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CHW SCHOOL Link

mental health and intellectual disability...

coordinators message...

It's Time.....

Welcome to the inaugural edition of the Children's Hospital at Westmead (CHW) School-Link Newsletter. The NSW School-Link Initiative is an existing partnership between NSW Health and The Department of Education and Training and has been working with mental health prevention, promotion and early intervention, pathways to care and school counsellor training for over ten years. The CHW has recently joined this state wide initiative. The theme of this newsletter and forthcoming editions and what distinguishes the CHW School-Link Initiative from your local Area Health Service School-Link team, is our special focus on the mental health of children and adolescents with an intellectual disability.

Children and adolescents with an intellectual disability experience mental health problems at a rate three to four times higher than that of children and adolescents without an intellectual disability. This statistic highlights a need to focus our attention on this vulnerable group of young people, in an effort to aim to close this statistical gap and provide effective interventions when needed. This statistic also highlights the need for the array of staff that care for young people with intellectual disability to further advance their mental health and intellectual disability literacy skills and collaboration to ensure the best outcomes for the child or adolescent. What this statistic fails to tell us however, are the challenges that each young person faces when experiencing a mental health problem or disorder. From our valued discussions with school counsellors in 2009, the complexities that communication limitations, challenging behaviour, and other health and environmental stressors place on diagnosis and intervention are clear.

This CHW School-Link Initiative, which is funded by the Mental Health Drug and Alcohol Office, aims to 'tackle' the gaps in the support of staff who work with children and adolescents with an intellectual disability not only to ensure services and intervention to those in need but to facilitate mental health prevention and promotion and ultimately an improved quality of life. Like a football coach we will travel with you on this journey over the next four years and together we will improve the mental health of children and adolescents with an intellectual disability.

Take your time to browse through our first edition. Please send your comments about this issue and suggestions for future articles to: schoollink@chw.edu.au. We look forward to your feedback.

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

Our first feature article is an excerpt from the literature review conducted by the Children's Hospital at Westmead School-Link team in preparation for the needs analysis into children and adolescents with mental health problems and disorders and an intellectual disability.

The prevalence of psychopathology in children and adolescents with an intellectual disability is much higher than in the general population. Both Australian and overseas studies have found that the rates of psychopathology in children and adolescents with an intellectual disability are in the vicinity of 40-50 per cent and that this population is at a four to five times greater risk of psychiatric disorder than children and adolescents without an intellectual disability (Rutter et al., 1970, Corbett, 1977, Einfeld & Tonge, 1996).

A Swedish study by Gostason in 1985 (cited in Dykens, 2000) estimated the prevalence rate to be as high as 70 per cent. Einfeld and Tonge (1996) reported on some of the difficulties in being able to obtain accurate prevalence rates due to factors such as: a scarcity of studies on children and adolescents with mental health problems and disorders and an intellectual disability compared to adults; a lack of standardised methods of assessment of psychopathology for this target group; stud-

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ies with sample sizes which are too small to make accurate measurements from; and insufficient detail around presenting symptoms of psychiatric disorders.

Follow-up studies conducted by Einfeld and Tonge (2000) and also by Einfeld et al. (2006) confirm the earlier estimated prevalence rates of psychiatric disorders in children and adolescents with an intellectual disability as 40.7 per cent, compared to 7-10 per cent in the general population as an epidemiologically derived population in a multicentre study in NSW of children and adolescents aged between 4-18 years of varying levels of intellectual disability. Einfeld and Tonge (2000) refer to a study by Richardson and Koller which further indicates that the prevalence of behaviour disturbance in individuals with an intellectual disability remains the same from childhood into young adulthood.

Assessment

Einfeld and Tonge (2000) report that the under-recognition of combined mental health problems and disorders and an intellectual disability is in part due to *'diagnostic overshadowing'* where a clinician regards the presenting symptoms to be sufficiently explained by an individual's intellectual disability and does not consider that the presenting symptoms may be due to a psychiatric disorder.

