Submission No 280

INQUIRY INTO THE PROVISION OF EDUCATION TO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS

Organisation: The Children's Hospital at Westmead

Date received: 19/02/2010

the children's hospital at Westmead

Legislative Council General Purpose Standing Committee No. 2

NSW Inquiry into the Provision of Education to Students with a Disability or Special Needs

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On 19th February 2010

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the children's hospital at Westmead

TRIM Ref: D10/326

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Dear Ms Parker MLC,

NSW Inquiry into the Provision of Education to Students with a Disability or Special Needs

The Children's Hospital at Westmead (CHW) thanks you for the opportunity to respond to this important inquiry by the NSW Legislative Council, as it provides an overdue opportunity to identify and address unmet needs of this special group of school students.

In order to respond to this Inquiry, CHW convened a multi disciplinary working group that included Carer Support Coordinator, Child Life Therapists, Nurses, Occupational Therapists, Paediatricians, Physiotherapists, Psychologists, Social Workers and Speech Pathologists all of whom specialise in areas related to disability and many of whom are recognised experts in their field. In addition, a number of our staff and departments chose to respond individually and these responses are provided in Appendices, along with other information that we believe is relevant to this Inquiry. An index of Appendices is provided at the end of this document. We respond only to those issues to which our expertise applies, using the item numbers provided in the Terms of Reference.

Representatives from CHW would be willing to also attend a Public Hearing if and when required. If you have any enquiry in regards to documentation submitted please contact Alison Jones on (02) 9845 3715 or email alisonj@chw.edu.au

Yours sincerely

Cheryl McCullagh

Director of Clinical Operations



BACKGROUND

At CHW we treat children throughout NSW as inpatients, outpatients; in our diagnostic and assessment units and outreach clinics. Our services assess and treat children and adolescents including but not limited to:-

- congenital conditions with ongoing complex physical and/or learning issues such as cerebral palsy; spina bifida; Rett syndrome; spinal muscular atrophy; muscular dystrophy; limb deficiency, epilepsy, peripheral neuropathies; connective tissue dysplasia conditions (eg arthrogryposis; osteogenesis imperfecta) intellectual disability (mild to significant); Autistic Spectrum Disorder
- Sensory conditions such as deafness; visual impairment
- > Acquired traumatic conditions such as spinal cord injury; acquired brain injury
- Chronic medical conditions such as renal conditions; haemophilia; rare metabolic conditions; diabetes; cystic fibrosis; cardiac conditions; liver disease; respiratory conditions including those children / young people with tracheostomies and/or who require long-term ventilation
- > Mental illness and/or conduct disorders/behavioural issues
- Developmental / learning issues / speech and language difficulties with no specific diagnoses.

1. NATURE, LEVEL AND ADEQUACY OF FUNDING

We consider that the Department of Education and Training (DET) proposed capping of funds will disadvantage students especially those with autism and mental health disorders (http://www.nswtf.org.au/campaigns/support/news/capped.html). Plans to allocate grants based on the prevalence of disorders in the wider community as apposed considering individual needs could be detrimental to the students with disability, their teachers and their peers. Some schools are known to have more experience than others and therefore attract more students. Families find it beneficial knowing that the school is familiar with the needs of students with disabilities. It is of benefit to have a ratio of children with special needs in any one school to allow for support for the student and family and other opportunities, but in practical terms this will not always be possible and may not meet the needs of the individual student.

2. ALLOCATION OF FUNDING

Funding allocation to enable these students to enjoy as inclusive an education as possible should be based on both the individual child's functional capacity and their disability or diagnosis. Every

diagnosis has known clinical and educational implications that inform us about the student's needs. However, assessment of their <u>functional</u> ability is also essential to complete the understanding of the child. Students who have no specific diagnosis but who have developmental, speech and language or learning delay can have significant difficulty accessing the school curriculum without appropriate support.

Assessment of the child's functional needs should be conducted prior to starting school to ensure the school is able to provide appropriate support from the beginning of school rather than waiting for difficulties to arise. The most suitable **functional assessments** should be investigated. We have provided a list of existing assessments in Appendix 1. Functional assessments should be used at the **time of transition** from pre-school to kindergarten; from primary to high school and from high school to adult life, but do not need to be repeated annually. Rather, once the functional assessment has established the need for extra support for a stage of school, and when the student has an established ongoing condition, reviews of the level of functional support required should be through a collaborative annual **Individual Education Plan** (IEP).

