



The Developmental Psychiatry Clinic

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Introduction

This article is a description of 'The Developmental Psychiatry Clinic'. This clinic is a tertiary clinic which in NSW may be the only truly multidisciplinary subspecialty clinic for young people with intellectual disability and emotional/behavioural problems which combines tertiary skills of paediatrics, child psychiatry, disability and education. It also has access to the disciplines of subspecialty speech therapy, clinical psychology, family therapy, educational psychology, occupational therapy, pharmacy, cross cultural consultancy, behaviour therapy and positive behaviour support.

Child Psychiatry has always required multidisciplinary skills, but the child psychiatry of intellectual disability requires intellectual disability subspecialty skills, at least for the most complex cases. It seemed timely to review the process, following the independent evaluation from the Centre for Disability Studies (2014), which recommended the capacity of this clinical partnership needed significant expansion to be part of a greater state-wide capacity as part of a hub and spokes model of specialist service expertise.

One question that has been raised by the Clinical Innovation and Governance Unit of ADHC (NSW FACS) is why this collaborative model has not been successfully replicated? I suspect the two essential components are subspecialty recognition of the multidisciplinary skills for mental health, and systematised clinical interagency collaboration, since no agency has the full complement of these disciplines, nor of comprehensive community service provision. Significant exceptions to this observation have developed with specific funding and clinical champions at the MRID.net at St Georges Hospital at Kogarah, the Fairfield Specialist Intellectual Disability Health Service, and the Giant Steps Neuro-psychiatric Clinic. MRID.net has championed multidisciplinary clinics at schools for special purposes that cater for children with intellectual disability. Their website provides guidance on developing medical clinics and information of the positive outcomes (www.schoolkit.org.au).

Each of these has subspecialty health and mental health components and strong interagency collaboration. Although this article describes our Developmental Psychiatry Clinic, I hope it also describes the recent growth and establishment

of a model of excellence for the child psychiatry for those with intellectual and developmental disabilities.

Although psychiatry has a range of specialist skills and expertise, I believe that it is important to be open in describing what is of concern from a mental health perspective, and the process requires an openness of the child and family. It follows on that intervention is a discussion on what elements can be changed or improved through what means, and what the client and family have a willingness and capacity to do. There is no doubt that managing a young person with major emotional/behavioural disturbance can be extremely challenging, and like other specialties of ill-health, not all mental health disorders will be successfully treated. That is to say that some have a long term challenging prognosis.

“Child psychiatry has always required multidisciplinary skills”

One reason for writing this document was to provide information on what is involved in a Developmental Psychiatry Assessment. It is always important to be watchful for what information is missing and, where that is evident or suspected, caution about the reliability of the assessment must be considered. Yet we expect a lot of clients to be open to such a wide range of clinicians, which can no doubt be daunting. However a tertiary service is only necessary when more focussed and limited approaches to understanding and intervening in a problem has been tried. Indeed, many of our clients and their families are feeling unsafe and are considering relinquishment of care as the final option. It is important that the client, their families and the locally involved clinicians are aware of the task that the clinic has to do and do not have unrealistic expectations.

Lastly, I feel that the further audience are fellow medical and non-medical clinicians who do so much for these clients, but without a psychiatric or developmental subspecial-

ty expertise. The same principles are likely to be valid for the Psychiatry Services for Adults with Intellectual Disability, as the developmental psychiatric disorders are still important in adulthood and as exemplified by the specialty service in ACT (Wurth & Brandon, 2014).

The Centre for Disability Studies Evaluation suggests that the Developmental Psychiatry Clinic and Partnership represents a world-class model of excellence. The strength of interagency collaboration limits the cost of such a service, for example compared to establishing subspecialty psychiatric in-patients, and yet can be highly cost effective in the context of the alternative of the cost of long-term community group homes.

