

The mental health and wellbeing of children and young people

February 2013

Children and young people with disability

The Commissioner for Children and Young People Western Australia (WA) undertook an Inquiry into the mental health and wellbeing of children and young people (the Inquiry) after hearing consistently from communities across the State about their concerns for the mental health of their children and young people, from infants to young adults.

The *Report of the Inquiry into the mental health and wellbeing of children and young people in Western Australia* was tabled in Parliament in May 2011.

This policy brief focuses on the mental health of children and young people (0 to 18 years) with disability. There are many definitions of disability. The *Disability Services Act 1993* (WA) defines the functions of the Disability Services Commission and defines disability as being:

- attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment, or a combination of those impairments
- permanent or likely to be permanent
- may or may not be of a chronic or episodic nature

and results in:

- a substantially reduced capacity of the person for communication, social interaction, learning or mobility
- a need for continuing support services.¹

The Australian Bureau of Statistics (ABS) defines a person as having disability '*if they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities.*'² For detail on the conditions this includes see Appendix 1.

Based on the ABS definition of disability, in 2009 it was estimated that 8.3 per cent of WA children and young people aged 0 to 14 years of age had disability.³

Overall, there is lack of data on children and young people who have disability and experience mental health problems. However, research indicates children and young people with disability do experience a higher level of mental health problems than those without.⁴

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) concluded that clinically-significant emotional and behavioural problems are around three times more prevalent in children with intellectual disability than in the general population.⁵

Children and young people with Autism Spectrum Disorders are at increased risk of emotional and behavioural problems including anxiety and depression.⁶



High rates of mental health problems have also been found in young people who are hearing impaired, have cerebral palsy, epilepsy or chronic illness.⁷

The Western Australian Aboriginal Child Health Survey found that Aboriginal children and young people who were restricted in physical activity or in daily-living activities or had vision problems were at higher risk of clinically-significant emotional or behavioural difficulties than those who did not.⁸

What do children and young people say?

In 2009, the Commissioner for Children and Young People WA undertook research⁹ about children and young people's views on what was important to their wellbeing. Of the nearly 1,000 children and young people who participated, six per cent had disability.

Inclusive of children and young people with disability, the top eight things that children and young people identified as important to their wellbeing were a loving supportive family, good friends, fun and activity, being safe, a good education, the basics, being acknowledged and freedom and independence.¹⁰

During consultations for the National Disability Strategy in 2008,¹¹ young people with disabilities from across Australia discussed the issues and barriers they face. Many of the issues identified impacted on the aspects of wellbeing identified in the Commissioner's wellbeing research and were described as affecting their mental health and wellbeing.

Bullying, discrimination and lack of support in school led to feelings of stress and isolation,¹² as experienced by this young person:

"They'd tease us about not being able to hear and how we can't understand them, and they mock us by giving facial expressions or imitate ridiculous made-up signs. Sometimes they would be behind us mumbling and calling names when we can't hear until our hearing friends tell us what they did to us. It's an embarrassment when people watch this happen and we have no idea until we're told"¹³

Similarly, social exclusion, isolation and lack of awareness of disability in the community were felt to be adversely affecting them.¹⁴ To address these issues young people recommended more disability awareness (in both schools and community) and more anti-bullying education in schools.¹⁵

Young people with disabilities identified the need for more counselling and improved mental health services, including more collaboration between mental health and disability services and specialised services for those from culturally and linguistically diverse communities and Aboriginal young people with disabilities.¹⁶

What were the Inquiry's findings?

