The aim of this Journal is to improve the mental health of children and adolescents with intellectual and developmental disability through enabling academic debate, research and commentary on the field.

**Description and purpose**
This journal is a modification of the previous newsletter; a vehicle of expertise about mental health information of children and adolescents with intellectual and developmental disability. As a product of CHW School-Link, this journal is supported by School-Link and a collaborative effort with a multi-agency editorial group from the Statewide Behaviour Intervention team of the Department of Aging Disability and Home Care, NSW Family and Community Services, and NSW Department of Education. We are extremely proud to present these ideas and invite you as authors to help develop this field and the knowledge base to help support children and adolescents.

**On our Website:**
www.schoollink.chw.edu.au
The website will be playing a crucial role in the information that CHW School-Link can provide to you.
- The collection of previous and current editions is located there with the ability to download articles separately.
- An invitation for contributions can be found on the website with instructions for authors.
- Upcoming training at conferences, workshops and other professional development opportunities will be continuously updated.
Welcome

2015 has been a busy and creative year for School-Link (and Bandaged Bear - the Children’s Hospital at Westmead’s mascot). We created our very first animated character ‘Jessica’ with the help of Hackett Films and our collaborators from the Statewide Behaviour Intervention Service- ADHC, Department of Family and Communities, and the Department of Education and The Department of Psychological Medicine from the Children’s Hospital at Westmead. The short animation, funded by Statewide Behaviour Intervention Service features Jessica in her school environment, where she narrates from her point of view the various adjustments and strategies that have been implemented to support her. The animation is part of a strategy to raise awareness of the mental health and wellbeing needs of children and adolescents with an intellectual/ and or developmental disability across mainstream schools.

The animation is the centre of a train the trainer workshop on mental health and intellectual/ and or developmental disability for school staff. The Children’s Hospital at Westmead School-Link Program was awarded an implementation grant from MH-Children and Young People to roll out the train the trainer workshop across New South Wales with the aim of creating a resource package for school staff to deliver back in their school environment.

Twenty-eight workshops have been scheduled across all Local Health Districts with over 800 registrations to date.

Twenty-one face to face workshops across twenty-one locations have occurred thus far. If you would like to ‘Meet Jessica’, workshops from our road show are still available in Ulladulla, Maitland, Newcastle, Central Coast, Wagga Wagga, Goulburn, Liverpool and a special video conference for remote areas. You can register online here: www.schoollink.chw.edu.au/register.

We sincerely thank our collaborators who have helped script the animation and our fellow School-Link Coordinators who have secured venues and spread the word amongst their local networks across NSW. A full evaluation will be conducted shortly. Resources will be available to registered attendees towards the end of 2015, once all workshops have been delivered and the final resource produced. As Lesley Whatson from the Statewide Behaviour Intervention Service notes: “It has been an exciting year of collaboration!”. Enjoy reading this edition of the journal and please send any feedback or your own contributions to schoollink@chw.edu.au

Happy reading!

Jodie Caruana
School-Link Coordinator
The Children’s Hospital at Westmead.
The Developmental Psychiatry Clinic

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 Neuropsychiatric 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-

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 sensorial 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 phenome

na 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

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/mhddao/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/pcs/psychiatry/developmental/

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

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

Effectiveness of Interventions

- **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

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<tr>
<th>Abbreviations</th>
<th>Description</th>
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<tr>
<td>SPS</td>
<td>Specialised Parenting Skills</td>
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<tr>
<td>BT</td>
<td>Behaviour Therapy; including carer/staff training</td>
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<tr>
<td>CBT</td>
<td>Cognitive Behaviour Therapy</td>
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<tr>
<td>PMed</td>
<td>Psychotropic Medication</td>
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<tr>
<td>SE</td>
<td>Special Education: skills to match needs</td>
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<tr>
<td>EC</td>
<td>Emotion Based Social Skills Training/Emotional Coaching</td>
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<tr>
<td>SST</td>
<td>Social Skills Training</td>
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<tr>
<td>SI</td>
<td>Safety Intervention, including room modification, CPI</td>
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<tr>
<td>Sp</td>
<td>Speech and AAC</td>
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<tr>
<td>FT</td>
<td>Family &amp; Systems Therapy</td>
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<tr>
<td>OT</td>
<td>Occupational Therapy/Sensory Integration</td>
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<td>Ph</td>
<td>Physiotherapy</td>
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<td>D</td>
<td>Diet</td>
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<td>AT*</td>
<td>Alternative Therapy</td>
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<td>CA*</td>
<td>Chelating agents, Oxygen Therapy</td>
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<tr>
<td>SC*</td>
<td>Stem Cell Therapy</td>
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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 multimodal 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 Watson, 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-
It is time that we moved on to community-based models of disability based health and mental health services

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; &

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!

References

Centre of Disability Studies. 2014. Evaluation of the Developmental Psychiatry Clinic and Partnership, Children’s Hospital at Westmead. Find the link on the School-Link website www.schoollink.chw.edu.au


Wurth P, Brandon S. The ACT mental health service for people with intellectual disability, 10 years on. Australasian Psychiatry 22 (1): 52-5.
This practical guide for high school teachers was developed from an original research project commissioned by the Catholic Education Office, Broken Bay Diocese, NSW and undertaken by Autism Spectrum Australia (Aspect). The original research paper documented the knowledge and views of experienced service providers as well as recent literature on teaching adolescents with Autism Spectrum Disorder (ASD). A number of group discussions were held and also documented, about the most effective ways to teach and support students with ASD in the classroom and beyond. During the many focus group discussions, strategies and suggestions were formulated and discussed. These suggestions form the basis of a comprehensive guide for teachers of adolescents with ASD in mainstream schools.

This useful book is organised into four main sections as follows;

1. Unravelling Autism Spectrum Disorder, Associated features and theories of thinking and learning
2. Implications of Autism Spectrum Disorder and Associated features for High School students with Autism Spectrum Disorder
3. How to combat common obstacles experienced by high school students with Autism Spectrum Disorder: Suggestions and Strategies
4. Post High School: Where to next?

The first section of the guide gives a description of ASD, its characteristics and its impact on the student. There is a good outline of theory of mind and executive functioning; this is coupled with case studies throughout the chapter.

