CHW SCHOOL Link

mental health and intellectual disability...

coordinator's message...

Welcome to the second issue of the second edition of our CHW School-Link Newsletter for 2011.

It is heartening to see this newsletter readership base increase to nearly 400 e-list members. This growing interest in mental health and intellectual disability for children and adolescents is also evident by the array of conferences that School-Link and our project sponsor Dr Dossetor and the CHW school-link team have been invited to present at. From the NSW Special Educators Conference here in Parramatta to the Australian Association of Special Education National Conference at the Gold Coast, to the Royal College of Physicians and The Society for the Study of Behavioural Phenotypes in Brisbane and half a dozen others we will be there spreading the word about the importance of mental health for children and adolescents with an intellectual disability. The Joint School-Link Conference between SSW and CHW held on May 27 was sold out with over 230 participants which also suggests that there is a need for professional development opportunities. The conference entitled "learning and growing together" delivered presentations from all three domains- health, education and disability.

This unique 'trioship' is also reflected in this newsletter which marks the beginning of our joint editorial group. We hope that you notice and enjoy the increased content from all three agencies. In this issue Dr David Dossetor (CHW) provides a succinct overview of barriers to the advancement of training and service models for children and adolescents with MH+ID (pg 2). Anders Hansson (ADHC) gives a review of a training day with Linda Hodgdon on the use of visual communication strategies to assist with behaviour (pg 6) and Michelle Jewell (ADHC) discusses a project that implemented Group Triple P Stepping Stones a positive behaviour parenting program in a School for Specific Purposes (SSP) (pg 8). Judith Longworth (CHW) discusses the use of the drug fluoxetine with Autism (pg 11).

We would also like to begin a new 'letter to the editor' column in our next issue. If you would like to write a brief reflection on topics raised in this newsletter or others we may have missed on MH+ID (approx. 200 words), please write to us. Selected entries will be published with the winning entry receiving a copy of the soon to be released "Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities: A Framework for Professional Practice" edited by David Dossetor, Donna White and Lesley Whatson – the first interdisciplinary text of its kind. Entries must be received by 1st August 2011. Happy reading (and writing)! If you have any feedback or contributions for future editions please email schoollink@chw.edu.au. ●

Jodie Caruana, School-Link Coordinator, The Children's Hospital at Westmead

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Learn more about School-Link and the Children's Hospital at Westmead project on page 16 or visit www.schoollink.chw.edu.au

a note from David Dossetor...

Associate Professor David Dossetor, Child Psychiatrist with a special interest in intellectual disability and autism, Area Director of Mental Health, Children's Hospital at Westmead.

Identifying factors that impede training and service development for mental health of children and adolescents with intellectual disability. Experiences from the development of a curriculum for inter-disciplinary training.

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Introduction

The mental health of children and adolescents with intellectual disability (ID) is a public concern. It is recognised that 30-50% of children and adolescents with ID have significant mental health problems. It is also found that the mental health of children and adolescents with ID constitutes 14% of mental health burden of all children (Emerson & Hatton 2007). 25% of CAMHS services capacity in UK is for ID and/or Autism. These mental health problems and the concomitant burden affect the quality of life of these young people and their families. They lead to 2-3 times greater financial burden for care, treatment & education as well as reduced income capacity. Over half of carers (59%) experienced a decline in physical health & two-thirds felt that their mental & emotional health was affected with depression, anxiety or stress (Cummins et al 2005). This is in the context of no designated mental health service for mental health and ID in Australia. The question of what impedes the training and service development for mental health of children and adolescents with ID arose during the development of a curriculum for inter-disciplinary training when we became aware there has been no previous textbook covering this area of multidisciplinary expertise (Dossetor, White and Whatson, 2011)?

Method

This paper is based from discourse with colleagues and trainees which identified some of the differences of mental health for children and adolescents with ID from mainstream mental health. This was in the context of developing the Training Curriculum Project, which is a 2 day inter-disciplinary curriculum. This project had 3 years funding from 3rd National Mental Health Plan and Aging, Disability and Home Care, NSW Human Services (ADHC) for a project manager (DW) and was a partnership project between the Department of Psychological Medicine at the Children's Hospital at Westmead with Statewide Behaviour Intervention Service (SBIS) ADHC (LW). Observations came from: a literature review; clinical experience of what works in a tertiary multidisciplinary multi-agency clinic; areas of demand for training from SBIS; a stake-holders' survey of areas of intervention-focused learning; evaluations and 3 month outcomes on workshops; commissioning 28 chapters which were independently reviewed for the textbook. In 2009/10 we provided 4 2-day workshops to >500 clinicians and the evaluation and feedback from the curriculum was positive and clinicians reported at three months that it had made a difference to their clinical practices.

The findings

The findings are presented under 8 headings below.

1. Ambiguous terminology

There is a lack of an internationally accepted language: The term "Mental Retardation" is still used in America. The term "Learning Disability" is used in UK, whereas this term is used in America is for Specific learning problems. In Australia you are never sure what group of problems this term is being used for. The term "Dual diagnosis" refers to ID and mental health problems in USA and UK, but mental health and drug and alcohol problems in Australia. There is widespread obfuscation of communication through agency/discipline specific jargon; we readily identified 125 abbreviations in common usage and no workshop attendee could accurately interpret all. One is forced to conclude that there is no evident common language.

2. Dichotomous and Divisive Concepts

Challenging Behaviours is a concept of poor social adaptation that implies an environmentally caused or maintained problem and needs a linear behavioural approach to intervention. This is the primary model used by Disability Services. Psychiatric Disorder is an alternative concept that implies a disease model of poor social adaptation identified by syndromal clustering of features and requiring the expertise of mental health services. Yet both models acknowledge bio psycho social factors. Some practitioners only work with one of these concepts although the research indicates that they frequently co-occur.

Professional discrimination persists against ID as illustrated by the comment: "if the patient can't talk then they can't have a mental disorder".

Most condition specific research is limited to Mild ID and there is little agreement on how mental disturbances are different in the earlier stages of mental development.

3. Problems of diagnosis of mental health problems in adult with ID

A mental health problem is defined as "*a diagnosable illness that significantly interferes with an individual's cognitive, emotional, or social abilities.*" Experts assert that generally it has been recognised that those "with ID have the full spectrum of mental illness, but usual diagnostic criteria are difficult to apply".

Methodical approaches to diagnosis are a recent development. The textbook of diagnosis of mental disorders in persons with an ID (DM-ID) was published in 2007. This diagnostic and statistical manual of mental disorder for people with ID was developed by an international, predominantly American, expert group. Each chapter reviews of the strength of the evidence supporting each diagnosis and the adaptations of diagnostic criteria for persons with ID. However the levels of Cochrane based scientific evidence are generally poor, mainly based on cohort studies and expert opinion. Nonetheless this manual of diagnosis gives people with ID entitlement to MH services. Its clinical usefulness was evaluated in 2006 with a field

trial 900 patients, 80 clinicians from 11 countries. This reported that the DM-ID was user friendly and more specific than the DSM-IV-TR (text revision 2004). The main alternative is the DC-LD (Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation) which was developed in UK (2001, Royal College of Psychiatrists). This provides a "consensus of current practice" for adults with moderate to profound ID leading to ICD10 diagnoses. Their approach is slightly different emphasising that "sometimes it is not the criteria that need alteration but a different method of eliciting the necessary information".

Nonetheless both diagnostic manuals identify a number of special problems of eliciting phenomenology in ID.

1. Firstly it is not possible to elicit subjective mental phenomena reliably < 7 years or an IQ <45. It is little surprise that debate still surrounds the age at which depression or psychosis can be identified in children.
2. People with ID have difficulty articulating abstract or global concepts eg depressed mood, because of limited cognitive and verbal skills.
3. They are more likely to give answers to please the interviewer.
4. They may to subject to intellectual distortion for example saying "yes" to "hearing voices", without understanding the implication of question.
5. "Diagnostic overshadowing" is the failure to identify co-morbid psychiatric disorder attributing disturbance to the underlying intellectual disability.
6. This has to be distinguished from baseline exaggeration or intensification of existing maladaptive behaviour. Examples include an increase in self injurious behaviour under a time of stress. A significant stressor can be an anniversary of a loss that carers may not identify, or a change of a teacher or other staff, or a classroom or accommodation or of family visits.
7. Conversely stress on coping with a lack of cognitive reserve leads to disintegration, disorganisation or psychotic behaviour implying that such a major stress response does not constitute a mental illness (although adjustment disorders are part of the diagnostic manual).
8. Delusions and hallucinations are frequently very difficult to distinguish from a range of normal developmental phenomena such as concrete thinking, pretend friends, and stereotypic thinking and imagination, especially in ASD.
9. Irritability including explosive anger may be the most common problem of

challenging behaviour but is also associated with depression and mania.