Collaboration and liaison among the relevant organisations including; DET; Health; Human Services (Aging, Disability and Home Care); non government organisations (NGOs) such as Northcott Disability Services; The Spastic Centre; Vision Australia and the student's family will enhance communication to benefit the student, not only when the functional assessment is conducted at times of transition, but also through ongoing contact. Effective collaboration requires <u>all</u> parties to have the capacity to respond effectively when needs are identified. Therefore, it is essential that collaboration is underpinned with resources and the ability to respond to identified needs in a timely way.

4. INTEGRATED SUPPORT SERVICES IN MAINSTREAM SETTINGS

From the parents / carers perspective the components to good education for their child, taking into consideration the issues associated with their medical condition, include:-

- Access to support services which are timely, flexible and ongoing,
- Choice, as no <u>one</u> school placement suits all. The experience of the CHW Child Development Unit (CDU), who see children with developmental delay / intellectual disability / autism, is that parents initially want mainstream schooling, but as the developmental delays become more noticeable and the

child differs from their peers, they become more focussed on receiving the appropriate level of intervention and support for their child in as small a classroom setting as possible.,

- Continuity of all staff involved with the child: caseworkers, therapists, teacher's aides, medical team, etc,
- Ongoing collaboration, input and sharing of information between Health / NGOs / Schools as well as teacher to teacher / therapist to therapist. For example, close links between school counsellors and health services assist in achieving better outcomes for the child and their family. The Specialist School Counsellor for students with acquired brain injury meets regularly with relevant health staff. This facilitates communication and planning between health and the individual school/s,
- Increase in language support classes, IM and IO Classes. (Information received from the DET implies there are sufficient numbers of these services / classes, but we recommend independent review and evidence based outcomes about parental and professional preferences; student outcomes and research trends on this issue.).
- Support to manage health issues / needs such as: dispensing medication; tracheostomy and suctioning care; incontinence care; assistance with feeding. Health issues affect educational capacity and managing the Health issue can be very disruptive to a child's ongoing education. (Appendix 2 details the MOU between DET and Health which is a positive step forward towards enabling schools to be supported in this important aspect of the student's time at school).
- Support to access the school curriculum and to safely enjoy the full school experience, including positive peer relationships and school friends.

While it must be exceptionally difficult for teachers in mainstream classes to manage all of these extra demands, in general families wish their child to attend a mainstream school on entry into Kindergarten. As a result there are wide-spread concerns that education services for children with disability are **under funded**.

6. ACCESS TO PROFESSIONAL SUPPORT AND SERVICES

As well as improved teaching and appropriate levels of teachers and teacher's aides, the intervention and necessary support (including equipment) needs to be present and active at the point where performance is required. In particular the support is needed in the classroom, playground, sport and recreation and excursions/camps. We propose the establishment of school based teams consisting of at least the following allied health professions: Speech Pathology; Occupational Therapy;

Physiotherapy, Nursing, Psychology and Social Work. These teams should be considered <u>practice</u> <u>based</u>, able to take direct therapeutic action when and if required. They should NOT be considered consultative teams; however they would be able to serve the function of co-ordinating collaboration between the child and family and all other professionals involved in that child's care and education.

Queensland has a well established model of support for students with special needs. Therapists are employed by DET, Queensland. They are integral members of the school staff rather than being the visiting "expert" and they liaise with the relevant specialist services:-

http://education.qld.gov.au/studentservices/learning/disability/specialists/index.html.

Another model of care to support students with physical disability is through School Therapy teams such as the teams that are based at Campbelltown, Liverpool, Randwick and the Hills District. The therapists are employed by Health and treat students with physical disability attending mainstream schools. These therapists, like those who are employed by Queensland DET, are able to follow up Home as well as School issues, such as self care / physical access / equipment.

Equipment to enable children with physical disability should also be considered. At present, some students are unable to attend school full time due to lack of appropriate equipment, for example, standing frames. This particular piece of equipment is no longer available from the NSW Government's PADP/Enable funded equipment list, as standing is classed as "therapy". We believe that DET are reluctant to provide standing frames for students to use in the classroom as if one student is given a frame, a precedent will have been set. (Refer to Appendix 2). Many years ago there was a Support Unit for DET staffed by therapists who were able to offer support and training. The Unit also had an excellent store of equipment which could be loaned out to schools for as long as the student required the equipment. The reinstatement of such a unit could be a partial solution to this ongoing issue.

