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mental health and intellectual and developmental disability... coordinator's message...

One of my tasks as the locum CHW School Link Coordinator is to put together the newsletter. The newsletter has gradually morphed into a specialist journal. This edition has articles and comment on a wide range of topics, with contributors providing perspectives from the education, health and disability sector. This in itself is tangible evidence of the existing commitment to the multi-disciplinary / inter-sectorial approach needed to improve outcomes for those with an intellectual disability and mental health problems.

Lifting the profile of this particularly vulnerable section of the population and the complex health and psychosocial issues involved is critical and the newsletter is one way of providing a focus on the energy and passion of those who work in the field. The feature articles in this edition illustrate how rapidly research and the structure of services are moving towards new responses.

In keeping with these aims, the Emotion-based Social Skills Training Team and NSW Department of Education and Community received a Special Commendation in the Mental Health Matters Awards from the Hon. Kevin Humphries MP, Minister for Mental Health and Healthy Lifestyles in recognition of their collaboration to provide intervention in schools to 400 children with ASD. Further the team has received charitable funding to extend their work and establish a 3 year Nikki Fellowship in clinical psychology, which will be advertised in January.

By the time this edition arrives on your desk the end of the year will be nigh. The resources and reading list will provides links to new ideas and the section on conferences and training has some of what is coming up in 2014.

Wishing you all a peaceful Christmas and the ability to accept the New Year Resolutions you know you will never actually follow through with - the ones you know you can do and the wisdom to know the difference.

Happy Reading, Terry Sarten
School-Link Coordinator
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Learn more about School-Link and the Children's Hospital at Westmead project on www.schoollink.chw.edu.au



a note from David Dossetor...



Draft Guidelines on the Pathways to Care for Children and Adolescents with Intellectual Disability and Challenging Behaviour and/or Mental Health Problems.

Associate Professor David Dossetor Director of Mental Health, Sydney Children's Hospital Network,
Lesley Whatson, Team Co-ordinator, Children's Team, Statewide Behaviour Intervention Service, Aging Disability and Home Care, NSW Department of Families and Communities and
Ron Balderston, Principal Psychologist for NSW Department of Education and Community.
Approved by the NSW Agency of Clinical Innovation Disability Network Executive Committee.

Introduction

These guidelines are written as a guide or aid for parents and carers of children and adolescents with intellectual disability and emotional or behavioural problems. Challenging Behaviour is often the term used by disability services to describe behavioural or emotional difficulties.

Common Problems and Delays in Developmental Competence

The common problems of emotions or behaviour in primary school aged children are: sleep problems, anger, aggression, non compliance, anxiety, moodiness, restlessness and hyperactivity, problems of socialisation, repetitive behaviours or interests, and self injurious behaviours. Many of these problems occur commonly in toddlers of any ability. As they develop in their capaci-

ties for language, social understanding, rule conformity, impulse control, concentration, memory, imaginary play and learning from their peers and making friends with skills of social reciprocity, most settle down in their behaviours in the years that lead to the run up to preschool and school.

This scenario is often made much more complicated for those with an intellectual disability by a range of other difficulties. They are more likely to have physical health problems or additional physical disabilities including hearing, sight, motor development and coordination problems, along with difficulty in developing coherent developmental capacities implicit in the skills described above. The development of emotional or behavioural problems are often therefore linked to a growing appreciation of ways in which your child may be failing to keep up with others in their skill development as problems of intellectual disability are recognised. This is then tempered by the quality of their relationship with their parents and carers in the development and style of their attachment relationship. Accordingly, the welfare of the immediate family is of importance to the wellbeing a child.

Health and Disability Services and the need to enable Collaboration

In Australia different services are available from a range of different funding sources and one of the main challenges for a service user is to enable different components of the service to link or collaborate with each other. An understanding of the models of care that are agreed upon by state and federal governments, including non-government organisations

(NGOs), can help work out what a child or family needs at different stages of the child's growth and trajectory. Parents carry primary responsibility for the welfare of their child and very often it is the parent or child's advocate who needs to ensure that different elements of the service system are adequately informed and connected to other parts of the service. All human services are under pressure and the parents/carer, along with the clinician, have to reach a shared understanding of the severity and priority of need. Children generally are of high priority, partly as early intervention is often of best value, and may ensure the best outcomes over time. Children are also often resilient, and can progress and recover in the context of a range of adversities.

Early identification, assessment, intervention, case management and coordination

For anyone, the primary access to health services is usually through a General Medical Practitioner (GP) who is well placed to coordinate and guide access to other services. A GP may enable access to a community clinician whether from community health or disability services such as a nurse or other allied health professional (psychologist, speech therapist, occupational therapist, physiotherapist, social worker). Making sense of a child's changing situation, the mixture of developmental progress, emotions and behaviours can be helped by having a clinician who provides a case managing or advisory role, balanced by access to clinicians of greater specialisation for more specific questions. Such case managers or mentors are often a key figure for making sense of a complex situation over time, often providing information on what other sources of help may be useful. Such case managers may be different for different families, and can be clinicians from health, disability, NGOs or education services or even a friend, relative or an experienced volunteer lay person or parent.



Currently disability services are progressively moving towards individualised funding so that the parents take on the role of choosing and brokering service options for their child. This will introduce Service Coordinators to work alongside Case Managers in this work.

Paediatricians, other medical specialists and Medicare Funded Intervention

Understanding complex issues of physical, developmental, emotional and social health often requires input from a general paediatrician, either through Medicare-funded services or through NSW Community Paediatric Services. This can vary according to where you live. If these problems remain complex or unclear, a general paediatrician may refer on to a specialist paediatrician, such as a developmental paediatrician, a neurologist or geneticist or any other specialty. Dentists, respiratory paediatricians, gastroenterologists, ears nose and throat surgeons, endocrinologists and sleep physicians may all be important in considering the cause of behaviour in those unable to communicate.

A general paediatrician has an important role in coordinating and interpreting different areas of subspecialty expertise. He or she is the main clinician to help with the recognition of a number of mental health problems seen in youngsters with intellectual delay such as Attention Deficit Hyperactivity Disorder (ADHD), language problems, Autistic Spectrum Disorders (ASD), or specific learning problems such as learning to read or other emotional or behaviour problems. Such a paediatrician will advise on what other services are needed. Medicare will fund up to 16 sessions for allied health intervention in Autism and up to 10 sessions for a mental health problem.

The more complex the situation, the more specialised the case management/case coordination. It is possible to have a number of case managers in Health, Disability, Education, an NGO and a lay or professional advocate who will need to be linked to each other and take account of each other's roles and expertise. Ultimately the parent/carer is the primary advocate who needs to ensure that there is appropriate communication and collaboration between different components of this important network. Parents/carers learn more about their child and over time become the experts on their child's specific needs. Parents or other case coordinators need to ensure information from one clinician in the network is made available to the next.

Parent Behavioural Management Skills

Most early childhood emotional and be-

“often it is the parent or child’s advocate who needs to ensure that different elements of the system are connected...”

havioural problems are best understood in terms of their behavioural elements. Research shows that the most effective intervention for early childhood problems from 3 to 12 years is skilled parent management, particularly with behavioural skills. The best known program for parent skill enhancement is the Positive Parenting Program or Triple P. Another well known one for mainstream children is 123 Magic. Below the age of 7 is when these problems are most common and most readily changeable. Parents often feel more comfortable learning these skills in a group setting whereby one learns from others' real life experience of their problems and what has helped. For families with a child with intellectual disability, Stepping Stones Triple P is to be recommended. It is designed to consider the added problems of delayed learning and other neurodevelopmental problems (including ASD), the additional burden of care and the challenge of integrating the disabled child into the wider family and community. Stepping Stones Triple P presents the state of the art skills in behaviour management while considering the wider family needs. The Signpost parenting program is an alternative developed in Victoria. In many ways a specialised program like Stepping Stones represents an introduction to applied behaviour analysis, which is the primary and best evidenced skill of clinicians working in disability services. Training in these skills is becoming more widely available. Ask for information from your local community health centre, the local ADHC service, the library, centre care, the school or NGOs.

Playgroup, Preschool and School

All children enter playgroup, preschool or school somewhere between the ages of 2 and 6 years. These organisations are both a challenge for the developing child and a resource. Child care workers and teachers are specially trained and experienced in the diversity of children. The way children engage, play and make and sustain friends is the best test of their adjustment and developmental competence. Staff are also skilled in helping children who have difficulties. Accordingly teachers and school counsellors are often an early source of advice and help where children

are having difficulty coping. Indeed in meeting a child's educational needs, it is critical to identify areas of special need in learning, social and emotional adjustment. The aim of education is to match the learning environment to the child's need to make school a positive and developmentally enhancing experience. Sometimes this requires a special placement or an application for additional funding/support to meet these needs. Alternatively this can lead to referral into early intervention services and therapies. Schools are also a good setting to develop mental health promotion and prevention initiatives, although this is identified as a whole of life challenge.

Disability Services (Aging Disability and Home Care, NSW Family and Community Services)

If a family and school are having trouble with the emotional and behavioural problems of a child, then this may be the time to involve Disability Services. Access to ADHC depends on demonstration of an intellectual disability, usually through an intelligence test and an adaptive behaviour assessment; tests that are normally provided by a psychologist or school counsellor. Disability Services will assess the child and the psychosocial need of the family. They may enable home-based or community support such as respite care, including home-based respite care, or vacation care, and access to a disability allowance (or other services for financial hardship) and other special opportunities for young people with intellectual disability. They may also guide access to other services such as advocacy or multicultural advice. For more complex or potentially dangerous behaviour disturbance, Disability Services may involve a specialist multi-disciplinary team which could include a behaviour practitioner, psychologist, occupational therapist, speech therapist, family therapist or physiotherapist. Each of these disciplines has special skills for this special need population. In recent years, NSW Government funding has enabled some enhancement of Disability Services which have built up teams of clinicians/practitioners including Regional Behaviour Intervention Teams and this increase in resource has led to greater capacity and preparedness to collaborate with other clinicians/agencies over complex cases.

With your permission the disability team, school and health practitioners will liaise with each other for optimal knowledge sharing. They may need to work closely with a paediatrician over the health needs and medication for the developmental psychiatric disorders. For example ASD and ADHD frequently co-occur with other

emotional or behavioural problems. Disability services frequently involve NGOs to provide on-going services, case management and support. NGOs are often effective in (frequently better at) enabling a total family involvement in their service/organisation. It must be remembered that many community based services for health, mental health and welfare are provided by NGOs who are in part funded by NSW Government to provide the network of services needed. With the roll out of the National Disability Insurance Scheme, Disability Care Australia will be key to coordinating services. The impact on siblings may need separate attention, and specific sibling groups can be helpful.

Child and Adolescent Mental Health Services (CAMHS)

In many districts of NSW, psychiatric problems of primary school-aged children are managed by Community Health Teams. Some CAMHS services are involved in severe anxiety disorders, depression and family relationship problems. CAMHS are generally for young people aged 12-18 and generally restrict their services to the more severe and treatable mental health problems: e.g. depression, severe anxiety, post-traumatic stress disorder, early presenting psychosis, schizophrenia and bipolar disorder. Acute mental illness including acute mental disorder of suicide risk, bizarre behaviour and dangerous behaviour are also seen by community teams but are often assessed by emergency departments services. Emergency services are expected to take those in need to the nearest emergency department. There are adult emergency mental health services (some are called PECCs (Psychiatric Emergency Care Centres) which include short stay beds) that will assess anyone over the age of 12 years old. Patients, regardless of age or intellectual ability, can be detained under the Mental Health Act if they are seriously mentally ill or sufficiently mental disordered to not to be considered safe. However such emergency services mostly provide crisis management and most patients will need to be followed up promptly by the network of community based services. Those under 16 years who present to emergency departments with acute mental health needs will generally need to be stabilised in the local medical/paediatric service with support from the acute mental health service. There are 50 adolescent mental health beds in the state, but transfer usually has to be planned, based on bed availability. For those under 12 years, in-patient care is likely to be under a paediatrician with support from the local CAMHS team, and a child or adult psychiatrist, according to availability. No patient can be refused mental health services on the basis of their disability, but the service may not provide a

service if a serious or treatable mental illness is not identified. Adult mental health services provide an overflow capacity for dangerous and seriously mentally ill teenagers who cannot be provided for in the CAMHS in-patient units. Access to child psychiatrists is required for mental illnesses that require medication and can be helpful for advice on managing complex combinations of psychotropic medications.

Complex Chronic High Risk Challenging Behaviour with or without serious mental illness.

Aggression is the most common challenging behaviour, but can also be the presentation of a major mental illness. Those with intellectual disability have higher rates of anxiety, depression and psychotic disorders, and psychiatric diagnosis can be difficult to establish reliably. There is a group of teenagers with intellectual disability and chronic additional problems of emotional and behavioural disability. They frequently have difficulty to treat developmental disorders such as ASD, ADHD or Impulse Disorder with aggression or may have recurrent self-injurious behaviour. They may not be diagnosed as having a serious mental illness; they often have episodes of acute mental disorder and violence. They may commit criminal offences but sometimes the law protects them from Juvenile Justice Detention due to diminished capacity from their intellectual disability. They frequently cause major hardship for their families and may be suspended from school. Due to their vulnerabilities, they are readily led astray or exploited by other disordered youth in the community and may be exposed to substance abuse. Frequently there are requests for long term care or foster placement. This is a growing population, and those with mild intellectual disability may end up in refuges or homeless.