Key findings relating to children and young people with disability and mental health include:

- Children and young people with disability are at a higher risk of developing mental health problems than those without disability.¹⁷
- Children and young people with disability face additional stressors which may include difficulties in communicating, forming and maintaining relationships and accessing programs and services (including recreation and education), pain, social isolation, bullying, alienation and discrimination.¹⁸



- There is significant unrecognised comorbidity. The mental health needs of children and young people with disability are poorly identified and conversely children and young people with mental health problems can have unrecognised learning difficulties, sensory-motor problems, attention, speech and language problems.¹⁹
- Dual diagnosis of disability (particularly intellectual disability) and mental health problems and disorders presents a significant barrier to accessing treatment services.²⁰
- Delivering services based on particular diagnoses and criteria across the disability and health sectors results in significant service gaps when:
 - a child or young person has a dual diagnosis
 - a diagnosis forms the criteria for a service and children and young people without this diagnosis are unable to get a service from any agency.²¹
- *The Fourth National Health Plan* recognises that mental health problems are more likely to occur in association with disability and physical illness and that there needs to be better coordination between the range of service sectors providing treatment and care whether for a person's disability or their mental health problem.²²
- The WA Disability Services Commission's strategy *Count Me In: Disability Future Directions* identifies the need to coordinate disability services and mainstream agencies to ensure people with disabilities who also have mental health disabilities receive appropriate health services.²³
- There is a need for improved access and coordinated mental health programs and services for children and young people with disability, including dedicated mental health early intervention and treatment services that allow for the dual diagnosis of disability and mental health problems.²⁴
- Children and young people with exceptionally complex needs, including those with a dual diagnosis of disability and mental health, require specialist services provided by appropriately trained professionals, coordinated between agencies.²⁵

Key recommendations of the Inquiry relevant to children and young people with disability are:

Recommendation 25: The Disability Services Commission work with the Mental Health Commission to identify services required to address the unique needs and risk factors of children and young people with disabilities in a coordinated and seamless manner.²⁶

Recommendation 3: A new collaborative service to address the needs of children and young people who have complex needs be established as a demonstration project. The development of this service should consider the models of Wraparound Milwaukee and the People with Exceptionally Complex Needs.²⁷

Recommendation 9: A strategic and comprehensive plan for the mental health and wellbeing of children and young people across Western Australia be developed by the Mental Health Commission. This plan provide for the implementation and funding of promotion, prevention, early intervention and treatment services and programs.²⁸

Recommendation 17: As part of the strategic and comprehensive plan for the mental health and wellbeing of children and young people across Western Australia, the Mental Health Commission identify the unique and specific requirements of and have regard for:

- Aboriginal children and young people
- children and young people who are vulnerable or disadvantaged for any reason.²⁹

Recommendation 35: The State Child Development Services receive significant investment to increase service to an appropriate level and reduce waiting times.³⁰

Recommendation 38: The current focus on bullying be maintained and enhanced by the continued development and implementation of evidence-based anti-bullying programs involving the Commonwealth and State Governments, non-government agencies, community, parents and children and young people.³¹

What does the research say?

Research indicates that not only do children and young people with disability experience higher level of mental health problems, regardless of the nature of disability,³² but that the more disabilities a child or young person experiences the more likely they are to have problems.

Flinders University found South Australian primary school students without disability had a one in eight chance of having a mental health problem, students with one identified disability had a one in three chance, and students with multiple disabilities had a one in two chance.³³

Mental health problems cause additional educational and social problems for the children and young people and increase the support needed from parents and carers.³⁴

Rates of identification, early intervention and treatment of mental health problems in children and young people with disability are low. The RANZCP Faculty of Child and Adolescent Psychiatry state that less than 10 per cent of children with neurodevelopmental and intellectual disability receive adequate mental health care.³⁵

The *2010–2020 National Disability Strategy* acknowledges that psychiatric disorders are among the conditions frequently not well diagnosed or managed in people with intellectual disability.³⁶

Reasons for the low identification, early intervention and treatment rates may include:

- Limited training about disability in the health and allied health sectors resulting in little understanding of the mental health needs of people with disabilities.³⁷
- Attitudinal barriers in recognising symptoms, for example, *'people with disabilities do not possess the intellectual or personal capacity to be affected by everyday psychosocial stressors and, therefore, are protected from mental illness'*.³⁸
- Symptoms of mental illness are often considered part of the disability or a *'challenging behaviour'*.^{39 40}
- Diagnosis of mental illness in people with disabilities is difficult and compounded by communication difficulties.⁴¹
- Poor early detection of emerging mental health problems.⁴²
- Limited training of psychiatrists and mental health practitioners in the assessment and management of people with intellectual and developmental difficulties.⁴³
- Discrimination in mental health services against people with intellectual and developmental disabilities.⁴⁴
- Lack of specialist mental health services.⁴⁵
- Service gaps between the health and disability systems.⁴⁶