Implications for ASD at high school are varied, including the challenges such as the complexity of the learning environment, increased workload, pace of work, nature of teaching, learning and assessment. The social development of students with ASD and their peer interactions are also discussed with emphasis on a multi-faceted approach that includes both prescribed social skills programs and in situ social skills development in the real world.

Ideas to combat obstacles include the use of a framework of inclusion. The example given in this guide is the PBS framework; Positive Behaviour Support. Other strategies include planning for transition, having a class-wide pedagogy, the use of ASD-specific approaches, individual learning plans, maintaining social interaction and socio-emotional support, reducing and alleviating anxiety with individual plans, interventions and supporting good mental health.

The final section of the book discusses planning for the future. There is an excellent table that describes post-school options: contacts and resources. They are not only Australian based but also cover the UK and the USA. This section also includes higher education disability services, access to employment and workplace support, mental health and community participation organisations.

There is an essential list of resources in the appendices which includes books, curriculum resources and online resources. The reference list is far reaching with some further reading is included.

Overall, this book is a great guide for teachers working in the field to encourage best practice. This is also a worthy resource for student teachers who are hoping to work with students with ASD. Although this is aimed at the high school setting, there are many strategies and tools that can be used across the lifespan. A bonus that this is an Australian

“Overall, this book is a great guide for teachers working in the field to encourage best practice”
The Practice Improvement Framework (PIF as it is affectionately known) is one of the long term systemic solutions to professional development in behaviour support services for the disability sector (OSP, 2011). It has been developed by the Statewide Behaviour Intervention Service, Clinical Innovation and Governance, Ageing Disability and Home Care, NSW Department of Family and Community Services. The development of the PIF has benefited greatly from its collaboration with people with disability, their parents and support networks, other government departments and agencies, key experts in this field, non-government organisations and private practitioners.

The PIF has been developed to include a number of peer reviewed components that a learner would typically move through sequentially. The knowledge translation methods include e-Learning modules, web based resources, videos and workshops.

The PIF caters to the differing proficiencies of learners regarding their knowledge of behaviour support by having an entry point for non-practitioners and an entry point for practitioners. Non-practitioners would start with Premier PIF before moving onto the Common and Positive Approaches to Behaviour Support (PABS) core standards; whilst practitioners start with the Common and PABS core standards.

The primary focus of the PIF is on the practical application of the knowledge acquired. We know that ‘training’ alone is not sufficient to imbed new learnings into everyday practice. Performance improvement is achieved by providing supported practice so that feedback can be provided in a safe, accurate and timely manner (Brinkerhoff & Apking, 2001). Consequently, each component of the PIF also includes a comprehensive appraisal process. This is designed to build the learners work based application and reflective practice skills through the professional supervision/ work practice support process. Each appraisal includes discussion questions, work samples and the opportunity for observation.

The PIF has also taken a ‘whole of organisation’ approach so that the investment in training and work practice support does indeed lead to improved workplace performance (Manchester, 2011). To this end the PABS core standard in particular, supports the content of the Behaviour Support:
Furthermore, the PIF would sit comfortably alongside the Positive Behaviour for Learning (PBL) framework. Whilst it is worthwhile exploring for Tier 1 Universal Prevention and 2 Targeted Interventions, it would be of most interest in relation to Tier 3 Intensive Individualised Interventions where the focus is on understanding the function of the behaviour in order to support the students’ skills and success at school (DEC, 2015).

As a result of needing to increase its availability more broadly, the PIF is now available to those providing behaviour support services via a new website http://PIF.learnflex.com.au.

To find out more about the Practice Improvement Framework please email PIF@facs.nsw.gov.au. To become a participant to complete the e-Learning you can register at http://PIF.learnflex.com.au.

References


Propranolol
Old drug with many uses

James W Black discovered propranolol (first drug in its class – beta (β) blocker) in 1960s and was awarded the Nobel Prize in Medicine for this in 1988. It is on the World Health organisation list of essential medicines. Propranolol is a non selective β1 and β2 adrenergic and noradrenergic blocker.

Beta (β) cells are present in the heart causing heart muscle contraction, also smooth muscle relaxation in other parts of the body as well an effect on glycogenolysis which affects blood sugar levels. There are three types of β cells, β1 which affects the heart rate and the AV node conduction of the heart and β2 which are responsible for smooth muscle relaxation such as bronchodilation (best known one specific for β2 agonist/bronchodilator is salbutamol (Ventolin®) and β3 are involved in breakdown of lipids and conversion of triglycerides to glycerol.

Some of the recognised uses for propranolol include treatment of hypertension, angina, tachyarrythmias (fast irregular heart rate), myocardial infarction (heart attack), racing heart beat and tremor associated with hyperthyroidism, anxiety and lithium therapy, essential tremor (adverse effect of numerous medications), rhythmic shaking about 4-12 cycles per minute (Hz), migraine and cluster headache prevention, excessive sweating, infantile haemangiomas, glaucoma, PTSD, akathisia, aggressive behaviours associated with brain injury and thyrotoxicosis.

Why is it used in mental health?
Propranolol is used in a variety of mental health conditions but usually when the first line therapy has not been successful. Most of the conditions where it is used it is for an unlicensed indication – the evidence for use may not be extensive.

Propranolol is used to correct the essential tremor (rhythmic shaking about 4-12 cycles per minute (Hz)) for those taking lithium and other medications where the tremor is causing distress. Propranolol is thus also used for restlessness (akathisia) also associated with adverse effects of medication usually antipsychotics. These indications would be targeting the component that causes smooth muscle relaxation and antagonism of the peripheral β2 receptors. Targeting the β1 receptors, may theoretically prevent fear conditioning and reconsolidation of fear associated with PTSD. Thus propranolol has been shown to be successful in some for treatment of PTSD and anxiety. It is commonly used amongst performers for performance anxiety as a one off dose prior to the performance. There are reports that early administration may help with the intrusive thoughts and reduce the severity of later symptoms in PTSD.

As propranolol works on the adrenergic system which controls the flight fight mechanisms of the body it is has shown some success in patients exhibiting violence or aggression.