Recent Developments

In January 2011 a Memorandum of Understanding was signed between the NSW ministers of health and disability which defines the services that Mental Health and Disability each provides. It also determined that senior management of local Disability Services and Mental Health Services should meet several times a year together to consider cases or issues of concern to either party. These meetings are designed to develop greater collaboration and a state-wide implementation committee is evaluating the progress.

The challenging behaviours and mental health problems of young people with intellectual disability contribute additional disability to their intellectual disability.

History confirms that these are complex to understand and manage, yet there is significant expertise to be found in those practitioners that have a special interest in this population. In addition there are significant human rights and equity of access issues that are drawing political attention, including a biannual independent report from the NSW Ombudsman on the deaths of people with an intellectual disability. It is recognised that services are imperfect, and it is hoped that the MOU will bring a system of cross agency, cross discipline collaboration on how to best help and in particular how best to manage this vulnerable population in the most appropriate community setting. Ultimately, the most complex cases need a conjoint process between health, mental health, disability clinicians and other interested stakeholders such as family members, to bring the best available clinical expertise and business management to resolve distressing conditions and their context.

“promoting emotional wellbeing and behavioural independence is key to children's development...”

In 2011, NSW Health funded the Agency of Clinical Innovation (ACI) to establish a Disability Network which provides a mechanism for clinical and academic leadership with a full range of stakeholder participation to provide a mechanism to advise NSW Government on the further developments of health services for people with an intellectual disability.

The Challenge for Disability Care Australia

Lastly, what will be the impact of the national investment in Disability Care Australia to supporting the central component of the quality of life of people with intellectual disability, that is to say their emotional and behavioural wellbeing? Most of the distressing cases are not about major mental illnesses needing specialised mental health intervention but are challenging behaviours in the context of complex developmental disorders. Indeed there are concerns that people with intellectual disability are having their liberty withdrawn by a failure to adequately support their placement in the community, and organisational pressure on emergency medical and psychiatric services leading them to be inappropriately hospitalised because of their developmental and major emotional and behavioural problems. They often end



up in locked wards, which are high risk environments, as the placement of last resort, although they are not detainable under the Mental Health Act.

The most significant need is professional expertise in improving skills and thereby improving participation. It is evident that all psychological therapies intervene through enhancement of skills and independence. This may be enabling sleeping on your own, learning to keep safe and respect others, being able to attend school, work and other community activities, and especially skills for understanding and developing friendships which in turn prevents both disruptive and law breaking behaviour and problems of emotional regulation. All such therapies are central to the key aim of National Disability Insurance Agency to provide support to enable participation. The only element of mental health treatment that does not fall under improved participation and supporting disability is the management of medications that minimise their disability in various ways. The cost effectiveness and the success of National Disability Insurance Agency will depend on their approaches to supporting the 50% of people with intellectual disability with long term emotional and behavioural problems. There are a number of key health and mental health organisations that National Disability Insurance Agency need to engage with to tackle this most critical challenge. Progress to community participation will require promoting skills in people with intellectual disability which will require specialised professional skills in the support/care staff which in turn will need

high levels of professional training, supervision and support. Improved outcomes will also depend on partnerships between National Disability Insurance Agency and Medicare Locals and general practitioners, and specialist health and mental health services. Improved access and outcomes will also require support and expertise from specialist intellectual disability health and mental health services. National Disability Insurance Agency/NDIS is in an early stage of development with pilot projects focusing on different elements of service provision. The organisation is evidently aware of some of the challenges and has published some documents on its website on how to use the funding in fair and cost effective ways, including the need for building professional skills. Further work is currently underway to ensure the maintenance of professional skills and sector capacity as ADHC slowly decreases its role in service delivery and the NGO's and private agencies take on this role. These structural changes over the next 2-3 years mean that the focus of new initiatives in the sector is to enhance the NGO and private service providers, and to implement systems that effectively support the provision of quality service to people with disability and their families. **Promoting emotional wellbeing and behavioural independence is key to recognising and developing the human rights of young people with intellectual disability.**

Please see the School-Link website for a flow-chart of pathways to care.

having your say on triple p...

The Stepping Stones Triple P (SSTP) a program for parents of children with disabilities has received support towards a potential national roll-out. The University of Sydney, University of Queensland and Monash University will be doing a survey in 2014 to determine the best way to facilitate training and delivery of the program across the country.

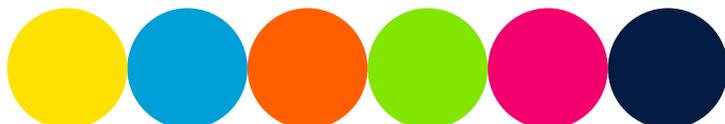
The survey will go to all practitioners and service providers in NSW that work with children with disabilities and their families to gather information on their experiences of working with families and their use of parenting interventions.

Parents of children aged between 2-10yrs with a disability will be invited to complete a survey on their experiences, the parental strategies they use in response to challenging behaviours and their awareness of parenting programs.

The information from the surveys will then be used to determine how SSTP can best be delivered to meet the needs of both professionals and families. Practitioners and service providers will be able to nominate themselves to receive free training in the suite of SSTP parenting programs.

The SSTP program will be available, at no charge, to parents and caregivers in late 2014. To get more information on this project contact

ths.steppingstones@sydney.edu.au



access to allied psychological services (ATAPS)...

WentWest, Western Sydney's Medicare Local has been delivering and managing The Access to Allied Psychological Services program (more commonly referred to as ATAPS) throughout the western Sydney LHD (Auburn, Parramatta, Holroyd, Blacktown and Hills LGA) since 2006.

ATAPS is a Commonwealth funded program designed to assist and support GP's and Primary health care services to engage patients with local and professional mental health clinicians. The ATAPS program provides short term intervention along with focussed psychological services to financially disadvantaged people in our communities who may not otherwise be able to access mental health services. WentWest delivers the ATAPS services at no cost to patients, where they would not otherwise be able to afford the fee charged by the Mental Health Professional or a gap payment. ATAPS removes any financial barriers to accessing mental health services that may have been preventing the patient accessing services.

The Western Sydney Medicare Local has expanded the ATAPS program to include assisting Children aged between 0 and 12 years of age, to receive support from a trained child mental health clinician (ATAPS Provider). In 2013 Children's Mental Health has been the major focus. Projections indicate that every dollar spent on effective early intervention, seven dollars is saved in future public service for children that go untreated, therefore highlighting the significance of identifying and treating emotional and behavioural difficulties in children as early as possible.

ATAPS is focused on continuing to expand the referral pathways to psychological intervention through ATAPS by providing school counsellors, directors of childcare services, social workers, Paediatricians and Psychiatrists the ability to refer children into ATAPS. WentWest are pleased to now include "Secondary Referral Agents" to create an integrated health system and greater ability of access points for individuals experiencing mild to moderate mental health concerns.

Secondary referrals are a great way to engage patients who are already engaged with a professional service and might be apprehensive about going to a GP allowing the patient to engage in 3 sessions as an entry point into accessing mental health services. After the 3 sessions the patient will need to engage with their GP to contin-

ue the treatment and obtain a mental health treatment plan.

Secondary Referral Agents include;

- Aboriginal & Torres Strait Islanders (ATSI) – Aboriginal Medical Services, ATSI mental health services
- At Risk Suicide – Acute Mental Health Team,
- Children - School Counsellors/ Principals, Child Care Directors, Paediatricians, Psychiatrists, social workers
- Perinatal – Obstetricians, Maternal and Child Health Nurses

How to refer – [For Secondary Referral Agents \(SRA\):](#)

- Patient (or parent/guardian) will need to provide consent and sign the referral form.
- Select a Mental Health Clinician who is an authorised ATAPS provider –
- For assistance please call the ATAPS team at WentWest on 02 8811 7100 or refer to www.wentwest.com.au/mentalhealth
- Send the completed Provisional referral form to WentWest via fax 02 8208 9941
- The SRA will receive a letter from WentWest to confirm the patient has been accepted into the program.

Treatment;

- After 3 provisional sessions the ATAPS Mental Health Clinician provides the patient's GP with a letter outlining the concerns and requests an ATAPS referral from the GP for further sessions.

How to refer – [General Practitioners:](#)

- Completes a Mental Health Treatment Plan (MHTP) and ATAPS Referral Form with the patient's (Parent/ guardian's) signed consent.
- GP approves or selects a Mental Health Clinician who is an authorised ATAPS provider –
- For assistance please call the ATAPS team at WentWest on 02 8811 7100 or refer to www.wentwest.com.au/mentalhealth
- Fax the ATAPS Referral Form and Mental Health Treatment Plan (MHTP) to the WentWest secure fax no. 02 8208 9941.
- The GP will receive a letter from WentWest to confirm the patient has been accepted into the program.

Treatment;

- After 6 or 9 sessions the GP receives a

Progress Report from the ATAPS Provider.

- GP arranges an appointment with the patient and conducts a mental health review.
- GP determines if the patient could benefit from additional sessions and completes the
- 'GP use only' section of the Progress Report.
- GP faxes the Progress Report to the WentWest secure fax no. 02 8208 9941.
- WentWest receives the Progress Report and contacts the nominated ATAPS provider to make arrangements for patient to continue treatment.

Treatment under ATAPS is for 12 sessions

“The ATAPS program requires identifying patients who are most vulnerable and prioritise services to the most appropriate patients...”

over a 12 month period. Under exceptional circumstances, an additional 6 sessions (18 Sessions in total) can be provided to a patient.

WentWest has engaged with over 90 mental health clinicians throughout the western Sydney LHD who are contracted to deliver ATAPS services. WentWest reviews and selects clinicians based on qualifications, experience, community needs as well as geographical location to assist the primary health sector and local referring agents. You can search for ATAPS Providers by going to the website www.wentwest.com.au/mentalhealth. Additionally WentWest employs 4 clinicians who are co-located within Local Health District sites to assist in service gaps and compliment the ATAPS services to existing community mental health services.

The ATAPS program requires identifying patients who are most vulnerable and prioritise services to the most appropriate patients. This is prioritised based on referral information, including Mental Health Treatment plan and Patient's Health Care Card. Referrals that are not appropriate for ATAPS are passed on to the selected ATAPS providers, however the patient is seen under Better Access – Medicare pro-

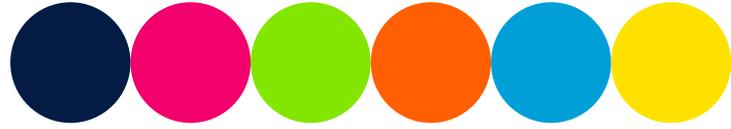
gram, which may result in the patient having to pay a gap fee for services.

Additionally patients who require intensive and urgent treatment can be referred via the ATAPS priority referral services, WentWest is able to respond to referrals for people at risk of suicide by having such referrals assigned to our employed clinicians, who are able to respond within 24 hours and provide an appointment within 72 hours.

Patients under the ATAPS Priority Referral services are eligible to receive up to 12 sessions in a 2 month period.

For more information please contact the Mental Health team at WentWest ataps@wentwest.com.au or 8811 7100.

Visit our website www.wentwest.com.au/mentalhealth



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Connecting health to meet local needs



**AUSTRALIA'S FIRST EVER AUTISM FRIENDLY PERFORMANCE OF THE LION KING
Saturday 14 June 2014, Capitol Theatre Sydney**

Autism Awareness Australia is thrilled to be partnering with Disney to bring you Australia's first ever autism friendly performance of THE LION KING!

This specially adapted performance will be suitable for individuals on the autism spectrum and their families, to enjoy the award-winning production in a friendly and supportive environment.

Slight adjustments to the production include removal of strobe lighting, reduction of any jarring sounds and lights focused into the audience, house lights being dimmed and flexibility to bring your own snacks.

Trained staff will be on hand, and dedicated quiet and activity areas set up, should anyone need to leave their seats.

Commenting on this special event, Autism Awareness Australia CEO, Nicole Rogerson, said, "We are delighted to be working with Disney to bring you this very special performance. It's encouraging to see iconic organisations be so open and welcoming to the autism community. We know parents will love the opportunity to have a fun day out with the whole family!"

The Lion King is the first major musical to hold an autism friendly performance in Australia, having already held successful performances in New York, London, Houston & Pittsburgh.

Tickets go on sale 9am Thursday, 24 October 2013 via a dedicated event website www.lionkingautismfriendly.com.au. Seats are limited and we urge everyone to be quick to avoid disappointment. For more information, please contact Elizabeth Sarian Elizabeth@autismawareness.com.au 0402 461 555

For more information about Autism Awareness Australia visit www.autismawareness.com.au

report on the society for the study of behavioural phenotypes conference – september 2013...

*Dr Peter Wurth,
Psychiatrist with Special Interest in
Intellectual Disability*

This international but modest, friendly, well-organised meeting was held in the beautiful town of Stellenbosch, 50km outside Cape Town. It was a very stimulating multi-disciplinary event which updated the exciting developments in the neurobiology and genetics of behaviour. As the only psychiatrist from Australia attending, I would like to share the highlights..