Fletcher et al. (2007) note that individuals with an intellectual disability can exhibit the full range of psychiatric disorders including affective disorders, anxiety disorders, psychiatric disorders, personality disorders and various other disorder clusters. The Diagnostic Manual of Intellectual Disability (DM-ID) outlines that people with a mild intellectual disability are more likely to be associated with psychiatric disorders, while people with a profound intellectual disability are more likely to be associated more with behaviour problems, and people with moderate and severe intellectual disability are associated with both psychiatric disorders and behaviour problems.

Hemmings (2007) notes the problems associated with the use of language based standard diagnostic criteria with people with an intellectual disability, especially as the intellectual disability becomes more severe and communication becomes limited. This may be a problem as the Australian Institute of Health and Welfare (AIHW, 2008) note that 60 per cent of people with an intellectual disability have severe communication limitations.

A review by DeNoyers Hurley (1996) found that many children and adolescents with an intellectual disability do not reach their full potential due to limitations placed on them by untreated psychiatric disorders. She also found that if a psychiatric disorder is left untreated from childhood or when it first appears, the condition tends to develop into a more serious disorder in adulthood. DeNoyers Hurley (1996) states that;- *'it is imperative that paediatricians are alert to the signs of psychiatric disorder in children and adolescents with MR/DD so that referral for appropriate services be accomplished'.*

Pathways to Care

Despite the high prevalence of mental health problems in children and adolescents with an intellectual disability there is evidence from the literature that there are a lack of services to meet the mental health needs of children and adolescents with an intellectual disability (McCarthy & Boyd 2002). McCarthy and Boyd report on how young persons with mental health problems and intellectual disabilities in the UK fall between a number of health care providers such as child and adolescent mental health services, disability services and paediatricians. The gaps in service provision to this population have been described by Cass et al. (1996 cited in Scior and Grierson, 2004) as '*the white hole'* as often the child is left without any service.

Both pathways to care and service provision within the Australian context for this population are not much different to what has been reported in overseas studies. In both of their 1996 and 2000 studies Einfeld and Tonge found that less than 10 per cent of young people with an intellectual disability and a clinically significant psychiatric disorder receive specialist mental health services (2000). In order to provide a more satisfactory clinical service to individuals with an intellectual disability and psychiatric disorder both report that this would require approximately 54 full-time specialist psychiatrists across Australia. The Dual Diagnosis Project, conducted by Queensland Health and the University of Queensland in 2002, were aware of only two psychiatrists who work full-time in dedicated positions within Australia- one in Adelaide and the other in Melbourne.

One of the key findings from the McCarthy and Boyd study (2002) was that the majority of subjects (64%) with persistent challenging behaviour from childhood into adulthood and those with a diagnosed psychiatric disorder from childhood received no specialist mental health care. The main explanation given as to why children and adolescents with an intellectual disability and mental health problems and disorders are not accessing appropriate services is that there is a lack of recognition within primary care services as to how to manage mental health issues for this population. McCarthy and Boyd see the educational setting as the universal provider and agency for children and adolescents with an

intellectual disability and see the school setting as being the best place to start in terms of training and establishing close links with specialist mental health services. They further support and stress the importance of identifying mental health problems in children and adolescents with an intellectual disability *well before* their transition into adulthood. Failure to do this often results in mental health problems becoming more chronic in adulthood and can adversely affect successful transition into adult services. Einfeld and Tonge (2000) also strongly support both availability of early assessment intervention and treatment services for children and adolescents as the persistence of serious mental health problems can start from an early age.

Mohr et al. (2002) in their research acknowledge that service systems within both health and community organisations are struggling to deliver mental health services to this population group. *'Many professionals feel ill equipped to assess and treat mental health disorders in this population'.* Mohr et al. (2002) further state that professionals who work separately to help individuals with an intellectual disability in addition to mental health problems often find themselves at a '*dead end'*. Mohr and Coutts strongly advocate for a collaborative approach and see this as the only way that individuals with an intellectual disability and mental health problems can receive the services that they need. *'Only with a collaborative effort between these two service systems (MH & ID), and in some cases with additional specialist input, will a person with an intellectual disability and disturbed behaviour that may be indicative of a psychiatric disorder receive appropriate assessment, treatment and support',* (Mohr et al., 2002).

