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 School-Link Initiative in Partnership with MH-Kids and the NSW Department of Education and Training

Executive Summary
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**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 (2009)
Dr David Dossetor, Jodie Caruana, Hebah Saleh, Helen Goltzoff

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Foreword

It gives me great pleasure to endorse the Children’s Hospital at Westmead (CHW) School-Link Project report, a needs analysis of mental health in Schools for Special Purposes (SSPs) that cater for children and adolescents with an intellectual disability. The 2.6 FTE project staff has provided a useful resource of information in a remarkable time frame and as a result the project will become an initiative with funding for a further four years, as part of the 4th National Mental Health Plan for the NSW School-Link partnership between NSW Health, Mental Health and the NSW Department of Education.

The CHW School-Link project reports on the mental health needs of children and adolescents in SSPs. Results are presented from a literature review, a web-based questionnaire survey of 35 of the 60 school counsellors and structured telephone interviews of a subgroup of 11 school counsellors. In keeping with other School-Link projects, the enquiry focuses on prevention, promotion and early intervention, pathways to care and the training needs in mental health.

The literature confirms that children with intellectual disability represent a major mental health burden that constitutes 14 per cent of the mental health problems of all children and adolescents. Whereas prevention and promotion and early intervention has an active agenda in mainstream schools, these approaches are not readily applicable to SSPs. Prevention, promotion and early intervention in SSPs has a developing literature and there is need to support such initiatives. Referral pathways to care for mental health problems are mainly to Ageing, Disability and Home Care, Department of Human Services (ADHC) and to Paediatric Services, and there is need to support the interagency collaboration, triage agreements and referral pathways to child and adolescent mental health services (CAMHS). The type and severity of the presenting mental health problems may need different responses according to the type and range of professional skills needed. School counsellors feel they need more specific training in the mental health needs of children and adolescents with an intellectual disability.

The CHW School-Link team are now developing a number of initiatives as part of their four year work plan. This will include: efforts to raise the awareness of mental health problems in children and adolescent with intellectual disability; training workshops for school counsellors, CAMHS staff and others that work with children and adolescents with an intellectual disability; providing support for school counsellors; supporting the development of prevention, promotion and early intervention initiatives for this population; and providing information on pathways to clinical services. Although the project has an initial focus on SSPs that cater for intellectual disability, the project aims to extend its influence to children and adolescents with an intellectual disability in mainstream and independent schools. It is hoped that all these initiatives will be promoted by the continuation of a CHW School-Link steering group and feedback to relevant steering groups to enable cross-government department governance and leadership, with senior representation from Department of Education, CAMHS, ADHC, Paediatric Diagnosis and Assessment Services and General Paediatrics.

The CHW School-Link project presents a real opportunity to improve the mental health of all children and adolescents with an intellectual disability in NSW. I am pleased that the Children’s Hospital at Westmead is able to coordinate such an important initiative on behalf of the NSW Government for the children of NSW.

Dr Antonio Penna
Chief Executive Officer
The Children’s Hospital at Westmead
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Introduction
The Children’s Hospital at Westmead (CHW) School-Link Project was funded by MH-Kids, NSW Health as part of the NSW School-Link Initiative. The project conducted a needs analysis of the training needs of school counsellors of children and adolescents with an intellectual disability and mental health problems and disorders in 58 NSW Government Schools for Specific Purposes (SSPs). Pathways to care and mental health prevention, promotion and early intervention programs were also scoped. The project was implemented between February and July 2009 with 2.6 FTE staff. This report outlines the background and findings obtained.

School-Link is a collaborative initiative between the Department of Health and the Department of Education and Training (DET) created to improve the mental health of children and young people in NSW. It is a key activity under the State Plan Priority F3 “Improved outcomes in mental health”. The School-Link Initiative recognises that schools are in a unique position to support the mental health needs of children and adolescents. The development and implementation of School-Link over the past ten years has built a foundation of organisational support and infrastructure to achieve the three key strategic actions of the initiative which are as follows:

1) Assisting in the identification of pathways to care for students with mental health problems and disorders (MHP).
2) Training and education for mental health workers and school and TAFE counsellors.
3) Supporting the implementation of school/TAFE based mental health promotion, prevention or early intervention programs.