Students with special needs, who use a **computer** to record their school work as their writing is compromised (due to ongoing physical disability / fine motor difficulties), request the use of a computer as a **special provision for external examinations** eg School Certificate / Higher School Certificate (HSC). These students are increasingly being granted the use of a writer/scribe instead of being allowed to use a computer. Use of a writer is a learnt skill which requires practise and many

students such as those with physical and/or speech and language difficulties, lack self confidence in dictating or are unable to relate to a writer, often another senior student. This, therefore, does <u>not</u> allow these students to be on a "level playing field". We recommend a review of the criteria by the Board of Studies NSW regarding the use of computers for students with ongoing fine motor difficulties /ongoing medical conditions such as arthritis, hypermobility, peripheral neuropathy where pain and fatigue are significant factors. (http://www.boardofstudies.nsw.edu.au/special-provisions)

7. TEACHER TRAINING

People involved in the education of children with disabilities, due to the complexity and variety of conditions, may **lack the skills and knowledge** needed for best outcomes. These concerns are expressed not only in NSW, but also internationally http://www.aamr.org/content_147.cfm?navID=31).

Support Teachers Learning Assistance (STLA) and Itinerant teachers with skills in specific areas such as visual impairment and deafness have given excellent support to mainstream teachers yet information indicates that these teachers' roles will be changed. Increased training is required to assist teachers, including input from Health, at both the undergraduate and postgraduate level. "Physical as Anything" (http://www.schools.nsw.edu.au/studentsupport/studenthealth/index.php) is an excellent overview of medical conditions but each school generally only has one copy and not all relevant teachers are aware of the resource. If the latest edition, presently being completed, is made available on the DET website teachers will have easier access.

Attachments:

Appendix 1 List of Functional Assessments

Appendix 2 Developments and Issues for the Long Term Ventilation children

Appendix 3 Letter from Dr Jacqueline Small, Senior Staff Specialist, Developmental Disabilities

Appendix 4 The provision of education for students with a disability or special needs: A focus on intellectual disability and mental health

Comments by the Developmental Team, Department of Psychological Medicine

References:

"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", Project report of The Children's Hospital at Westmead School-Link Initiative in partnership with MH-Kids and the NSW Department of Education and Training.

Letter from Dr Jacqueline Small, Consultant Disability Service Unit (DSU) Burwood

The Royal Children's Hospital, Melbourne Policy Briefs:

Policy brief No 17 2009: Translating early childhood research evidence to inform policy and practice:

http://www.rch.org.au/ccch/resources.cfm?doc_id=10885

Policy Brief No. 17 'Integrating Services for Young Children and their Families'

References Policy Brief No.17 'Integrating Services for Young Children and their Families'

Case Study: Toronto First Duty

"All genuine claims, rigorously checked, Sydney Morning Herald, Thurs 14/1/2010 pg 12

"Autistic Pupils unfairly treated", by Bruce McDougall, The Daily Telegraph Fri 08/01/2010 pg

APPENDIX 1 - List of Functional Assessments

- The School Functional Assessment (SFA) is comprehensive but is lengthy to administer (http://www.pearsonpsychcorp.com.au/productdetails/184/1/28);
- A comparable model already in place for NSW students with special needs transitioning from High School could be a useful assessment strategy.
- The functional assessment process commonly used in the Education Queensland schools is
 a diluted version of work by Gary W. LaVigna, Thomas J. Willis and Anne Donnellan in the
 Behaviour Assessment Guide (1993).

 (http://www.learningplace.com.au/deliver/content.asp?pid=19071)
- 4. A functional assessment based on the World: Health Organisation's International Classification of Functioning, Disability and Health (ICF)

 http://www.who.int/classifications/icf/en/.
- 5. For students with language difficulties who have not been identified as having additional learning needs prior to starting school, could be identified through the new Best Start Kindergarten assessment

 (http://www.curriculumsupport.education.nsw.gov.au/beststart/index.htm)

APPENDIX 2

Developments and Issues for the Long Term Ventilation children:

- Current Memorandum of understanding between Department of Education and Training (DET) and Department of Health to support students on long term ventilation in school. This includes (DET) supporting the carer staff post discharge into the community.
 - Support currently provided by (DET) has allowed students prior to discharge the provision of special transport to and from school.