The components to the Developmental Psychiatry Assessment:

1. Clinic Philosophy: It is possible for all children and their families, including those with intellectual and developmental disabilities to have “a good enough” Quality of Life. Our aim is to strive towards a better quality of life and to try to help a child and family understand and manage extremes of emotions and behaviours better. This clinic is generally not looking for a cure, but for better adjustment and relationships. This positive and hopeful framework provides a basis on which to join with the client and family, even in a context of adversity. Our capacity to help requires an open, trusting and non-judgemental approach to understanding everyone in the family and is a lengthy process. Although human emotional wellbeing and relationships are infinitely complex, scientific study of children and families has led to a systematic way of making sense of a child’s predicament. These involve assessing and understanding *quality of life, child development, mental development and health, family and community relationships and functioning*. We call this the bio-developmental-psycho-social-cultural framework.

The expression ‘good enough’ quality of life starts with no one expecting perfection, but accepting the potentials for life that you have been given. It also involves respecting everyone and their capacity for independence, no matter how disabled they may be. Further, all children have to be assessed in the context of their family, the relationships with parents, siblings and other significant people.

2. Quality of Life is a subjective and personal perception, based on the question of: How satisfied are you with your life as a whole. It is related to adequacy on the following domains:

- An adequate standard of living
- Feeling safe
- Reasonable health
- Connected to valued relationships
- Linked to a community
- Contributing a worthwhile role
- A sense of purpose and productivity
- Having a hope for the future.

The empirical research shows the evaluation of quality of life is pretty similar and fairly good for most of the popula-



tion. One extraordinary element is that most people find a ‘good enough’ quality of life in the face of considerable adversity. For example, most people with chronic ill health adapt to finding adequate quality of life. Being particularly intelligent or being a slow learner of its own is not a predictor of quality of life, nor is being rich or poor. Against this background, it has been suggested that psychiatric disorders are important ‘disorders of quality of life’, affecting many of the domains above. Accordingly having an intellectual or developmental disability may make achieving a quality of life more challenging, but still the target to aim for. For families with a child with intellectual disability the main challenge is the additional and persistent burden of care, over a typical child, and their quality of life depends on being able to share this burden with other caring people. These days, health services have to justify their interventions by demonstrating that they contribute to health-related quality of life in the context of an affliction. Indeed the internationally accepted concept of health is not just a concept of an absence of disease but a sense of health and wellbeing in physical, psychological, social and spiritual or cultural dimensions.

3. Development: The first stage of understanding emotions and behaviour in an individual is to understand the developmental context: that is the degree to which areas of human development are behind the norms for their chronological age, or delayed. Biological disadvantage is ex-

pressed in a developmental framework of skill sequence. We describe this in terms of the age at which a typical child achieves these milestones of skills.

The main domains of development are:

1. **Motor and Sensory** development and integration, including coordination, sitting still, a capacity to integrate different sensory experiences to calmness, a pre-requisite for concentration. Sensory processing have greater importance in those with problems of theory of mind, and more generally in those with emotional regulation.
2. **Independence** skills such as dressing, eating and toileting skills, the best measure of general intelligence before developing the '3Rs'.
3. **Communication & Language:** receptive, expressive, verbal, non-verbal (including object and picture communication).
4. **Emotional, Social and play skills**, the most complex skill and difficult to measure but the descriptions of the sequence of skills is recognised by all.
5. **Quality of imagination**, presence of stereotypic rigidity or imaginary preoccupation at the expense of social interaction versus ability to build reciprocal ideas with others.
6. **Educational** and other higher skills
7. **Community integration skills:** keeping safe, accessing services, managing money. Schools are the primary setting in which these skills are tested and developed.

The rules of development include: if development is delayed, it is likely to be uneven across different domains. If one area is delayed then there is an increased risk that another area is affected and these patterns have strong genetic influences.

Development of the mind: The mind is by definition a subjective experience, but developmental concepts are critical

to understanding that children are not diminutive adults, but rather the skills of adult mental health depend on appreciating the development of competencies of the mind. Understanding the development of mental competencies helps identify reasons why they may not be coping and showing maladaptive behaviour. Some have greater degrees of reliable psychological measures than others. Appreciating mental developmental sequences helps us develop an understanding of what their subjective experience may be. These developmental capacities include:

- Identification of self and non-self
- Motor regulation and coordination, sensory modulation
- Selective attention and attention switching
- Communication skills and theory of mind
- Mood regulation and empathy
- Self-concept and self-esteem
- Reciprocal social interaction and relationship building
- Reality testing, perspective taking and other executive function skills