The RANZCP Faculty of Child and Adolescent Psychiatry states that an evidence-based, multi-disciplinary, family-centred approach to interventions is needed. These should take account of the cognitive abilities of the child and the family and school context.⁴⁷ They suggest there is evidence which demonstrates targeted prevention and early intervention programs for children with chronic conditions (and their siblings) are effective. These programs include:

- parent education and training
- treatment of associated medical conditions
- behaviour management and psychological treatment
- speech and occupational therapy to improve communication and play skills
- special education with aide support
- family support and respite services.^{48 49}

The following strategies have been proposed to improve the identification of mental health problems in people with disability:

- addressing attitudinal barriers
- further education and training
- improved screening and identification processes
- improved early detection and intervention.⁵⁰

Assessment tools are also needed that are accessible to people with complex communication needs and reflect the range of needs of people with disabilities.⁵¹

What about the siblings of children and young people with disability?

According to KidsMatter:

“Having a brother or a sister with a disability or serious illness can affect siblings in different ways. They may be a range of emotions – jealousy for parents spending more time with the children with the disability, guilt for complaining about the strains that a child with a disability puts on the family, or joy when their brother or sister accomplishes something.”⁵²

The RANZCP states that there is a lack of currently available data regarding the siblings of children with disability or chronic illness.⁵³ Research and anecdotal evidence supports the view that illness and disability affects the lives of all family members.⁵⁴ There is reasonable consensus that siblings of children with chronic conditions are at risk of behavioural, mental and physical health problems.⁵⁵

The RANZCP proposes a number of key priority areas for improvement and action, including, but not limited to:

- inclusion of siblings in government policy and strategy
- improved data collection on the number of siblings that are affected
- use of appropriate assessment tools and referral pathways
- workforce development on the needs of siblings

- evaluation of the limited sibling support groups that do exist
- coordination and collaboration between agencies.⁵⁶

What is being done?

A number of developments relevant to the mental health of children and young people with disability have occurred since the Inquiry:

- The Mental Health Commission has developed a 10-year strategic policy, *Mental Health 2020: Making it personal and everybody's business*, which acknowledges the need for shared approaches between mental health and services for people with disability and acquired brain injury as well as better outcomes for people with co-occurring problems and complex needs through joint planning and protocols, common assessment frameworks, community brokers, case management and joint programs.⁵⁷
- The Mental Health Commission's *Action Plan 2011-2012* includes an initiative to co-ordinate services for people with co-occurring conditions, working with the Department of Housing, Department of Health, Office of the Public Advocate, Department of Corrective Services, Drug and Alcohol Office and the Disability Services Commission.⁵⁸
- A youth People with Exceptional Needs (PECN) jointly led by the Department for Child Protection, Mental Health Commission and Disability Services Commission has been established. This utilises the same principles and models of care as existing adult PECN and is informed by the Wraparound Milwaukee model⁵⁹ as per Recommendation 3 of the *Report of the Inquiry into the mental health and wellbeing of children and young people in Western Australia*.

What more needs to be done?

To improve the mental health and wellbeing of children and young people with disability the following is required:

- The Disability Services Commission work with the Mental Health Commission to identify the services required to address the unique needs and risk factors of children and young people with disabilities and their siblings in a coordinated and seamless manner.
- The development of a strategic and comprehensive mental health plan for all children and young people in WA that includes targeted mental health promotion, prevention, early intervention and treatment programs to address the mental health needs of children and young people with disability and their siblings.
- The Disability Services Commission, the Mental Health Commission and the Departments of Health and Education identify and address any gaps in the training requirements of staff in relation to disability, mental health and dual diagnosis.
- Continued investment in the WA Child Development Service to reduce waiting times and increase services to ensure early identification of developmental and other disabilities and timely access to health, education, parenting and disability programs and supports.
- Improved access to mainstream mental health services for children and young people with disability who have mental health problems and disorders.
- Dedicated early intervention and treatment programs and services for children and young people that allow for the dual diagnosis of disability and mental health problems.