Current issues and identified needs around this memorandum of understanding

- Support from (DET) is implemented after discharge into the community. Inpatients are unable to attend their local schools until they are discharged home unless the support is provided by The Children's Hospital at Westmead.
- A Memorandum of understanding is required to progress further with an emphasis on the transition of the long term ventilated children from an inpatient setting back to their local school in the community. This should include:
 - i. Identifying and working towards reducing time spent in hospital/institutional setting (including hospital schooling) and focus on transition to preadmission educational setting and routine.
 - ii. Beginning transition process back to school from hospital at the time that the student is deemed 'medically stable' and discharge process commences.
 - iii. (DET) supporting access to carers for school prior to the student discharging as part of the transition back into the community for the child.
 - iv. Formalisation of the transition process and support, is required that outlines; the point at which transition to school can commence from the hospital setting, support provided by (DET) at this stage e.g. equipment, carer support, transport.
- 2. Support and provision of specialised equipment from (DET) that is essential for transition back to school and access to the curriculum:
 - (DET) does not currently support the funding and provision of specialised equipment such as standing frames that are essential for transitioning students with complex needs such as those students who are dependant on ventilation back to school and to maximise their attendance and access to the curriculum. Standing frames are used to relieve pressure and facilitate a change of position during the day for high risk children who cannot sit in their wheelchairs, specialised buggies etc thus allowing the child to attend school longer and have complete access to the curriculum.
 - There are currently no funding bodies that support this equipment as it is primarily considered the responsibility of the (DET) to provide all necessary opportunity (including equipment and technology provision) for students to access the curriculum.
 - Children and families directly impacted by this are unable to attend school full time, become socially isolated and immense strain and pressure is placed on the family when the child does not have the opportunity to access school full time.

- 3. Currently The Children's Hospital at Westmead support the transition of children into their local community and education program by:
 - Completing risk management plans and assisting in the development of new medical plans for the child.
 - Educating staff and students at the school on the ventilator and changed needs of the client.
 - Linking the school with appropriate community services such as; physiotherapy, case managers, occupational therapists etc. that can provide the student and education facility with ongoing support and review of needs.
 - Provide all necessary training through the Respiratory Support Service for allocated carers funded through (DET).
 - Assist in the clarification of the roles & responsibilities of Teacher's Aides and Carer staff.
 - Provide any ongoing support as required.
- 4. Current Allied Health representation on the (DET) Equipment and Technology committee for South West Sydney Area.
- 5. <u>Future project</u>: Development of an annual training day for community therapists, Area Health Services and Education staff that is directed by needs identified by these supports.

Corinne Browne
Case Manager/Occupational Therapist

Sandra Pengilly Child Life Therapist

APPENDIX 3

The Director General Purpose Standing Committee No 2 Parliament House Macquarie Street SYDNEY NSW 2000

4th February 2010

Dear Ms Parker MLC,

NSW Inquiry into the Provision of Education to Students with a Disability or Special Needs: <u>Students with Intellectual Disability</u>

This important new inquiry by NSW Parliament into the provision of education services to students with a disability, such as intellectual disability, or special needs provides an overdue opportunity to identify and address unmet needs of this special group of children. Children and adolescents with **intellectual disability require special consideration** due to a complex interplay of factors such as (modified from an excerpt from Australian Association for Doctors in Developmental Disability Medicine submission to NHHRC, 2008);

- Limitations in general everyday functioning to the extent that independence is impacted and lifelong support from responsible adults required
- Communication limitations that may prevent the person from expressing needs and wants.
- Coexisting health problems that are often complex and chronic.
- Genetic Syndromes that may have implications for future health development and other members of the family.
- Diagnostic overlay mistakenly assuming problems such as challenging behaviour are related to the disabilities.
- Poverty and the addition impact this has on educational experiences, and family resilience.
- Many health professionals involved in care on an ongoing basis
- Many members of society attaching less value to people with disabilities.
- Health promotion, campaigns and research tending to ignore people with intellectual disabilities.
- · Limited or poor whole-of-life decision making and planning
- Family stress and the need for long term support and services

Given the complexity of the more significant developmental disorders/disability that children may have, no single professional or agency can expect to be able to fully meet the needs of the child and their family. An essential outcome for this review must involve strategic plans and specific proposals for improved collaboration across agencies and professionals.

Parents of children with disability often feel that they are the only informed resource for their child's educational and therapy needs. Parents are frustrated by how hard it is to access

services recommended by specialists, especially if their child is in a mainstream setting. Establishing and maintaining interagency collaborations between organisations, eg schools and DH/ADHC services, can be at times challenging, with bureaucratic processes determining the model of services provided, and long wait lists often delaying provision of service. Limited collaboration across agencies and between professionals may restrict the ability of schools to implement up to date strategies and to be aware of the latest knowledge or scientific advances in related areas. With the emphasis on early intervention, there is often a substantial reduction in available services past school age, often despite complex needs remaining.

The challenges related to adaptation to a diagnosis of developmental or intellectual disability continue to confront, and potentially confound, both carer and professional well into the school years. Children not uncommonly approach school age without the parent being fully aware of the long term implications of the developmental disorder, and unaware that their child "won't catch up". This then fuels expectations of cure, and disappointments when this doesn't eventuate, and demands for curative treatments. This situation arises due to a range of factors including presentation of significant disorders during school years, limited access to comprehensive diagnostic services even during the preschool years and limited allowance made for the lifelong impacts on and adjustments by parents of a child with a disability. In a culture where normalisation and inclusion dominate, there is often little opportunity to discuss significant disability that has lifelong implications.