These skills are best evidenced by the capacity of a young person to make new good quality peer attachments. Arguably the two most important skills are the development of attention and concentration, a pre-requisite for learning (hence the importance of ADHD), and the development of theory of mind which is the capacity to appreciate that others have separate thoughts and feelings to your own (central to the developmental delays in ASD). This may be because competence in each of these domains underlies the other more complex domains. These are initially learned in joint activity with the primary attachment figures (parents), and from this interaction children learn to appreciate their own moods and feelings, and learn that they can modulate them and control them.

4. Mental Health: From these foundations comes the quality of adjustment and flexibility of the mind: what we call



mental health. These capacities vary from adjustment and flexibility to maladjustment and problematic and can be rated on a clinical rating scale (1-7; low to high functioning):

1. **Physical and neurological wellbeing**, including sensory disabilities of deafness, or blindness.
2. **Behaviour**, loss of control versus the capacity for modulation and responsive calm. This includes responsiveness to non-verbal expression of emotion and thought, what is called affect. Sensory sensitivity may be best considered in behaviour, and appreciating sensory need is now recognised to be an important part of self-regulation.
3. **Communication** evaluation includes intent, engagement, responsiveness and independence of communication but within the appreciation of reciprocity.
4. **Moods** include those that are negative: anxiety, anger, obsessions and depression and the capacity to self-manage and recover. Moods can also be excessively positive with excitement euphoria, and mania. Agitation is best seen as a complex, distressing and disabling mood state that is found with many mental disorders. Mood regulation also includes a capacity for emotional attunement with significant others.
5. **Thoughts or Cognitions** include thoughts of feeling fearful, sensitive, controlled or hateful versus capacity for reciprocal thinking, learning and engagement. Any cognition of delusional intensity involves a loss of cognitive reciprocity.
6. **Intellectual or cognitive competence and coherence** include attention, memory, narrative, sense of time, perception, executive function.
7. **Insight and Social Reciprocity**: a capacity to take perspective of one's own thinking, in relation to others, other times and circumstances, and adapt.

None of these capacities are developed at birth, but slowly and progressively develop and are learned. These developmental processes and their influence on mental phenomena distinguish child and adolescent psychiatry from being a diminutive form of adult psychiatry. Similarly, a mental state assessment involves considering each dimension of assessment and then testing how they fit together through testing insight compared with an independent other (clinician).

5. Contributors to the ease or difficulty of Child Rearing:

Some children are easy to bring up and others are more difficult. There are a whole range of factors that contribute to how easy or difficult a child is to bring up:

- Health problems, especially neurological, including sensory deficits
- Intellectual ability, including learning problems and neuropsychiatric deficits
- Temperament, which has genetic and environmental contributors
- Environmental Milieu: emotional warmth, stimulation, predictability and consistency
- Earlier experiences, positive, or traumatic
- Attachment style and strength

“The strongest influence on child development is the quality of relationships”

Younger children are more influenced by circumstances, but with time and age develop their own personal and persisting attributes. These factors contribute to the development of the brain and its capacity and connectivity. These factors also contribute to vulnerability and resilience. It is also recognised that children that are a greater challenge, such as those with ASD are more likely to have an impact on the functioning of their family. Indeed, it is known that differences in the genotype in a child elicit differences in the parenting response. Greater individual resilience is both a function of greater neurological connectivity and also better social and relationship connectivity. ASD is a condition that is recognised in problems of connectivity in both domains.

6. Family Functioning: How children develop or grow up is affected by a range of factors, but the strongest influence is the quality of relationships. Those of parents and family members are primary, and the basis from which a child develops relationships with those outside of the family. Accordingly, the qualities of family functioning need to be assessed to understand a child in context. These qualities are assessed along a number of domains.