Indeed it is concluded that families and professionals alike are at risk of diagnosing serious psychiatric disorder where none exists. Conversely the literature also illustrates that non specialised doctors (GPs) fail to identify mental disorder eg depression in this population. Further there is no advice on how to tackle these special problems, apart from consulting "an expert".

4. Comparing diagnoses in America and UK

Tsiouris and colleagues (2008) probably did the largest study of 4468 clients, ¾ of whom were in out of home residential settings, and found psychiatric disorder in 60%. The main DSMIV psychiatric diagnoses in order of frequency:

- Impulse Disorder 21%
- Anxiety Disorder 19%
- Schizophrenia and other psychoses 18%
- Depression 14%
- Bipolar Disorder 12%
- Obsessional Compulsive Disorder 11%
- Personality Disorder 8%
- Sleeping Disorder 4%
- Eating Disorder 3%
- Tourettes 2%

Almost as interesting was the absence of many other diagnoses described as of high prevalence in DM-ID such as Adjustment Disorders; Post traumatic Stress Disorders; Substance-related disorders; Sexual & Gender Identity Disorder; Dementia; Mental Disorders due to a General Medical Condition Nos. None of the childhood disorders that are also recognised to continue into adulthood were identified such as Learning Disorders; Motor Skills Disorders; Elimination Disorders; Pervasive Developmental Disorders; ADHD and Disruptive behaviour disorders; Somatoform & factitious disorders; Other Disorders of infancy, children and adolescents eg Attachment Disorders and Stereotypic movement disorders incl. self injurious behaviour; Behavioural Phenotype of Genetic Disorders.

The Epidemiological study in Scotland by Cooper and colleagues (2007) was of 1023 adults over 16yrs with mild, mod or severe ID. The PAS-ADD checklist, a screening questionnaire, was used to screen the population and the psychiatric diagnosis was made on the PAS-ADD 10 (The psychiatric assessment schedule for adults with a developmental disability) which relies on a key informant to identify and rate symptoms and produces diagnoses using algorithms (Costello et al, 1997).

The types of ICD10 Psychiatric Disorder were:

- Psychotic Disorder 4.4%
- Affective Disorder 6.6%
- Autistic Spectrum Disorder 7.5%
- Anxiety Disorder 3.8%
- Organic Disorder 2.2%
- Pica 2%
- Hyperkinetic Disorder 1.7%
- Personality Disorder 1%
- Alcohol/substance abuse 1%
- Obsessional Compulsive Disorder 0.7%
- Sleep Disorder 0.6%
- Other mental ill-health 1.4%

Why is there such disparity of diagnoses identified and of their frequencies? The American study is of service users, where the UK study is more epidemiologically representative. It is evident that research diagnostic tools identify lower levels of disorder than specialist clinicians seeking to understand disturbance. However one is still left to conclude that there is a lack of uniformity of diagnostic concepts and of thresholds of diagnosis. It suggests a lack of diagnostic reliability at least across an international community of clinicians. Indeed behind these discrepancies lie different diagnostic and schools of psychiatric thought. This is reminiscent of the 1980s when ADHD was diagnosed at rates ten times that in UK, before international collaboration clarified the concept and the dimension of severity which is dealt with differently in the different diagnostic systems. Evidently the research process to establish an international consensus is yet to be investigated and funded.

5. The Need for Special Diagnostic Skills

Part of the problem is the need for special diagnostic skills to make a psychiatric diagnosis in people with ID, as has been illustrated in research on identifying depression in ID.

For example Hurley (2008) found that in a retrospective review in a clinic population that most patients with ID and depression did not meet the required number of diagnostic criteria for DSM or DM-ID. Patients with ID and depression do not complain of depressed thoughts. They still had depressed mood, sadness, crying, anhedonia and withdrawal which distinguished from anxiety or bipolar disorder. Few reported suicidality.

Torr and colleagues (2008) in an Australian study compared GPs' and long term paid carers' capacity for identifying features of depression in patients with ID having a routine assessment. These findings were then compared with subsequent assessment with a comprehensive

specialist psychiatric assessment. The study used a 53 item checklist for depression and factor analysis identified the consistent features of depression: depressed mood (6 items), loss of interest (5 items), loss of social interaction and communication (8 items). Carers identified the features of depression but GPs failed, even with the carers present. Depressed thinking was not a reliable feature of depression reflecting limited communication skills. GPs focussed more on sleep, appetite, weight control and general functioning. In this cohort, expert opinion found that 30% had depression but 25% had a Pervasive Developmental Disorder.

GPs are normally viewed as the gate keepers to specialist services, including mental health. Such evidence indicates that access to mental health services for people with ID is disadvantaged by the lack of workforce training. Both GPs & general psychiatrist will fail to provide the same level of case identification as a psychiatrist with special experience in intellectual disability. There is a need for further education and support for the recognition of subspecialty psychiatry skills in ID.

6. Differences in defining mental health problems in children and adolescents with ID

Child and adolescent mental health defines a psychiatric disorder *as any disturbance of behaviour or emotions sufficient to cause significant impairment to the child or those caring for them.* The longitudinal study of young people with ID indicates 40% have a severe mental health disorder (Einfeld & Tonge, 1996). The Developmental Behaviour Checklist (DBC) measures the range **and severity of disturbance but doesn't** translate to psychiatric disorders. Although it is observed that psychiatric disorders in ID create greater problems for their families, there is no study that has quantified the additional impairment of Psychological Disorder in ID versus that of ID alone. In children and adolescents with ID a clinician may ascribe disturbed behaviour to a Mental Illness, a Mental Disorder, a Developmental Disorder, a Challenging Behaviour or Behaviour Problem. However the use of these labels is substantially a subjective determination affected by profession, employing agency and different theoretical models.

Mental health services, including child and adolescent mental health services have progressively prioritised their business to **severe mental illness** and the provision of **emergency intervention services for acute mental disorder.** The concomitant community message that "mental health is everyone's business" suggests all child orien-

tated services have to understand and manage mental health problems.

Aggression is the most common community based childhood problem but research finds that by the age of 10 years such behaviour is an entrenched and **chronic problem that generally doesn't** improve in psychiatric in-patient units. Accordingly most conditions are best treated in the community which requires shared responsibility between families, neighbourhoods and all government departments. Too often the Juvenile Justice system becomes the default service for a lack of community based mental health services.

7. Mental health problems in children and adolescents with ID are different and need different approaches, e.g. ADHD and other developmental disorders.

The way mental health problems in children and adolescents with ID present are different to those with average IQ. For example 30-50% of children with severe ID have ASD (compared 1% in the average population). The significance and meaning or validity of a diagnosis may be different for different levels of ID. Using ADHD as an example, Anstel and colleagues (2006) reviewed ADHD in Mild ID. Although they confirmed the diagnosis could be made reliably, there were differences in the predictive validity of this diagnosis. The differences included: the prevalence is 30%, with equal frequency in girls as boys, stronger factors of family functioning, and a stronger association with depression and social impairment. Further standard drug treatment is not as effective and patients are more prone to side effects.

In contrast for ADHD in severe ID there is a lack of research for reliability and validity, although it can be observed that these cases are more affected by general neurobiological factors as well as the polygenic processes considered important in ADHD of average IQ.

Further ADHD is associated with other developmental disorders. Examples include:
- ADHD and Developmental Coordination Disorder each occur in community studies at a rate of 7%, but co-occur in 50%.
- ADHD is found in 50% of teenagers with ID plus autism vs 15% with ID without autism (Bradley 2006)
- ADHD is found in 78% of PDD in clinic population (Lee & Ousley 2006)
- Genetic studies confirm linkage between ID and Autism indicating a commonality of development processes behind both.
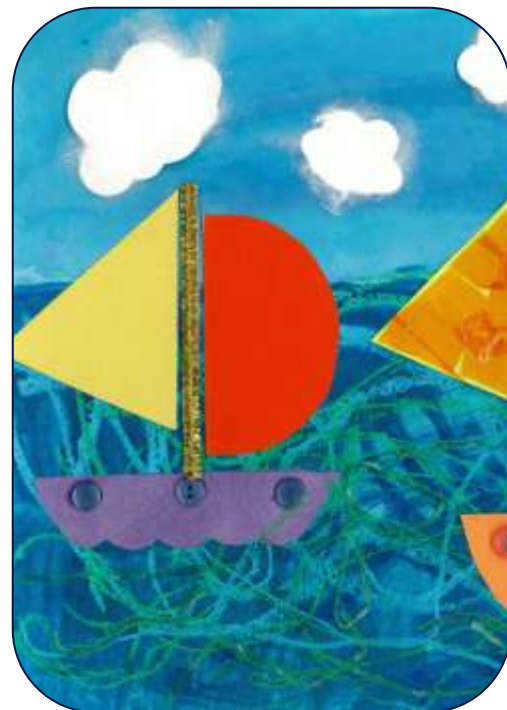
ADHD is particularly high in behavioural phenotypes:
- Smith Magenis Syndrome 90%, Fragile X 75%, Williams Syndrome 65%, Charge Syndrome 50%, Neurofibromatosis 50%, Velo cardio facial syndrome 43%, Cornelia de Lange's Syndrome 40%, Soto's Syndrome 38%, Tuberose Sclerosis 35% and Turners Syndrome 24%.
- In Fetal alcohol syndrome ADHD is found in 49%, ID in 55%, learning disorders 46%, ODD 41%, anger problems, mood disorders and sleep disorders in 50%.