- A multidisciplinary approach to mental health screening, assessment, early intervention and treatment of children and young people with disability that allows for dual diagnosis.
- The development of mental health assessment tools for children and young people with disability, for example, those with communication difficulties.
- Agencies providing services to children and young people with disability and their families recognise that siblings of children and young people with disability may also have mental health needs.
- Improved data collection on children and young people with disability and mental health problems and on the siblings of children and young people with disability.
- On-going implementation and formal evaluation of youth PECN.
- Relevant recommendations from the *Review of the admission or referral to and discharge and transfer practices of public mental health facilities/services in Western Australia* are implemented.⁶⁰

Other relevant information

Commissioner for Children and Young People WA

- The following publications are available on the Commissioner for Children and Young People's website www.ccyp.wa.gov.au
 - *Report of the Inquiry into the mental health and wellbeing of children and young people in Western Australia*
 - *Speaking out about mental health: The views of Western Australian children and young people*
 - *Building Blocks: Best practice programs that improve the wellbeing of children and young people - Edition One,*
 - *Children and Young People's Views on Wellbeing – Research report*
 - *Children and young people of parents with a mental illness policy brief*

Disability Services Commission

- The Disability Services Commission strategy document *Count Me In – Disability Future Directions* is available at: <http://www.disability.wa.gov.au/about-the-commission/about-the-commission1/count-me-in/>
- Information on Disability Service Commission funded services and supports is available at: <http://www.disability.wa.gov.au/services-support-and-eligibility/services-supports-and-eligibility-new/>

Mental Health Commission

- The Mental Health Commissions' strategic policy *Mental Health 2020: Making it personal and everybody's business* and the *Action Plan 2011-2012* are available at: www.mentalhealth.wa.gov.au



- Professor Bryant Stokes' Review of the admission or referral to and discharge and transfer practices of public mental health facilities/services in Western Australia is available on the Mental health Commission website:
http://www.mentalhealth.wa.gov.au/media_resources/policies/stokes.aspx

Department of Families, Housing, Community Services and Indigenous Affairs

- The *National Disability Action Plan 2010-2020* is available at
<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>

KidsMatter

- The KidsMatter website is www.kidsmatter.edu.au/

Royal Australia and New Zealand College of Psychiatrists

- *Intellectual Disability and Mental Illness* is available at: www.ranzcp.org/Home.aspx
- *Addressing the needs of siblings of children with disability or chronic illness* is available at: www.ranzcp.org/Home.aspx

Appendix 1

The Australian Bureau of Statistics definition of disability

A person has a disability if they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities.

- This includes:
 - loss of sight (not corrected by glasses or contact lenses)
 - loss of hearing where communication is restricted, or an aid to assist with, or substitute for, hearing is used
 - speech difficulties
 - shortness of breath or breathing difficulties causing restriction
 - chronic or recurrent pain or discomfort causing restriction
 - blackouts, fits, or loss of consciousness
 - difficulty learning or understanding
 - incomplete use of arms or fingers
 - difficulty gripping or holding things
 - incomplete use of feet or legs
 - nervous or emotional condition causing restriction
 - restriction in physical activities or in doing physical work
 - disfigurement or deformity
 - mental illness or condition requiring help or supervision
 - long-term effects of head injury, stroke or other brain damage causing restriction
 - receiving treatment or medication for any other long-term conditions or ailments and still being restricted
 - any other long-term conditions resulting in a restriction.⁶¹

¹ *Disability Services Act 1993* (WA), section 3.

² Australian Bureau of Statistics 2009, *Disability, Australia, 2009*, cat no 4446.0, [website], viewed 15 November 2012: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4446.0Glossary12009?opendocument&tabname=Notes&prodno=4446.0&issue=2009&num=&view=>

³ Australian Bureau of Statistics 2009, *Disability, Aging and Carers, Australia, State Tables for Western Australia*, cat no 4430.0 viewed 15 January 2013:

<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02009?OpenDocument>

⁴ Commissioner for Children and Young People WA 2011, *Report of the Inquiry into the mental health and wellbeing of children and young people in Western Australia*, Commissioner for Children and Young People WA, Perth, p.92.