The McMaster Model of Family Functioning (Miller *et al*, 2000) includes 6 dimensions of family functioning that are considered across the relationships of everyone in the nuclear family. These skills and styles are assessed along the following dimensions and can be assessed on a clinical rating scale (1-7):

1. **Problem Solving: (a) Practical** eg finance/home management & **(b) Emotional** eg loss & adversity
2. **Communication: (a) Practical** eg organising & **(b) Emotional** eg empathic skills
3. **Roles:** clear and agreed with accountability
4. **Affective responses:** the extent of emergency emotions of anger, anxiety, obsessions, and depression versus warmth and support
5. **Affective involvement**, varying from overinvolved at one end of the spectrum to flexible to detached at the other end.
6. **Behavior control** and safety

Family function includes the quality of the marital relationship, the physical and emotional health of both parents, and the degree of connectivity, both engagement with and support from wider family, friends and community. Social isolation of a family is a poor prognostic indicator with a lack of access to a wider problem solving approaches and

an intensification of pressure on nuclear family relations. All families have problems, but families with better functioning are more likely to solve problems, which are more likely to persist in those with less good functioning. Modification of family functioning may be part of the process of solving the presenting problem. Where there are major problems of functioning, such as some of the problems that arise in substance abuse, then changes in the family may be an essential prerequisite of helping a child.

7. School and other influences. School (and preschool) is the second most influential environment for child development. Schools provide corroborative information on how a child is developing as an independent person. It is also important in ensuring a common understanding with the teachers over progress and needs, and how to meet them. Often the question is whether the environment matches the developmental needs of a child. In children with intellectual disability, the engagement, observations and management of other agencies is critical, such as respite care and other health and disability professionals. Their ability to communicate and collaborate and their professionalism is often a key determinant of outcome. Complex cases necessarily involve many carers and professionals. One challenge is evaluating the quality of care or professional skills and intervention of all contributors.

8. Other assessment measures: For health-related quality of life we use the **Measure of Function (MOF)**, which is based on the **Child Global Assessment Scale**, used routinely by all mental health professionals, but the MOF has more descriptors to consider physical and intellectual wellbeing, not just mental wellbeing (*Dossetor et al, 1997*). A similar version modified for families to use, simply asks the family to rate a category, rather than give an individual number. We have used the MOF to help us estimate how much of the impairment of functioning is due to health and development and how much is due to problems of emotional and behavioural disturbance. This often highlights the critical additional handicap caused by the emotional/behavioural disturbance. We also use the clinician friendly **Global Assessment of Family Functioning**, (*Rey et al, 1996*). Both of these measures can be used to measure progress. We find these useful measures in addition to those that NSW Mental Health requests that you fill in such as the **SDQ** (www.sdqinfo.com) and **NSW Mental Health Outcomes and Assessment Training for Children and Adolescents (MH-OATCA)** (www.health.nsw.gov.au/mhdao/programs/mh/Pages/children-facilitator.aspx). The **Developmental Behaviour Checklist** is also a useful validated instrument which has greater value than the SDQ in this specialist population (www.med.monash.edu.au/scs/psychiatry/developmental/

[clinical-research/dbc/](http://www.med.monash.edu.au/scs/psychiatry/developmental/clinical-research/dbc/)). The **Beech** is also a useful family related quality of life instrument specifically designed for families with a child with intellectual disability (*Hoffman et al, 2006*).

