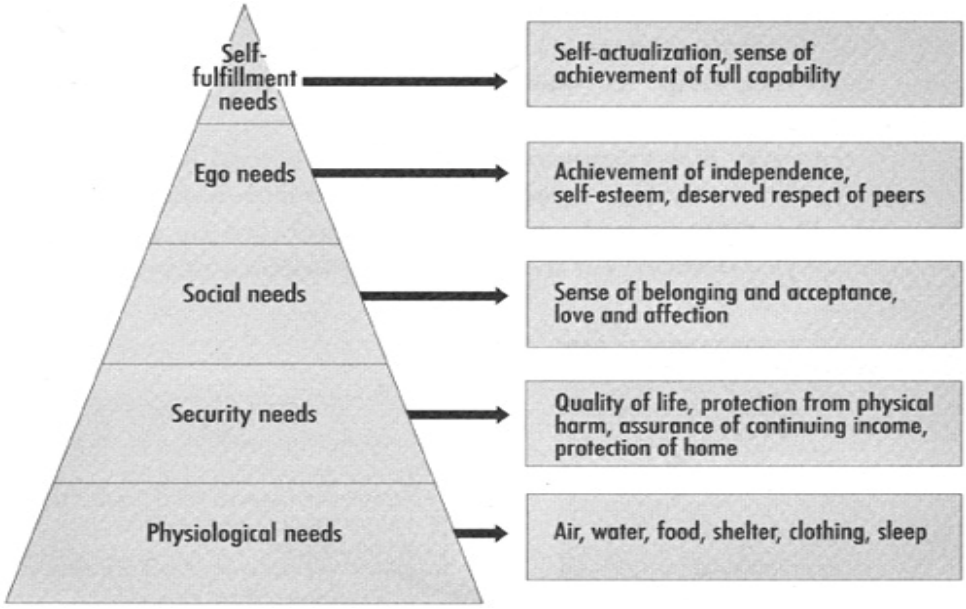
The process of ‘good enough’ empathic attunement in the first 15 months of life confers a neurobiological advantage in the generation of the capacity for appropriate affective regulation later in life. Failure of this process can lead to high anxiety and dissociative

states when stressed. This can be particularly prominent in those with intellectual disability where obstacles in the way of the attainment of such attunement abound, amplifying any inherent lack of higher cortical modulatory functioning.

Dissociation is described within bio-evolutionary and evolutionary psychology frameworks. The way in which anxiety and dissociative states present is described through assessment of those states. Particular emphasis is placed on the quality, security, and enduring nature of relationships in such an assessment and on the imperative for these basic needs to be met if repair of affective dysregulation is to occur. The repair of affect regulation can and does occur within stable caring relationships if those relationships can withstand some strenuous testing.

Figure 23.1.

Maslow's Hierarchy of Needs



Source: Maslow (1954, 1970) from www.businessballs.com/maslow