

Conclusion

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Developmental Framework For Neuropsychiatric Conditions

There is no doubt that children and adolescents with intellectual disability and mental health problems are challenging for families and the practitioners that support them.

There may be no easy answers or solutions, but there are some valuable lessons to help make a difference. This includes the application of *holistic professional practice* that combines a bio-developmental-psycho-social-cultural framework, evidence-based medicine, values-based practice, and collaboration.

The *developmental* component of the framework is the area of importance for this population. The term ‘developmental’ has traditionally been used to imply that certain aspects of behaviour change over time. In those with intellectual disability the emphasis is on the need to consider development as a sequence of acquiring skills, understanding and indeed conscious mindfulness. In the absence of adequate scientific knowledge of the complexity of development and of deviancy from these processes, developmental theory provides a guiding framework for understanding disability and intervention.

Considering symptoms from several theoretical frameworks at the same time is not new for child mental health practitioners. Similarly, models of the development of emotional recognition, theory of mind, an internal voice, inter-subjectivity and social reciprocity may do more to help us understand and treat Autistic Spectrum Disorders (ASD) than tracking genetic or biochemical markers. There is little doubt that the problems that children and adolescents with intellectual disability present with are frequently due to biological difference and are often amongst the most challenging that professionals working in mental health encounter.

Service Differentiation Of Mental Health Disorders

One experience of the training events for the educational program was that some of the ideas and information presented were commonplace for some practitioners, but novel for others. This variation was dependent on the practitioners' professional backgrounds, previous training, experiences and work settings (e.g., disability services, mental health services, educational settings). Approaches to understanding difficult behaviour are dichotomised into 'challenging behaviour' and 'mental disorder'. The former (externalising/disruptive disorders) are based on a linear model of behaviour (antecedent, behaviours and consequences), the latter on the recognition of syndromes or patterns of behaviour that go together in meaningful associations. One is derived from behavioural and social psychology and the other from the medical model. However both these models have come to rely on both environmental and biological causal factors such as neurochemical systems and physical ill-health.

All practitioners have to be aware of these models, albeit to different degrees. However in practice, many mental health services do not provide significant treatment services for externalising/disruptive disorders, with a few exceptions. Additionally, it is suggested that there is a third group of developmental psychiatric conditions that are now not seen as core mental health. This group includes young people with Autism and ADHD for whom paediatricians provide the mainstream of service. This is not to malign mental health services but illustrates that as understanding grows about mental health needs, resources do not, so are devolved to general paediatrics and community health.

Furthermore, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and *International Classification of Diseases* (ICD) have grown from a process of

categorising members of the community who present with severe mental health impairment requiring treatment services. With the expansion of psychology and epidemiology there is growing acceptance that most troubled emotion and behaviour can be better understood in a dimensional frame of more healthy and competent to less healthy and impaired (Hudziak, Achenback, Althoff, & Pine, 2007). However, when working with children and adolescents with intellectual disability and mental health problems, the developmental context has to be taken into account. That is, their mental health should be considered in relation to the norms for developmental competence or mental developmental age before taking account of other dimensional or categorical models of understanding mental ill health, whether this is due to environmental vulnerability (e.g., as occurs in conduct disorder) or genetic vulnerability (e.g., as occurs in ADHD).

Validity Of The Developmental Framework

A developmental model is difficult to validate. A number of child psychiatric disorders have moved from a categorical to a dimensional concept with epidemiological based research, notably in the diagnosis of ASD and ADHD. This reflects moving from a research hypothesis of single gene or brain defect as an explanation of these disorders to a multifactorial model of growing complexity. Psychometric studies don't help us either. The measures of Autism, in terms of social intelligence, compared with a normal population are two to three standard deviations outside of the norm. With this level of difference it isn't possible to determine whether this might be a developmental or dimensional disorder. As observed in the chapter on 'Mental Illness and Intellectual Disability', there are significant questions about the reliability and validity of

mainstream psychiatric disorders in those with moderate and severe intellectual disability. Particularly in those with intellectual disability, there is room for constructive questioning of mental health orthodoxy. The implicit risk and harm of a categorical or deconstructive model is that it medicalises a disorder, such as that of Autism, and assumes there will be a specific medical intervention. Such assumptions contribute to the stigma of difference and families feeling powerless to help such a child.

Developmental models, such as those of Piaget and Kohlberg have had powerful influences in child psychology. Attachment theory in addition to cognitive development emphasises the importance of the environment and relationships to development. In practice many specialist clinicians of different disciplines working with children and adolescents with intellectual disability work from an underlying developmental framework. It has not however been promoted as a coherent cross disciplinary model. A developmental framework makes such disorders understandable by comparison to other children of equivalent mental or social developmental age. This is humanising for the child and family and creates a common language and goal to promote development rather than cure.