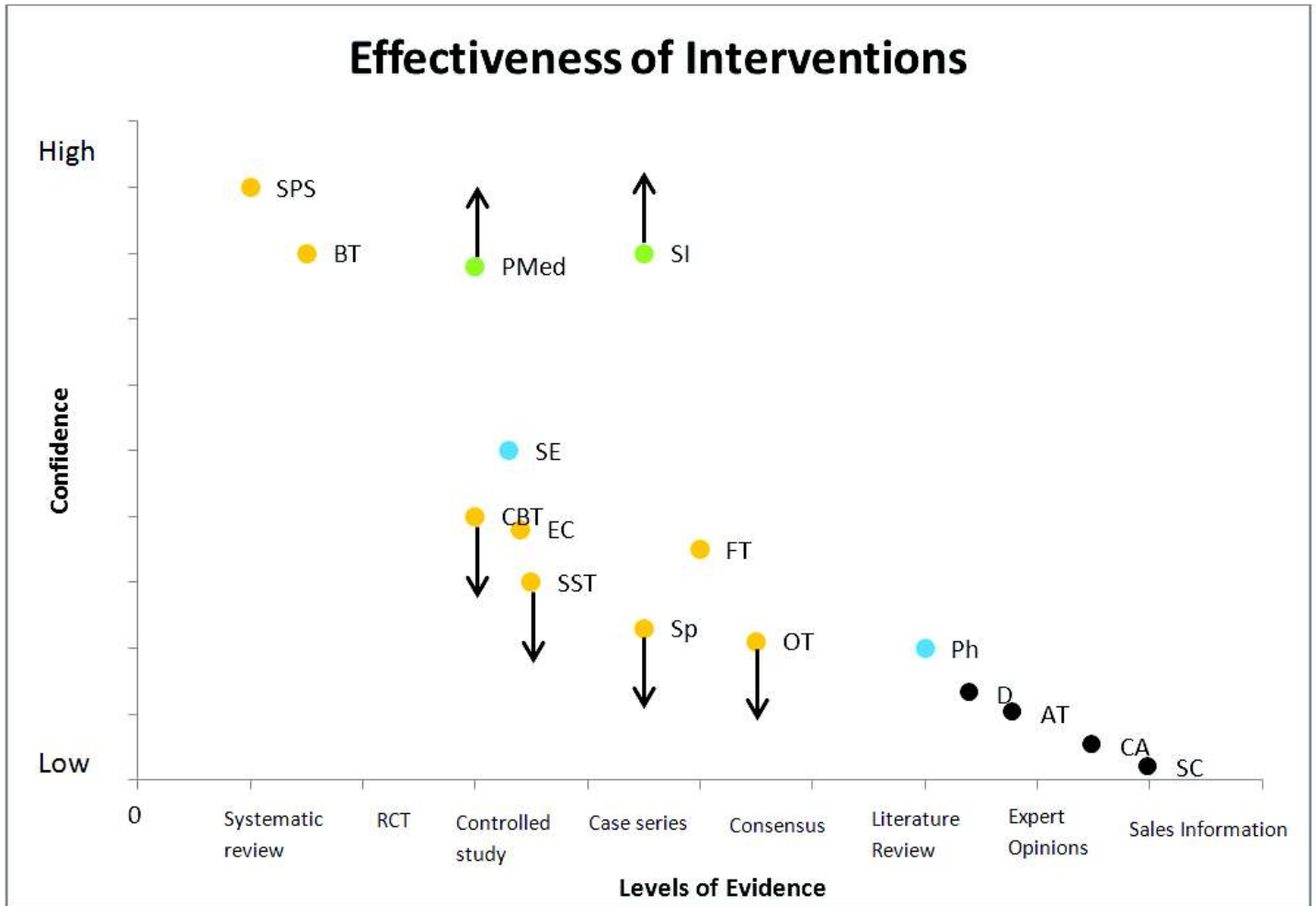
9. Formulation: At the end of an assessment, we aim to describe the presenting predicament in the context of the child, family and wider network, describing both strengths and weaknesses, resilience and vulnerabilities, protective and moderating, predisposing and perpetuating factors and aim to establish an agreed view of this formulation with the responsible parent(s) or adult, and the child as far as is possible and reasonable. This becomes the basis from which to look at options for treatment. We may emphasise different theories of causal emotional and behavioural disturbance to those for treatment, as we need to focus on what can be changed.