Chris Oliver, neuropsychologist and director of the Cerebra Institute, Birmingham, presented on both the fundamentals of behavioural phenotypes and the management of behavioural problems in neurodevelopmental disorders and genetic syndromes. He noted that the term 'challenging behaviour' is now outmoded given the lack of specificity, and prefers to describe individual behaviours such as self-injury and its various subtypes. Operant conditioning and other psychological models of the aetiology of these behaviours fail to take into account the wide variety of patterns of behavioural disorders seen in different genetic syndromes. Examples include high rates of self-injury in Smith Magenis Syndrome (SMS) and Cornelia de Lange Syndrome (CdLS), but low rates of aggression, with a reverse pattern more typical of Angelmans syndrome. Aggression tends to be low in Williams and Down syndrome. The aggression seen in Angelmans appears to be particularly attention-seeking, consisting more of grabbing and pulling than of striking. Increased rates of autism spectrum disorder (ASD) seen in different syndromes are not explained by severity of intellectual disability (ID). In SMS the constant drive for parental contact combined with an inverted melatonin cycle creates particular distress for parents. There is a need to pursue genetic diagnosis where possible, in order to pursue more accurate understanding and behavioural management, although 50% of individuals with ID remain undiagnosed. In a second talk he noted the high prevalence of severe behavioural disorders in severe ID, ASD, and in some genetic disorders, and that there is an 84% persistence of behavioural problems over a 20-year period! He is interested in the role of pain, and e.g. in patients with CdLS. While reflux is the commonest cause of pain in this popu-

lation, there are many others. He highlighted the use of the FLACC Scale, standing for Face, Legs, Activity, Crying and Consolability for assessment of pain in non-verbal individuals (<http://bcmartin.yolasite.com/resources/FLACCSCALE.pdf>). He noted a variety of behavioural signs suggestive of reflux, such as excess salivation, bruxism, thirst, scratching of the throat and chest, bad breath, dental problems, and episodes of otitis media.

Carole Samango-Sprouse, Director, Neurodevelopmental Diagnostic Center for Young Children, Maryland, presented on Klinefelters disorder (47XXY), which occurs 1/500, with considerable under diagnosis. They can have subtle ASDs. There are androgen receptors in the frontal and temporal lobes. A double blind controlled trial of early androgen treatment showed significant improvements in performance at 3, 6 and 9 years.

Alex von Gontard from Hamburg presented on incontinence of urine and faeces in Angelman and Rett disorders, noting high rates in both, probably secondary to the severity of ID. He advocated ultrasound as the preferred investigation, which can show thickened bladder wall, increased residual volume and the presence of faecal impaction. Management can proceed along standard lines using an alarm, desmopressin, anticholinergics and laxatives.

VCFS (22q11 deletion syndrome) was a subject of a presentation by psychiatrist Dr. Evers from the Netherlands. He noted the high prevalence of ASD and ADHD in childhood, with cognitive decline in a subgroup in adolescence, especially those who subsequently develop psychosis. There is a 50% reduction in expression of the COMT gene, leading to less metabolism of and increased levels of dopamine and noradrenalin neurotransmitters. Bipolar disorder and schizophrenia are common.

Jim Harris from Johns Hopkins University described brain structural abnormalities in Lesch Nyhan Syndrome, a syndrome first described in 1973. There is reduced cortical volume and thickness, especially in the medial orbito-frontal region and anterior cingulate gyrus, areas associated with emotional regulation and hyperactivity. Stereo-

typed, automatic behaviours are common, as is severe self-injury. Management is unsatisfactory, with hyperuricaemia responding to treatment with allopurinol, but without any improvement on behaviour.

Flora Tassone from UC Davis has found that there are significant numbers of copy number variations in Fragile X pre-mutation carriers, suggesting a 'two hit model of phenotypic variability'. This was a theme throughout the conference, namely that variability in the phenotype in a given syndrome may be explained by a second hit, leading to recommendations for array CGH testing even in individuals with defined genetic abnormalities such as DS and Fragile X. Individuals with the pre-mutation for Fragile X are prone to FXPOI and FXTAS but some are also prone to higher rates of autism, epilepsy, migraine and psychopathology. Individuals with the pre-mutation (55-200 CGG repeats) have an excess of micro RNA as a result of reduced binding to FMRP, which is in lower concentrations. This excess RNA leads to excessive production of neurotransmitters. 20% of a sample of 50 pre-mutation carriers harboured novel genomic events not observed in 8000 normal individuals.

“90% of children with FASD are in developing countries. South Africa has >10 % incidence...”

Catherine Lord from New York presented on syndromal and non-syndromal ASD. 20-40% of ASD is secondary to an identified genetic syndrome. She noted that there is still a major problem in defining the essence of autism, other than as a cluster of behaviour. DSM5 argued intensively about the diagnostic criteria for ASD. The diagnoses of Asperger's and PDDNos have been discarded. Communication difficulties have been collapsed into the social deficits, with a second criteria for repetitive behaviours or interests. Substantial impairment in expressive communication warrants a second diagnosis. The DSM5 subcommittee noted that from twelve sites, with the same data on autism screening questionnaires such as the ADOS, there was extremely wide variation between diagnoses, with some cen-



tres reporting high rates of Asperger's and others reporting none. The variability was due to the diagnostician rather than the patient population. There has been a major outcry from consumer groups about the abolition of the diagnosis of Asperger's disorder. Specifiers can be added, such as With Rett disorder, Fragile X, seizures etc. Onset must be in early childhood, not necessarily at less than 3 years, and individuals must continue to exhibit impairment. The new criteria favour sensitivity over specificity.

Day 2 started with an extended session on Foetal Alcohol Spectrum disorder (FASD). Western Cape in South Africa has the highest incidence in the world. 90% of children with FASD are in developing countries. South Africa has >10 % incidence, compared to Italy with 2%. It is a disease of the poor, with contributions from environmental adversity and malnutrition on top of alcohol exposure. The full syndrome represents the extreme end of the spectrum, when significant dysmorphic features are found. Identification of FASD children is therefore difficult. There are profound deficits in cognitive, motor and behavioural functions. Alcohol affects all stages of brain development, and the final picture is very heterogenous. Intellectual deficits are typically in the borderline to mild range. Behaviourally there is much overlap with ADHD. Social skills are poor. Dysmorphic features in FAS include thin upper lip, flat philtrum and flat mid-face. Affected individuals have a significantly increased risk of adult alcohol abuse. There is significant loss of white matter integrity on MRI scanning in affected infants; affected children fail to condition to eye blink; three-dimensional photography can successfully identify subtle dysmorphic features and identify affected children; and affected individuals performed significantly worse on the Reading the Mind in the Eyes tests, after controlling for IQ and executive function, suggesting a deficit in higher order Theory of Mind function. A

UK national clinic for individuals with FASD was established in 2009, offering a two-day comprehensive assessment of children and adults. Higher rates of ADHD and ASD were found. 3D photo recognition is central in identifying the characteristic dysmorphology. The majority of the attendees were adopted, and all of the adults had a forensic history.

André Strydom presented on The Londowns Consortium, a multidisciplinary investigation into cognition and Alzheimer's disease in Down syndrome (DS). 100% of individuals with DS have Alzheimer pathology at the age of 35, with 50% showing clinical dementia from the age of 50. It is unknown what protects the other 50%. Of 340 patients studied, the youngest with dementia was 32. Trisomy 21 produces an overdose of 300 normal genes.

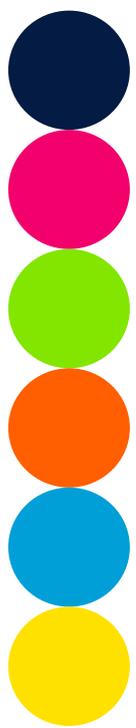
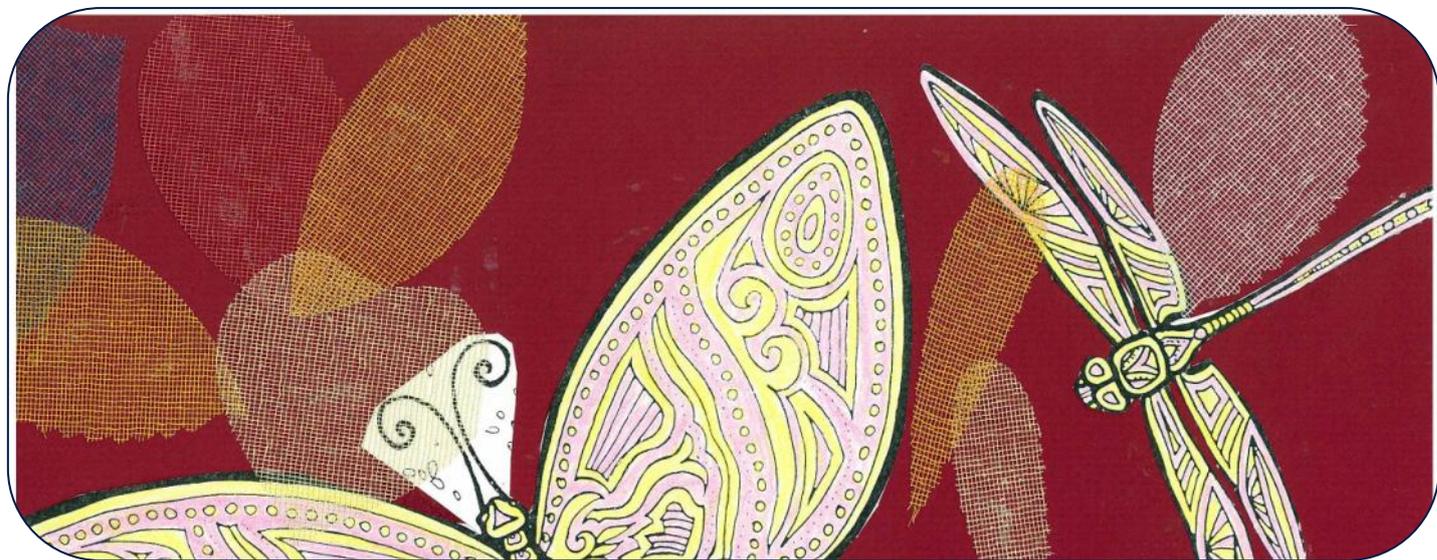
There were several presentations on Tuberculous Sclerosis Complex (TSC). TOSCA, the TS registry to increase disease awareness, is an international retrospective and prospective disease registry, assessing manifestations, interventions and outcomes, with particular focus in Europe on a trial of everolimus, an mTOR inhibitor. This medication has been found to shrink both renal and brain tumours, so long as treatment is maintained. Work is underway on the impact on epilepsy, and perhaps shortly on neuropsychiatric manifestations. The goal is to enroll 2000 patients of the estimated 2 million sufferers worldwide. The TAND checklist, (TSC Associated Neuropsychiatric Disorders) is under development, modelled on a similar scale, the HAND which is used in individuals with HIV. IQ is normal in 50%, 20% have a mild to severe ID and 30% are in the profound range. Aggression is common. 50% have ASD and 30-50% ADHD. Epilepsy affects 75-90%. Only 18% TSC patients in the UK are ever assessed for TAND. This checklist will cover ten domains, takes around 10-15

minutes and annual review will be recommended. Early results of the current pilot project are promising. Challenging behaviours of self-injury and aggression in TSC were found to be strongly persistent over time. There is huge phenotypic variability in this condition. Rates of SIB across different studies vary from 10-40%, and aggression from 13-58%. Risk factors include severe ID, ASD, ADHD, male sex, and possibly pain secondary to brain and kidney tumours.

Petrus de Vries who hosted the meeting gave a very comprehensive presentation on the neuropsychiatry of TSC. 70% of cases are sporadic, with 30% autosomal dominant. Both the TSC 1 and TSC 2 genes, found in 90% of cases, can produce the condition, as a result of the TSC 1 and TSC 2 proteins binding together. This combined protein blocks the inhibition of production of mTOR, the concentration of which rises dramatically, creating widespread overgrowth, resulting in tumours and other manifestations. Rapamycin, a streptomycin-like antibiotic discovered on Easter Island, shrinks these lesions and has been licensed to treat the angiomyolipomata which occur in the kidney. It appears to be effective against SEGAs, (the subependymal giant cell astrocytomata) that occur in the brain. These often present late, and regular MRI surveillance is required. Excessive suppression of mTOR can cause problems of memory, but mTOR activity is currently unmeasurable.

Randi Hagerman gave a very comprehensive and stimulating talk on molecularly targeted treatments for genetic disorders. Rett syndrome has a frequency of 1/10,000 females. There is a reduction in MeCP2 which produces a GABA/glutamate imbalance, and reduced levels of BDNF and PSD95. BDNF stimulates neuronal connectivity. Memantine and dextromethorphan trials are underway. Insulin Growth Factor 1 stimulates the production of BDNF. Therapeutic trials are underway.





