

# Guidelines on the Pathways to Care

for children and adolescents with intellectual disability and challenging behaviour and/or mental health problems

## Introduction

This guideline is intended to assist parents and carers to make sense of the system which exists to support them and their child with intellectual disability and challenging behaviour and / or mental health problems, at different stages and ages. Health, Mental Health, Disability Services, non-government agencies, family members and others work collaboratively to bring the clinical and economic expertise and knowledge together to support the person and their family, in what can be complicated and distressing circumstances.



**At this early stage, positive relationships in the home work to support the child's wellbeing.**

A child or young person with intellectual disability and emotional or behavioural problems may not progress beyond the usual sleep problems, anger, aggression, anxiety, restlessness, moodiness and repetitive or self-injurious behaviours of the normal pre-school child.

Usually when language, concentration, memory, self-control and social understanding and peer relationships grow, behaviour will mellow. However, a child with intellectual disability may not experience this mellowing process and will often have other health problems or disabilities, such as hearing, sight, physical coordination and skill development needed for relationships and social understanding.

As the child's skills are noticed to be less advanced than their peers, so too behavioural and emotional problems, become more apparent. At this early stage, positive relationships in the home work to support the child's wellbeing.

## MORE INFORMATION

### Accessing NSW Health Services for People with Intellectual Disability

For guidance on accessing NSW health Services for people with intellectual disability, please see the Intellectual Disability consumer resources page on the Agency for Clinical Innovation website

[www.aci.health.nsw.gov.au/  
resources/consumer-  
resources#intellectual](http://www.aci.health.nsw.gov.au/resources/consumer-resources#intellectual)

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# Early identification and parenting skills

Research shows the most effective intervention for 3-12 year olds for early childhood problems, is skilled parent management, especially for behaviour problems. Before 7 years of age is the best time to change behaviour.

There are a number of programs to assist parents. Triple P Stepping Stones is a good way for parents to

learn with other parents who have children with an intellectual disability, who need help to fit in and learn alongside others. (123 Magic and Signpost are other good programs).

Adjustment and developmental competence is seen in how a child mixes with others in the early school situation, somewhere between 2 and 6 years of age. The trained teaching

staff are experts in identifying areas of special learning or socialising need and matching that with the right environment to help the child cope and develop. Sometimes they recommend a special placement or additional support or early intervention / therapy depending on what is of most benefit to the child.

## Health and disability services roles

### Parent or Carer

The parent or carer role is the primary relationship for a child and carries responsibility to advocate on their behalf. The services to assist families / carers of a child with disability are often offered by different agencies and levels of government. This complicates the process for gaining support and information and co-ordinating services and professionals. Early intervention is best for young children, however opportunities for learning and growth continue beyond the early years of a child's life.

### The General Practitioner (GP)

The General Practitioner (GP) has an important role in care co-ordination and guidance. They can link the child to community health or disability services such as nurses, speech therapists, psychologists, physiotherapists and others. A case manager may also be useful in advising, assisting and supporting a child's family over time to access the necessary services.

### General Paediatrician

A general paediatrician is a specialist in children's health and development. Their services may be Medicare funded, or available through NSW Community Paediatric Services. The general paediatrician may refer the child to a specialist paediatrician eg a paediatric neurologist or a developmental paediatrician. The general paediatrician will recognise the mental health problems, or Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) or learning and language problems, and may then give advice on where additional services and support are available.



Sometimes a child's health and behaviour are so complex they may need a case manager in each sphere of their life e.g. education, health, disability and support.

The parent / carer has the ultimate responsibility and will often become the expert case manager for their own child, making links with professionals across every area of their child's life.

This requires time, energy and a good grasp of different services. Most parents require the assistance of a case manager to manage this.

## Disability services

Disability services may have skills useful for a child with particular behavioural or emotional problems.

To access Disability services, a child needs to have an intelligence test or an adaptive behavioural assessment to show they have an intellectual disability. This is done by a psychologist or a school counsellor. Disability services aim to support the family / carer and the child based on their assessment of need.

A specialised multi-disciplinary team of people such as psychologist, occupational therapist, physiotherapist, family therapist and others, may be needed or even a Regional

With the permission of the parents, disability, school and health professionals might work together with the family to share knowledge and skills to benefit the child.

Behavioural Intervention Support Team which is made up of different professionals from different agencies.

With the permission of the parents, disability, school and health professionals might work together with the family to share knowledge and skills to benefit the child. For example, a specialist non-government agency may be part of the team to support a child with ADHD and ASD and involve the family.

Siblings may need additional and separate support.

## Child and adolescent mental health services (CAMHS)



Community Health teams often assist primary school age children with psychiatric problems. CAMHS is involved with severe anxiety disorders depression and family relationship problems for 12-18 year olds, but usually focus on schizophrenia, psychosis, bipolar, severe anxiety and other severe disabilities. It is usually the hospital emergency department which sees acute mental health issues like suicide risk or bizarre and dangerous behaviour.

Adult emergency health services (e.g. Psychiatric Emergency Care Centres) will assess children over 12 years of age. Emergency services can follow people up in the community.

For people under 16, acute mental illness can be treated in a paediatric medical ward with acute Mental Health service support. NSW has 50 adolescent mental health beds, which are in high demand.

For children under 12 years of age, a paediatrician will see them with CAMHS support if they are admitted to hospital. Mental Health services must establish a serious and treatable mental health problem in order to treat a patient. For people with intellectual disability, this can be difficult.

Adult inpatient Mental Health services support patients who cannot be admitted to a CAMHS unit, due to lack of beds. Children need to see a paediatric psychiatrist if their mental illness is to be treated with medication or if advice regarding complex combinations of psychotropic medications is needed.



# Chronic complex high risk challenging behaviour with / without serious mental illness

Aggression is typical in mental illness, but could also be due to behavioural challenges. Some children with intellectual disability also have chronic emotional and behavioural disability. ASD, ADHD or impulse disorder are particularly difficult when combined with behaviours such as aggression or self-injurious behaviour.

These children may have acute episodes of mental health and their limited ability to understand may be a factor in needing to protect them from Juvenile Justice Detention when they do offend. Their diminished capacity means they can be exploited and are often more susceptible to substance abuse. Schools and families often struggle to support them. Those with borderline intellectual disability are at risk of becoming homeless.

Practitioners with special interest and significant expertise in this field are a great support. Children with chronic complex high risk challenging behaviour with / without serious mental illness and borderline intellectual disability and their families, benefit greatly from a conjoint process between key involved clinicians and agencies which includes the child and their family, to resolve distressing conditions and their context.

## The future

The Memorandum of Understanding between NSW Mental Health and Disability services (Jan 2011) gives guidance on how services might cooperate for the good of the child with intellectual disability, including, for example, regular meetings of key senior officials of each department to ensure collaboration.



Children with intellectual disability can also have challenging behaviour and mental illness, which creates additional disability for the person and difficulties for the system, in managing their health needs.

In 2011, NSW Health funded the Agency for Clinical Innovation to establish an Intellectual Disability Network which provides clinical and academic leadership with a range of stakeholder participation, in order to advise government on further developments to improve the health of people with intellectual disability.

The NSW Ombudsman and other government and non-government bodies work collaboratively across systems and with individual families for the benefit of the child with intellectual disability.

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“Thumbs up” image courtesy of Maria Heaton, Co-chair of the Intellectual Disability Health Network.