10. Treatment: The developmental psychiatry clinic has a multidisciplinary multimodal approach to intervention. **Diagram 1** shows the range of approaches that are used in the treatment of the emotional and behavioural problems of young people with intellectual and developmental disabilities and gives a measure of the size of the effects of different interventions for emotional and behavioural disturbance and the level of scientific evidence for each modality of intervention. The colour scheme also gives an indication as to how quickly an intervention type brings about change. This summary provides an overview agreed by our team of multidisciplinary clinical experts, and there will be differences for different elements within one treatment type such as different medications and for different disorders. Much of modern mental health treatment is through approaches to developmental enhancement and positive psychology. Medication is more likely to be needed in the acuity of a severe situation, but long term recovery still depends on engaging in approaches to developmental enhancement. These developmental concepts equate to the care and recovery models used in adult mental health. In those with intellectual and developmental disability, medications are less likely to work than in mainstream populations, and have more side effects or adverse events, but the more impaired the young person is, the more likely it is to be an essential part of the treatment. Medication management therefore requires to be approached with caution and patience, with attention to detail in how the medication works in this disorder and in this child. Except where there may be other medical problems requiring hospitalisation, these medications need to be trialled in the normal community environment of the child. Nonetheless, medication is always only one element in a treatment plan. If more care is required than can be provided by the family, then additional care support and respite should be sought from disability or welfare services. Evaluating the contribution of a medication, requires a stable, good enough caring environment; (hospital can often be a disturbing and traumatic environment especially for the developmentally vulnerable).

Diagram 1, on treatment effectiveness also provides a template to consider what approaches have been tried and to what level of adequacy and to what effect, and what has not properly been considered or implemented. Multimodal

“Evaluating the contribution of a medication, requires a stable, good enough, caring environment”

Effectiveness of Interventions for emotional and behaviour disturbance in children and adolescence



- Rapid Effect: days to weeks
- Intermediate Effect: weeks to months
- Slow long term effects: months to years



Arrows indicate direction of effect in more severe disturbance

Abbreviations	
SPS	Specialised Parenting Skills
BT	Behaviour Therapy; including carer/staff training
CBT	Cognitive Behaviour Therapy
PMed	Psychotropic Medication
SE	Special Education: skills to match needs
EC	Emotion Based Social Skills Training/Emotional Coaching
SST	Social Skills Training
SI	Safety Intervention, including room modification, CPI
Sp	Speech and AAC
FT	Family & Systems Therapy
OT	Occupational Therapy/Sensory Integration
Ph	Physiotherapy
D	Diet
AT*	Alternative Therapy
CA*	Chelating agents, Oxygen Therapy
SC*	Stem Cell Therapy

intervention is the norm for complex cases whereby several modalities of intervention may be needed at one time, so they can lever off each other to improve the patient's functioning. This chart also highlights that all the necessary professional skills are not found in any one agency, and multi-modal treatment requires the collaboration of different disciplines and different agencies. The coordination and collaboration required is itself a challenge and often it falls to the family to be the organiser and go-between, although a case manager and other professionals can also contribute and can be essential in complex cases.

Safety Intervention is the intervention that stands out in the list as not being widely recognised as a therapeutic intervention. Generally it is an area that causes unnecessary controversy. Parents have a duty to keep their children safe, and have legal authority stronger than any external agency, so long as they in turn do not use coercive approaches or assault their children. If implemented it generally works and works immediately. However it takes time, money and effort to design an appropriate and engaging setting for example with sensory soothing activities. Generally, enabling safety intervention that protects the client and other members of the family from assault and a capacity for enabling 'chill out' is often a critical ingredient to interrupting the psychological rewards and behavioural reinforcement gained from

violence. It is also a key step in building autonomy skills of self-regulation. Some of these issues have been looked at in the chapter on 'Promoting Resolution and Safety: a case study (Dossetor in Whatson, Corfield and Owens, 2011, Ch 21).