⁵ The Royal Australian and New Zealand College of Psychiatrists 2011, *Addendum: Prevention and early intervention of mental illness in infants, children and adolescents: Planning strategies for Australian and New Zealand*, The Royal Australian and New Zealand College of Psychiatrists, Melbourne.

⁶ Tonge B & Brereton A V nd, *Adjustment and wellbeing in young people with ASD*, Department of Education and Early Childhood Development Victoria, p. 1, [website], viewed 5 December 2012,

<http://www.eduweb.vic.gov.au/edulibrary/public/stuman/wellbeing/autism/factsheet4.pdf>

⁷ KidsMatter 2009, *Understanding the mental health needs of children with disabilities*, p. 3, [website], viewed 5 December 2012, <http://www.kidsmatter.edu.au/sites/default/files/public/KMPC1-201205-disabilities-Understanding-needs.pdf>

⁸ Zubrick S et al 2005, *The Western Australian Aboriginal Child Health Survey: The Social and Emotional Wellbeing of Aboriginal Children and Young People*, Curtin University of Technology and Telethon Institute for Child Health Research, Perth, pp. 116–117.

⁹ Commissioner for Children and Young People WA 2010, *Speaking Out about Wellbeing: The views of Western Australian children and young people*, Commissioner for Children and Young People WA, Perth.

¹⁰ Commissioner for Children and Young People WA 2010, *Children and Young People's Views on Wellbeing – Research Report*, Commissioner for Children and Young People WA, Perth, p.28.

¹¹ Youth Disability Advocacy Service 2008, *National Disability Strategy Youth Roundtable Report*, Youth Disability Advocacy Service, Melbourne, [website], viewed 13 December 2012, <http://www.ydas.org.au/sites/default/files/Youth-Roundtable-Report-December08.pdf>

¹² Ibid, pp. 7–8.

¹³ Ibid, p. 7.

¹⁴ Ibid, pp. 12, 16.

¹⁵ Ibid, pp. 18, 27.

¹⁶ Ibid, p. 25.

¹⁷ Commissioner for Children and Young People WA 2011, *Report of the Inquiry into the mental health and wellbeing of children and young people in Western Australia*, Commissioner for Children and Young People WA, Perth, p. 92.

¹⁸ Ibid, pp. 92–93.

¹⁹ Ibid, p. 94.

²⁰ Ibid, p.94.

²¹ Ibid, p.94.

²² Department of Health and Aging 2009, *Fourth National Mental Health Plan: an agenda for collaborative government action in mental health 2009-2014* [website], viewed 7 November 2012, Government of Australia, <http://www.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-f-plan09-toc>, pp.31 & 41

²³ Disability Services Commission nd, *Count Me In: Disability Future Directions*, Disability services Commission, Perth, pp. 19 & 20, [website], viewed 15 January 2013, <http://www.disability.wa.gov.au/about-the-commission/about-the-commission1/count-me-in/>

²⁴ Commissioner for Children and Young People WA 2011, *Report of the Inquiry into the mental health and wellbeing of children and young people in Western Australia*, Commissioner for Children and Young People WA, Perth, p. 94

²⁵ Ibid, pp.94–95.

²⁶ Ibid, p.95.

²⁷ Ibid, p.56.

²⁸ Ibid, p.63.

²⁹ Ibid, p.72.

³⁰ Ibid, p.112.

³¹ Ibid, p.112.

³² The Royal Australian and New Zealand College of Psychiatrists 2011, *Addendum: Prevention and early intervention of mental illness in infants, children and adolescents: Planning strategies for Australian and New Zealand*, The Royal Australian and New Zealand College of Psychiatrists, Melbourne.

³³ Dix K 2010, *KidsMatter for students with a disability: Evaluation Report*, Ministerial Advisory Committee: Students with Disabilities, Office of the Minister for Education, South Australia, Adelaide, p. ix.