Why use in the developmental disability setting?
Propranolol may be effective in controlling rage, irritability and aggression, in ASD and ADHD. Controlling aggression associated with organic brain dysfunction as there is good evidence to show efficacy for the management of agitation and aggression in patients with acquired brain injury.

Often, antipsychotics or D2 antagonists such as risperidone are used to treat challenging behaviours especially in the context of autistic spectrum disorder. One of the adverse effects of risperidone and some of the older antipsychotics is extrapyramidal side effects including involuntary movements and muscle spasms and propranolol has been prescribed.

Beta blockers have membrane stabilising effect and GABA-mimetic activity; as well as presynaptic 5HT1A antagonists.
These characteristics are what is needed for a good anxiolytic, thus is used second or third line for anxiety symptoms.

What should I be looking at for adverse effects or side effects?
Propranolol causes adverse effects by blocking the adrenergic receptors which will cause dizziness, bradycardia (slowing of heart beat) and hypotension (low blood pressure) and minor effects on other receptors.

Propranolol and other beta blockers can inhibit the effect of melatonin on the body thus causing insomnia and other sleep disturbances. If affecting sleep, propranolol should be taken during the daylight hours to ensure there is no effect on the body’s natural melatonin levels. It has been known to be used successfully with patients with Smith Magenis Syndrome where there is an inverted melatonin circadian cycle.

Propranolol’s effect on smooth muscles can inhibit bronchodilation and can also precipitate asthma and being an antagonist for beta receptors should not be used for patients with asthma and especially counters the effect of salbutamol and the other beta agonists used to treat asthma symptoms. In these situations, a cardio selective beta blocker such as metoprolol can be used.

Propranolol and the other beta blockers are also associated with fatigue and coldness of the extremities. Some sleep disturbances with nightmares have also been reported. Beta blockers can affect the carbohydrate metabolism causing low or high blood sugar levels in patient who are either have diabetes or not. They can also interfere with metabolic and autonomic responses to hypoglycaemia thereby masking symptoms such as tachycardia (fast heart rate). Weight gain has also been reported. Urinary retention, joint pain, dysuria as well as sexual dysfunction and decreased libido have also been reported.

Other important information about propranolol
Propranolol is also used in the prophylaxis of migraines and in some cases for treatment of anxiety. Propranolol is extensively used in cardiology from the treatment of acute cyanotic episodes in neonates with tetralogy of Fallot and used in heart failure and arrhythmias in the elderly. Beta blockers act principally by attenuating the effects of the sympathetic system on automaticity and conductivity.

Propranolol is also used to control blood pressure so when using it for other indications it is important to monitor the blood pressure to ensure it does not drop too much thus causing dizziness and falls.

When being used for migraine prophylaxis it can begin to work within 2 weeks but may take up to 3 months on stable dose to see the optimal effect. But when used to treat tremor can work within days.

Propranolol has also been used in PTSD acting theoretically by blocking the effects of stress from prior traumatic experiences.

When it is used in context of violence and aggression the mechanism is poorly established but it is assumed to be related to central actions at the β adrenergic and serotonin receptors. This may be through affecting the stress response of the adrenal gland.

Propranolol and other beta blockers have also been reported to exacerbate psoriasis and alopecia and rashes have also been reported.

Propranolol and other beta blockers can blunt the symptoms of hypoglycaemia in diabetics and mask the clinical signs of hyperthyroidism.

References:
BNF for Children April 2015 (accessed through CIAP 7/5/15)
Clinical Handbook of Psychotropic Drugs for Children and Adolescents 3rd ed 2015
The Taking Time Trauma-Informed Framework has been developed to guide service providers who support people with intellectual disability. It was informed by the literature, consultation with people with intellectual disability, and support from the consultation and governance and groups established through Ageing, Disability and Home Care, Department of Family and Community Services (ADHC, FACS.). Trauma theory and other areas of knowledge are discussed in a literature review which is a companion document for the Framework entitled Taking Time – A Literature Review: Background for a trauma-informed framework for supporting people with intellectual disability (Jackson, Waters & Abell, 2015).


The Framework is presented in 8 parts:
1. Introduction
2. The Taking Time Framework
3. The Framework in Action
4. Supporting Information from the Research
5. Conclusion
6. Appendices
7. References
8. Acknowledgements

The vision and aims of the Framework are multiple and have a specific focus on people with intellectual disability including:

- reducing trauma and re-traumatisation
- facilitating healing from past trauma
- supporting the use of trauma-informed practice
- strengthening reflection on practice and self-care approaches
- improving appropriateness of the broader system’s responses
- enhancing quality of life
- enabling society to gain from the contributions of people with intellectual disability
- facilitating a compassionate and responsive society that demonstrates the right for dignity for all.

Some of these aims are easier to grasp and achieve while others are more aspirational. No single paradigm, including trauma-informed practice, is sufficient to achieve these aims on its own. Consequently, this Framework draws on other theories that support the understanding of trauma and trauma-informed practice. Nonetheless, the Framework is predicated on the view, informed from research and practice, that trauma-informed practice can make a major contribution to achieving these aims and aspirations. It is also predicated on the view that the alternative – where an organisation is not aware of the implications of working with people who have experienced trauma – can sometimes be harmful.

A useful definition of trauma-informed practice is as follows:

A program, organization, or system that is trauma-informed realizes the widespread impact of trauma and understands potential paths for recovery; recognizes the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatization ( Substance Abuse and Mental Health Services Administration [SAMHSA], 2014, p. 9).

The key elements of the Taking Time Framework are:

- Foundational value – values underlying trauma-informed practice supporting people with intellectual disability
- Guiding principles – as tools of the mind to inform practice, services and the system
- Knowledge and skills – to enable the principles to become action, which are embedded in an ongoing learning cycle
- Environment and resources – what the physical and social environments provide to promote safety and the provision of appropriate resources to achieve this
- Policies and procedures – enabling organisations’ internal systems and documents to reflect the spirit, intent and actuality of trauma-informed practice
- Leadership and organisational culture – what is required to ensure ongoing commitment at an organisational and sector level

The Taking Time Framework is represented in this hourglass diagram.
The voices of people with intellectual disability are illustrated through the themes that arose when they were asked for their thoughts about trauma and what could be helpful.