Taking these observations into account suggests that ADHD in ID represents the specific problems of developing coherence & efficiency of consciousness, rather than a specific disease process. It may still be helpful to identify co-morbid ADHD particularly based on the evidence and experience of the reduction of impairment from drug treatment.

In conclusion Developmental Disorders have high risks of co-occurrence, which are highly genetic and may all relate to problems of developing neural complexity.

8. Other problems in mental health for children and adolescents with ID

In the provision of mental health services for children and adolescent with ID there are a number of other problems. These include:
- Different models for understanding mental health are used by different disciplines and agencies.
- Some agencies are individual centred and lack of family centred approach.

- There is a lack of clinicians with evidence-based practice expertise, and experience in both mental health and ID.
- There is an increased association with complex medical problems.
- There is a lack of recognition of the range of the disciplines and agencies required to be optimally involved.
- There is a lack of inter agency collaboration with service cost shifting.
- There is a lack of service structure for more severe problems.
- There is a lack of attention to Prevention Promotion and Early Intervention
- There is limited empirical evidence on the contributions to be gained from occupational therapy, physiotherapy, speech therapy, psycho-pharmaco therapy, family therapy and systemic practice which are all considered part of comprehensive treatment. (The best evidence is for parent training and behaviour therapy.)

As a result, families experience a rotating front door of inexperienced community clinicians. Problems escalate without effective intervention. This provides some explanation to why parental murder/suicide ideation is such a frequent presentation in the families of children and adolescents with mental health problems and ID.

Solutions for the mental health problems for children and adolescents with ID

Our educational research identified the need for a coherent curriculum for mental health for children and adolescents with ID. This included:
- A framework that is applicable for all professionals working with children and adolescents with ID
- In the context of the family life cycle for a child with ID
- With a focus on the quality of life for child with ID and family
- Within a developmental framework that
  – informs multidimensional assessment
  – provides a context for understanding behaviour
  – and an alternative approach for understanding developmental psychiatric disorders eg ADHD and ASD
- That assumes multi causal mechanisms to disturbance and disorder
- Puts an emphasis on multimodal skill building/positive psychology
- Requires multidisciplinary/multiagency collaboration

In practice a specialist mental health service for children and adolescents with ID needs a multidisciplinary/multi-agency team that works closely together. Although the team uses a multi causal framework as a common language for mental health problems in ID, clinical expertise and consensus decides whether these causes may be additive, or whether one may be dominant in an individual case. There is a valuable tension between developmental models versus deconstructive (illness) models.

A Problem solving service system needs to be tiered so as to involve greater expertise with difficult to solve problems with rules of interagency collaboration. This could lead to a final common pathway of complex case conference, where clinical judgement and service management meet.

Specific Prevention, Promotion and Early Intervention approaches are needed for this population as generic mental health strategies are not applicable (CHW School-Link Needs Analysis, 2010). Some of the components should include:
- Universally available **specialist** parent training
- Emotional literacy programs in schools
- Multidisciplinary approaches to building skills

Conclusion
The scientific evidence in mental health problems in ID is still in an early stage of development. Mental health for children and adolescents with ID is different from adult psychiatry for ID and mainstream child and adolescent psychiatry. A curriculum framework is necessary to establish a coherent service with interdisciplinary and interagency collaboration. Specialised clinicians are positive on the impact that such services can have on the morbidity from co occurring psychiatric disorder in ID in partnership with families and child orientated agencies. Lastly developmental psychiatry for in children and adolescents with ID has much to contribute to mainstream psychiatry. After all, how can you be interested in "losing your mind" without studying the development of the mind. ●

This paper was presented at ASID Conference Brisbane and IASSID Conference Rome, Sept and Oct 2010.

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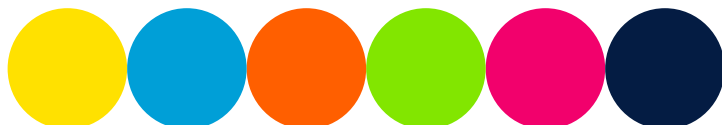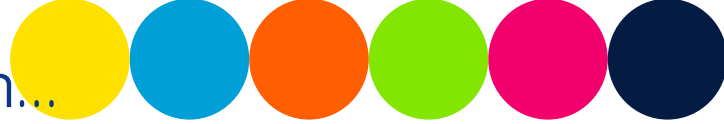
Discovering the Possibilities with Visual Strategies:
A Training Day with Linda Hodgdon, M. Ed., CCC-SLP Communication Specialist.

By Anders Hansson,
State-wide Behaviour Intervention Service

Linda Hodgdon is a Communication Specialist from Detroit, Michigan. She works with students who have communication difficulties, many of whom have been diagnosed with Autism Spectrum Disorders (ASD). Linda is renowned worldwide for her accomplishments and contributions in the development and use of *Visual Strategies* and the effectiveness of using these with children who do not respond well to spoken language alone, especially as a means of facilitating a higher level of understanding for both the child and their communication partner, e.g. teacher, parent, peer.

Linda's lecture was organised by the *Autism Noticeboard* and was held at the Waterview Convention Centre in Sydney's leafy Bicentennial Park. While most attendees were Speech Pathologists and teachers, some psychologists, parents and an Occupational Therapist also attended. I think most would agree with me when I say it was an exceptionally worthwhile and stimulating training day. This article intends to give readers a flavour of what Linda covered and where they can find out more about the *Visual Strategies* concept and some of the available resources online and in printed form.

> "Autism and other communication disorders have not changed – the technology has, and you still need to know how to use this new technology and understand what it is supposed to achieve"

Linda firstly introduced us to the *Visual Strategies* concept and its application with a special focus on the school context. Here, she noted the importance of acknowledging the individual differences in skill levels among children with ASD. She said, "the concept of using visual strategies will be consistent, but the implementation will reflect differences to match the individual's needs and abilities". Here she emphasised the power of observation as an important aspect of an "informal assessment" approach, rather than only relying on formal assessment tools often used out of context.

Secondly, Linda drew our attention to the student's communication partner and the fact that the student is only ½ of the communication interaction. She dispelled the often-heard comment "He/she understands EVERYTHING I say", by asserting that there can be many reasons why a student understands apart from, or instead of, verbal communication, e.g. gestures/body language, printed material, signs, pictures, etc. Linda described that the most common errors made by a student's communication partner included:

- Overestimating level of overall functioning from performance of splinter skills
- Assuming understanding because the student can perform familiar routines
- Appearance of higher level of linguistic ability due to echolalia

Thirdly, Linda spoke about the use of *Visual Strategies* as a means of facilitating the process towards positive behaviour change in students with behaviour problems including the teaching of social skills, coping skills for dealing with transitions and establishing visual routines and activity schedules.

The importance of communication partners being able to self-reflect and be mindful about the variables that they bring to the interaction with their students was emphasised, e.g. where on the continuum from *relaxed* to *strict* they are in their interaction style, or how past experiences affect their ability respond sensitively to a child's needs.

Finally, Linda provided some samples and examples of *Visual Strategies* for improving communication including the use of new technology, such as the iPhone and iPod Touch and FLIP, a new generation digital camera. Linda provided a live demonstration of its use and showed how easily and quickly the recorded images could be transferred to the computer screen. The take away message from this segment of the training was that "autism and other communication disorders have not changed – the technology has, and you still need to know how to use this new technology and understand what it is supposed to achieve". In other words, investigate and test (whenever possible) before purchasing product.