It is widely acknowledged that diagnosis is a critical period for families and a process designed to understand the needs of the child and family in order to best advocate for and plan services. Service models need to adapt to the needs of the child and family, as it is suspected that unresolved issues related to diagnosis may underpin limited engagement with intervention, limited acceptance of professional advice and difficulties establishing realistic goals and outcomes. This is supported by a recent survey by CHW School Link project.

Ongoing access to specialist services is currently severely limited, and in urgent need of enhancement. In children with intellectual disability, complex issues continue to arise through the school years, that require involvement of specialised services for diagnosis and management. Challenging behaviour is common and often poorly diagnosed. Undoubtedly it is an important cause for stress, and possible breakdown for family and services, including schools. There are few, if any, services in the public health sector that can provide these much needed services, yet health professionals, including paediatricians, allied health and psychiatrists, certainly have important roles in addressing these problems.

Recommendations;

Service Model

- a) The service model must be one of multidisciplinary collaborations involving relevant agencies, including for example, Health, ADHC, as well as education with policies developed to support these efforts
- b) Service models must respond to the lifelong and complex needs of these students, eg collaborative schools clinics involving different agencies held on an ongoing basis to address issues as they arise (eg Cairnsfoot School) and be based on family centred models of care
- c) Individual education plans developed with key partners, including carers, that identify the needs of the child must be in place and inform ongoing education and

- management within the school, with curriculum focussed on functional abilities of the child
- d) Retention of specialised therapy services within a therapy model, but development of MOU to ensure implementation of a service model that achieves a high level of cooperation, provision of consultation/therapy services and educational support between agencies in particular with those schools with high concentrations of students with special needs
- e) That provision of and funding for support of a child in a school not be restricted by the number of children with disability already at that school.

Service Standards

- a) Services must be consistent with accepted and transparent standards eg, Disability Services Act 1993
- b) Policies that acknowledge key life stages, eg diagnosis, transition to school, transition to high school, and transition to adult services and are embedded in a family centred model of care must be developed and evident in practice
- c) Policies related to behaviour management of students with disabilities need to be made available, in particular those that relate to restrictive practices, eg isolation of students.
- d) Services be based on sound and good quality evidence

Specialised skills required

- a) Education of students with significant disabilities requires teachers to have specialised education expertise, knowledge of best practice in fields of communication and behaviour management, and skills in effective collaboration with other professionals and carers
- b) Establish minimum knowledge and skills sets in relation to education of children with special needs, eg use of visuals for children with autism

• Diagnosis and assessment

- a) All special schools to establish and maintain relationships with local child disability/development services in DOH
- b) enhancement of local child development/disability Diagnostic and Assessment teams to ensure services can be provided to school age children with complex developmental needs eg challenging behaviour

Future planning

a) Population data be collected to clearly document the needs of the child with developmental disabilities and the services provided in order to inform further planning and identification of needs.

Yours sincerely,

Dr Jacqueline Small

MBBS FRACP MPH(Hons)

Senior Staff Specialist, Developmental Disabilties

APPENDIX 4

The provision of education for students with a disability or special needs: A focus on intellectual disability and mental health

Comments by the Developmental Team, Department of Psychological Medicine The Children's Hospital at Westmead

There are many health concerns that that co-exist with children and adolescents with a disability or special needs; mental health problems and disorders are an unfortunate yet inevitable statistic that cannot be avoided amongst this population. To think about the provision of education to students with a disability or special needs, one will need to think about the mental health problems and disorders that are so often associated in order to ensure equitable practices among all students.

Introduction

Prevalence rates of children and adolescents with an intellectual disability and a mental health problem or disorder are estimated to be an alarming three to four times higher than that of the general school-aged population (Einfeld and Tonge, 1996). Figure 1 shows that 40.7% of children and adolescents with an intellectual disability have experienced a mental health problem or disorder, whilst statistics for mental health problems and disorders amongst all school aged children is 14% (Sawyer et al, 2000). Students with an intellectual disability therefore comprise a significantly larger percentage of the total amount of students who experience mental health problems and disorders than their population estimates would merit (as high as 14% as noted by Emerson and Hatton (2007)). This particular group of students with a dual diagnosis of both intellectual disability and a mental health problem or disorder and those who are at-risk of developing a mental health disorder require additional support to ensure that educational equity is achieved.