The 15 guiding principles underlying this Framework’s approach to trauma-informed practice are summarised as follows:

1. Taking Time to understand and embrace each person’s goals and aspirations, their unique strengths and support needs including communication, problem-solving and other cognitive processes.

2. Understanding and recognising trauma and its impacts including the potential relationship with behavioural difficulties that may be experienced by the person.

3. Creating opportunities for people to make or find their own meanings and to create the environment that supports them to communicate their feelings.

4. Promoting a safe physical and emotional environment tailored for each individual.

5. Being culturally respectful and informed and working towards cultural competence.

6. Supporting the person’s control, choice and voice to have or work towards genuine autonomy, self-determination, participation, and respect for human rights and freedoms.

7. Sharing power and governance in a genuinely inclusive way.

8. Valuing safe and genuine relationships in the process of recovery.


10. Ensuring access to supported trauma-specific treatment (which may require adaptation and extra time for people with intellectual disability) delivered by appropriately trained professionals.

11. Acknowledging recovery is possible for everyone and the importance of hope, fun, joy and peer support in the present and the future.

12. Integrating practice that has a holistic view of the person and the recovery process, and facilitates communication among services and systems to support continuity.

13. Acknowledging staff need to be and feel safe, and acknowledging the potential for vicarious trauma and need for self-care and organisational care.

14. Acknowledging the need for transparent trauma-informed processes and systems that emphasise the importance of reflective practice.

15. Adopting a trauma-informed organisational approach which requires a healthy organisational culture and positive leadership approach.

The Framework includes ideas for translation into practice at both service and system levels, and includes vignettes which provide examples in action within NSW. A number of organisations are in different stages of implementing trauma-informed practice from an individual, program or organisational perspective.
The opportunity to ‘take time’ – to research, reflect and develop a trauma-informed framework for supporting people with intellectual disability – was made possible by Statewide Behaviour Intervention Service (SBIS), Clinical Innovation and Governance, Ageing Disability and Home Care, Family and Community Services.


References


You can request a recording of the for the Taking Time– Framework: A trauma informed framework for supporting people with intellectual disability webinar by contacting kellie.vansebille@facs.nsw.gov.au

This webinar provides an introduction to the Taking Time Framework developed by Berry Street’s Take Two Team in partnership with the Statewide Behaviour Intervention Service, Clinical Innovation and Governance, Ageing Disability and Home Care. The webinar outlines why all disability services need to operate in a trauma informed way and how agencies can go about achieving this.
Occupational Therapy is the therapeutic use of self-care, work, and play activities to increase independent function, enhance development, and prevent disabilities, and may include adaptation of task or environment to achieve maximum independence and to enhance quality of life.” (American Occupational Therapy Association, 1986). Occupational Therapists use a wide knowledge base and a variety of therapeutic techniques to treat children and adolescents by developing an individualised, functional and activity-based program to target their emotional, cognitive and physical needs.

Sensory processing is an integral part of the assessment and intervention process when working with children and adolescents with intellectual/developmental disability and mental health problems. Sensory processing is the “ability to take in sensory information from one’s own environment, to organise this information, and to use it to function in daily life.” (Kranowitz, 2005). For many children and adolescents with intellectual and developmental disability (ID/DD) and mental health problems they have difficulty in the way their brain takes in, organises and uses sensory information. This may influence the development of their fine and gross motor skills, motor planning, self-care independence, speech-language, social-emotional skills and the ability to self-regulate their behaviour.

There are many cases that would typically be supported by an occupational therapist, a typical case: A 12 year old boy diagnosed with moderate intellectual disability, anxiety and ASD. He also demonstrates sensory processing difficulties and a poor ability to self-regulate his behaviour and emotions. These challenges all have a significant impact on school and home participation, and behaviour. Following the assessment process which included home and school observations, a program is developed with recommended strategies to address his challenges and help support his participation.

Some cases can be more complex; A 10 year old boy diagnosed with mild intellectual disability, Tourette’s, Obsessive Compulsive Disorder and ASD who has also has been diagnosed with Executive function and sensory processing difficulties. These challenges all have a significant impact on school and home participation, and behaviour. Following the assessment process which included home and school observations; a program was developed with recommended strategies to address his challenges and help support his participation.

Resource ideas for schools
Sensory-motor equipment that would be beneficial for schools:
- Trampoline/ mini-trampoline, therapy (gym) balls, playground and climbing equipment, swings, sensory room
- Weighted modalities e.g. weighted blankets, lap bags, shoulder bags
- Creating sensory fidget boxes/bags
- Sensory friendly zones e.g. spaces for “down time” when the child feels stressed or overloaded
- Texts: (see reference list)
- How Does Your Engine Run? A Leaders Guide to The Alert Program for Self-Regulation
- Take Five! Staying Alert at Home and School
- The Out-of-Sync Child: Recognising and Coping with Sensory Integration Dysfunction

Resource ideas for a sensory diet in special schools
“Each person needs certain amounts and types of sensory input or activity each day to be the most alert, adaptable and skilful. We can achieve and maintain optimal levels of arousal for performance by timing and carefully selecting our sensory-based activity.” (Wilbarger & Wilbarger, 2007). A sensory diet is a planned and scheduled activity plan designed to meet a child’s specific sensory needs. By providing a “just right” combination of sensory input a child can achieve and maintain optimal levels of arousal and perfor.
A balanced sensory diet can help the child focus, attend, interact and help prevent behaviours of concern. Ideas:

- Do some “detective work”. Observe and try to determine the purpose behind their sensorimotor behaviours i.e. seeking or avoiding behaviours; strengths/difficulties, what do they do to calm/alert?
- Chart the child/adolescent’s arousal/level of alertness throughout the day over a few days recording high arousal, optimal level and low arousal. Is there a pattern to it? i.e. low arousal (lethargic) after lunch.
- Incorporate the child’s goals, preferences, resources and limitations
- Play and leisure activities for children; and leisure and workout routines for adolescents
- Movement, deep pressure touch and heavy work activities have the most significant and long lasting impact on the nervous system (long term arousal changes).
- “Sensory snacks” refer to activities that have short term impact such as oral sensory motor activities
- Ideas need to be practical to work within the daily routine i.e. set activities for specific and regular times of the day
- Planning should be done in collaboration with school staff, allied health team and parents/carers
- Base activities on child preferences and motivations

References


Effective learning and support teams provide a mechanism for the coordination of all aspects of teaching and learning in a school. They make a valuable contribution to whole school planning and the development of school policies and practices that are data and evidence driven, and focused on learning outcomes.