Linda is the author of two excellent books on the use of visual strategies titled:

- Solving Behaviour Problems in Autism: Improving Communication with Visual Strategies
- Visual Strategies for Improving Communication: Practical Suggestions for School and Home

For more information about Linda and resources visit www.lindahodgdon.com.

Anders is a Senior Clinical Consultant with the Statewide Behaviour Intervention Service, which is part of the Office of the Senior Practitioner, ADHC, NSW Department of Family and Community Services. ●

On Linda's website you will find a link to Linda's online newsletter;

Another View: Effective Solutions for Autism, Aspergers and More..

You can subscribe online to keep up with her visual strategies journey along with book and product reviews.

upcoming training...

Intellectual Disability:

Mental Health Focus Dual Diagnosis: Mental Illness and Intellectual Disability. 29th and 30th of June 2011. 9.00-5.00pm. Kiama. Contact Tina and Cherie on 02 4295 5532.

Intellectual Disability and Mental Health Webinar . *Mental Health Professionals Network*. Tuesday 14th June 2011. 6.30-8.00pm. Register online at www.mhpn.org.au/news/events.aspx#webinar. Other webinars are also available.

Promoting Social and Play skills in children with ASD/Intellectual Disability. *Training and Behaviour Intervention Support Service.* 18th August 2011. 10am to 12.30pm. Free for parents and teachers. Living in Cumberland/Prospect region. Contact email tabiss@interactiondisability.com or phone 1300 668 123.

Mental Health:

Borderline Personality Webinar Recording. *Mental health professionals network* presents an online webinar. Download the webinar from their website http://www.mhpn.org.au/News/Events/BorderlinePersonalityDisorder.aspx You can also view post-webinar resources.

Running the Cool Kids program with complex cases– An advanced workshop. Professor Ron Rapee, *Centre for Emotional Health, Macquarie University.* 22nd July. 9.00am-4.00pm. $320. North Ryde. Register at http://shop.accessmq.com.au/shop/ Enquiries 9850 4084.

The Black Dog institute has several forms of training. One is their lunchtime seminars. **Understanding depression, bipolar disorder and building resilience,** 16th June, Rouse Hill. 7.30-8.30pm. **Understanding mood disorders and resilience** 28th June, 12-1pm, Randwick. **Navigating teenage depression,** 29th June, 6.30-8.30pm, Grafton. **Building personal resilience**, 30th June, 9.30-12.30pm. Grafton. Visit www.blackdoginstitute.org.au to register and view other training opportunities.

Autism Spectrum Disorder:

Autism and Asperger's workshop: *teaching strategies and behaviour support* with Sue Larkey. Monday 29th August. Newcastle. $33 for parents, $110 for professionals. 9.30-3.00pm. Contact 1300887776

Free workshops for parents/carers of school aged children with Autism. Run by the Australian Autism Education & Training Consortium. 9th March 2010 – 30 September 2011 Australia wide. Free. Contact 1300 881 971 or visit www.autismtraining.com.au

Introduction to ASD and mainstream school strategies– South West Sydney. Autism Spectrum Australia. 23rd June 2011, Campbelltown, 9.00am-4.00pm. $198. Contact bdelrosario@autismspectrum.org.au

Aspect Asperger's Syndrome Seminar – Port Macquarie. Practical support strategies to promote positive functioning. *Dr Tony Attwood and Autism Spectrum Australia.* 22nd July 2011. 9.00-4.00pm. $130. Contact Tracy Matejka on 4855 6266 or hunter@autismspectrum.org.au

Access free webinars from the **rethink autism** website. Webinars are constantly updated so check regularly for new topics. Visit www,rethinkautism.com/Community/webinars

Donna Williams: Walking in Autistic Shoes. *Autism Advisory and Support Service.* 28th July 2011. 10.30am and 7.00pm. $30. Liverpool Catholic Club. Ph. 9601 2844. or email info@aass.org.au

Other:

Workshop with the Guardianship Tribunal for people with a disability their carers and service providers. 20th July, 2011. Free. Charlestown. 1pm-3.30pm. Contact Judy or Juliet on *4943 9786.*

Mental Health Focus– Dual Diagnosis. Discusses realistic cases and evidence based practice. Natasha Langovski. This workshop has been postponed from June until October 2011. Broken Hill. $330. Contact Moira or Carina for further information 9879 2600 or *remind@sfnsw.org.au.*

Challenging Behaviour:

Content and process issues in managing disruptive child behavior. Dr Tracy Rhodes. Centre for Emotional Health, Macquarie University. 24th June. 9.00am-4.00pm. $320. North Ryde. Register at http://shop.accessmq.com.au/shop/ Enquiries 9850 4084.

Developmental Disabilities and Challenging Behaviour: Research to Practice and Policy. Faculty of Health Science and Brain and Mind Research Institute, University of Sydney and NSW CID. 30th September, 2011. 9am-6pm. Registrations open in July. Enquiries to Professor Stewart Einfeld, stewart.einfeld@sydney.edu.au or 9351 9213

Disability:

Conference for nurses working in developmental disability areas. **Owning our practice.** 3-4th November 2011. Parramatta. Visit www.pandda.net or call 0418 878 523.

Social Workers in Brain Injury Conference; Building on Strengths: Resilience across Social Work Practice in ABI. Australian Association of Social Workers. 29th July 2011. Westmead Hospital Education and Conference Centre. contact Sharee Lussick on 0416 099 399 or email sharee@accessbis.com.au or Denise Young on 6330 5155 or email denise.young@gwahs.health.nsw.gov.au

Action PACT learning is a division of the Cerebral Palsy Alliance which offers a wide variety of courses. Visit www.cerebralpalsy.org.au for their training calendar and registration forms.

Macarthur Disability Services presents **Dual Diagnosis** by Bruce Todd and Bob Tsapilis. Review of major dual diagnosis categories such as schizophrenia, personality disorders, mood and anxiety disorders. Campbelltown. 12th October, 9.30-3.30pm. $350. Contact Vanessa , 4621 8400 or vanessah@mdservices.com.au

Cerebral Palsy Alliance Sports, Technology, Arts and Recreation Expo. 6th August 2011. 10am-2pm. Prairiewood. Contact 8777 1721 or astammel@cerebralpalsy.org.au

Triple P Stepping Stones...

Running Group Stepping Stones Triple P within a school - How Successful is it?

The results from a project involving the implementation of a Group Stepping Stones Triple P program within a school for special purposes

Michelle Jewell
(Occupational Therapist -
Parramatta Community Support Team, Ageing Disability and Home Care, Department of Human Services NSW,)

Introduction:

Group Stepping Stones Triple P is a group family intervention for parents and carers of preadolescent children with disabilities who have, or are at risk of developing behaviour problems. Group Stepping Stones Triple P has been specifically designed by Sanders, Mazzucchelli and Studman (2009) as a positive parenting program for parents of children who have a disability. The group format incorporates Triple P parenting training methods and introduces additional strategies drawn from disability research literature. The group program focuses on helping parents and carers to develop effective management strategies for dealing with a variety of childhood behaviour problems and developmental issues. It incorporates positive parenting strategies to improve relationships within the family and encourage skill development.

The program consists of 9 face to face sessions and two individual phone calls. The sessions focus on parent-child interaction and the application of parenting skills to a broad range of target behaviours, The sessions incorporate 25 recommended strategies divided into the categories of:

- Developing positive relationships
- Encouraging desirable behaviour
- Teaching skills and behaviours
- Managing misbehaviour.

The key principles of positive parenting discussed in the program are:

- Ensuring a safe, interesting environment
- Creating a positive learning environment
- Using assertive discipline
- Adapting to having a child with a disability
- Having realistic expectations'
- Being part of the community and;
- Taking care of yourself as a parent.

Many studies have been completed demonstrating the effectiveness of the Triple P parenting program and specifically Group Stepping Stones Triple P. In one particular randomised control trial completed by Harrison (2006) of 28 families who received either Group Stepping Stones Triple P or their usual early intervention service, parents who received the group were reported to be using more consistent, behavioural responses to their child's behaviour (Sanders, Mazzucchelli & Studman, 2009). These parents also reported less parental inter conflict and increased sense of parental efficacy (Sanders, Mazzucchelii & Studman, 2009).

The implementation of the program and results:

Recently the Parramatta Community Support Team, Ageing Disability and Home Care (ADHC), Department of Human Services NSW organised and implemented a group program with the school counsellor of a School for Special Purposes. This group consisted of twelve parents who had expressed a desire to complete the Group Stepping Stone Triple P program either through the school or through ADHC Parramatta. Ten of these participants completed the entire program.