There remains a tension between basic research which uses deconstructive hypotheses versus child and family centred clinical approaches which work from the face validity of a developmental framework. This tension is helpful in terms of enhancing knowledge of the efficacy of different interventions. However the best evidence supports family and environment based interventions for parenting skills and behaviour management. Neuroscience and psychopharmacology also have a role, but this is the language of subspecialty disciplines with limited demonstrated validity. In the absence of a scientific leap creating a paradigm shift, the dominant framework should

be developmental. Science will continue to make incremental advances, but it is probable that the development of the brain and the mind is sufficiently complex that a paradigm shift is not likely. It is more likely that small shifts will add to the understanding of developmental processes and sequences. Although child psychiatry teaches clinicians to consider competing explanatory models of disorder, in the mental health of children and adolescents with intellectual disability, the developmental model of emotions and behaviour is central.

Collaboration And The Modern Multidisciplinary Team (MDT)

A developmental framework enables a common language across different members of the multidisciplinary team. In practice in Australia, where there is no specialist mental health service for people with intellectual disability, these models help guide where first to seek help. For example, challenging behaviour is first dealt with by disability services, developmental psychiatric conditions by paediatricians, and other psychiatric syndromes by mainstream mental health services. The more complex, severely disabling, and co-occurring conditions require close collaboration between these three service systems and special education services.

Families are the cornerstone, not just of the care of these children and adolescents, but the best source of management and treatment of their most troubling problems. Families have not been sufficiently engaged in the partnership with practitioners in the process of understanding what they can do for their children and what service providers need to do to enable them. This partnership still needs to advocate for significantly greater recognition and greater provision of services in communities.

The establishment of a common language and knowledge base through the educational program has begun the process of defining what distinct specialist skills and training are required for expert clinical practice in meeting the mental health problems in intellectual disability (see Table C1). Working at the coalface of tertiary clinical cases with clinical research questioning is likely to be the most fruitful source of innovation in intervention (Kealey, 2008).

[Insert Table C1. here]

Skills development in the clinical areas highlighted in Table C1 would assist clinicians in the provision of specific interventions for addressing the needs of this complex group of young people with autism and intellectual disability. Recently, the importance of treatment approaches focused on skill building was emphasised by a parent presenter at a seminar for parents and carers. The parent spoke with the clarity of experience when she advised, ‘Don’t waste your time looking for a cure for Autism, there is no cure for Autism. What matters is working on building skills for your child in both their strengths and their weaknesses’ (Wilson, 2009).

The Need For An Action Plan Of Service Development And Function

The need to have access to the skills of a MDT (as outlined in Table C1) for complex cases necessitates collaboration (at minimum) between doctors, dentists, psychiatrists, psychologists, speech pathologists, occupational therapists, family therapists, physiotherapists, nurses, teachers, and school counsellors. There is evidence to indicate that equity of access requires availability to each of these disciplines. However these

clinicians also need to have specialist experience and expertise in intellectual disability and be supporting of and engaged with their non-specialist colleagues in the same discipline. Multidisciplinary collaboration is required between practitioners in the different agencies of health, mental health, disability, and education. The family needs also require the engagement of a whole of government approach including social services and welfare, housing, police, criminal justice, advocacy, legal services, and of course the growing non-government sector.

The collaborative process is difficult in terms of practitioner skills and organisational rationing of services, but essential for complex cases. Complex cases therefore need a charter of collaboration for adequate service provision. Limited resources require a tier structure of services, whereby higher tiers provide case-centred management advice and educational support for lower tiers. Distance need not be an excuse with modern video-consultations between tiers of service. The quality of collaboration has to be measured across agency to provide an external measure of efficacy. Services need to be designed to be 'forever learning'. The services, the tiers, the charter of collaboration, and measures of outcomes and collaboration need to be made open to public access and scrutiny.

Holland (2009) described some of the components for and complexity of assessment and formulation for adults with intellectual disability which can also be applied to children and adolescents with intellectual disability. These components included,

- Consideration of individuals' different trajectories of development due to biological, temperamental and environmental qualities;
- Assessment of the nature and extent of impairments and associated disabilities;

- The contribution of developmental disorders, sensory issues, physical health, and psychiatric illnesses;
- The influence of life circumstances;
- Skills to cope with the demands of his/her environment; and
- System factors including the quality of attachment and relationships with family, community, and services.