The learning and support team also provides a mechanism for embedding the learning and support framework into the culture and practice of the school. It plays a key role in leading and developing professional commitment by all staff to high expectations for every student, including those students who require adjustments to their learning.

Quality teaching and learning is central to the work of the learning and support team, making it a key decision making body within the school. This is important because the prime responsibility for meeting the specific learning needs of individual students with difficulties in basic areas of learning lies with the school and the classroom teacher.

The learning and support team is a whole school planning and support mechanism.

To remain responsive to the changing needs of individuals and groups of students, the learning and support team uses whole school data to underpin the decision making process.

The learning and support team has a key role in developing and supporting teachers’ capabilities to design, implement and evaluate programs and personalised learning and support plans. To do this, the team works cyclically through a series of planning steps to address the needs of individual students, groups of students and staff.

The learning and support team:
- identifies students with additional learning and support needs regardless of cause
- analyses data and evidence to understand more fully students’ learning and support needs
- prioritises the needs of these students and their teachers
- allocates resources (teachers, funding, programs) to meet the needs of students
- regularly evaluates efficacy of interventions and re-aligns services.

Each step in the planning process is supported by effective communication and collaboration.

What makes an effective learning and support team?
Effective learning and support teams bring together the energies and strengths of the whole school and its community to plan personalised learning and support to enhance the quality of the learning experience and build the capacity of staff.
An effective learning and support team has:
- effective leadership
- a whole school approach to the implementation of a learning and support framework
- a clear understanding of the learning and support team’s role
- involvement of parents/carers that is valued and supported
- effective processes for the identification and referral of students with additional learning and support needs
- professional learning for staff to build teacher capacity
- effective use of data to inform school planning and priorities
- regular reviews of the effectiveness and capacity of the team

**Membership**
Each school will determine the membership of the learning and support team depending on its needs. There should be a core membership with additional people taking part in the planning and intervention process when appropriate.

**Core membership usually includes**
- a learning and support team coordinator (the principal or a member of the school executive);
- school counsellor
- teacher representative/s
- other support staff as needed such as learning and support teachers, English as a second language teachers, Reading Recovery teachers, Aboriginal Education Officers.

**Additional members could include:**
- parents/carers
- students where appropriate
- school learning support officers or teaching assistants
- allied health professionals such as speech pathologists and occupational therapists

"The learning and support team is a whole school planning and support mechanism"
The European Society for Child and Adolescent Psychiatry (ESCAP) met in Madrid 20-24/6/15. Madrid was balmy and hot. Spain’s rich history as an empire builder is manifest through its fine architecture and memorable art galleries such as the Prado and Reina Sofia with a great range of paintings by Picasso, Miro, and Goya, and a couple by Munch. Madrid also looks after tourists with Tapas bars and dining in the squares in the long evenings. The Conference dinner was in the opulent rococo 19th Century Casino.

This major international meeting that rivals the American Academy of Child and Adolescent Psychiatry for size, but is so rich for the multi/cross cultural content. It is an internationally collaborative conference that enables one to take stock of where child psychiatry has got. There were an excellent series of ‘state of the art’ hour-long plenaries.

**ASD Treatment:** Sally Rogers, Professor of Developmental Psychology from the Mind Institute of UC Davis California, presented on early intervention in ASD. Lovaas was more or less right! Research on The Early Start Denver Model (ESDM) has consistently demonstrated that intensive intervention of 20 hours per week at two years of age for one year will enable language in most cases and lead to a dramatic and long term gain in IQ of 20-30 points, from a start of 50-60! RCTs and replications, including one from Melbourne (Vivanti et al, 2013), have led to the belief that outcome in ASD can be plastic! She showed impressive before and after videos, where skilled implementers demonstrated the development of reciprocal language and communication. 88% became verbal, and many showed significant changes of ADOS assessments 2 years after intervention. They have also shown that one hour a week intervention with parents and child, with the parents as implementers of a number of ‘low intensity models’ including additional approaches such as pivotal response training (PRT), has almost the same benefits. This means that we need to have widespread availability of ESDM or equivalent in Australia, as we cannot afford not to relieve such long-term disability. She has also done work on identifying ASD from an earlier age, and showed that symptoms of ASD generally start to become evident at 6 months, although the features are similar to attachment disorders. However 50% of parents report abnormal features by 1 year which should mean that diagnosis should be feasible by 1-2 years of age in these cases, rather than 4-5 years, which is the current age by which a professional diagnosis is usually made. This is of especial value as the brain may have greater plasticity with earlier intervention, and progress may be easier with teaching of skills at an appropriate age.

The positive emotions generated by intervention is motivating for both child and parents. Intervention should be provided based on a provisional diagnosis, rather than waiting for long-term changes. She concluded: “For some you can prevent ASD, and for some you can reverse their symptoms. Almost all can be improved!” Of note even Sir Michael Rutter has now acknowledged that the increase in prevalence of ASD has to be accepted as real and that aetiology of emotional environment (or neglect) in conjunction with oligo or polygenetics needs a fuller consideration.

Stefan Eliez, Professor of Child and Adolescent Psychiatry Geneva and the next president of ESCAP, presented on Vis a Vis: a fun web-based intervention for school aged ASD children on teaching them to read emotions in the eyes. It is performed with the support of an adult to reinforce social learning 4x20 minutes a week for 12 weeks. They have good pre/post results. It is available to anyone at a minimal price and can be accessed free by institutions: http://www.visavis.unige.ch/ vav/ index.php/ en-GB/. Interestingly
improvements correlated with increased activation in the fusiform lobe, which is recognised to be underactive in ASD.