The program utilises pre and post evaluation and assessments which are the most effective way to monitor change in the participants and success of the program. The assessment tools used included the Depression-Anxiety-Stress Scales (DASS), The Developmental Behaviour Checklist (DBC) and the Parenting Task Checklist.

The Developmental Behaviour Checklist (DBC; Einfeld and Tonge, 2002) measures parental and other primary carers' perceptions of behavioural and emotional problems in children aged 4-18 years. At the pre assessment phase the 90% of the parents gave a Total Behaviour Score in the clinical range for behaviour problems. Clinical range refers to high levels of disruptive/anti-social, self absorbed, communication disturbance, anxiety and social rating behaviours that may warrant professional assistance to address. At the post assessment phase 80% of the scores were below clinical range therefore indicating the parental perception of the negative behaviour and emotional problems in their children had reduced following the program.

The Depression-Anxiety-Stress Scales (DASS: Lovibond & Lovibond, 1995a) is a self report inventory assessing symptoms of depression, anxiety and stress in adults. At the pre -assessment phase of the program 50% of the participants showed a total DASS score to be in clinical range. Clinical range refers to scales of depression, anxiety and stress that

may require professional assistance. At the post - assessment only 20% of the participants were still in clinical range indicating a 30% improvement in the DASS scores for the group. This indicates that the Group Stepping Stones Triple P may show positive Improvements in the overall depression, anxiety and stress felt by parents and carers of children with disabilities.

Group Stepping Stones Triple P program has demonstrated improvements in parental confidence, as well as improvements in parental stress, depression and anxiety

The Parenting Tasks Checklist (Sander & Woolley, 2005) is designed to assess parents' task specific self efficacy. Parents rate how confident they are that they can deal with their child if they engage in difficult behaviour in common parenting situations. Two dimensions are measured; these are behavioural self efficacy (confidence in dealing with specific child behaviours) and setting self efficacy (confidence in dealing with difficult behaviour in different settings). At the pre-assessment phase 20% of the participants were in the clinical range for setting self efficacy and 30% of the participants were in the clinical range for behavioural self efficacy. Clinical range refers to the possible need for professional assistance to improve setting self efficacy and behavioural self efficacy. At the post-assessment phase only 10% of the participants were in the clinical range for behavioural self efficacy and no participants were in the clinical range for setting self efficacy. This indicates the Group Stepping Stones Triple P program may assist in improving parental confidence in dealing with difficult behaviour across different environments.

There were also successful anecdotal reports from parents including comments such as "We learnt a lot of things from this Stepping Stones Triple P program to apply to our child and to improve his attitude. So thank you very much" and "Triple P Program was very satisfying for me I learnt a lot from it and I would do the program again if I was asked. P.S. The book is very helpful. Thank you".

Conclusion

In conclusion from the reports of the pre and post assessment as well as anecdotal evidence, this particular Group Stepping Stones Triple P program has demonstrated improvements in parental confidence, self efficacy, child behaviour as well as improvements in parental stress, depression and anxiety. This Indicates that many parents and carers of children with disabilities should be encouraged to attend a Group Stepping Stones Triple P program being run in the community area they live or at a local school.

The experience of running a program within the school was effective for long term networking of the participants in the program. This is important to ensure improvements in social relationships and informal ongoing support for parents and carers in managing child behaviour. A school setting demonstrated enhanced engagement with the program and a reduction in dropout rates of the participants. The networking between community organisations and schools and subsequent improvements in this relationship is an important secondary outcome. This relationship and implementation of the program in schools is an important step towards early intervention and identification of childhood behaviours and subsequent prevention of severely disturbing childhood behaviours in adolescents and the future. Childhood behaviours can become increasingly disruptive and harmful to family relationships and the day to day life of a family and person with a disability hence the importance of early intervention and improvements in positive parenting and parental confidence in dealing with behaviours of their children in which this program provides. ●

References:

Sanders, M.R., Mazzucchelli, T.G. and Studman, L.J. (2009). *Facilitator's Manual for Group Stepping Stones Triple* P *for Families with* a *Child who* has a *Disability.* The University of Queensland and Disability Services Commission of Western Australia.

Harrison, J. (2006). *Evaluation of a Group Behavioural Family Intervention for Families of Young Children with Developmental Disabilities.* Honours dissertation, Charles Sturt University.

facts and figures...

Interesting Facts to Know!

A recent federal court ruling has highlighted the lack of protection for students with severe social and behavioural disabilities. Read here; http://rightnow.org.au/news-article/walker-vs-state-of-victoria-and-disability-discrimination/

The World Health Organisation and the World Bank have released a *World Report on Disability.* The repost suggests that more than a billion people in the world today experience disability. Visit http://www.who.int/disabilities/world_report/2011/en/index.html

Its national Cerebral Palsy Awareness week. 31st July– 6th August 2011. Focus on seeing people with cerebral palsy firstly just as people and to work together to achieve social inclusion. Visit http://www.cpaustralia.com.au/index.php/site/news/cpawarenessweek

The Australian Institute of Health and Welfare has released a report Young Australians: their Health and Wellbeing 2011. There is unfortunately a high rate of mental disorders in young people. Access http://www.aihw.gov.au/publication-detail/?id=10737419261

The Australian Government Department of Families, Housing, Community Services and Indigenous Affairs has released a program called 'Bringing Up Great Kids'. Check out their website which includes information for parents and professionals., and a training calendar. www.childhood.org

resources...

- An Australian made company that provides visual supports to prompt communication and interaction is See-n-Speak. Take a look at their website to see a list of their resources and visual support available. www.seeandspeak.com.au
- The Communities and Families Clearing House Australia as part of the Australian Institute of Family Studies has developed a series of brief, evidence-based practice sheets that provide an overview of a specific practice. Of interest is '*Assessing and Responding to Parent Support Needs in Disadvantaged Families*' and '*Engaging Disadvantaged Families in Child and Family Services*'. Visit http://www.aifs.gov.au/cafca/pubs/sheets/index.html
- NSW council for Intellectual Disability has recently developed a position paper on mental health 'The place of people with intellectual disability in mental health reform: position paper'. You can download this document from their website www.nswcid.org.au/images/pdfs/MentalHlthrfm0311.pdf
- In February 2011, the Early Childhood Intervention Infoline began operating through Parent Line. The Early Childhood Intervention Infoline is funded by Ageing, Disability and Home Care, Department of Human Services NSW and provides a service for families who have questions about their child's development or who have a child who has been diagnosed with a disability. The free 24/7 professional helpline is 1300 1300 52. www.parentline.org.au.
- An interesting website with some great stories about disability is www.abc.net.au/rampup/ This is a media website that is a place for people with disability to have their say.
- Beyondblue has developed a directory of e-mental health services and therapies. It helps people to find self-help internet-based programs available in Australia that are aimed at helping those with depression, anxiety and other illnesses. Visit the website at http://www.beyondblue.org.au/index.aspx?link_id=107.1203
- A website for general practitioners has a copy for download of an intellectual disability mental health first aid manual. It gives a description of intellectual disability and the factors contributing to mental health problems for this population. Visit http://gpsynergy.com.au/documents/id_manual_March09.pdf
- The 'Tell Someone' Website is aimed at educating people with a mild intellectual disability and their family and community about family violence. It clearly articulates that families come in all shapes, sizes, and types including people living in residential settings with carers. It includes plain English information and a series of videos with very clear messages from people with disability sharing their experiences. It was developed by an agency in Victoria but the messages and information would have valuable application and benefit to people with disability generally. www.tellsomeone.org.au
- Headspace mental health, drugs and cyberbullying factsheets in ten languages, this includes Italian, Greek, Simplified Chinese, Arabic, Vietnamese, Spanish, Hindi. Croation, Farsi and Dari. Visit http://www.headspace.org.au/is-it-just-me/find-information/downloadable-fact-sheets

reading list...

De Ruiter, K.P., Dekker, M.C., Verhulst, F.C. and Koot, H.M. (2007). Developmental course of psychopathology in youths with and without intellectual disabilities. *Journal of Child Psychology and Psychiatry*. Vol 48, Iss 5, Pp. 498-507. This is an additional article that conveys the link between intellectual disability and psychopathology. Great to discuss at parties.

Eapen, V. (2011). Genetic basis of autism: Is there a way forward? *Infant Child and Adolescent Psychiatry*. Vol 24, Pp. 226-236. This is a difficult read but an interesting adjunct to Associate Professor David Dossetor's article in our previous edition and also an interesting paragraph on page 230 about ASD and ID.