The Down Syndrome mouse is a close model. There is excess GABA, and GABAa antagonist trials are underway. Both Lithium and fluoxetine down-regulate mTOR and restores neurogenesis in adult mice with Down syndrome. Exercise stimulates neurogenesis. However a trial of memantine in DS failed and some patients got worse. Antioxidants can be helpful and melatonin is a potent antioxidant. She emphasised the importance of treating the epilepsy that is common in autism. ADHD in autism often responds better to clonidine than to stimulants, although the latter can be helpful. Sleep disorders can respond to melatonin. Both risperidone and aripiperazole are FDA approved for autism. Serotonin synthesis is reduced in autism, hence the role for SSRIs and buspirone. The Early Start Denver model of intensive intervention from the age of 2 has shown that subsequent EEGs on a face recognition task are normal. However no baseline measurements were obtained, so it is not yet known if this Early Start program normalises a previous abnormality. We need to add learning programs to drug therapy to capitalise on any subsequent improved potential.

mares in REM sleep, prominent in the later part of the night. In the early years there is far more REM than non-REM sleep, but only 20% of sleep in adults is REM. Obstructive sleep apnoea (OSA) reduces executive functioning, lowers mood and possibly IQ, impairs immune function and retards growth. Recurrent hypoxia has much more significant effects than chronic hypoxia, with recurrent re-oxidation causing oxidative stress and apoptosis. OSA is common in Downs, in VCFS post-pharyngoplasty and in Pierre Robin syndrome. However there is no reduction in IQ in this latter syndrome if obstructive sleep apnoea is treated early. Time in neonatal ICU delays the onset of melatonin rhythms. Multiple medical comorbidities adversely affect sleep. Many syndromes have specific problems, such as the morning melatonin peak in Smith Magenis syndrome, which can be treated with beta-blockers at times, with melatonin often unhelpful. Both morning light therapy and modafinil can help wake the patient. Individuals with autism have multiple sleep problems. Patients with Angelmans syndrome can benefit from melatonin, but some are slow metabolisers and require a low dose. Individuals with cerebral palsy can wake and startle as the result of increased muscle tone, which can be treated with a nighttime dose of baclofen or diazepam. Treatment with melatonin reduces sleep latency, but is not helpful with sleep consolidation. Movement and light, even low lights such as from a phone, can turn off melatonin. Melatonin lowers seizure threshold and can interfere with SSRIs and warfarin. She emphasised the importance of fine detail in understanding the daily routines, which often provides clues to effective behavioural management.

range of programs of early intervention for children with ASDs that show moderate and helpful improvement across the board but with wide individual variation. Improvement is only in those skills focused upon, with poor generalisation to other areas, and persistence of benefit is poor. Benefits are greater in those with a higher IQ and better language skills, and lessen where families are under significant stress. Most follow-up studies have been limited to 6-12 months. The major predictor of long-term outcome is baseline characteristics. The UK website 'Research Autism' summarises the evidence from current research. She noted that the mainstay of treatment for behavioural problems has focused on a reduction of attention for inappropriate behaviour and an increase in attention for positive and adaptive behaviours. But the literature is biased towards positive results and this is typically much easier in theory than in practice. Studying behavioural phenotypes is important and illustrates the extent to which accurate knowledge of the underlying aetiology can guide psychological, educational and medical interventions. She noted that there is an increased prevalence of autism with paternal age over 40, a possible contributor to the apparently increasing prevalence of autism in the community. The website <http://deevybee.blogspot.com> is a good source of rational analysis of the many claims for successful intervention made on the internet.

In Conclusion, the conference emphasised the increasing relevance of making a diagnosis of the aetiology of the ID and rapidly increasing relevance for targeted treatments across all domains of intervention - psychological, educational, general medical and specific molecularly targeted treatments. The next conference is in New York from 10-13th October 2014 and London in 2015.

The conference closed with Pat Howlin presenting on psychological and educational intervention for ASD. There is a

“the conference emphasised rapidly increasing relevance for targeted treatments across all domains of intervention...”

Honey Heussler, Developmental Paediatrician from Brisbane, gave an overview of the management of sleep disorders in neurodevelopmental disorders. Poor sleep adversely affects intracellular signaling and mitochondrial function. Parasomnias occur in deep sleep, mostly early in the night, and night-

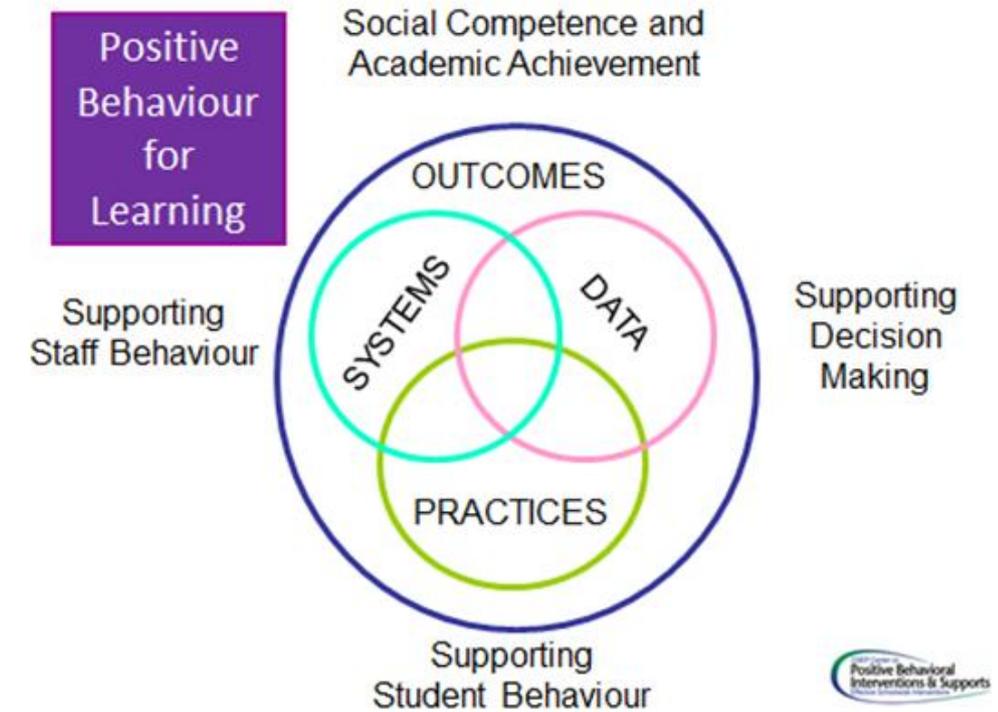
using the positive behaviour for learning framework to meet the academic and social needs of students with special needs...

**Leanne Neville -
PBL Project Officer,
Public Schools NSW**

Positive Behaviour for Learning (PBL) is a systems approach that addresses the diverse academic and social needs of students in schools to support them achieving outcomes that will enable them to be successful. PBL is a multi-tiered framework that guides the establishment of a continuum of supports that may be modified to meet the needs of ALL students. Critically, Positive Behaviour for Learning emphasises a problem solving approach focused on building the capability of teachers to (1) recognise student learning and support needs (2) respect learner diversity and (3) respond effectively to student need.

School-wide Universal Prevention reinforces one of the most important and powerful aspects of a whole school systems approach to behaviour and academic learning – the prevention of problems. When both academic and behavioural instruction are consistently utilised school-wide and in the classroom, it is easier to identify where learning errors might be occurring as well as how to correct them. Effective classroom management and instruction are critical components of Universal Prevention. When implemented systematically, the majority of students (80-90%) will be sufficiently supported by the prevention strategies implemented at this level.

At the Advanced Tiers level, students who are unresponsive to universal prevention strategies are considered at risk, and therefore provided with more specialised support beyond the school-wide plan. Here the PBL / Learning and Support team focuses on reducing the number of existing cases of problem behaviours by establishing efficient and rapid responses including differentiated delivery of the social and academic curriculum. Small group targeted interventions are characterised by instruction that is more specific. The goal is to assist students to build essential skills, reduce or prevent the likelihood of problem behaviour occurrences and to enable these students to be supported by the school-wide PBL effort. When universal prevention is sufficiently embedded, there will often remain a small proportion of students who will



require more personalised and intensive intervention and support. These students have complex needs and often present with a range of disabilities. Here PBL/ Learning and Support teams work with families and other support agencies with a focus upon reducing the intensity and or complexity of existing cases of problem behaviour by providing supports that are: function based; contextually appropriate and person centred; strength based and instructionally oriented; and linked to the school-wide universal prevention approach.

“PBL provides a framework to organise and plan school-wide support and interventions to meet the specific needs of students in the school setting...”

PBL provides a framework to organise and plan school-wide support and interventions to meet the specific needs of students in the school setting, both broadly and when additional needs arise, with small group and individual student interventions. The application of a combined data, systems, practices approach enables schools to

organise their resources effectively and address the specific needs by making data based decisions, using evidence based practices and developing effective, efficient systems that support staff to implement, monitor and manage interventions across a multi-tiered continuum. This approach enables schools to braid together a wide range of initiatives and policies into one continuum that can be modified in intensity to meet the academic and social needs of all students.

PBL is supported by a large body of research undertaken over 20 years that provides strong evidence for its effectiveness (Richter, Lewis and Hagar, 2011). A specific PBL research collaboration with the University of Western Sydney began in 2006. This project involved 28 schools in the area formerly referred to by the Department of Education and Communities as Western Sydney Region. The success of that project led to a major longitudinal study funded by the Australian Research Council and the Department of Education and Communities. The study, *Enabling schooling success: Psycho-social drivers and the impact of positive behaviour for learning intervention on behaviour, well-being, academic engagement and achievement* will finish mid-2014 and will further enhance our understanding of the implementation of PBL in Australian schools.

Applying the framework to a broad range of settings including Schools for Specific Purposes (SSPs)

Currently there are more than 800 schools across NSW Public Schools (representing 36% of the State) that are trained to implement Positive Behaviour for Learning. This includes 32 Schools for Specific Purposes that service students with a range of disability and complex learning and behavioural needs. One of the key advantages to using the PBL framework is its broad application to a wide range of settings and the capacity for schools to modify the intensity of support provided across the multi-tiered continuum. Whilst Universal school-wide support is made up of essential features such as developing school-wide expectations and a teaching matrix from which to explicitly teach and reinforce expected behaviours and social skills, the delivery of these in terms of frequency, form and structure can be modified and intensified to suit the needs of the students and the setting. For example in an SSP for students with intellectual disability, the implementation of a universal school-wide strategy often necessitates the implementation of a communication program to support staff in teaching all students to develop essential communication skills and to learn the school-wide expectations. So whilst the core features of implementing PBL and the science of behaviour remain the same, the context influences the delivery.

Implementing the essential features of PBL: Considerations for intensification of support across the multi-tiered continuum

Universal Prevention



- Learning adjustments provided to meet differing needs and to suit communication, cognitive, social and emotional, physical and developmental level
- Explicit teaching methods to address individual learning needs e.g. communication supports, sensory considerations in order to facilitate the understanding of school-wide expectations
- Increased opportunities across settings in the school and beyond to practice and promote generalisation of skills
- Responses to behaviour – consideration of function of behaviour, teaching intensified and modified to correct learning errors
- Staff training and commitment is essential. Strong focus on building staff capability to understand, recognise, respect and respond to the behaviour and learning needs of students specific to their context

Advanced Tiers - Targeted Support

- Small group intervention – targeted at class level and based on student need

- Staff capacity building through mentoring arrangements

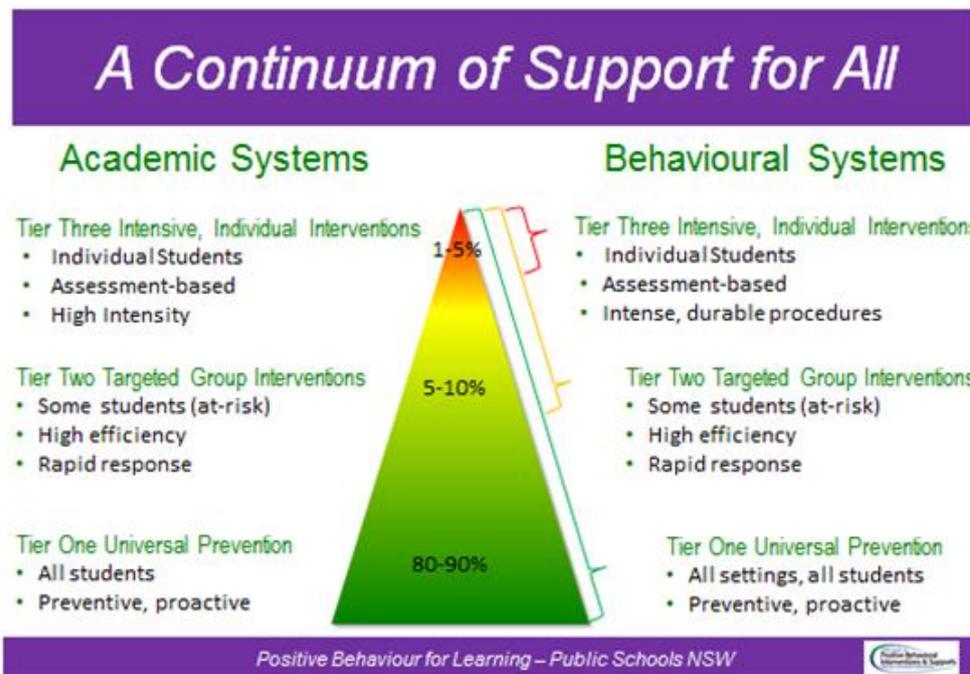
Advanced Tiers - Intensive Personalised Support

- Increased complexity of clientele in SSPs due to level of disability, emotional and behavioural disorders, trauma and multiple diagnoses and impact of these variables on behaviour
- Support for teachers – high level of professional development in understanding behaviour and providing behaviour support to re-engage students in learning
- Required flexibility in learning programs
- Focus on nurturing and supporting staff and student well-being

An Exemplar: Applying the PBL framework to a School for Specific Purposes (SSP)

Halinda School is an exemplar of an holistic approach to education and the implementation of the PBL framework in a special needs setting that effectively braids together initiatives into an integrated system of support that meets the social and academic needs of all students and supports and values all stakeholders. Halinda School is positioned in Whalan, Western Sydney and services students with diverse abilities, accommodating and adjusting for a range of disabilities including Autism, Physical and Moderate to Severe Intellectual Disabilities. Led by Principal Jan Eccleston, the school has worked systematically to develop a multi-tiered system of support, developing a positive school culture and climate for staff, students, family and community. Having a large number of students with high needs requires an intensification of the support provided across the continuum. Staff has been supported to shift to a problem solving approach that is positive and strengths based through effective communication and consultation, ongoing professional development, a culture of inclusivity and strong community partnerships.