**Prevention of Mental Illness:** Celco Aranga, Professor of child and adolescent psychiatry in Madrid and Boston made an important case of the critical need for prevention and prevention research, focusing specially on risks for very early onset psychosis. He quoted the 19th century American reformer, Frederick Douglas: “it is easier to build stronger children than to repair broken men”. 20 years ago it was not considered possible to prevent diabetes, heart disease or cancer, but the research funding into prevention in these “high status” areas is 200 times that of mental health with 200 times the number of publications! Prevention in these well-funded areas has made dramatic progress against all expectations.

However when you consider that 80% of all health morbidity in adolescents and young adults is psychiatric, and this is the starting point of adult mental disorder, the lack of priority for mental health funding and research defies understanding. For example, in UK only 4% of MH research funding goes into prevention. This lack of priority is reflected in the context of the lack of funding for C&A mental health services in Europe as well as in Australia where staffing at 30% of a basic first world service, and pressures as reported by NSW Faculty of C&A Psychiatry are greater than ever before. The problems include a lack of clear models for prevention of serious mental illness and the potential cost of intervention but these problems were dealt with in other areas by the investment in research.

However he made a compelling case for looking in greater detail at ways of enhancing neurodevelopment of the brain in our population. He quoted that large effect sizes are observed in some prevention/early intervention studies, and the dramatic cost/benefit of investment in research driven mental health intervention (as I outlined in ‘Health Economics for Mental Health and Intellectual Disability’ Schoollink Newsletter 2013; 4(2) 2-7). It seems that the critical stage for intervention in psychosis is in utero and infancy, and early signs of neurodevelopmental problems are seen in infancy.

There is a range of relevant genetic loci, which are a risk, but they are a risk for most mental health problems. Psychotic symptoms are surprisingly common and are found in up to 15% of young people, which are a risk for schizophrenia, suicide and other psychiatric disorders but they think these experiences are normal. In fact the risk factors for schizophrenia are risk factors for all psychiatric disorders.

Psychosis is a reflection of abnormal developmental trajectory: motor delays in the first year, language and speech delays, solitary play and low IQ. Yet only 20% of infants are ever assessed for developmental delay. These neurodevelopmental problems predict psychiatric disorder, and the best predictor of psychosis is any other mental illness and problems in neurodevelopment in infancy and childhood. He proposed a staging model: that cognitive, motor and social delay develops into social isolation, which leads on to mental health symptoms and in due course on to psychosis. Those that don’t get psychosis have an alternative psychiatric disorder. 75% of those with prodromal psychosis have had depression. He concludes that rather than looking at behaviour as a risk for psychiatric disorder, one should look at developmental trajectory. 33% of those with psychosis had motor development problems.

Academic failure occurs before any symptoms. Parental education, child poverty and neglect affect neurodevelopment. These observations make a good case for developing good epidemiology of population child mental health in which the key is neurodevelopmental optimisation from multifaceted approaches. This includes increased risk with older fathers, smoking and vitamin D levels in pregnancy and obstetric complications. These are preventable risk factors for psychosis.

- Any abuse increases the risk for any mental health disorder.
- Bullying increases the risk of psychosis by 5 times, and can be treated with parent training.
- Nursing home visiting has long-term benefit.
- Preschool enrichment programs improve cognitive control and executive function, IQ and lifetime income, and reduce the number of arrests.
- Treating ADHD prevents the development of substance abuse.
- Stopping child abuse reduces the rates of psychotic symptoms.
- Bullying and low IQ interact to increase the risk of the other.
- Cannabis reduces the age of onset of psychosis. Animal models suggest that peri pubertal diazepam prevents dopamine hypersensitivity, which is an animal model for psychosis.

This model suggests that (drug) intervention for minor problems at a sensitive stage prevents progression on to serious mental illness. There is also some suggestion that antioxidants alter the defence to psychosis.

Sally Rogers’ presentation on the evidence for neurodevelopment recovery and enhancement is great timing. It remains remarkable that in Europe you need 2 hours training and an exam before you can own a dog, yet we don’t obligate parent training! Nonetheless it is encouraging to hear that the European Union has declared that child and adolescent mental health prevention is the top priority for mental health research (Haro et al, 2014). Such a focus suggests programs on parenting, campaigns on bullying, school-based prevention research, research into healthy mental health lifestyles and research/intervention into high-risk

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“positive emotions generated by intervention is motivating for both child and parents”

“One of the best risk factors for all mental illness is a ‘latent distress trait’ found in 70% of MH cases”

groups such as abused kids and the neurodevelopmentally vulnerable. We should expect similar leadership on mental health prevention in Australia, but where is the research on the changes in current mental health policy where we are allowing mental health to be demedicalised and a shift of emphasis to the NGO welfare sector before there has been adequate recognition of the medical priority of child mental health.

In Finland, they have just introduced psychological rating assessments of all kids in all schools. They are not sure whether making schools more aware of the mental well-being of their pupils will reduce or increase the demand for mental health services. It seems to me we need routine measurement of mental health, connectedness, resilience and creativity at the same time as collecting information on developmental trajectory and mental health problems, in order to get schools competing for the best mental health scores, not just cognitive exam results.

Neurodevelopmental Disorders:
Jan Buitelaar Professor from the Donders Institute at Radboud University Medical Centre in Holland presented on ‘ADHD & ASD: 2 manifestations of the same condition?’.
There certainly is overlap of symptoms, they commonly co-occur, they share genetic variance and processes and also are associated with Developmental Coordination Disorder, Tic Disorder, Learning Disorders and a range of other developmental problems. He also presented on Neurofeedback for ADHD, with promising pre/post results in clinical but not cognitive improvement, but it wasn’t clear why the control group, focusing on amplifying brain electrical activity in a non-relevant brain location also provided improvements in ADHD symptoms. May be neurofeedback is an attention trainer.

Katya Ruby, professor of cognitive neuroscience at the Maudsley Hospital, presented on neuroimaging of disorders such as ASD, OCD, ADHD and Disruptive Behaviour Disorder. It was interesting to hear about the smaller size of basal ganglia in ADHD. Long-term treatment with stimulants reverses the reduction of dopamine production and the basal ganglia size, and improves activity in the right inferior frontal cortex and insula. They also reduce mind wandering which is seen by activity in identifiable “default mode networks”. ASD has smaller cerebellum and a ventro medial frontal cortex deficit. She described the diagnostic problems of neuroimaging because results are compared with average data, whereas if one allows the computer network to learn diagnostic specific patterns this increases image-based diagnosis eg up to 90% accuracy in ASD and Schizophrenia. She predicts that, in combination with genetic risks, neuroimaging will soon have diagnostic or subtyping value.