Hodapp, R.M., and Dykens, E.M. (2009). Intellectual disabilities and child psychiatry: Looking into the future. *The Journal of Child Psychology and Psychiatry*. Vol 50, Iss 1-2, Pp. 99-107. Although a couple of years old, this article gives an overview of intellectual disabilities in the past and then discusses the hopes for research in the future.

Magnuson, K.M. and Constantino, J.N. (2011). Characterization of depression in children with autism spectrum disorders. *Journal of Developmental and Behavioural Pediatrics.* Vol 32, Pp. 332-340. An interesting discussion including phenotypic overlap between the two conditions and available literature.

McCarthy, J. (2007). Children with autism spectrum disorders and intellectual disability. *Current Opinion in Psychiatry.* Vol 20, Pp. 472-476. A good overview by a leader in the field.

Mutkins, E., Brown, R.F. and Thorsteinsson, E.B. (2011). Stress, depression, workplace and social supports and burnout in intellectual disability support staff. *Journal of Intellectual Disability Research.* Vol 55, Iss 5, Pp. 500-510. A great Australian article to help take a step back and make sure professionals are taking care of themselves when working with ID.

Totsika, V., Hastings, R.P., Emerson, E., Lancaster, G.A. and Berridge, D.M. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: Associations with autism spectrum disorder and intellectual disability. *The Journal of Child Psychology and Psychiatry.* Vol 52, Iss 1, Pp. 91-99. This study touches on maternal mental health, something that may be overlooked. Compares ASD with and without ID.

Van der Putten, A., Vlaskamp, C. and Schuivens, E. (2011). The use of a multisensory environment for assessment of sensory abilities and preferences in children with profound intellectual and multiple disabilities: A pilot study. *Journal of Applied Research in Intellectual Disabilities.* Vol 24, Pp. 280-284. Gives confidence to teachers and carers working with moderate to profound intellectual disabilities. Hoping to use multisensory environments.

the medicine cabinet:

Fluoxetine and Autism

Judith *Longworth*
Senior Clinical Pharmacist
Department of Psychological Medicine
The Children's Hospital at Westmead

Fluoxetine belongs to a class of medications known as the Selective Serotonin Reuptake Inhibitors (SSRIs) which increase the levels of serotonin in the body. There have been several clinical trials for use of fluoxetine in major depression, premenstrual dysmorphic disorder, panic disorder, bulimia and obsessive compulsive disorder (OCD) in adults and then paediatric clinical trials for major depression and OCD . These have led to the licensing or approval for use of fluoxetine for these conditions in children and adolescents by the FDA (USA Food and Drug Administration, the federal medication licensing organisation). Unfortunately, probably due to low patient numbers in Australia the same government support for treatment has not yet happened here with the TGA (Therapeutic Goods Administration of Commonwealth Department of Health the Australian medication licensing body). Nonetheless in 2005 ADRAC (Adverse Drug Reaction Advisory Committee) of the TGA recommended that fluoxetine to be the SSRI of choice for adolescent major depression. Over the last decade, the use of Fluoxetine amongst other SSRIs in children with autism has become increasingly common, both in Australian and overseas.

SSRIs increase the amount of the neurotransmitter serotonin in certain parts of the brain particularly the higher centres of the frontal lobes. In the mid-1980s clomipramine, an early non-selective serotonin reuptake inhibitor belonging to the tricyclic group of antidepressants was found effective in reducing OCD symptoms. Cerebrospinal fluid studies of levels of serotonin metabolite are shown to rise during clomipramine treatment. This effect in OCD was specific to those the antidepressants with inhibitory effects on serotonin reuptake (SSRIs).

Fluoxetine is the oldest of the SSRIs on the market and the original trade name was Prozac. Randomised control studies have show that SSRIs (eg fluoxetine) with clinical case management are beneficial for adolescent depression and are as effective as SSRI treatment in conjunction with cognitive behaviour therapy and cheaper (eg Dubicka et al, 2010). However CBT remains the first line of treatment recommended for mild and moderate depression.
Although SSRIs are used for children and adolescents with autism with comorbid depression and OCD, there is a specific clinical research hypothesis that SSRIs may have role in reducing repetitive behaviours, one of the core features of Autism. The clinically observed benefits of SSRIs in Autism has suggested that there may be similarities between the mental processes of OCD and stereotypic behaviour. Children and adolescents may display many forms of repetitive or stereotypic behaviours. It is postulated that these may be caused by low levels of the neurotransmitter, serotonin in the brain, which are also found in many cases of Autism. These repetitive behaviours include the following;

Stereotypy – purposeless movement, such as hand flapping or body rocking.
Compulsive behaviours – following certain rules that must be applied rigidly, such as arranging objects in a certain way.
Sameness or resistance to change – for example, insisting that furniture not be moved, wearing the same clothes or shoes, eating the same food, or refusing to change activity.
Rituals and routines – performance of daily activities in the same way each time, such as routines around mealtime or bedtime.
Restricted behaviour – limited range of interests, such as preoccupation with a particular television program or character.
Self-injury – actions that injure oneself, such as biting and head-banging.
These behaviours can cause problems at home, at school, and interfere with the **child's ability to learn and interact socially.**

As with all medications introducing them into the body can cause adverse effects, these can be minimized by starting at a low dose and this could be a quarter of the tablet and then slowing increasing the dose. As the tablets are dispersible in water a solution can also be made and a dose taken from the solution to give the correct dose. When introducing medication in this fashion the body can adjust to some of the minor adverse effects and thus minimise inconvenience.

Most tables of adverse effects come from the clinical trials conducted in adults when fluoxetine is compared to inactive placebo medication. Those adverse reactions when compared to placebo are ranked:
Common, ie. an incidence of 1% or more: nausea, agitation, insomnia, drowsiness, tremor, dry mouth, diarrhoea, dizziness, headache, sweating, weakness, anxiety, weight gain or loss, sexual dysfunction, rhinitis, muscle pain and rash.

Infrequent, an incidence of between 0.1-1%: sedation, confusion, palpitations, tachycardia, hypotension, electrolyte and blood problems eg bruising or bleeding, and extrapyramidal (neurological) reactions.

Rare, an incidence less than 0.1%: elevated liver enzymes and other potentially serious effects on the liver, blood, and central nervous system.

Allergic reactions such as rashes, itching and hives have been reported and if these happen should lead to medical review. Amongst other adverse effects that should have medical review are an increase in suicidal thoughts or actions and changes in mood that reflect increased agitation, activity, excitability or irritability. There has been particular publicity concerning this small risk of "behavioural activation" with increased impulsive behaviour that includes self harming behaviour. This side effect does seem to be more frequent in children and adolescents than adults. There is no evidence of increased actual suicide, which overall has fallen dramatically as these medications have become more available.

Fluoxetine can also interact with numerous medications and complementary medicines such that it can affect the blood levels of the other medication. So always let the clinicians treating other conditions know when fluoxetine is being taken.

When fluoxetine is given to be effective it has to reach a therapeutic dose as well as blockade of the receptors that it is targeting in the brain. This can take up to 4 -6 weeks depending on how long the therapeutic dose takes to achieve ie these medications are not quick fixes. Then the length of time to be on fluoxetine will depend on how the medication is being used. ●

Currently a group of clinicians at the Children's Hospital at Westmead, Sydney Children's Hospital Network, are part of a national, multisite randomised research trial to test the value of fluoxetine on the repetitive behaviours of children and adolescents with Autism. If anyone is interested in further information please contact Simone Cohen, study coordinator mobile phone number : 0402522249

AAC apps– speaking APPropriately…

Jane Farrall, April 24, 2011.
spectronicinoz.com

Jane Farrall has completed a Masters in Special Education **and is a former Chairperson of AGOSCI (Australian Group on Severe Communication Impairment) and is the founder and organiser of the Big Mouth Camp, a camp for school aged students using speech generating devices and their families.**

http://www.spectronicsinoz.com/blog/tools-and-resources/aac-apps-speaking-appropriately/

Today on the iTunes store, there are around 100 Augmentative and Alternative Communication (AAC) Apps. These are specifically designed to be used by people who have complex communication needs – for people who want to use their iPhone or iPad to communicate face-to-face with others. Many of these AAC Apps are among the highest priced Apps in the App Store – but are they worth the cost? And what do they offer that more traditional speech generating devices **don't?**

The answer to those questions depends on a large number of variables – including the App itself, the needs of the user, other communication options available to the user and how the user can physically access the iPad or iPhone. **Let's start by** discussing the Apps.