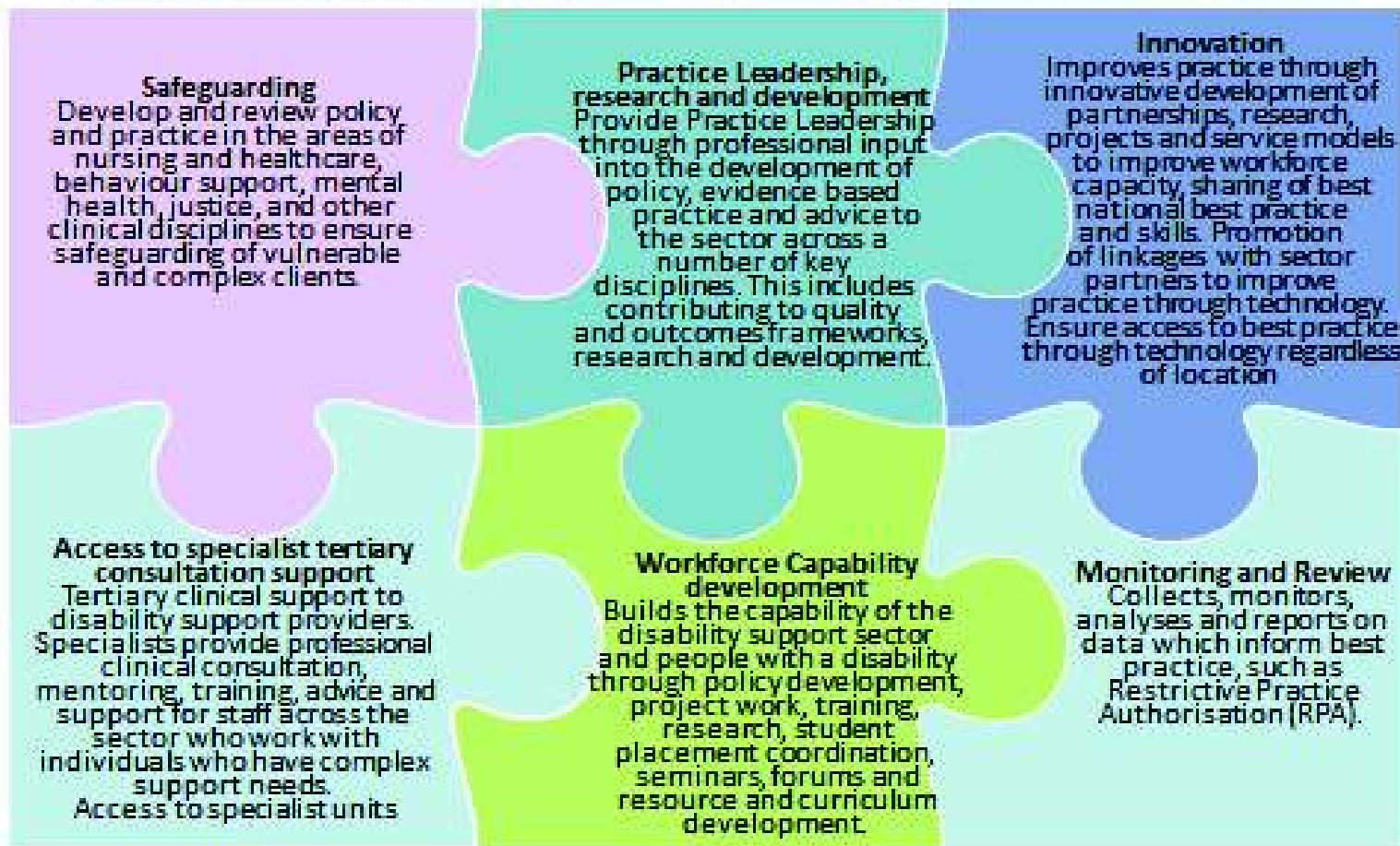
When attending a clinic, it is helpful to bring past assessments by other doctors and clinicians, any psychometric assessment (IQ test), and a recent school report. It is especially helpful to have information on psychotropic medications that have been used in the past, with information on their dose, benefits and any side effects.

Lastly, when attending the clinic, it is important that parents remain in charge of their child and their behaviour, and bring distractors/toys and additional adult help if there is a risk of their behaviour being difficult to contain in a long consultation. A crisis of behaviour in the clinic becomes a medical emergency and gets in the way of assessment and planned help.

Current Issues

An overview of the different contributions from different disciplines and agencies is given in the previous article in the last edition of the magazine (Dossetor, 2015, editorial pages). The skills and approaches of each discipline is de-

NSW Disability Clinical Innovation and Governance : Key Functions



scribed in their respective chapters in “The Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities: a framework for professional practice” (Dossetor et al, 2011). The growth of partnership between Health, Disability and Education is an appropriate natural development of combining a holistic, life-trajectory approach, with the latest developments in mental health expertise and intervention skills. The level of difficulty and the lack of evidence-based clinical models in dealing with these problems probably underlies why this didn’t happen earlier in the social history of integrating children and adolescents with intellectual disability in our society. Although Developmental Psychiatry has an emphasis on what may be called developmental psychiatric disorders, the approach to mental state assessment suggests that all mental disorders can be conceptualised as problems of social adaptation, reciprocity and integration.