Improving diagnosis:
Ian Goodyer Professor of C&A Psychiatry in Cambridge presented on new diagnostic hypotheses for depression, which although is a reliable diagnosis has little validity. That is to say we have difficulty predicting which cases will get better and which will not. Just taking the current accepted symptomatic criteria, you could mathematically divide the symptom combinations into 100 subtypes. He then presented on
potential subtyping and bio-markers. How important are age effects? Is pre-pubertal depression with a prevalence of <1% and equal number of males, different to that in adolescents with a prevalence of 3-6% and a predominance of females? The 80% prevalence of mental health in adolescents’ health morbidity suggests that age and stage of development is important.

His team is using item response theory, latent analysis statistics and hierarchical analysis to try to create more predictive models. For example this shows that the presence of misery is an important predictor of depression in adolescents but weight gain/loss is not. One of the best risk factors for all mental illness is a ‘latent distress trait’ found in 70% of MH cases.

Paradoxically latent distress trait is average in ADHD and low in in conduct and disruptive behaviour disorder (doesn’t that ring true clinically!). Psychotic experiences and depression are not related epidemiologically, except when united by latent distress, when it is indicative of greater severity. It is generally found that a higher rate of symptoms is indicative of more severe depression and greater difficulty in treatment.

In the 1950s Peter Medawar said ‘genes propose and environments dispose’. One such example is the presence of genetic low level of serotonin transporter gene (5HTTLPR) plus history of child mistreatment was highly predictive of depression, when each on its own is not. He felt there was likely to be some endocrine risk factors and cognitive subtypes, such as persistent levels of high morning salivary cortisol that would contribute to further subtyping. For example teenage boys but not girls with high morning cortisol levels plus high depression score increases your risk of depression 15 times to 50%. This ultra high-risk group of boys also had memory deficits for autobiographical memory.

Why should adolescence be such a sensitive period for risk of adult mental illness? Possibly it is related to the development of myelination in the brain. Various studies show a reduction in grey matter volume in depression. For example in controls the grey matter size increases, while in the depressed adolescent it goes down.

The normal myelination process involves the myelination of the limbic system early in adolescence whereas the myelination of the prefrontal cortex lags behind well into the twenties. It may be in this lag phase between 15 and 25 years that predisposes adolescents to both depression and substance abuse. These epidemiological observations create novel hypotheses for identifying high clinical groups for major mental illness in adulthood. His presentation makes sense of why academics are already saying that DSM5 is already out of date. For my view, it is not out of date, but a valuable consensus clinical description, but work such as his, may in the future help us define different subgroups for whom different treatments may benefit.

The global decline in violence: My trip is coloured by my reading of the remarkable book by Stephen Pinker, Professor of Psychology at Harvard, ‘The better angels of our nature’ (Penguin, 2011; p1-1026)), which collates comprehensive evidence that we live in the safest times since civilisation began.

The last 40 years have seen a decline in homicide and violence for all reasons across the globe, and even 9/11 and problems in Iraq are small fry compared to global total deaths. This decline he documents not only includes wars and murders but also the decline of other forms of violence such as infanticide, especially of disabled children, the decline in bullying, child abuse including sexual, and the abuse of women and homosexuals. He attributes this to the global decline of dictatorship of any type, the decline of reliance on religious ideology and the growth of democracy with the separation of power between state and legal system.

Lastly it is related to the growth of reading (on the back of education) that has lead to a growth in empathy, as reading exposes you to another person’s point of view. This impacts of the type of relationships moving on from a zero sum game of confrontation, in game theory terms, to relationships of mutual gain. He describes progress of mankind as evolution followed by human social development, followed by history, but it seems that science and in particular medical science has helped bring consensus in humanism over ideology, and of course psychological development, and science is part of this remarkable history, despite unsettled times and set backs. In this context the growth of understanding child development and mental wellbeing is still a critical stage of human development.

The global spread of child mental health: There was a remarkable session on child psychiatry in the developing world. ‘Our own’ Joe Rey, retired professor of child psychiatry at University of Sydney and Director of Rivendell has edited a highly regarded free on-line textbook under the auspices of IACAPAP (the International Association of Child and Adolescent Psychiatry) which has already had 74,000 downloads. The website provides podcasts and interviews with patients (http://iacapap.org/iacapap-textbook-of-child-and-adolescent-mental-health).

Teaching is aided by downloadable PowerPoint slides, which are easy to use. It is increasingly being used in countries like Myanmar, where there is no child psychiatrist, or Nepal, Ethiopia or Egypt but also in some of the big teaching centres of the first world. This has been backed up with the WHO’s mhGAP Intervention Guide (mhGAP-IG) for mental, neurological and substance use disorders for non-specialist health settings, which is an evidenced-based training in low intensity clinical skills for non medical professionals (http://www.who.int/mental_health/publications/mhGAP_intervention_guide/en/).

A further complementary initiative is the use of a ‘Massive Open Online Course’ (MOOC) (presented by Bruno Falissard Professor from University of Paris Sud and president of IACAPAP). IACAPAP provides regular on-line training in C&A...
“We all have a duty to increase awareness and raise the debate that child mental health matters”

Mental Health with 6 hours of learning for 5 weeks, including 20 short videos followed by questions and quizzes, whereby clinicians can obtain a child and adolescent MH certificate. 10,000 clinicians particularly in lower and middle-income countries have taken this course. It is so exciting to learn that our first world understanding of child mental wellbeing is just as applicable to understanding young people in these developing nations.