In addressing the essential features of school-wide Universal Prevention strate-



gies, Halinda School has focused on student engagement and well-being by implementing strategies that address learning dispositions, social functioning, happiness and satisfaction. This has seen the restructuring of playgrounds; the implementation of a high level of visual communication; and staff training to improve their understanding of students' behaviour. Staff have developed a sense of shared responsibility for all students in the school. The whole school focus on engagement has seen the effective use of data to track and address the needs of students with low engagement who require a more personalised approach and those with high engagement in need of additional learning challenges. Aligned with the essential features of PBL Universal Prevention, there is a strong emphasis on effective acknowledgement and reinforcement of appropriate behaviour and other areas of learning such as communication, social skills and functional literacy.



“Halinda School has focused on student engagement and well-being by implementing strategies that address learning dispositions, social functioning, happiness and satisfaction...”

Targeted group interventions have focussed on family engagement. Halinda School understands the impact of parent connection and works closely with families and community groups in a spirit of collaboration. Families are provided with many opportunities to support them and their children and address specific identified needs. These include outreach programs offered through TAFE, communication workshops offered by the Department of Ageing, Disability and Home Care, the development of a community garden, and bus tours to support students' transition to post school options. Additional programs to support students include signing choir, music groups, and a wheelchair buddy system have been very successful in supporting students to develop skills around safety, responsibility and empathy. A sense of *‘being, belonging and becoming’* is deeply ingrained in the school culture.

Where intensive personalised support is required, staff at Halinda School conduct a ‘360 degree ecological inventory’ including home and school environments, support services involvement, the student's learning history, skill levels and functional behaviour analysis. This approach is supported by current research (Howard I. Bath, 2009; Uniting Care Children, Young People and Families - Social Justice Unit, 2011; Department of Employment, Education and Training, 2004). The analysis of the gathered information, behaviour data and research literature form the basis for planning interventions using a student ‘strengths based’ approach and includes the monitoring of progress and effectiveness.

Redefining the purpose of school at this particular point in time for the individual student may be required if a student's emotional status, is compromised. Starting from where the student is in terms of his/her emotional needs facilitates the development of trust, emotional security, self-regulation and resilience. Principal Jan Eccleston notes that this process is important in developing ‘the quality school life picture’ for the rehabilitation and education of the student.

Footnote: The Public Schools NSW Positive Behaviour for Learning leadership team are working collaboratively with cross-functional and interagency teams to develop an effective and integrated support framework that improves the efficiency and effectiveness of support provided for students with additional needs such as disability and mental health needs including the impact of trauma.

In addition an Advanced Tiers Project team has been established and is currently working to develop consistent content state-wide to continue to build the capability of school teams and PBL coaches across NSW.

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PBL wiki: <http://pbisupport.pbworks.com>

PBIS: www.pbis.org

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collaboration, not the emperors new clothes..

Terry Sarten
CHW School-Link Coordinator

The calls for organisations to work together are becoming louder as the volume and complexity of issues creates elaborate pathways between services, agencies and consumers. This is as evident in the disability sector as it is in many others. The current CHW Stepping Stones project that combines expertise in health, education and disability services to deliver and evaluate a parent focused programme has shown how shared knowledge benefits all involved. Often the difficulties of moving from talking about joined up work to developing a process to make this happen can be hampered by misleading terminology. It may be that what is needed is cooperation, coordination rather than collaboration.

The word collaboration is often used as the gold standard for interagency work but sometimes it is the wrong label, serving to disguise what is actually happening. Like the Emperor's New Clothes, pseudo collaborations can create the impression something is there when it is not. This can be very damaging to relationships, resulting in frustration and the perception that a project has failed when in fact it may actually be operating in another guise. This has particular relevance for those working with intellectual disability with mental health problems because of the complexity of the clinical challenges that can present. There is agreement that these require input from a range of sectors: mental health services, health, disability, education, families and non-government agencies need to work together as no single perspective is able to see the whole picture. In the chapter on The Community clinician and interagency collaboration in Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities – A Framework for Profession-

al Practice the authors note that "it is often assumed that the term collaboration is understood and that clinicians are familiar with what constitutes collaborative practice – believing that they function is a collaborative framework when this is not necessarily the case."

Collaboration can be described as a process of individuals and groups working together for mutual benefit, with an emphasis on building bridges between people and agencies to bring together the needed clinical skills and resources for the benefit of the patient or client. (Darlington et al, 2005; Howarth & Morrison, 2007; Padgett et al 2004; Sloper 2004).

The 'silo' effect evident in most organisational systems can be huge barrier to joined-up work both within organisations and the external agencies and service providers they interact with. Attempts to negotiate beyond this structural malaise can be very testing. Being clear from the start about the type of relationship needed to create change can be valuable for all involved.

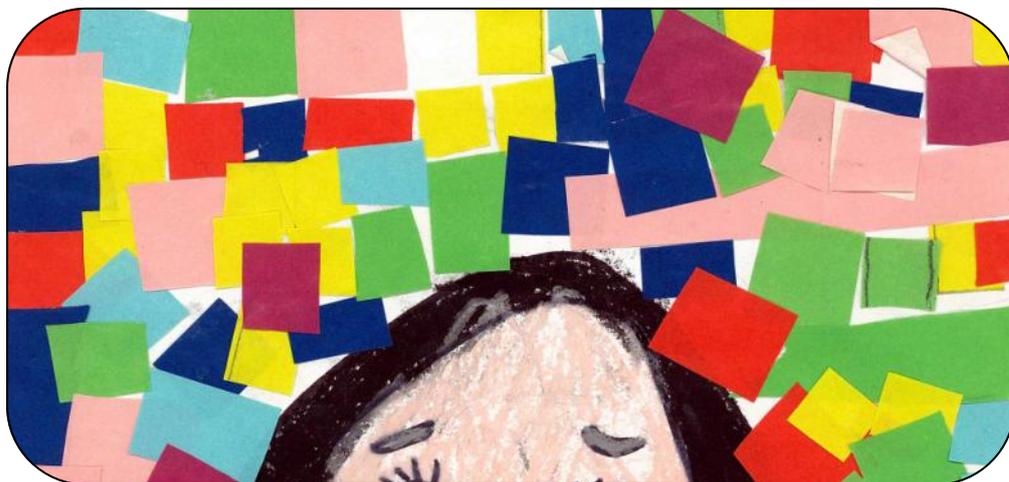
There are various types of joined working models that sit along a continuum that covers coordination, cooperation, consultation and partnerships. Thinking an organisation is doing one of these when in fact it is doing something else can lead to confusion and a loss of focus. It is important at the initiation of a project to be clear which of these models will be used with agreement on descriptive language to avoid misunderstanding as the project evolves. Collaboration, coordination, cooperation, partnerships and consultation are equal valid ways of working across boundaries but how they operate within different structures is principally defined by the power dynamic. It is the organisational willingness to concede power that defines both the process and outcomes.

Consultation at its best provides a path for meaningful dialogue. Recognising it is the organisation that initiates consultation that has the power to accept or reject the responses, to be genuine the process must be built on acknowledging the nature of the exchange and how what is learned can be applied to practice. Often consultation is maligned as a shallow ritual of engagement with no real desire to actually listen. Asking organisations and consumers for their thoughts if done well can promote change and lead to the development of other stages along the continuum but should not be confused with them.

Coordination can be defined as a negotiated willingness for organisations to work together around particular functions. For example it may be agreement on coordinated case management or referral. This requires a degree of shared decision making but does not usually require organisation to relinquish their power. It may not be operating in the same way as collaboration but it can be very effective in improving outcomes for consumers.

Cooperation works at a higher structural level where organisations have formal arrangements to connect aspects of their differing roles around shared activities rather than contesting ownership. This requires a degree of diluting power to allow all parties to work together. A classic example of this is when organisations apply criteria to service provision that clash with those of other organisations that can lead to consumers falling through the service gaps. Organisations that rely on specific diagnosis for admission to service may find themselves at odds with potential service allies that operate using another set of admission criteria, leaving the consumer stuck in the service gap. Adopting a cooperative model can mean better outcomes for those using the services and more effective use of resources but to be effective organisations need to concede some of their power and share resources. This ideal can be confounded by competitive funding models that can inhibit cooperation.

Collaboration in its truest form requires organisations to trade away their power in exchange for the potential of working together. When a relationship is actually functioning collaboratively the rewards for all participating organisations and those receiving their services can be huge but getting there is not easy.



To be effective it must operate at all levels, from senior management to case workers and administrative staff. It requires considerable work to set up and a long term commitment to maintain. Because of the time frames involved the process can falter when its champions leave an organisation or restructuring throws a spanner in the works.

Within collaboration there are subsets of function that like the frame of a house provide a foundation for engagement. Advisory committees may support organisation or programmes with advice and technical assistance. Affiliation connects organisations with similar interest and alliances are the alignment of shared interests. A coalition is usually a specific issue focused arrangement. Co-sponsoring describes organisation sharing participation in a programme or service but this may not be as equals. Networks provide support and a medium for the exchange of ideas.

The term partnership is frequently used to describe all the variations above because it requires an exchange of ideas and functions in order to make any of them work. This dilutes the special meaning of partnership and its value to organisations. Partnerships function best when the partners agree to harness their institutional power together towards a common aim, recognising the need to overcome their diverse strengths and weaknesses if they are to succeed. In an environment where contestable funding pitches service against each other, partnerships can allow organisations to build alliances that benefit the communities they service. Unlike collaboration, partnerships allow organisations to find ways to work together that is not bound to function but to a shared philosophy.

All these models operate across a continuum have an equal value with some being a better fit to the situation than others. The

first step in considering which approach is appropriate is to look at what is needed by both the families and organisations. There may be conflicting pressures, very different focuses and abilities to respond to the presenting issues. Time and resources may be limited.

High level collaboration may not be essential or needed to facilitate a team approach to a particular group of cases and it may prove more resource effective to arrange a coordinated response that can react to the particular presenting issues. Alternatively, a cooperative arrangement could result in a more established way of working around systems. The long-term bigger picture issues may need the power of real collaborative effort to create change.



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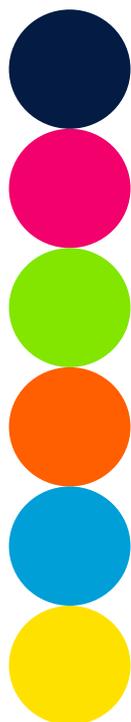
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neuropsychological profile of children with autistic spectrum disorders (ASD)...

Dr Phil Ray Senior Clinical Psychologist & Clinical Neuropsychologist, Psychological Medicine

Tsatsanis (2005) writes that autism is characterised by considerable clinical variability and that any approach to understanding autism where a single construct is adopted is highly suspect. Core deficits in autism are those of social development, verbal and nonverbal communication and behavioural difficulties. However, at the root of these core symptoms are impairments in cognition including joint attention, perceptual processing, sensory perception, attention, memory and executive functioning, each of which can vary greatly between each child. Overall, children with autism and other related conditions may share certain core features but their individual cognitive profiles and pathways to learning are highly individual.

Intellectual Profile

Several papers have identified specific differences in the cognitive profiles of children with ASD. The popular conception is that children with autism have impaired verbal functioning when compared with good visuo-spatial skills; while children with Asperger's have impaired visuo-spatial skills relative to normal verbal functioning (Miller et al, 2000). It is also hypothesised that children with high functioning autism have a higher overall IQ, generally greater than 70, but still have a higher visuo-spatial IQ relative to their verbal IQ (Gunter et al, 2002). However these profile findings are inconsistent. Mayes et al (2003) found that such discrepancies in children on the autistic spectrum were a function of age which diminished over time. Ghaziuddin et al (2004) found no such IQ discrepancies when testing a cohort of children with high-functioning autism. Overall Tsatsanis (2005) suggested that IQ profiles in autism should be seen as "scattered" and highly variable between children and that one should be cautious when making diagnostic interpretations from such profiles.