As mentioned earlier there are around 100 AAC Apps currently in the iTunes store. *Proloquo2Go*, the first AAC App, developed jointly by Samuel Sennott and AssistiveWare, remains one of the best options available. It offers a range of vocabulary, a comprehensive symbol set, Symbolstix, and allows users to string together symbols to speak sentences or phrases. Users can also pull up a keyboard and type what they want to say. Proloquo2Go reflects good practice in AAC and is used by thousands of people worldwide. Numerous articles have been written in newspapers and magazines about how Proloquo2Go has been successful in giving children and adults a voice – **while harnessing the "cool" factor** of the iPad and iPod touch.

The iPad (along with Proloquo2Go) has been a game changer for children and adults with autism spectrum disorder (ASD) in particular. So much so that Apple featured the use of the iPad with children with ASD in their launch of the iPad2.

Following on from this success, a number of other AAC Apps have been released upon the world. These vary enormously in quality and price – and some of them fill a different niche to the one carved out by Proloquo2Go. Many of them do not reflect good practice in AAC – and are incredibly overpriced for what they offer. They may not include any symbols, or **don't let the user string together words to** create novel sentences. Some of them crash frequently, or have very poor quality speech – despite their comparatively high price tag.

Of course, some of the new Apps are good quality – *Predictable* , an AAC App released earlier this year, is well designed and well thought out. It is designed for literate end users and offers customisation, control and alternative access options. Similarly, *Verbally*, another AAC App released only a few weeks ago, is a high quality AAC App that is free of charge to the end user. Unfortunately, though, these high quality Apps tend to be in a minority rather than a majority – definitely a case of user beware! (And to assist potential users, I maintain a regularly updated list of AAC Apps, along with ratings, at http://www.spectronicsinoz.com/article/iphoneipad-apps-for-aac)

Moving on from the Apps, we need to look at the hardware. I am, I must admit, completely addicted to my iPad. I love it. I can understand why many users and families want this cool, elegant and easy to use piece of technology as their speech generating device. And I hope that the **ease of use and "cool" factor of this tech**nology is providing many traditional speech generating device manufacturers with ideas for their next generation of devices. I really look forward to seeing what impact this consumer technology has on speech generating devices as a whole.

Just as I can understand why families want this technology, I can also understand why many professionals are worried about the iPad being used as a speech generating device. **The volume isn't suffi**cient for many situations, the hardware is a lot more fragile than many of the dedicated speech generating devices and the access options for people with physical disabilities are limited. At this stage, if I need to use a head switch or foot switch, I have only very limited control of a small number of Apps on my iPad. For this group of users, a dedicated speech generating device is still the only option which gives complete control and flexibility. As a therapist – I could spend a lot of time trying to **"make" this technology work for someone** when there is a piece of specifically designed technology that will work straight away and with a range of well designed page sets which only need minimal customisation for the user. Of course – this **doesn't apply to everyone.** Some people fly with their iPad from day one – while others are still trying hard to get to the first step a year later. Sometimes, this is because the hardware and/or App are an inappropriate match for the end user. Sometimes, however, it is due to poor setup and support.

And that brings me to my next point – expertise. Because this technology is cool, widely accessed and relatively cheap – suddenly we have a huge turn around in AAC recommendations. Historically, speech generating devices have been recommended primarily by speech pathologists, many of whom have specialised in AAC for years. We know the technologies available and what they can do. Furthermore, once a device has been recommended we can provide support to ensure the best possible outcomes for an individual. This model of expert assessment and recommendation, however, is now being consistently bypassed when recommending AAC Apps and iPads or iPhones. People with little or no knowledge of AAC are suggesting this option as a solution – the **best App for the individual isn't necessarily** being considered and the setup of the communication pages for best outcomes **isn't always happening.** In addition, once an individual or family receives the App and hardware, no expertise is provided to ensure good outcomes for the user. Model**ling the user's AAC pages frequently does**n't happen – and in many cases the vocabulary design does not reflect good practice in AAC. As a result, nearly every day we hear stories of people who received an **iPad and an AAC App that they haven't** been able to use – or of a person who received an iPad for AAC but only uses it for game playing or for watching videos.

This technology is great – and some of the Apps are great too – but we need to use our usual selection and consideration principles and make an educated decision about whether this is the best option for each user – or whether some of the other AAC technology currently available might

suit their needs better. Or – in fact – whether a combination of technologies might have the best possible outcomes for a user. An iPad with an appropriate App with well designed vocabulary and appropriate support can be amazing – but we need to ensure that all our usual selection processes are used for each and every individual to ensure the best outcomes for them – whether this includes an iPad or not.

And to illustrate this point – **I'd like to tell you about Crystal.** Crystal is a 16 year old with complex communication needs. She has been using low tech communication books and high tech speech generating devices since she was very young. Currently she has a low tech PODD and a DynaVox MT4 with a PODD page set on it.

Crystal is independently mobile – but walking can be difficult for her and carrying her DynaVox **MT4 hasn't always been possible** due to weight and size. Last year, her mother purchased an iPad and Proloquo2Go for her to use. **Her mother's initial plan** was for this to be for her use at social events where her MT4 was too heavy for Crystal to carry.

Her school was delighted to hear that an iPad was coming. They suggested to her mother that the iPad was sent every day to school and her MT4 stop coming. Crystal's mother spent around 40 hours trying to program all the vocabulary from her PODD page set into the iPad – and in the **end she wasn't able to do this completely** as she had fewer symbol choices and reduced page layout options.

After several weeks her school suggested **that the iPad didn't need to come to** school any more – and asked for her speech generating device to start coming again. They reported that it was much harder to Crystal to find vocabulary on her iPad and that it was slower for her to use to complete school work. The decision for school has been that her DynaVox MT4 remains the most appropriate tool for this situation. In fact, they are now upgrading to a DynaVox Maestro as they feel the bigger screen and increased portability of that unit might be an even better option for school.

However – in social situations the iPad and Proloquo2Go has taken on a life of its own. It breaks the ice – people who **wouldn't normally chat to Crystal with her** low tech book or her Speech Generating Device are happy to walk up and start chatting – the iPad itself has become an incredible conversation starter as total strangers ask her how she likes it. Crystal can carry it independently – and is enjoy-

ing chatting with as many people as she can.

The iPad and Proloquo2Go alone wouldn't meet her needs – but combining her Dyna-Vox MT4 and her iPad has led to a communication system for Crystal that has had outcomes that no other communication options have given her. Each device is used in the most appropriate situation – leading to fewer communication breakdowns and much better outcomes for Crystal. ●

Visit spectronicsinoz.com to access reviews and updates of current and new release iPhone, iPod and iPad applications for AAC. Applications include symbol only apps, symbol and text-speech apps and also text only apps. Visit the website regularly to keep up to date with what is on the market or subscribe to their blog.

Featured Apps

PhotoTell, $12.99

App allows user to make albums with up to 9 images/photos per page and attach a recording to each item. Use can add on images or take photos with camera. This is a great talking photo album.

Proloquo2Go, $239.99

Full featured AAC app with a default vocabulary of over 7000 items, with some language arranged pragmatically. Every cell can be customised and the user can has access to SymbolStix picture symbols as well as importing their own. A message window allows users to construct a sentences by stringing words together. A keyboard can be used to type for text-to-speech and typing can be inserted into the message window and added to a sentence. Word prediction is available to support typing.

Extract from spectronicsinoz.com

blog this...

There are some great blogs out there on the internet that will help you keep up to date with information about whatever topic you want to know about, from origami to molecular biology. Sometimes, these blogs can give you information faster than you can search it and all the hard work is done for you. All will allow you to receive recent blogs by email and most will also have Twitter and Facebook accounts for the tech savvy so you can read about Intellectual Disability and Autism on your iPhone under the covers at night.

Keeping up with DS (Down Syndrome)
http://keepingupwithds.blogspot.com/

Keeping up with ds is a blog housed by Down Syndrome NSW (DSNSW). DSNSW is a family support and information organisation, established in 1980, and governed by families of people with Down syndrome and their friends, located in New South Wales, Australia. DSNSW is based in Sydney, but offers its services across the state of New South Wales. This blog has up to date information from DSNSW with access to their favourite blogs and website. You can follow their blogs by email or follow on Facebook.

About The Author
Roger Stancliffe is Associate Professor, Disability Studies, at the University of Sydney's faculty of Health Sciences. Assoc Prof Stancliffe, and his work, particularly on community living and active support is well known to families of people with Down syndrome in NSW.

ClearHelper
www.clearhelper.wordpress.com

The Clear Helper Blog tracks a project to discover and to develop best practices of Web accessibility for people with intellectual / cognitive disabilities. Part of this effort is a future Clear Helper Web Site. It is intended to provide tutorials about using computers and the Web.