For example a teenager who stops eating and drinking may have depression or PTSD if you know to elicit the features, or a boy recurrently thrown out of schools may have ADHD. Such simple stories indicate that evidenced based understanding of children and adolescents applies the world over. The influence and growth of this knowledge should be unstoppable, and only limited by local politics and funding. But as we know it isn’t all good news in mental health: in a session on mental health policy Professor Anastopolous from Athens described the rise and fall of child mental health. 25 years ago following the stepping down of the dictatorship and the introduction of democracy a significant community based psychiatry and child psychiatry service was established. Following the recent Greek financial crisis and subsequent austerity, murders and thefts have doubled and many child mental health services have been closed! They now have to review what their priorities are. Similarly in Slovenia the financial crisis is leading to the shutting down of child mental health services.

There were many other interesting presentations, for example on the importance of using clozapine in treatment resistant psychosis in children and adolescents, the modified treatment of OCD in ASD with CBT and response prevention intervention (diagnosed on a YBOCS). Michael Bowden our head of department presented on his PhD into the psycho-social risk factors in children having liver transplants, and although they have low rates of psychiatric disturbance, he now has the team sensitive to the risk factors.

I presented on the Developmental Psychiatry Clinic and Partnership independent review by the Centre of Disability Studies, which I described as ‘15 years of service development in 15 minutes’: but will this important initiative for children and adolescent with intellectual disability and severe mental health problems continue to thrive, or will the closure of ADHC put us back again?

Globalisation was promised to improve the lot for everyone, but appears to have only benefitted a few fabulously wealthy.

Urbanisation: Argentina is the most urbanised country in the world, with 95% living in cities of whom 50% have moved to towns in the last 20 years. How does one organise health care in towns of 20 million with rising rates of poverty and crime?

Decivilisation: ie the decline of care to the most vulnerable with increasing child mortality in much of the globe and increasing morbidity in the elderly.

Demographic Change: We have smaller families and potential population decline; for example China is trying to increase family size from an average of 1.1 to 1.2, and there are similar demographics changes in Europe. The middle class has grown eg in India and China, but is getting squeezed in the developed world, concentrating capital in the hands of a few, with both parents being obliged to work...
while ending up with less purchasing power. Private health care is increasingly for the rich with the development of 2 speed health care service systems.

**Insularisation:** While we have more and more electronic communication, we have more loneliness and less human contact. School children are exposed to different cultures with different ways of thinking and different expectations. There is a marked rise in single children, without brothers or sisters to learn from. There is a rise of single parent families, now 28% in London. There is what the Archbishop of Canterbury called ‘the epidemic of serial monogamy’ with rates of divorce and remarriage, which makes it difficult for both children and the elderly to know which parent will care for them. There is the prolongation of childhood with a lack of exposure to responsibility till the 20s which is what confirms a person’s self worth and self value. There is the rise of parent substitutes whereby children are increasingly brought up by carers so parents can work; particularly in Arabia children brought up by Filipino carers. Children spend less time with their parents. What age does childhood go up till? In India a girl is likely to be married and have a child by 13. The decline in the middle class also leads to a decline in moral norms.

**Problems of providing mental health care:** The development of Commodification by the world bank, everything is valued: health is controlled by cost constraint on choice of treatment not on the benefit to the patient. Health services are commodified by occasions of service and KPIs, not the worth of the patient and the doctor patient relationship. There is Fragmentation of medicine eg the surgeon of the right thumb! Psychiatry is subspecialising into schizophrenia specialists or specialists in bipolar disorder or early intervention. We now need case managers to explain the health system to the patient. **Medical Ethics** now focuses on the right to die, rather than the duty to live. There were 2000 assisted suicides in Belgium last year. The easiest to treat are now getting priority access to health, whereas the complex case has to wait. There is significant task shifting: as there are insufficient psychiatrists, GPs now have to treat psychiatric disorder. There are major problems of transition to adult mental health services. It is difficult to know who is responsible: the parents, the GP, the school or the psychiatry team. The primary carer used to be the parent, but now we don’t who is the proper parent. There is a failure of primary prevention: there is still inadequate iodine supplementation, leading to cretinism in parts of the world, and lead paint damages 500,000 children in the USA. Kids don’t get glasses, which cost $1.50 in Pakistan. General health checks should include mental health. All parents need parenting classes. There is a lack of consensus on priorities in health versus prevention and protection. There are high-risk groups who lack intervention: children of prisoners, or of parents with a mental illness. School dropouts create an urban problem. There is so much debate about the evidence on drugs, yet where are the RCTs on educational reform the largest investment in children, which happens with regular political change. **Areas of potential action:** we need to review the legislation and rules on availability of child mental health services. We need to speak not just of the levels of problems, but the capacity for improvement. ESCAP could set consensus international standards of training and practice against which to benchmark. So much of future developments are bound up with political process and we need to use enlightened opportunity to make politicians aware of the challenge. 30 years ago Rutter said that to a large extent we as an international specialist profession can shape the future of child mental health and this remains true. As a previous CEO of the Children’s Hospital at Westmead said: “the future mental wellbeing of children and adolescents will have more impact on the future of Australia than climate change”. This conference reminds us of this truth. We all have a duty to increase awareness and raise the debate that child mental health matters.

**References**


The beautiful artworks in this journal are taken from the participants of the **Operation Art project** at the Children's Hospital at Westmead. You can find out more at [https://www.artsunit.nsw.edu.au/visual-arts/operation-art-2014](https://www.artsunit.nsw.edu.au/visual-arts/operation-art-2014)

**Reading List**


*This approach includes individual planning, curriculum, positive behaviour support, environmental supports, and structured teaching approaches that are student focused, Teachers focused elements are professional development, learning and support team, family involvement and support and supported transition and inclusion.*


*This supplement of the Journal of Intellectual Disability Research has an overview of the abstracts presented in Florence, Italy. The presentations had a developmental focus.*


*This study assessed intellectual functioning, adaptive behaviour, autistic symptomology, behavioural problems such as hyperactivity/lack of attention and also prosocial behaviours and their changes over time.*


*There are strong links between school excellence and wellbeing. Schools should consider teaching and learning and the development of wellbeing as parallel, integrated, complementary processes. This document suggests a planned approach to incorporate this wellbeing framework.*


*Parents of children with developmental disabilities are more susceptible to stress and have a greater burden or adversity than other parents. Overall specialised services were found to be helpful by parents. Some negative experiences were tabled which included wait times, change of support worker, access and equity and failure to recognise parent contribution. This is an interesting article with a small sample.*

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