Sensory Perception

Ornitz et al (1968) identified a range of hypo and hypersensitivities in 150 participants with autism. This was interpreted as an inability to modulate sensory input which would then manifest itself in excited states of behaviour (e.g. hand flapping, spinning), inhibition and disinhibited

dysregulation. This inability to appropriately modulate, process and respond to external sensory stimuli is seen as one of the major factors that contribute to the social and communication deficits associated with autism (Ornitz et al, 1976).

High levels of variability in internal arousal states have also been identified as contributors to the responsiveness of children with autism to external stimuli. In 1992 Temple Grandin wrote about her profound hypersensitivity to touch and sound. When in a high state of arousal hand flapping and whirling can provide much needed sensory input when the present external environment is lacking. By the same token moments of significant inhibition, or "shutting down" as Tsatsanis (2005) describes it, can also provide the desired quiet for the child with autism when the environment is overstimulating.

"Children's individual cognitive profiles and pathways to learning are highly individual..."

Rogers et al (2003) suggested that sensory perception is probably the most under researched area of autistic related behaviour, yet it is the one characteristic that consistently separates children with autism from developmentally matched controls. Behaviours include a preference for visual patterns, variability in reaction to sounds and sights, hypersensitivity to pain, cold, heat, and inappropriate use of objects such as licking, mouthing and peering. However, research has failed to find a significant relationship between sensory perceptual sensitivity and the severity of the autistic presentation but a relationship with adaptive behaviour has been demonstrated (Rogers, et al, 2003).

The neurological substrates thought to be responsible for sensory perception include the thalamus. The thalamus is traditionally referred to as the sensory gateway of the brain but it is also thought to be involved in multiple processes that take on the role of the transmission, tuning, and integrated processing of information (Tsatsanis, 2005). Tsatsanis et al (2003) found the

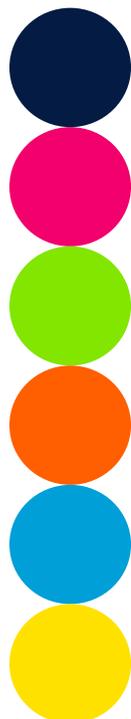
thalamus does not develop to the expected size in relation to the rest of the cortex in children with autism. Using neuropsychological testing and functional MRI, Nair et al (2013) found results that indicate involvement of abnormal thalamocortical connectivity in sociocommunicative and cognitive impairments in autism spectrum disorder. Therefore there is the suggestion of thalamic involvement both at an anatomical and a connectivity level.

However, attentional systems and theories which also involve the thalamus are thought to have superseded the emphasis on sensory processes. Recent thinking aims to understand how children with autism attend and select relevant stimuli. Townsend et al (1994) proposed that attention was a major area of deficit in children with autism where the coordination of attention and arousal systems are abnormally developed.

Attention

Information comes in a continual flow of external and internal stimuli. Attentional capacities involve the ability to override the impulse to attend to what is most attractive, striking or novel and to attend to what is required to meet our external and internal goals. In autism the intense focus on certain stimuli already provides a bias in attentional processing at the expense of more socially salient information. The focus on intense and repetitive activities heavily biases selective attentional skills at the detriment of what is required from the world around the child.

Sustained attention for repetitive visual information is thought to be relatively intact in children with autism (Garretson et al, 2001). However, Fantie et al (1998) found that attention was variable in children with Asperger's Syndrome which presented as inconsistent response patterns on attentional tasks. Attentional deficits in autism are typically displayed during more complex tasks that require selective attention and attentional shifts. Townsend et al (1996) found that adults with autism had significant difficulties in attentional shifting and ignoring irrelevant stimuli. Tsatsanis (2005) reported that this was interpreted as perseverative and an impairment in the ability to shift from one task modality to another. Mann & Walker (2003) suggested that



speed and expectancy were major factors. The idea was proposed that individuals with autism find it difficult to make rapid changes in their expectations so when stimuli and the necessary response changes they still perseveratively respond in the set way they have before.

This can of course be linked at an executive functioning level where there is an overall deficit in the central executive. Burack et al (1997) identified impairments in efficient task performance where deficits were found in the ability to selectively attend to what is relevant in the context of ignoring what is extraneous.

Developmentally, the concept of joint attention is significant for children with autism. Joint attention, acts to bring together attention for both environmental stimuli and other people the child is socialising with at the time. Deficits in both attention and social domains are theoretically proposed by Tsatsanis (2005) to be due to neuropsychological and cognitive deficits (Ozonoff et al, 1994). Adamson (1995) proposes that as infants coordinate their attention to objects and people (joint attention) this has significant implications for their ability to obtain a consistent means for expressing themselves, developing language, and other aspects of development. As a result, it is proposed that each child's attentional profile will be different, with varying levels of deficit on all aspects of attention including sustained, selective, divided, visual and verbal attention. Differing levels of processing speed, cognitive switching and impulsivity will also present. Therefore, due to the implications for cognitive ability, education and social skills, it is vital that a thorough cognitive profile is obtained to maximise treatment and outcomes for children with autism.

Memory

Children with autism are thought to learn best through rote learning and classical conditioning but show limited capacity for flexibility, abstraction and generalisability. For example, digit span and word list performance for unrelated words has been found to be normal (Bennetto et al, 1996) however recall of a semantically related list of words was impaired (Tager-Flusberg, 1991). When semantic cues are given, retrieval improves. This suggests that these word list impairments are not deficits in encoding but in free recall. Tsatsanis (2005) suggested that individuals with autism may encode words and their meanings but due to executive and attentional deficits, they employ inefficient encoding and retrieval

strategies. Minsheu et al (2001) found that tasks requiring a greater level of semantic organisation impact negatively on participants with autism.

Bennetto et al (1996) examined whether children with autism performed similarly to children with frontal lobe lesions. The participants consisted of children with high functioning autism and children with intellectual disability. The children all performed similarly but those with autism made more intrusion errors and overall profiled in a similar way to those with a frontal lobe head injury. Therefore, there may not be a problem with semantic or episodic memory per se but with organisation during encoding and retrieval and internal intrusions during encoding due to disinhibition. Renner et al (2003) found that children with autism had different encoding and retrieval styles as implicit and explicit memory was normal but pattern of recall was atypical. This is supported by Cabexa et al, 2000) who found in PET studies that episodic memory is associated with increased blood flow in the right frontal lobe.

Executive Function

The executive control theory has been used to explain executive dysfunction in children with autism. The executive control theory proposes that our ability to understand the mental states of others is a result of the development and use of executive functioning (Cundall, 2007). Cundall gave an example of this with the thought; 'I believe my friend sees my chocolate in the bowl'. This type of thought requires higher order functioning, including the ability to self-monitor, to monitor the behaviour of others, and to be able to plan and predict others' feelings, thoughts and behaviours. Cundall claimed that everyday behavioural, emotional, or social encounters such as these are generally presented as 'problems' to be solved by one's executive functions. Therefore, as children with autism commonly have difficulties in these areas, Cundall suggested that the primary deficit in the disorder is with executive functioning. Several studies have investigated executive functioning in children with autism and a mixed profile of difficulties has emerged, including difficulties with cognitive flexibility and planning.

Cognitive flexibility is the ability to adapt cognitive processing strategies to face new and unexpected conditions in the environment (Cañas, et al, 2003). It is also required to multi-task. Turner (1997) suggested that as restrictive, repetitive patterns of behaviour are key features of autism, one would predict that children

with autism would have significant difficulties with cognitive flexibility. Kleinhans, et al (2005) administered selected tests from the Delis-Kaplan Executive Function System (D-KEFS; Delis et al, 2001) and found that tasks requiring cognitive flexibility produced the most consistent deficits.

These findings have been supported elsewhere. Russell et al (2003) found that children with autism showed consistent failures in cognitive flexibility and perseverative behaviour. Rinehart et al (2001) suggested that the findings implicate the basal-ganglia and thalamocortical circuits which may underpin executive functioning in these children. This proposal was based on the work of Alexander et al (1986) who claimed that this brain region



plays a role in generating unique or novel responses and a range of studies has found that cognitive flexibility is a consistent deficit in children with autism.

neuroscience of caregiving: a seminar with Dr Daniel Hughes...

By Anders Hansson, Statewide Behaviour Intervention Service

“There is no fixed neuropsychological profile for disorders on the autistic spectrum...”

Planning abilities have also been highlighted as an executive dysfunction in children with autism (Hill, 2004). Hill suggested that planning requires an individual to create a plan of action for a task while simultaneously self-monitoring and maintaining that plan to ensure it is being executed. Hill also suggested that planning involves the ability to re-evaluate and update one's actions. Rumsey et al (1988) found deficits in planning and organisation on the Rey-Osterrieth Complex Figure test despite children showing an adequate ability to copy its component parts. Booth et al (2003) also used a drawing task to measure planning ability and found that children with autism tended to show both a detail-focused drawing style and planning deficits. Similarly, Ozonoff et al. (1991) administered two measures of planning - the Wisconsin Card Sorting Test (WCST; Berg, 1948) and the Tower Test (Boys et al, 1982). In this study 96% of the participants with autism were found to have executive functioning deficits compared with the control group. In particular, a lack of efficiency and poor planning were found.

Conclusions

There appears to be no doubt that children with autism present with a range of cognitive deficits. All facets of cognitive functioning have been found to be involved including memory, attention, intellectual ability and executive functioning. However, the research shows that there is no fixed neuropsychological profile for disorders on the autistic spectrum. Therefore, while the diagnostic requirements are fixed it is clear that each child's pattern of cognitive deficits is not. As a result, the only thing one can say with certainty is that each child with autism will likely have some form or a pattern of cognitive deficits. Exactly what that pattern or profile of deficits looks like will require further investigation.

Please visit www.schoolink.chw.edu.au for the references to this article.



Dan Hughes is a clinical psychologist from Pennsylvania, United States, who has been a pioneer in using attachment and neuroscience in resourcing adaptive and positive connections between traumatised children and

their parents or caregivers. His approach is family centred and offers very practical strategies for a wide range of professionals who work with vulnerable children and their relationship contexts. The principles of his approach apply to any context where social engagement is desired. Dan's seminar was organised by the *Australian Childhood Foundation* and was held at Sydney Convention Centre in Darling Harbour. I think most would agree with me when I say the event was exceptionally worthwhile and stimulating.

The first day focused on the brain in relation to the development of secure attachment relationships and how developmental trauma or chronic stress can interfere with this development. We learned that this can result in the affected person living in fear, distrusting others and being *defensive* rather than being *socially engaged* in their relationships. This can be devastating, with persistent feelings of shame and low self-worth stifling the person's ability to live their life as they would like.

The good news is that Dan's therapeutic approach, which focuses on the whole family, provides hope for breaking this pattern. The approach provides the person and their attachment figures (e.g. parents, carers, teachers, partners, therapist) with a therapeutic framework that promotes playfulness, acceptance, curiosity and empathy in their relationships.

Dan refers to this as PACE (Playfulness, Acceptance, Curiosity, Empathy). A playful stance provides a sense of safety from which the child can re-engage with the world and most importantly with their attachment figures. Acceptance refers to being able to engage non-judgementally with the person and accepting their subjective experience. This encourages a sense of trust and respect within the relationship.

A sense of curiosity within the PACE therapeutic model is vital to enable the exploration of presenting and emerging themes and introducing new meanings to the narrative for the person and their attachment figure/s.

The last “ingredient” of PACE – empathy – is required to enable the attachment figure to “empathise with” the person and allow the person to experience this.

This *intersubjective* experience is considered the central agent of change (Hughes, 2007).

On the second day, Dan explored the PACE therapeutic model further and shared his therapeutic experiences anecdotally using several video clips of PACE in action. This was invaluable and definitely the highlight of two wonderful days of professional development.

Dan is the author and co-author of several excellent books on the use of a brain-based attachment approach in therapy, parenting and relating, including

Hughes, D. A. (2006). Building the Bonds of Attachment: Awakening Love in Deeply Troubled Children. NJ: Jason Aronson Inc.

Hughes, D. A. (2007). Attachment-Focused Family Therapy. NY: W. W. Norton & Co.

Hughes, D. A. (2009). Principles of Attachment-Focused Parenting: Effective Ways to Care for Children. NY: W. W. Norton & Co.

Hughes, D. A. (2011). Attachment-Focused Family Therapy Workbook. NY: W. W. Norton & Co.

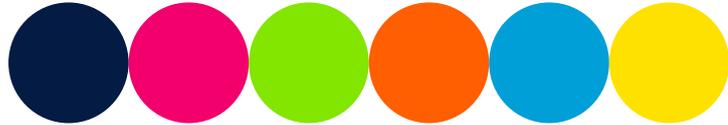
Hughes, D. A. & Baylin, J. (2012). Brain-Based Parenting: The Neuroscience of Caregiving for Healthy Attachment. NY: W. W. Norton & Co.

For more information about Dan and resources visit www.danielhughes.org.