In the case study which Mohr et al. (2002) presented in their research they found that positive outcomes for the client were achieved only when services followed the key elements of a collaborative model.

Most of the research and studies around service provision and pathways of care for mental health problems and disorders and an intellectual disability are focused around adults with an intellectual disability. There are very few studies which address the pathways to care needs of children and adolescents with these needs. A literature review by Hudson and Chan (2002) identified a number of significant gaps and factors affecting access to mental health services for people with an intellectual disability and mental health problems. The main barriers to access they listed were: a lack of understanding of this population by general practitioners and caregivers; a lack of specialised training for mental health practitioners; the complexity of definitions and symptoms of mental illness which make a diagnosis difficult; and separatist attitudes of mental health and disability services.

Conclusion

This literature review has outlined the complexities in diagnosing mental health problems and disorders in children and adolescents with an intellectual disability which is further supported by the varying prevalence rates reported in the literature. Throughout this report the Einfield and Tonge (1996) prevalence rate of 40.7% will be used. The lack of specialist services especially for children and adolescents with an intellect disability has been identified by several authors, as having significant consequences for the successful early intervention of mental health problems and disorders. The literature then suggests that in order for the adequate care of the large percentage of children and adolescents that may experience mental health problems and disorders specialised services are required. ●

Excerpt from Dossetor, D., Caruana, J., Goltzoff, H. and Saleh, H. (2009). *Leading the Way in Mental Health and Intellectual Disability. A Focus on the needs of Children and Adolescents in Schools for Specific Purposes in NSW*. The Children's Hospital at Westmead.

Emotion Based Social Skills Training ...

Children With Autism, Their Parents, & Teachers: A New Training Program

The Children's Hospital at Westmead in association with The Department of Education and Training NSW is researching two innovative training programs that address social and emotional difficulties in students with Autism Spectrum Disorders. The programs were developed by a team of clinicians at the Children's Hospital at Westmead and University of Sydney, and build upon the DET Autism Training for School Counsellors. This exciting collaborative project is being offered for the first time in a school setting and we welcome your involvement in this program.

What is the Emotion-based Social Skills Training program?

EBSST is a group training program that aims to provide training for school counsellors to be accredited EBSST group facilitators; build school counsellors' knowledge of emotional and skills in addressing the social and emotional difficulties of children with Autism; enhance students' knowledge of emotional and social skills and the application of these skills in specific contexts; provide an environment for students to practice their emotional and social skills and receive feedback; provide parents with training regarding the ways in which they can respond to their child's emotions and behaviour; provide teachers with training to address the social and emotional deficits in children with Autism; parents and teachers are included in the EBSST program to encourage skills to be maintained over time, and to help their child/student use social and emotional skills in the home, school and other environments.

What training and support will be provided to school counsellors?

- An intensive 2 day training and accreditation course for school counsellors in how to effectively deliver the EBSST program including manuals for school counsellors, students, parents and teachers. Other materials include videos, scripted Powerpoint presentations, social stories and visuals.
- Ongoing clinical supervision and support from clinical psychologists at the Children's Hospital at Westmead.
- Access to the EBSST website and discussion board.

What students are eligible for EBSST?

Students aged 8-12 years old, who have a confirmed or suspected diagnosis of an Autism Spectrum Disorder (including Autism, Asperger's Syndrome, and Pervasive Developmental Disorders – Not Otherwise Specified) and:

- ability within the average or above range or
- mild intellectual disability.

Two EBSST programs have been developed: (1) students with Autism Spectrum Disorder and ability within the average or above range; and (2) students with Autism Spectrum Disorder and mild intellectual disability.

What does EBSST involve? EBSST involves training and accreditation, program delivery including parent participation and research

The EBSST program will provide school counsellors with new skills for working with children with Autism, their parents, and teachers; school counsellors and teacher professional development and supervision.

Who can I contact for more information?

If you have any questions or would like more information about this exciting and innovative opportunity to develop your skills in working with children with Autism Spectrum Disorder please contact Jan Luckey from DET or Dr Michelle Wong from the Children's Hospital at Westmead on ebsst@chw.edu.au. ●