³⁴ The Royal Australian and New Zealand College of Psychiatrists 2011, *Addendum: Prevention and early intervention of mental illness in infants, children and adolescents: Planning strategies for Australian and New Zealand*, The Royal Australian and New Zealand College of Psychiatrists, Melbourne.



³⁵ Ibid.

³⁶ Council of Australian Government 2011, *2010–2012 National Disability Strategy*, Australian Government, Canberra, p.60.

³⁷ National People With Disabilities and Carer Council 2009, *Shut Out: The Experience of People with Disabilities and their Families in Australia*, Department of Families, Housing, Community Services and Indigenous Affairs, Canberra.

³⁸ Hagliss N et al 2005, 'The Bridging Project: Physical disability and mental health', *InPsych*, [online], August 2005, <http://www.psychology.org.au/publications/inpsych/bridging>

³⁹ The Royal Australian and New Zealand College of Psychiatrists 2011, *Addendum: Prevention and early intervention of mental illness in infants, children and adolescents: Planning strategies for Australian and New Zealand*, The Royal Australian and New Zealand College of Psychiatrists, Melbourne.

⁴⁰ Hagliss N et al 2005, 'The Bridging Project: Physical disability and mental health', *InPsych*, [online], August 2005, <http://www.psychology.org.au/publications/inpsych/bridging>

⁴¹ Ibid.

⁴² Ibid.

⁴³ Royal Australian and New Zealand College of Psychiatrists 2012, *Intellectual Disability and Mental Illness*, Royal Australian and New Zealand College of Psychiatrists, Melbourne, p.2

⁴⁴ Ibid, p.2

⁴⁵ Ibid, p.2

⁴⁶ Ibid, p.2

⁴⁷ The Royal Australian and New Zealand College of Psychiatrists 2011, *Addendum: Prevention and early intervention of mental illness in infants, children and adolescents: Planning strategies for Australian and New Zealand*, The Royal Australian and New Zealand College of Psychiatrists, Melbourne.

⁴⁸ Ibid.

⁴⁹ Faculty of Child and Adolescent Psychiatry 2010, *Prevention and early intervention of mental illness in infants, children and adolescents: Planning strategies for Australian and New Zealand*, The Royal Australian and New Zealand College of Psychiatrists, Melbourne, p. 16.

⁵⁰ Hagliss N et al 2005, 'The Bridging Project: Physical disability and mental health', *InPsych*, [online], August 2005, <http://www.psychology.org.au/publications/inpsych/bridging>

⁵¹ Ibid.

⁵² KidsMatter, *Understanding the mental health needs of children with disabilities*, <http://www.kidsmatter.edu.au/families/about-difference/additional-needs/understanding-mental-health-needs-children-disabilities>

⁵³ The Royal Australian and New Zealand College of Psychiatrists 2011, *Position Statement 69: Addressing the needs of siblings of children with disability or chronic illness*, The Royal Australian and New Zealand College of Psychiatrists, Melbourne, p.1.

⁵⁴ Ibid, p.1.

⁵⁵ Ibid, p.1.

⁵⁶ Ibid, pp.1–2

⁵⁷ Mental Health Commission 2011, *Mental Health 2020: Making it personal and everybody's business*, Mental Health Commission, Perth, p.36.

⁵⁸ Mental Health Commission WA 2012, *Action Plan 2011–2012*, Mental Health Commission WA, Perth, p. 6.

⁵⁹ Report from Minister Helen Morton to the Joint Standing Committee on the Commissioner for Children and Young People, *Inquiry into the mental health and wellbeing of children and young people in Western Australia: Overview of progress*, April 2012

⁶⁰ Stokes B 2012, *Review of the admission or referral to and the discharge and transfer practices of public mental health facilities/services in Western Australia*, Department of Health & Mental Health Commission, Perth.

⁶¹ Australian Bureau of Statistics 2009, *Disability, Australia, 2009*, cat no 4446.0, [website], viewed 15 November 2012: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4446.0Glossary12009?opendocument&tabname=Notes&prodno=4446.0&issue=2009&num=&view>