Anders is a Senior Clinical Consultant with the Statewide Behaviour Intervention Service, which is part of the Clinical Innovation & Governance Directorate, ADHC, NSW Department of Family and Community Services.

The Regents of the University of California. (2013). Picture of Dan Hughes, retrieved September 9 from <https://www.uclaextension.edu/attachment/Pages/Gallery/hughes.jpg>

upcoming training...



Helping Families Change conference. Issues, strategies, and innovations related to parenting and family interventions. February 19-21, Sydney. \$1250. Visit the website for more information and to register. www.helpingfamilieschange.org

Minds Matter Conference presented by the University of New England seeks to discuss the mental health issues confronting rural and regional Australia. 3-5th April 2014. \$395. Aanuka Resort, Coffs Harbour NSW. Visit <http://www.une.edu.au/research/research-centres-and-institutes/crn-mental-health/minds-matter-conference> for more information. You can also contact Sandra Eccles on 6773 4515

Hanen TalkAbility supported by Autism Spectrum Australia. Various regions Sydney Metro, Illawarra and Central Coast. Visit www.autismspectrum.org.au/registration

Linking Up for Kids conference presented by ARACY. Sydney 14 - 15 April 2014. \$490-900. Building strong partnerships between health, hospital and education systems to enhance child and youth wellbeing- a vision for the future. For more information call 0418 283 397 or email nikki.abercrombie@aracy.org.au. www.childwellbeing2014.net.au

Macarthur Disability Service is delivering the following accredited training in 2014; Certificate IV in Disability, Diploma of Community Services (Mental Health), Advanced Diploma of Disability amongst some other management course. Contact the MDS training team on 4621 8400 or training2@mdservices.com.au.

Resourcing Families presents **Individualised funding in NSW: what it could mean for you.** Broken Hill. 26th February 2014. Free. 10am-12pm. Contact 9869 7753 or email info@resourcingfamilies.org.au

Childhood Trauma: Understanding the Basis of Change & Recovery 4-8 August 2014 Melbourne Convention Centre. Up to \$1600. visit www.childtraumacnf.org for more information.

NDS NSW State conference. *The future just ain't what it used to be.* 10-11th February. Sydney. Contact Miriam Sosin, Events Coordinator, on 02 9256 3133 or email miriam.sosin@nds.org.au or visit www.nds.org.au

47th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities. March 5-7th, 2014. Chicago, Illinois, United States of America. \$300. <http://kc.vanderbilt.edu/gatlinburg/>

Inclusion Training: An opportunity to have your say by Dr Christine Baxter for the *University of Sydney Centre for Disability Studies*. 21st February. \$50. 9.30-3.00pm. Contact 9036 3600 or email Margaret.carrick@sydney.edu.au

NSW ACI Intellectual Disability Network Forum. 7th March 2014. Free. 9-4pm. Register at www.aci.health.nsw.gov.au

transition forum 2013...

Transition Forum October 2013 at the Children's Hospital at Westmead

By Wendy Edmonds

Every year the Carer Support Program at the Children's Hospital at Westmead organises the Transition for Carers Forum. The forum is aimed at the carers of non-self-managing young people and it is held during Carers Week.

It can be a daunting, stressful and confusing process for these young people and their families/caregivers when transitioning from the paediatric to the adult health services as well as negotiating change in education or program options. The forum seeks to provide a range of information to support families through this time. Presenters covered topics including: the transition process from paediatric services, what happens when you reach adult health care, who can support this process with the family as they navigate the health service. Speakers also provided information on guardianship from the Office of the Public Guardian and post-school educational and program options.

After the presentations and lunch there



was an Expo where carers could access information and speak to representatives from various organisations that provide support or programs for non-self-managing young people. The organisations present included Ability Options Breakthru People Solutions, Achieve Australia, Afford, Department of Human Services and a partnership broker funded by DEEWR.

There were 37 attendees at this year's

forum. Some carers who had registered were unable to attend due to the bush fires which started in several areas around Sydney that day.

Evaluation of the event was positive with feedback showing the forum had increased attendee's knowledge about transition and that the topics covered were very relevant.

The forum will be held again on Friday October 17th 2014. The location will be at Doreen Dew Lecture Hall at the Children's Hospital at Westmead. This venue makes it possible to have teleconferencing participation for rural families who would like to hear the speakers.

Transition information nights for families are held twice a year in addition to the forum. These focus on transition within the health system. Information about the Forum, the transition evenings and the Carer Support Program can be found here <http://www.chw.edu.au/parents/csp/>

For further information please contact Wendy Edmonds or Kelly Bowler: 98453590

personalised learning and support for students with additional needs: every student every school...

Katrina Worrall

*Principal Psychologist,
NSW Department of Education and
Communities*

The NSW public school system is large and complex. In 2013 there are more than 740,000 students enrolled in more than 2,200 primary, secondary, central and special schools. More than 50,000 classrooms operate across the state each day.

Some students need additional support to access the full range of education opportunities and to achieve success. These additional learning and support needs may relate to a range of circumstances for the student, their family and their schools. They may be short term or ongoing throughout schooling. They may relate to disability or difficulties in learning or behaviour from a variety of causes.

Over time, a wide range of specialist services and programs have been put in place to provide additional support for students with disability and special needs in public schools.

These include:

- specialist services and programs targeted for individual students; and
- programs that provide specialist resources to schools to support students experiencing difficulties in learning.

These programs and services play an important part in the full range of services provided for all students in public schools. Concentrating efforts in highly specialised approaches for certain students, or for certain aspects of their learning and support in isolation, is no longer adequate.

Students with additional learning and support needs in our schools

Around 90,000 students, or 12% of the total NSW DEC school population, have a disability and/or additional needs relating to difficulties in learning or behaviour.

Of these 90,000 students:

- Around 35,000 (4.7% of all students) have a confirmed disability against the Department's criteria for its targeted specialist services: intellectual, physical, hearing, vision, mental health and autism.

- A further 55,000 (7.3% of all students) have additional needs relating to disability or difficulties in learning or behaviour, including dyslexia, reading and/or communication delay and attention deficit hyperactivity disorder (ADHD).

Over time, the proportion of students with confirmed disability enrolled in NSW public schools has increased from 1.9% in 1988 to 6% in 2011.

The changing profile of students

The number of students in NSW public schools with disability or additional learning and support needs has increased considerably in recent years. In particular, there has been a sharp increase in the number of students with autism spectrum disorders and students with mental health disorders.

The reasons for this growth are complex. However, the experience in NSW schools

is consistent with that of other education jurisdictions nationally and internationally.

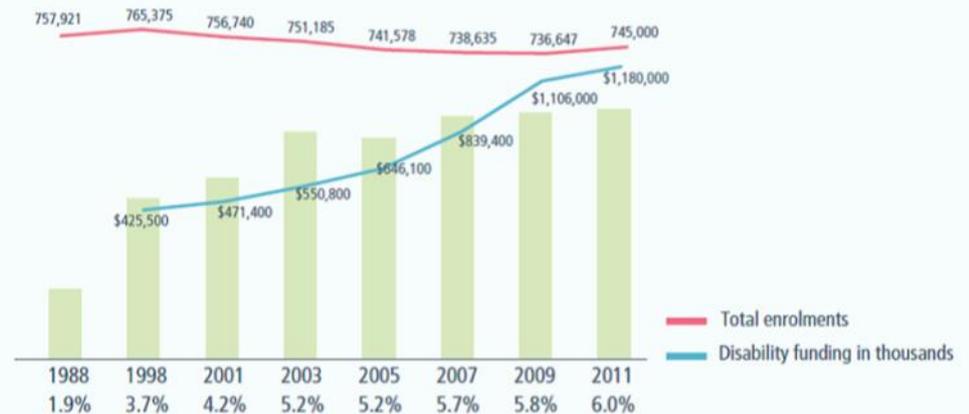
The changing nature of service delivery

Students with additional learning and support needs are enrolled in every school and are being taught in every classroom. The current specialist service model recognises the type of disability that a student has rather than the additional educational needs of each student.

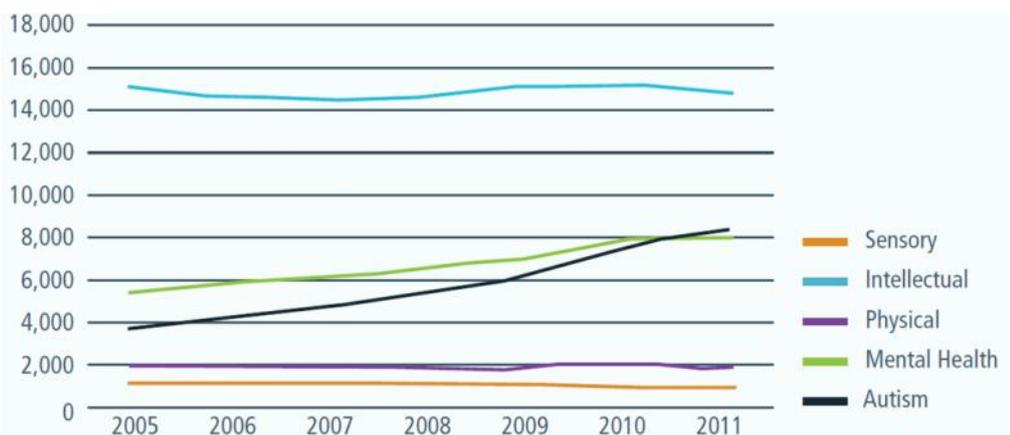
Lack of access to services in remote and rural areas of NSW is also reported by parents and schools to be a major challenge in providing additional support for students.

Obligations and expectations around disability

The introduction of the Disability Standards for Education in 2005 has contributed to changed expectations about access and participation in education for all students



Annual enrolment of students with confirmed disability – showing percentage of total enrolments



Students with confirmed disability in NSW government schools by disability type, 2005-2011

with disability. It has also changed expectations about how students with disability are supported to access learning experiences that their non-disabled peers take for granted.

“Over time, a wide range of specialist services and programs have been put in place to provide additional support for students with disability and special needs in public schools...”

In education, there is an increasing emphasis on every student acquiring a common set of core skills to equip them for further learning and adult life. Across the community there is also a growing emphasis on a ‘person-centred’ approach to the way services are provided to support the needs and aspirations of people with disability and their families.

Education is a key area of focus for the National Disability Strategy, together with other important areas such as health and wellbeing, personal and community support, rights protection, economic security and accessible communities. The need to find better ways of ensuring schools meet the additional learning and support needs of every student with disability is consistent with directions under this strategy.

How *Every Student Every School (ESES)* works

A specialist teacher is available in every mainstream school to support students with additional learning and support needs and their classroom teachers.

This is achieved through the re-organisation of some specialist support services. This reorganisation has directly allocated more than 1,800 existing specialist teachers to schools. These allocations will be adjusted every three years. Funding will be adjusted annually to reflect changes in school needs.

Principals, through their school learning



and support teams, are responsible for determining how resources are used to best meet the learning and support needs of students in their school. This will enable more students to access support without the need for formal applications and paperwork outside the school. Schools have the flexibility to work together to share or pool their resources to provide specific programs or activities to support learning outcomes for students in their schools.

Students with a confirmed disability who have moderate, complex or highly specialised targeted support in mainstream schools will continue to be supported by existing arrangements. Special classes in regular schools and special schools will also continue to operate under existing arrangements.

Special schools as centres of expertise

Specialist schools and settings have developed deep knowledge and understanding of learners with additional learning and support needs. There is opportunity for schools with knowledge, expertise and specialist resources for supporting students with intellectual disability, mental health and behaviour needs, to collaborate, develop and share their knowledge more widely across the school system. This is achieved by funding special schools to undertake locally designed projects in the following areas of priority need:

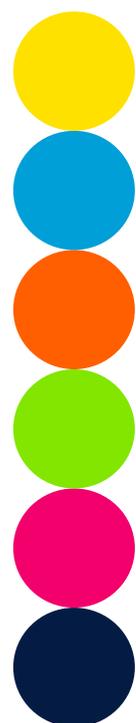
- Assistive or augmentative technology and software as a vehicle for students to access the curriculum
- Case management of students with

high and complex support needs in health and/or behaviour (including mental health) and collaborative interagency practice to support students and their teachers.

- The provision of support and adjustments to learning programs to allow students whose communication delay or disability prevents them from accessing regular curriculum outcomes.
- Supporting transition needs of students with disabilities, including preparation, transfer, induction and consolidation of student's access and engagement in education.
- Building learning and support plans through collaborative parent and community partnerships.

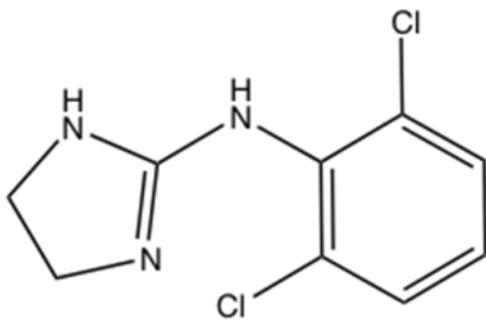
Each local project will incorporate a networking strategy integral to its implementation to build and share knowledge and expertise across schools. Networking strategies will be integrated across schools within their region. Peer support groups comprising principals from intellectual disability, mental health/behaviour and hospital school settings, together with academic contributors, will support the development of high-quality projects and outcomes.