Major Findings
This inaugural report leads the way in identifying the specific needs of children and adolescents with mental health problems or disorders and an intellectual disability enrolled in SSPs as identified by school counsellors. The report highlights the gaps in supporting the mental health needs experienced by these students, the professional development needs of their school counsellors and provides recommendations to improve mental health outcomes in this population. The needs analysis was conducted via a literature review, a survey of 35 school counsellors of students with an intellectual disability enrolled in SSPs and an in depth telephone interview with 11 of these school counsellors. The major findings include:

Children and adolescents with an intellectual disability are a high risk population for mental health problems and disorders.
- 40.7 per cent of children and adolescents with an intellectual disability experience a mental health problem or disorder as reported by Einfeld and Tonge (1996) and Einfeld et al (2006). This is three to four times higher than the general population.
- In NSW there are over 11,000 students with an intellectual disability in support classes in Government schools.
- Children and adolescents with an intellectual disability account for approx 3 per cent of all children, yet Emerson and Hatton (2007a) report that children with an intellectual disability account for 14 per cent of all children with a diagnosable mental health disorder.
- Children and adolescents with mental health problems or disorders and an intellectual disability have additional support needs which may be associated with increased costs and burden of care.
Identification of mental health problems and disorders in children and adolescents with an intellectual disability is complex and requires a collaborative approach involving a variety of stakeholders and service providers.

- School counsellors report that distinguishing between mental health problems and disorders and challenging behaviour in students with an intellectual disability is often difficult. There is no standard or common screening tool to facilitate identification processes.
- School counsellors have a varied role within their SSP as they work on average one to two days per week in their SSP. School counsellors in SSPs refer to a wide variety of agencies and consider feedback from teachers, school learning support officers (formerly known as teachers’ aides) and parents or carers.
- The majority of children and adolescents with an intellectual disability and mental health problems and disorders are being referred to the Ageing, Disability and Home Care, Department of Human Services NSW (ADHC) and/or Paediatricians including Developmental Diagnosis and Assessment Services, whilst the number of referrals to local Child and Adolescent Mental Health Services (CAMHS) is low.
- The major perceived barriers in accessing mental health services include: a lack of adequate services, especially for increased at-risk groups such as students from regional and culturally and linguistically diverse (CALD) backgrounds; a lack of clear referral pathways and interagency cooperation; and limited expertise in working with children and adolescents with the dual diagnosis of an intellectual disability and a mental health problem or disorder.

Mental health promotion, prevention and early intervention (PPEI) strategies for children and adolescents with mental health problems and disorders and intellectual disability needs further development.

- Current resources for mental health promotion and prevention do not adequately address the needs of students with an intellectual disability and are therefore not being utilised by many SSPs. A small number of promotion, prevention and early intervention programs are currently in use by SSPs, although, school counsellors report a limited relevance and/or effectiveness of these programs.
- The small number of promotion, prevention and early intervention programs that are available to students with an intellectual disability are designed for students with a mild level of intellectual disability. There is very limited evidence for programs suitable for students with a moderate or severe intellectual disability. There is evidence that the general principles of promotion, prevention and early intervention are valid (Hendren et al, 1994) and with such a high prevalence rate of mental health problems and disorders in children and adolescents with an intellectual disability, both universal and targeted approaches need to be developed and made available.

School counsellors, school staff, CAMHS and other professionals who provide care and treatment for children and adolescents with an intellectual disability and mental health problems or disorders need ongoing specialty training.

- The NSW School-Link phase training was developed around key topic areas following consultation with a range of professionals and has been available to all school counsellors. As topics have not been designed to focus on the specific or additional needs of students with an intellectual disability, school counsellors from SSPs report that the School-Link phase training was less helpful for students with an intellectual disability and mental health problems or disorders at their SSP, when compared to students in the general population.
- Ongoing professional development for school counsellors in the area of mental health and intellectual disability has not been widely available, yet is in high demand.
• School counsellors requested more training on a variety of topics including interventions, identification and prevention and promotion programs for students with mental health problems and disorders and an intellectual disability.
• Mental health services would benefit from further professional development to build capacity to deal with the complex needs of children and adolescents with an intellectual disability, especially in the areas of alternative communication strategies.

