

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.

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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 capacities 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 car-

ry 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 behavioural problems are best understood in terms of their behavioural elements. Research shows that the most effective inter-

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vention 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 manage-

ment 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 sig-

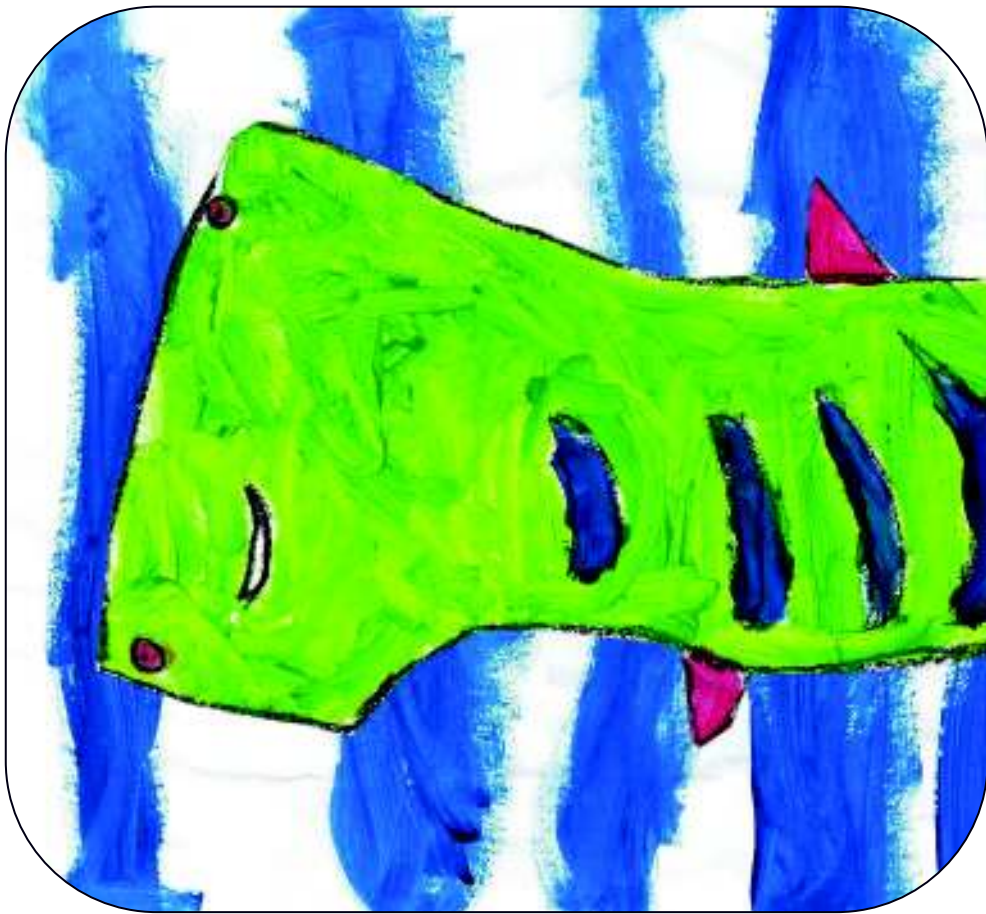
nificant expertise to be found in those practitioners that have a special interest in this population. In addition there are significant human rights and equity of access issues that are drawing political attention, including a biannual independent report from the NSW Ombudsman on the deaths of people 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 Disability Care Australia 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 Disability Care Australia 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 Disability Care Australia 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 Disability Care Australia and Medicare Locals, 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. Disability Care Australia/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. There are major risks that the community may lose professional skills with ADHC changing to a funding provider and aiming to devolve most of its professional expertise and clinical personnel to the non-government sector. These structural changes over the next 2-3 years may threaten the capacity for the new initiatives to improve the circumstances for people with intellectual disability. However promoting emotional wellbeing and behavioural independence is key to recognising and developing the human rights of young people with intellectual disability.

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