Further information about Every Student, Every School: Learning and Support can be accessed at: www.det.nsw.edu.au/every-student-every-school



the medicine cabinet: clonidine...

Judy Longworth
Senior Pharmacist
The Children's Hospital at Westmead



Background

Clonidine is an older medication that has been used in medicine, especially paediatrics, for many years. As a result, many doctors have become accustomed to using it safely and it has been used in many different ways. Clonidine has always been used to lower blood pressure and is used in emergencies to do this, such as when a child is very ill in the Intensive Care Unit. It does this by working on parts of the nervous system that respond to adrenaline, and cousins of adrenaline, to dampen their activity. It acts like a break on the adrenaline-type system in the brain. It has been used in general medicine for everything from hot flushes around menopause to migraine, chronic pain in cancer to painful periods.

Why is it used in Child Psychiatry?

Dampening down adrenaline-type activities in the body helps reduce the stress response as well as our blood pressure. It can make a child less “wired” or over activated. It can make a child sleepy and less

twitchy in the muscles. When people are withdrawing from drugs like morphine, and alcohol, they can become very overactive, sleepless, “wired” and twitchy. Clonidine can make them less stressed and less worried and help them through the withdrawal. Children and young people who have been through severe physical and emotional trauma benefit from reducing the volume on their reactions to stress. The indications for clonidine, then, are: Attention Deficit hyperactivity Disorder, Sleep disorders, Tourette syndrome, Withdrawal syndromes in those with established addictions such as opiates (eg heroin) and alcohol, Severe anxiety disorders and Post Traumatic Stress Disorder

A more general statement of indications would be to help children to be less overactive, less stressed, less impulsive and distractible, less worried and more sleepy, when they have trouble doing so.

Clonidine when taken regularly can take up to 4 weeks to have a full effect at the required therapeutic dose. But clonidine is also found to have a short lived effect, lasting for only 4 hours and help to control impulses.

Adverse effects

The main adverse effects of clonidine are dry mouth, dizziness, low blood pressure and drowsiness. Some of the side effects are also the reasons we use the medication. For example drowsiness may be wanted. The “dry mouth” effect is used in patients for whom drooling is a problem. Most adverse effects relates to the action of clonidine on the body so it has the potential to cause dizziness due to dropping blood pressure, but also drowsiness, sleep disturbance and sedation. This can be helped by not standing up too quickly and not taking hot showers. Also if a child is going pale and might faint, then lying down will help. Other side effects include reports of nausea and vomiting as well as constipation and dry mouth. Dry mouth can be helped by sucking on sugar free lollies, or gum. Mood disturbance and nightmares have been reported infrequently as well. Most children don't notice these side effects, while adults do. With prolonged use, it is important to remain aware of an additional unusual side effect of depression or misery, which is reversible on ceasing the medication.

Adverse effects by incidence

Very common (greater than 1 in ten patients) adverse effects include: Dizziness, Orthostatic hypotension (a drop in blood pressure that occurs upon standing up),

Drowsiness (dose-dependent), Dry mouth, Headache (dose-dependent) and Fatigue
Common (between 1 in 10 and 1 in a hundred) adverse effects include: Anxiety, Depression, Constipation, Sedation (dose-dependent), Nausea/vomiting, Malaise (generally feeling unwell), Abnormal liver function tests, Rash and Weight gain/loss
Uncommon (1 in a hundred to 1 in a 1000) adverse effects include: Delusions, Hallucinations, Nightmares, Pins and needles, Slow normal heart rate, Raynaud's phenomenon (tips fingers become white or red or blue because of blood flow changes), Itchiness and Hives

Rare (1 in thousand and 1 in 10,000) adverse effects include: Swelling of breast tissue in males, Impaired ability to form tears, Heart block leading to a slow and sometimes irregular pulse, Nasal dryness, Bowel slowdown or stoppage, Hair loss and High blood glucose

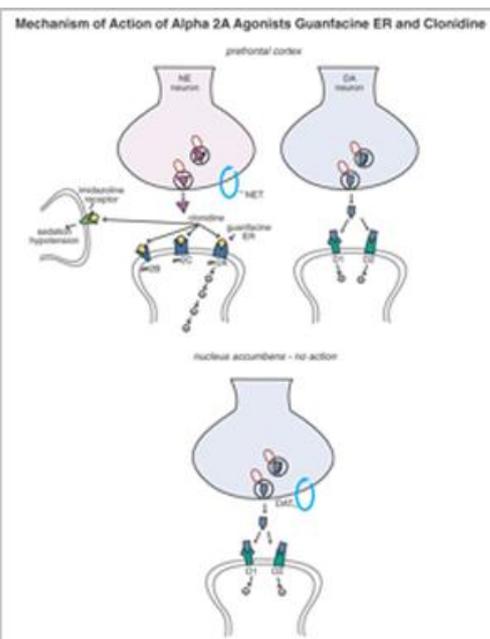
Withdrawal – rebound high blood pressure and the need to taper slowly (incidence unknown)

If a child has been on clonidine for some time, sudden ceasing of clonidine can cause a rapid rise in blood pressure. This is called rebound hypertension. If we imagine that taking clonidine is pushing blood pressure down like someone pushing down the end of a diving board, then stopping clonidine is like letting go of a diving board that has been held down. The blood pressure will go up – sometimes dangerously so. For this reason most clinicians recommend that clonidine should generally be gradually tapered off when discontinuing. It is important not to stop and start it without advice from the prescribing physician. It is also important not to skip or avoid doses.

How is it used?

Some medicines used to treat ADHD, like Ritalin, Concerta and dexamphetamine, make it difficult for children to sleep, even though they help with concentration and school work. Clonidine is sometimes added to ADHD therapy to help with sleep. The doses used are smaller than the doses used to lower blood pressure in very unwell children. Doses such as 100 micrograms (100 millionths of a gram) are used. Even though this can still lower blood pressure, the child normally rapidly adjusts and the blood pressure moves back to normal over a week. At these lower doses clonidine is anxiety relieving and helps reduce impulsive behaviour. At higher doses it becomes sedating. It can therefore be used for different purposes at different doses.

At the beginning of treatment, a child can



be dizzy, light headed, or even faint. Medical advice should be sought and the dose adjusted accordingly. If feeling tired all the time, especially early in treatment, the dose might need to be adjusted, then increased to the desired dose when the body adjusts to the clonidine

When used for impulse control, clonidine is sometimes used on 'a when needed basis' and then a dose is given at the first sign of 'losing it' to get the full effect of the medication, as it still takes 40 minutes before it is absorbed by mouth into the body. If given too late then the episode may have escalated too much for the medication to be effective and the episode will need to 'run its course'. The child may take a longer time de-escalate and recover themselves. Most clinicians avoid this approach because the use of the medication can inadvertently reinforce the behaviour in the longer term. We can end up prescribing impulsively.

Other adverse effects include constipation which can be managed with making sure there are enough fibre as well as cereals and fruit in the diet as well as drinking enough fluids. Mild laxative might also help if dietary measures are ineffective.

Clonidine is also quite toxic in overdose so it should be handled with care and kept out of the reach of children. Further information about clonidine can be found www.choiceandmedication.org/queenslandhealth

FOR PRESCRIBERS

The licensed indication under the Therapeutic Goods Administration Clonidine is marketed in Australia by Boehringer Ingelheim, under the trade name of *Catapres*[®]. Clonidine XR has been approved by the FDA in the United States for the treatment of ADHD. In Australia, while ADHD is an accepted use for clonidine (which in Australia is only available in immediate release formulations) it has not been approved by the TGA for this indication.

It is the only alpha partial agonist on the Australian market and is available in tablet form as well as an injectable. Overseas, another alpha partial agonist, guanfacine, which is more selective for α_{2A} receptors, is available and designed for use in ADHD.

Clonidine is available as a long acting preparation and as skin patches. It is also an Imidazoline 1 receptor (I_1) which mediates the sympatho-inhibitory actions of imidazolines to lower blood pressure and sympathetic arousal more generally.

Five P450 enzymes-CYP2D6, 1A2, 3A4, 1A1, and 3A5-catalyzed measurable for-

“It acts like a break on the adrenaline-type system in the brain...”

mation of 4-hydroxyclohidine. CYP2D6 accounts for approximately two-thirds of the activity.

How to give

Clonidine begins to work within an hour. Plasma level of clonidine peaks in approximately 3 to 5 hours and the plasma half-life ranges from 12 to 16 hours. Following oral administration about 40-60% of the absorbed dose is recovered in the urine as unchanged drug in 24 hours. About 50% of the absorbed dose is metabolized in the liver. Two thirds of this metabolism is achieved via the CYP 2D6 pathway.

Doses are usually given in portions of whole tablets, which are 100 or 150 micrograms. Clonidine is also readily dissolvable in water so a crushed tablet can be dissolved in freshly boiled and cooled water and then a portion of the final solution given as a dose if needed, for example, in a syringe by mouth. This is useful for some children who find swallowing tablets difficult.

A general guide is:-

A) *Start at 1-2 micrograms / kg / day per day in three divided doses* (for example 100 micrograms /day might be 25 micrograms before school, 25 micrograms after school and 50 micrograms at night, two hours before bedtime).

B) *Four times a day requires a lot of cooperation* - Where parents are not too stressed, and therefore forgetful, children are compliant at school, and teachers are willing, a four times a day regimen to start with 25 micrograms at 7am, 11am and 3pm and 100 micrograms at night, can be implemented. This achieves a smoother introduction and more continuous effect, but requires very tight administration.

Maximum initial dose - Limit the total dose to 350 micrograms in 24 hours within the first 4 weeks of using clonidine and allow two weeks for each increment. Pharmacokinetic steady state is achieved after five half lives (ie around three days) but pharmacodynamic steady state may take closer to a month.

D) *Adjust to individual need* - The dose then

needs to be adjusted according to effect. Intermediate doses can be achieved by such as 37.5 microgram doses can be achieved from a quarter tablet of the 150 microgram tablet.

How does it work?

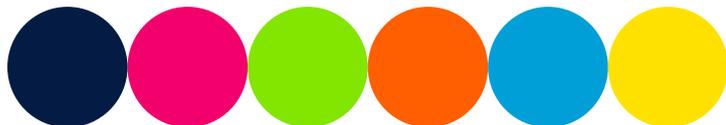
Clonidine's primary role is as an antihypertensive agent. It stimulates the brakes (alpha adrenergic (α) auto-receptors) of the sympathetic nervous system. Clonidine is a non-selective agonist of α_2 auto-receptors, with actions on α_{2A} , α_{2B} , and α_{2C} receptors. Although the actions of clonidine at α_{2A} receptors exhibit therapeutic potential for ADHD, it is the actions at the other receptors that increase the potential for adverse effects.

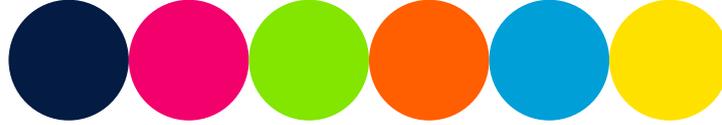
α_2 receptors are found in high concentrations in the prefrontal cortex of the brain (the brakes for the rest of the brain and behaviour) but low concentrations in the nucleus accumbens (where addictions are enabled). The most prevalent of the three subtypes of alpha-adrenergic receptors in the prefrontal cortex is α_{2A} and these mediate the hyperactivity, inattention and impulsivity of ADHD. Alpha α_{2B} receptors in the thalamus are associated with sedative effect. Alpha α_{2C} receptors are located in the locus coeruleus with a few in the prefrontal cortex that are associated with hypotensive and sedative effects. Clonidine blockade of the post-synaptic receptors can increase noradrenaline signalling to normal levels.

Clonidine also has action on imidazoline receptors, which are thought to be responsible for some of the sedating and hypotensive actions. The stimulatory effect of clonidine on imidazoline receptors in a particular part of the locus coeruleus neurons (nucleus paragigantocellularis) means that there is a stimulus of quite particular cells reaching right forward to the frontal lobes. We therefore have reduced adrenergic activity in some areas and increased in others. This means that there are both stimulating and inhibitory effects of the adrenergic system. "Increased behavioural brakes and decreased behavioural accelerators" is a summary of clonidine's role.

Managing withdrawal rebound hypertension

There are two main strategies for managing clonidine withdrawal:- 1. Reintroduce of clonidine for mild cases and 2. Alpha and beta-blockers, for more urgent situations. NB: Beta-blockers should NOT be used alone to treat clonidine withdrawal





as alpha vasoconstriction can still continue.

Overdose

Clonidine overdose is characterised by a classic triad of CNS clinical signs, and a biphasic haemodynamic response: *Triad of Signs of Clonidine Overdose*. CNS depression (stupor or coma), Respiratory depression (breathing reduced or stopped), Miosis (pin-point pupils), *Biphasic Haemodynamic Response Post- Overdose a)*

Hypertensive phase b) Hypotensive and bradycardic phase.

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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

The beautiful artworks in this newsletter are taken from the participants of the **Operation 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**

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