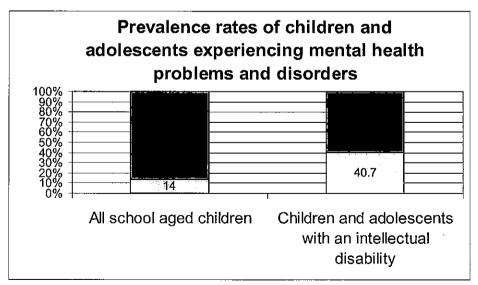


Figure 1: Prevalence rates of children and adolescents experiencing mental health problems and disorders (Adapted from Einfeld and Tonge, 1996 and Sawyer et al, 2000)

Links between mental health and education

There is a clear link between mental health and education outcomes. Poor mental health has been associated with poor school performance or educational underachievement (Fergusson and Woodward, 2002) and in turn the school environment can influence aspects of the student's mental health such as behaviour and attitudes (Rutter *et al*, 1980).

Schools are in an ideal position to monitor mental health risk factors and enhance protective factors to increase the wellbeing of children. The World Health Organisation identifies that schools are the best place to universally promote mental health as almost all children and adolescents attend school; schools are seen as strong social bodies; schools can be a safety net protecting a child or adolescent's psychological wellbeing and schools can also build or undermine capacity and self esteem (Hendren *et al*, 1994). Adequate prevention and support of a mental health problem or disorder is important for any student, but when that student has special needs, especially an intellectual disability, the complexity of intervention and management is increased and the provision of education may be compromised.

Challenges to providing adequate support services

Firstly the diagnosis of a mental health problem or disorder in students with special needs is a key area of concern. Communication limitations that may be experienced by students with an intellectual disability often make it difficult for a mental health problem or disorder to be diagnosed. In addition, often the behaviours that may be displayed by the student with an intellectual disability and a mental health problem are attributed to the disorder that is associated with the intellectual disability and not the mental health problem, a dilemma referred to as diagnostic overshadowing. Often students displaying externalising behaviour are treated for their challenging behaviour but not the root cause which may be a mental health problem or disorder.

Another area adding to the increased complexity in the intervention and management of mental health problems and disorders for students with special needs such as an intellectual disability is the lack of staff speciality. The majority of staff in key primary agencies that cater for students with special needs do not have the specialist skills to make an accurate mental health and intellectual disability diagnosis. This is evident in child and adolescent mental health services (CAMHS) for example whereby the staff are specially trained in mental health but not intellectual disability and in disability services where staff are trained in their area of speciality but often need additional training on mental health. Availability of staff is another key area of concern as long waiting lists for CAMHS services decreases any chance of early if any intervention. Amongst schools, school counsellors received generalised training that is not specific to intellectual disability (Dossetor *et al*, 20009).

Once a mental health diagnosis is made, the complexity of managing the student's health and educational needs are further complicated by the range of agencies that are involved in the care of the student. Whilst sometimes interagency collaboration works very well, often here is a lack of planned or agreed processes to coordinate individual cases across agencies (disability, education, health, mental health, developmental services). Effective and efficient collaboration is needed and a lead agency for case coordination needs to be appointed. One example of good practice is the Burwood Disability Services Unit that conducts clinics within schools for specific purposes (see the appendix by Small within this submission).

Furthermore, collaboration across state departments is made much more difficult when services are located in the same geographical region, but are from different areas depending on state departments. One geographical area such as Westmead will fall in three different areas when viewed through NSW Health, NSW Department of Education and Training or Ageing, Disability and Home Care (ADHC) lenses. Similar departmental labelling and the evaluation of the collaboration process are essential across departments for changes to be made when required.

Finally, as more students with intellectual disability are enrolled in mainstream schools, policies and practices will also become a challenge. Schools need to implement specific policies that comply with the needs of students with special needs which are different to mainstream policies; for example, suspension is an extra disadvantage for this population that may need a different management plan as the suspension becomes a problem for parents and the student alike if the student is continually absconding from school. Indeed a child with an intellectual disability will have delay in the development of intent, insight and moral understanding. Any school based challenging behaviour intervention should assess this developmental context before any "punishment" such as suspension is considered. In many instances problem solving approaches to supporting the child and the behaviour in school is likely to be the most appropriate response, rather than an approach that punishes the child and family. Specialised resources and policies are required for students with a mental health problem or disorder and intellectual disability, as are policies for ensuring medications are taken within the school setting.

The role of mental health prevention and promotion in schools for students with special needs. As the prevalence rates of students with both an intellectual disability and mental health problem or disorders are three to four times higher than that of the general school-aged population (Einfield and Tonge, 1996), the role of mental health promotion and prevention in schools in paramount.