Involvement by People with Disabilities
Every step of the way in the development of the new Web site, people with intellectual/cognitive disabilities will be included as advisers and testers. Interviews are being conducted to determine subjects for tutorials. People are being asked what causes them the most trouble when using the Web in general, a specific Web site, or a site feature.

About The Author
The author of this blog is John Rochford, Director of Technology for New England INDEX, a project of the Eunice Kennedy Shriver Center at The University of Massachusetts Medical School. John has worked with children and adults with intellectual disabilities and/or Autism since the 1980s. As a consultant, John provides behaviour services, and specialises in skill acquisition. John has a Master of Science in Applied Behavior Analysis from Northeastern University. John has been developing accessible Web sites since the mid 1990s for nonprofits and governments throughout the United States. You can follow John through RSS feeds or Twitter: @ClearHelper

Left Brain/Right Brain: Autism news, science and opinion
http://leftbrainrightbrain.co.uk/

Left Brain/Right Brain first came into existence in 2003, under the domain kevinleitch.co.uk. Over the years it has changed its basic form a few times but its core content and interest has always been autism and the news, science – and bad science – associated with it. This is a very comprehensive blog and website with updates daily. You can follow the blog online, subscribe by email, RSS feeds, follow on Facebook or Twitter: @kevleitch to keep up-to-date.

About the Author
Kevin Leitch owns and is Lead Editor for Left Brain/Right Brain. He is a Web Developer, divorced with three children. His middle child is classically autistic (Kanners/Low Functioning are two other medical based descriptions of the category of autism doctors place xyr into). Kev also has two step-daughters of whom one is also autistic. Kev is a member of The National Autistic Society.

reviews...

Book Review:

Lawrence, C. (2011). *Successful School Change and Transition for the Child with Asperger Syndrome: A Guide for Parents.* Jessica Kingsley Publishers, London.

This book considers how parents and professionals can best prepare a child with Asperger Syndrome for the transition from primary to secondary school. The transition checklist that she provides in the appendix is useful. While the book is written specifically for parents, a number of strategies may be useful for children with a range of disabilities who are facing similar challenges, particularly those who may share some of the characteristics of children with autism spectrum disorders.

Moss, J. (2011). Book Review. *Journal of Applied Research in Intellectual Disabilities.* Vol 24, Pp. 290.

Website Review:

www.speechbite.com

speechBITE is an online database that provides open access to a catalogue of best interventions and treatment efficacy across speech pathology practice. You can use the database to gain access to citation and abstracts of interest to speech pathologists which are given ratings. You can search for articles by target area, intervention, service delivery mode, method, client sub-group and age group. This is an interesting concept that may help with literature reviews and case studies. Similar databases include psycBITE (Psychology), PEDro (Physiotherapy), and OTseeker (Occupational Therapy). Check out the links page to find their websites.

Organisation Review:

http://pubsites.uws.edu.au/ndco/

The National Disability Coordination Officer Program in Western Sydney assists people into post school education training and employment. It is funded by the Australian Government Department of Education, Employment and Workplace relations and is hosted by the University of Western Sydney. NDCO program works directly with individuals, parents, education providers, employment services and community and government services. Their goals are to improve transitions, increase participation and establish better links. You can view their website for more information, resources, links and research into transition between school and post school options.

> Have you been to a conference, read a book or visited a website that you loved?
> Send us an overview to: schoollink@chw.edu.au

Conference Review:

Dr Phil Ray, Clinical Psychologist Department of Psychological Medicine **The Children's** *Hospital at Westmead*

In March this year we were fortunate enough to receive a talk from Adam Guastella, Principal Research Fellow at the University of Sydney. He discussed his 2010 NHMRC supported research on the role of oxytocin in children with autism. As I'm sure most readers are aware, autism is a neurodevelopmental disorder characterised by a qualitative impairment in social interaction, including difficulties with eye gaze and processing facial expressions, and a lack of social reciprocity. Adam's recent research has highlighted the beneficial properties of oxytocin in improving peer recognition, social approach and bonding behaviour in children with autism.

Oxytocin, a neuropeptide found in the brain, has been found to be central in the mediation of social, attachment and affiliation behaviours (Insell, 1997). These have included infant attachment, pair-bond formation and social memory. Oxytocin is also related to activating reward neural pathways which increase

motivation during social activities (Dadds, 2010). Adam Guastella and colleagues have found that administration of oxytocin to both healthy individuals and those with developmental disabilities has resulted in improvements in emotion recognition and facial processing (Guastella et al., 2007, 2008 & 2010). This suggests a possibly revolutionary treatment for the social interaction deficits that children with autism face.

In the most recent paper, Adam and his colleagues recruited 16 male participants aged between 12 and 19 years who had autism or Asperger's Disorder; participants were screened by a neuropsychologist and a psychiatrist to confirm their diagnosis. Only males were recruited as autism and Asperger's are more common in males. Participants took either oxytocin or a placebo via nasal spray (the oxytocin spray is not readily available and was developed for the study). Participants were then assessed using the 'Reading the Mind in the Eyes' Test (RMET). This test looks at an individual's ability to identify complex emotions through facial expressions*. Adam and colleagues found that oxytocin improved performance on
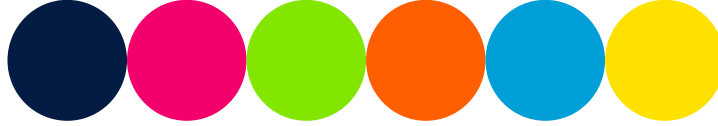
the RMET test for 60% of the participants. This means that over half of the participants had improved emotional facial recognition skills after taking the oxytocin nasal spray.

Adam's research has obviously exciting implications as the authors suggest this raises the possibility of oxytocin being used as a brief intervention to improve social interaction difficulties in children with autism. Further research is currently underway examining the benefits of oxytocin with other age groups and clinical groups. Therefore, this looks like an exciting area of developing research that is worth keeping an eye on.

Individuals interested in participating in oxytocin research trials should contact 93510881 or write to autismcares@med.usyd.edu.au. Two trails are currently being conducted. Trial one is for male and female participants with a diagnosis of Autism aged between 3 and 8. Trial two is for male only participants with a diagnosis of High Functioning Autism aged between 12 and 18

*A sample of the test can be found on the following web address: http://glennrowe.net/BaronCohen/Faces/EyesTest.aspx

in the news...

Swan 'Proud' of $1.5b boost for mental health
Daniel Franklin, www.abc.net.au/news, 10th May 2011

The Treasurer has announced an extra $1.5 billion for mental health services. The package, spread over five years, aims to provide more intensive and better coordinated services, target-ing communities in need and helping detect problems earlier. It brings the Government's over-all commitment to mental health to $2.2 billion. The new funding includes:$571m for severely mentally ill, $419m for teens, young adults, $220m for primary care and $32m for National Mental Health Commission.
This package will focus on support for the severely ill - by funding organisations to coordinate both clinical and social support and helping to relieve the pressure often felt by families, and those with mental illness, in navigating a complex system," Mr Swan said. "We will also address prevention and early detection for young people by investing further in headspace and early psychosis and interventions centres."

Budget to provide more support to students with disabilities
Prime Minister of Australia www.pm.gov.au 3rd May 2011

New budget funding of $200 million is to provide extra support for students with disability in Australian schools which will deliver new services, equipment and support. Services include speech and occupational therapists, special equipment, additional hours of in-class support, adapted curriculum and teacher support. Under this new initiative, schools will work with fami-lies, support agencies and health and student welfare professionals to focus on students.

A New big picture is busting myths about NSW Kids
NSW Commission for Children and Young People, 10th May 2011

A picture of NSW children brings together information from major data sources using new com-munication technologies to make this information about NSW kids easily accessible to policy professionals and decision makers who can use it to inform their work. A free iPad app is also being developed to support this work. "Having all this information in one location gives us a unique helicopter overview of children's lives while providing fascinating insights into the many different areas," said the NSW Commissioner for Children and Young People, Ms Megan Mitchell. Produced in collaboration with the UNSW's Social Policy Research Centre (SPRC), the information is being released in a series that includes an introduction to NSW Children and their families, economic well-being, child care and education, health and well-being, safety, children in communities and children who offend. Visit the online databook at http://picture.kids.nsw.gov.au/

The beautiful artworks in this newsletter are taken from the participants of the **Op-eration Art** project at the Children's Hospital at Westmead. You can find out more at http://www.pau.nsw.edu.au/Visual_arts/Operation_Art/index.htm

A sincere thankyou to all children and adults involved in the production of these artworks and this newsletter. Remember; **Think Kids**

contact us...

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