The rates of relinquishment of care of these disabled young people (under 18 years) are considerably higher than the rate of that of a the mainstream population and over 14% of those in out of home care had a disability, with 20% of those in residential care (Victorian Equal Opportunity and Human Rights Commission, 2012) and have been rising steadily. The majority have high behaviour support needs, and multiple disabilities. Others had complex physical disabilities or a severe medical condition. In recent years, there have been similar enquiries in South Australia (Crettenden et al, 2014) and Queensland (Endeavour Foundation, 2012), with similar findings. It was felt important not to pathologise the families but to recognise they feel inadequately supported, compelling them to relinquish care. The cost of residential care is estimated to be 7 times the support costs of maintaining such children in family care (approximately \$100,000/year) but individual high needs packages where 2:1 care is needed can cost \$800,000/year. The service is crisis driven and lack approaches to prevention. There is growing evidence that mental health intervention is the most cost effective health intervention, yet receives the least financial investment, in terms of cost and benefit to our community. I suspect the above figures indicate that this also applies to subspecialty multidisciplinary disability health, or developmental psychiatry.

All three enquiries supported the development of the NDIS for lifetime support and early intervention. They also recommended active long term case management, greater availability of residential respite, including options such as shared care, and services for positive behaviour support and behaviour management. Unfortunately, in NSW, the transition of the state government disability service to the non government sector may significantly diminish all these components of service, as well as having an impact on leadership in 1. Safeguarding professional standards, 2. Practice leadership research and development, 3. Innovation, 4. Access to tertiary consultation, 5. Workforce capability development, 6. Monitoring and review processes (Diagram 2).

The lifetime cost for the state to support people with intellectual disability and complex needs should mean that the new models of person-centred funding from NDIS should

“It is time that we moved on to community-based models of disability based health and mental health services”

find mechanisms to enable tertiary subspecialty multidisciplinary multiagency clinical partnerships such as the Developmental Psychiatry Clinic to have its place in the service system. Such services are not part of the current private or public mental health/health service structure. The NDIS may help challenge the stigma attached to people with an intellectual disability and their families, and will need to appreciate the scale of the challenge of those most disabled, particularly with the secondary impairment for emotional and behavioural disturbance and provides funding mechanisms to support their complex needs.

The maturity of collaboration and clinical efficacy in the Developmental Psychiatry Clinic has been demonstrated with case examples where many families no longer feel on the verge of relinquishing care, and other cases whereby highly difficult teenagers have been placed in temporary voluntary care, but through the determination of the family and the collaboration of all agencies, that the teenager has been able to return home, with a family who have benefitted from respite and a new or revitalised multidisciplinary multiagency intervention and support plan. This flies in the face of the traditional literature which has seen respite and residential respite as part of an inevitable path to relinquishment of care, only countered by the fear of your child being institutionalised. The key components for successful community care for young people with intellectual disability involves services that focus on the main causes of family breakdown:

1. Parental acceptance and attunement;
2. Tackling the burden of care and providing respite;
3. Supporting the welfare of the carers and other family members; &
4. Managing the problems of delayed development and the associated problems of emotional and behavioural disturbance (Nankervis et al, 2011).

It is time that we moved on to community-based models of disability based health and mental health services. For such a multiply handicapped and disadvantaged population, long term family care should be a choice balanced with adequate community-based support including multidisciplinary multiagency approaches to complex problems of emotional behavioural disturbance. This also requires a concerted approach to the other 3 factors of parenting skills, respite and carer and family support.

If the Developmental Psychiatry Clinic and Partnership is lost, it may represent the loss of a model best practice for



future service capacity and development. Subspecialty mental health skills are still early in its development and multidisciplinary subspecialty paediatric and mental health skills have only flourished by the active partnership between health, disability and education sectors. It may be costly to fund such multifaceted expertise, but the cost will be so much greater for the child, the family, the community, the state and the country if we don't!

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