Little attention has been paid to the mental health prevention, promotion and early intervention of children with special needs as highlighted by Dossetor *et al* (2009). Existing programs for use in mainstream classes and schools often fail to meet the needs of students with special needs especially those students with a moderate or severe intellectual disability. Resources need to be developed to address equity in access to a mental health promoting curriculum to ensure that these high risk students build their well being and resilience, and therefore their optimal ability to learn at school.

An existing parenting program that addresses the mental health needs of children with an intellectual disability and/ or developmental delay at the systemic level include the Triple P Stepping Stones program developed by Queensland University (Sanders et al., 2004). The standard Triple P parenting program has also displayed effectiveness with students who have been diagnosed with conduct disorder.

Access to professional support services, such as speech therapy, occupational therapy, physiotherapy and school counsellors

Access to school counsellors

School counsellors have a varied role within each school they work in. In a survey of school counsellors who work in Schools for Specific Purposes (SSPs) that cater for students with an intellectual disability in NSW, the majority of school counsellors were allocated two days or less per week to their SSP, with almost half spending less than one day in their SSP (Dossetor *et al*,

2009). This is concerning given the high and often complex needs of students with special needs such as those with an intellectual disability.

The role of the school counsellor is varied with many tasks competing within a limited time frame as highlighted by Dossetor *et al* (2009). The main role identified by school counsellors in their SSP was to support staff, parents and students. Other important roles included assessment and referral, and liaison with other agencies. Minimal time was identified as being available for school counsellors to deal with the mental health problems and disorders of students such as psycho-education, consultation, case management, meetings and behaviour management plans.

It is of great concern that school counsellors only have minimal time available for mental problems and disorders of their students, as students with a mental health problems or disorder are more likely to access school counselling than any other service. The Mental Health of Young People in Australia: Child and Adolescent Component of the National Survey of Mental Health and Well-being states that counselling in schools was one of the most frequently accessed services utilised by students as identified by their parents (Sawyer et al, 2000). This is an important insight given that the survey recognised that only 17 per cent of all children with a mental health disorder accessed a mental health service.

It is also a great concern that school counsellors only have minimal time available for mental problems and disorders of their students, as children and adolescents with an intellectual disability are a high risk population for mental health problems and disorders. The amount of children and adolescents with an intellectual disability in NSW government schools who are likely to experience a mental health problem or disorder is at least 4,500 given that there are over 11,000 students in support classes for intellectual disability (DET, 2008). This figure rises significantly when students in regular classes are considered.

In order for students with special needs to reach their full potential, all schools and SSPs in particular (as their students are in a significantly higher risk category for developing mental health problems and disorders) would benefit from having a full time school counsellor or at the very least increased hours of a school counsellor in order to cater for the varying developmental and mental health needs of the student population.

Adequacy of pre-service and post-service teacher training

It is evident that school counsellors require more training to meet their needs in both pre and post service training as represented by a survey conducted of school counsellors in NSW SSPs working with children and adolescents with mental health problems and disorders and an intellectual disability (Dossetor *et al*, 2009). Although this survey was centred on the pre-service training and ongoing professional development of school counsellors, it may be assumed that teachers would also have a similar outcome, if not poorer when considering the mental health of children and adolescents with an intellectual disability as mental health is not always accounted for in pre-service and post-service training for teachers.

Pre-service training

Pre-service school counsellor training had not effectively prepared participants for their role in working with students with mental health problems and disorders and an intellectual disability in a SSP. Half of the participants noted that there is nothing like experience to prepare you for such a role. Improvements to pre-service training, school include exposure to SSPs in their

practicum, learning about assessing this population, specific intellectual disability training and resources on how to assist staff with challenging behaviours.

Ongoing professional development

In the Dossetor et al (2009) report school counsellors reported that their pres-service training could be enhanced by access to further information, access to specialists, programs for school counsellors, teachers and parents, further training on case management, pathways to care, self management and communication strategies.

A review by Costello *et al* (2007) across five countries including Australia revealed that professionals receive little formal training in assessment and care of people with mental health problems and disorders and an intellectual disability. This could potentially have some serious ramifications such as; a lack of specialist knowledge in this area, lack of appropriate referrals and limited reporting of mental health problems and disorders just to name a few. Not all is so negative though; Costello *et al* (2007) have examined some good training practices which warrant replication across professions and countries. Similarly, in NSW, training from the Children's Hospital at Westmead conducted in collaboration with ADHC and the State-wide Behaviour Intervention Service has been a positive model of practice for collaborative cross professional training about mental health and intellectual disability (Reference). The Training Project entitled "mental health for children and adolescents with intellectual disability: a framework for professional practice", has provided a gateway for professionals who work in many different sectors.