Conclusions and Recommendations
There is a clear need to improve the education and training of school counsellors and school staff of SSPs, CAMHS and other professionals who work with students with an intellectual disability and are at risk of, or who experience, mental health problems and disorders. Children and adolescents with an intellectual disability may have many risk factors but few protective factors that are associated with the development of a mental health problem or disorder. The communication limitations of many children and adolescents with an intellectual disability further complicates the challenges in identifying the early signs and symptoms of mental health problems or disorders. The CHW School-Link Initiative has the capacity to lead the way in improving mental health outcomes of children and adolescents with an intellectual disability through the implementation of the following recommendations:

Recommendation 1
CHW School-Link project should continue as part of the NSW School-Link Initiative and will focus on the mental health needs of children and adolescents with an intellectual disability from a multidisciplinary perspective in recognition that there are many stakeholders working with this population. This recommendation has been unanimously supported by the Steering Group for the CHW School-Link project.

Recommendation 2
CHW School-Link project to become the CHW School-Link Initiative and develop a four year work plan, in line with the four year funding allocation from the Department of Health under the 4\textsuperscript{th} National Mental Health Plan, reporting to MH-Kids.
Major focus areas will be to:
• Raise the awareness of the mental health needs of children and adolescents with an intellectual disability to school and mental health staff to encourage a stronger community focus in line with recommendation 10.7 Working Collaboratively of the Wood inquiry (Wood, 2008).
• Increase the identification and diagnosis of mental health problems and disorders for children and adolescents with an intellectual disability.
• Develop and clarify referral pathways to care for children and adolescents with an intellectual disability and mental health problems and disorders.
• Develop and provide education and support to mental health staff, including guidance on assessment and management of mental health problems in children and adolescents with an intellectual disability.
• Support initiatives in mental health promotion, prevention and early intervention for children and adolescents with an intellectual disability.
• Develop a strategic framework outlining the key focus areas to address the needs of children with an intellectual disability and mental health problems and disorders.
Recommendation 3
Establish a CHW School-Link Steering Committee as outlined in the NSW School-Link Memorandum of Understanding (MoU) between the Department of Health and Department of Education and Training (DET) to:

- Assist in the development of a four-year CHW School-Link Work Plan.
- Assist in the evaluation of the CHW School-Link initiative.
- Provide expertise and support to the CHW School-Link Initiative staff.
- Provide support and expertise to school counsellors, and other school professionals, working in public sector schools.

The Steering Committee will include representatives of MH-Kids, Department of Health, Department of Education and Training, CAMHS, ADHC, and Paediatric Diagnosis and Assessment Services.

CHW School-Link Initiative Work Plan
Initial areas that could be considered by the Steering Committee in the development of a CHW School-Link Initiative work plan may include:

- Develop a communication plan to raise awareness to a wider constituency on the mental health needs of children and adolescents with an intellectual disability.
- Develop better understanding of criteria for identifying children and adolescents who have an intellectual disability and mental health problems.
- Support improvements in pathways to care for children and adolescents with an intellectual disability.
- Develop a learning module to address the needs of school and mental health staff working with children and adolescents with mental health problems and disorders and an intellectual disability.
- Support of school and mental health staff, working with students with mental health problems and disorders and an intellectual disability.
- Support of the development of prevention and early intervention programmes/strategies for students with an intellectual disability in SSPs.
- Develop a multidisciplinary framework for working with children and adolescents with mental health problems and disorders and an intellectual disability across agencies.

This report provides the basis for a communication strategy and an intervention framework to support many issues that arise when working with children and adolescents with mental health problems and disorders and an intellectual disability. This can only encourage further research from both key stakeholders in this project and other external agencies that may want to have some input into the four year work plan. In the context of the recommendations of the Wood Enquiry, there is a fresh opportunity to improve collaboration and a multidisciplinary approach for these children and adolescents in SSPs in NSW.

The CHW School-Link scoping project has clearly demonstrated that students with an intellectual disability and mental health problem or disorder are a disadvantaged population and there is much to be done to improve identification of mental health problems and disorders, improve treatment services, improve the training of education and mental health professionals working with these students, improve promotion, prevention and early intervention programmes and the development of pathways to care.

Over the next four years, CHW School-Link looks forward to leading the way in contributing to the literature and working with key stakeholders to improve the mental health outcomes of students with mental health problems or disorders and an intellectual disability.
References


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