Such assessments lead to a formulation and a hypothesis of what may be causing the current predicament, which is then tested by the process of intervention. However, formulation requires the MDT to be able to weight the different components of the evaluation and apply clinical judgements. Optimal clinical judgement is only possible with experience, mutual professional trust, and flexibility, as not all team members will be equal in understanding a clinical predicament. Thus many various intervention approaches may be taken by the MDT. Some examples of different clinical formulations include

- Nothing further can be done without a shift in family relationships and attitudes, treating parental mental health problems or responding to parental burnout including respite care;
- Medication is a first necessity for bringing about change for other approaches to be helpful;
- A combination of approaches is needed, such as a functional analysis, enhancing communication skills, a sensory assessment, family and cultural assessment and neuropsychiatric testing; and
- A systems theory review of individual, family and service provider relationships is required.

There are also clinical ethical considerations associated with engagement, assessment and intervention, for example that of identifying disability in the absence of adequate services for the juvenile offender with impaired communication and moral insight, who prefers to be identified as 'bad' rather than 'disabled'.

The Need For Multidisciplinary Subspecialty Mental Health Teams

It is evident that for the more intellectually disabled and those with more serious disturbance and disorder that it is important to have psychiatrists and other allied health disciplines that identify as having special expertise in intellectual disability. Not only is such expertise needed for the optimal service provision for different subgroups of those with intellectual disability in terms of quality of life, morbidity, and mortality, but it is likely to be significantly cost saving to the broader community through enhancing autonomy and reducing dependency on long term government welfare and care.

Recognising the need for subspecialty skills also challenges professional organisations to recognise their value and to support workforce development in such subspecialty skills. This is a huge challenge as professional bodies all too readily marginalise subspecialty expertise, under similar political and social pressures as happens to people with an intellectual disability of any age.

Advocacy: Families That Care, And Acceptance By The Community

The breakdown of extended family networks and loss of community connection is slowly generating a catastrophe of care particularly for children and adolescents with intellectual disability. More needs to be done to help break down the prejudice, stigma, and social isolation that these families experience. The frequency with which

practitioners encounter parents with murder-suicide ideation reflects the lack of community recognition of need and inadequate community based support services. Murder-suicide is such a publicly horrific event when it occurs. Every clinician, friend, and neighbour should be alert to this alarm bell of coping breakdown and recognise their duty to make a difference. The level of distress and potential for adverse events should be a wake up call for the need for comprehensive mental health services for children and adolescents with intellectual disability.

Studying The Development Of The Mind: Is It A Prerequisite To Understanding Losing One's Mind?

Development of the mind involves developing capacities of,

- Identification of self and non self;
- Motor regulation and coordination;
- Arousal modulation and selective attention;
- Communication skills and an internal voice;
- Mood regulation;
- Self concept;
- Reciprocal social interaction; and
- Reality testing and perspective taking.

The external validation of this process is the capacity for developing good quality peer attachment relationships as the best measure of youth mental health and future mental health as an adult.

Nonetheless, the closer professionals get to understanding the neurobiology of the basis of mental illness, it is suspected that it will be found that there are a range of

commonalities between the processes of development of the mind and losing one's mind (Starling & Dossetor, 2009). Indeed genetic research suggests that biology of mental processes involves considerable commonality of processes between the two (Mouridsen & Hauschild, 2008). Mainstream psychiatry and mental health services should pay greater heed to understanding the developmental processes witnessed in those with intellectual disability and autism, even if it is only to further understand the processes of mental illness of the mainstream adult population. Mainstream mental health clinicians may also be drawn to the fascination of better understanding the developing mind and as a result show greater interest in the plight of those with intellectual disability and mental health problems and add their voice to advocate for this needy population.

Table C1.

Areas Of Clinical Expertise And Innovation In Mental Health And Intellectual Disability

Clinical Expertise And Innovation

1. Specialist evidence-base parent training skills e.g., Stepping Stones Triple P (Sanders, Mazzucchelli, & Studman, 2003).

2. General health promotion and prevention especially with a focus on other chronic disabilities.

3. School based prevention and early interventions e.g.,
 - a. Positive behaviour learning;
 - b. Inclusion approaches and practices;
 - c. Inclusive communication strategies;
 - d. Focus on developing mindfulness of self and others; and
 - e. Focus on emotion-based social skills learning

4. The role of exercise and coordination for self esteem, motor/sensory modulation and attention.

5. Sensory profiling and sensory diet interventions for management of arousal levels and motor calmness, relaxation and playfulness e.g., Floortime (Greenspan & Wieder, 1998).

6. Augmentative and alternate communication, especially capitalising on using new electronic devices for socially acceptable forms of visual communication.

7. Problem solving and self monitoring skills.

8. Emotion-based social skills training.

9. Modification of cognitive behaviour skills therapy.

10. Neuro-biological research e.g., based on behavioural phenotypes, new metric and imaging techniques and the effects of medication.