Bates et al (2004) outlines several recommendations for the training of staff working with clients with an intellectual disability and mental health problems and disorders that may have positive results for practice with this population; these are as follows:

- Programs to provide information and address skill deficits in assessment and intervention.
- Opportunity for awareness raising and sharing of knowledge.
- Internet and website development to facilitate contact between colleagues across the international community.
- Education and training programs to be of mutual benefit to staff from a range of professional backgrounds and settings (Bates et al, 2004).

Conclusion

The provision of education to students with a disability or special needs must consider mental health problems and disorders that are so often associated with this client group, specifically those with an intellectual disability to ensure best practice. Schools are an ideal setting to focus on mental health problems and disorders as there are links with educational outcomes. Similarly there are links between mental health problems and disorders and the school environment. Prevention, promotion and early intervention mental health programs targeted towards special needs populations are an ideal starting point for all school settings that cater for children and adolescents with a disability, special need or dual diagnosis.

Access to support services such as communication tools to enhance assessment and treatment, staff specialty in dual diagnosis and cross agency collaboration are common challenges that need to be addressed within this population. Pre-service and post service training for teachers and other staff about mental health problems and disorders and intellectual disability is

inadequate and needs further consideration as do the policies for students with an intellectual disability in mainstream schools.

For further information about the needs analysis conducted by School-Link at the Department of Psychological Medicine, Children's Hospital at Westmead titled 'Leading the Way in Mental Health and Intellectual Disability: A focus on the needs of Children and Adolescents in NSW Schools for Specific Purposes' please contact;

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References

- 1. Bates, P., Priest, H.M. and Gibbs, M. (2004). The Education and Training needs of Learning Disability Staff in Relation to Mental Health Issues. *Nurse Education in Practice*. Vol 4, Pp. 30-38.
- Costello, H., Holt, G., Cain, N., Bradley, E., Torr, J., Davis, R., Edwards, N., Lennox, N. and Weber, G. (2007). Professional Training for those Working with People with Intellectual Disabilities and Mental Health Problems in Bouras, N. and Holt, G. Eds. (2007). Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities. Cambridge University Press.
- 3. DET. NSW Department of Education and Training. (2008). *Statistical Bulletin; Schools and Students in New South Wales, 2007*. Data Collection Unit; Planning and Innovation. Sydney.
- Dossetor, D.R., Caruana, J., Saleh, H and Goltzoff, 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. (internal document)
- 5. Einfeld, S.L. and Tonge, D.J. (1996). Population prevalence of psychopathology in children and adolescents with intellectual disability: II epidemiological findings. *Journal of Intellectual Disability Research*. Vol 40, Iss 2, Pp. 99-109.
- Einfeld, S.L., Piccinin, A.M., Mackinnon, A., Hofer, S.M., Taffe, J., Gray, K.M., Bontempo, D.E., Hoffman, L.R., Parmenter, T. and Tonge, B.J. (2006). Psychopathology in Young People with Intellectual Disability. *Journal of the American Medical Association JAMA*. Vol 296, Iss. 16, Pp. 1981-1989.
- 7. Emerson, E. and Hatton, C. (2007). Mental Health of Children and Adolescents with Intellectual Disabilities in Britain. *British Journal of Psychiatry*. Vol 191, Pp. 493-499
- 8. Fergusson, D.M. and Woodward, L.J. (2002) Mental Health, Educational, and Social Role Outcomes of Adolescents With Depression *Archives of General Psychiatry*. Vol 59, Pp. 225-231
- 9. Hendren, R., Birrell Wisen, and R., Orely, J. (1994). *Mental Health Programmes in Schools*. Division of Mental Health, WHO (World Health Organisation).
- 10. Rutter, M., Tizard, J. and Whimore, K. (Eds). (1970). Education, Health and Behaviour. Longman, London.
- 11. Sanders, R., Mazzucchelli, T.G. and Studman, L.J. (2004). Stepping Stones Triple P: The Theoretical Basis and Development of an Evidence Based Positive Parenting Program for Families with a Child who has a Disability. *Journal of Intellectual & Developmental Disability*. Vol 29, Iss 3, Pp. 265-283.
- 12. Sawyer, M.G., Arney, F.M., Baghurst, P.A., Clark, J.J., Graetz, B.W., Kosky, R.J., Nurcombe, B., Patton, G.C., Prior, M.R., Raphael, B., Rey, J.M., Whaites, L.C. and Zubrick, S.R. (2000). The Mental Health of Young People in Australia: Child and Adolescent Component of the National Survey of Mental Health and Well-being. Mental Health and Special Programs Branch, Commonwealth Department of Health and Aged Care.