

**INQUIRY INTO TRANSITION SUPPORT FOR STUDENTS
WITH ADDITIONAL OR COMPLEX NEEDS AND THEIR
FAMILIES**

Organisation: Ability Options

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Inquiry into transition support for students with additional or complex needs and their families

**The Standing Committee on Social Issues
26^h August 2011**

About Ability Options

Ability Options was founded in 1976 as a union between the Rotary Club of Guildford and the NSW Health Commission and provides support services to people with a disability. During the mid-70's a courageous group of people including parents, brothers, sisters, advocates got together and decided to enable their family members to leave long term institutional care at Rydalmere Psychiatric Hospital and move into housing in the community. All of these people had a primary intellectual disability.

There are currently 440 people supported by Ability Options through the National Disability Agreement and state based funding (NSW). Up to 89% of people have a primary intellectual disability diagnosis with support needs that range from low to very high. There are a high percentage of people with secondary disabilities and complex support needs.

Ability Options currently supports more than 3000 people and their families across NSW through the following mix of State and Commonwealth funded programs:

- Open employment
- Supported employment
- After school and vacation care for teenagers with disability
- Children's Out of Home care services
- Supported living
- Case management
- Self managed supports for 0-6 year olds, 18-45 years and 45-65 year olds
- Post school and day program options
- Community access, development and training
- Housing options and asset maintenance

The **aims** of the organisation are:

- To promote the independence, worth and dignity of people with disability.
- To provide a range of supported living options for people with disability.
- To promote employment opportunities and conduct work and other training for people with disability.
- To provide counselling and any other assistance to people with disability to

- encourage their participation in their community.
- To liaise with other community agencies to improve existing services offered to people with disability.
- To encourage and promote advocacy for people with disability.

The **mission** of the organisation is:

- To provide people with disabilities better opportunities that will enable them to enhance their lifestyles and achieve their goals.

The scope of this Inquiry is to report on programs and services for children with additional and/or complex needs and their families during transitions between stages of education, and in particular:

We welcome the opportunity to make a contribution to this Inquiry and include some comments below.

Our feedback is based on:

- Our experiences with families in the Early Start service with its focus on issues relating to entry in Early Childhood Centred;
- Our experiences in working with school leavers; and
- Ongoing feedback and our annual consultation process with people with disability and their families. Our experience with people with a range of developmental disability.

The focus of our submission is on the transitions at either side of school: the transition into early childhood education centres; and the transition from secondary school into post school programs and opportunities.

Critical to our work is an underlying understanding that people with disability and their families are the experts on their own lives and it is the role of service providers such as Ability Options to strengthen, enhance and support that expertise. In addition our person centred, strength based approach to working with individuals and their families enables us and them to work together on what is possible, focusing on ability not disability, and the removal of barriers that impact on engagement.

Definition of Disability

In 2007, the World Health Organisation (WHO) moved to a new definition of disability using the International Classification of Functioning, Disability and Health (ICF 2001). This definition is a tripartite definition based on the interaction of individual 'impairment', functional capacities and environmental barriers. The WHO defines disability as a contextual variable, dynamic over time and in relation to circumstances.

*“A **disability** may be physical, cognitive, mental, sensory, emotional, developmental or some combination of these.*

Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.

Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives"(ICF 2001).

The WHO definition of disability is broad and takes account of individual impairment, functional capacities (and strengths) and environmentally imposed barriers. As a social definition of disability it therefore considers the adjustments necessary to environments that create barriers and reinforce individual limitations.

Transition into Early Childhood Education

Ability Options is piloting the NSW funded Self-Managed My Plan My Choice Early Start Intermediary Service, targeting families with children with disabilities aged up to 6 years old, who live in the South West Sydney Local Planning Area. This two year pilot aims to build on a family's knowledge, skills and capacity to self-manage the needs of their child. We are now in the final months of this pilot and since the beginning we have been supporting 33 children and their families.

From the perspective of families in this pilot it appears that the transition for children with disability into early childhood education systems is relatively smooth, especially when a child has received a clear and early diagnosis of their disability Critical to that smooth transition appears to be the role of the paediatrician.

The following brief "stories" of how families have utilised the Early Start funding illustrate some key elements that make for successful transitions into Early Childhood Education:

One Early Start program participant family utilised some of their annual \$8000 funding allocation to learn Auslan (Australian Sign Language), in order to communicate with their son, who because of his disability utilised sign language. This enabled the family to really 'get into the world' of their son.

Another family used their resources to pay for additional support staff in a mainstream preschool. The school had previously denied access to the child because of his level of support needs. The child made lots of friends, many of whom will transition with him into the local school.

Yet, another family used their daughter's funding to pay for her local (not disability specific) dance and music lessons. An assessment by her Physiotherapist after

one year of dance and music classes identified that she needed significantly less physiotherapy than anticipated, because she had been physically active.

In our experience, one of the key elements in supporting children with disability and their families in transitioning into mainstream Early Childhood Centres (and from there into primary school) is to support families to focus on what is possible and support that possibilities with the necessary resources. A strength based approach encourages families to think about and envision opportunities and possibilities for their child and encourages families to be filled with hope and expectations of what their child might be able to achieve (as would parents of children without disability).

Early Intervention and other resources

Access to therapy is important and the lack or limited availability has been a major concern to families. Our Early start services have shown us that resources that are not linked to therapy supports are critical. Hence the need for resources that are used in building capacity, building on existing strength and opportunities as identified by the family.

Resources for children with disability to access therapy have become more readily available (including through the recent Commonwealth funded 'Better Start' program). The Better Start program provides access to early intervention services for preschool children to support transitions to school. This builds on the Helping Children with Autism program. However, the Better Start programs' eligibility is based on diagnosis Cerebral palsy, Down syndrome, Fragile X syndrome, and moderate or greater vision or hearing impairments, including deaf blindness. Thereby excluding other children with complex functional support needs. Those without a specifically allocated package of support have to rely on access to services through long waiting lists, funding services themselves which can be prohibitive or rely on other assistance provided directly to preschools.

The Department of Education, Employment and Workplace Relations (DEEWR) recently sought public comment on the Inclusion and Professional Support Program (IPSP) guidelines for child care services. The Inclusion and Professional Support Program (IPSP) was established by DEEWR in 2005 to promote and maintains high quality care and inclusion for all children in eligible child care services.

DEEWR has identified the following feedback about the current operation of the program:

- aspects of the IPSP are administratively burdensome;
- there is scope to improved targeting of some aspects of the IPSP to better meet the needs of individual services;
- the IPSP guidelines and funding arrangements do not focus adequately on identifiable and measurable outcomes for the investment;
- a number of stakeholders have argued for increases in the funding provided (in particular to the Inclusion Support Subsidy (ISS) and to the Inclusion Support Agency's (ISA's).

The Inclusion Support Program (ISP):

- assist child care services to include children with disability or with inclusion needs
- aims to remove the barriers to access for children with additional needs through the provision of inclusion support, achieved through Inclusion Support Agencies (ISAs)
- ISA's provide practical advice and support to assist child care services to build capacity and to access training Flexible Support Funding (FSF), and Inclusion Support Subsidy (ISS). These funding sources can be used to contribute to the cost of an additional child care educator/carer for services with a child or children with ongoing high support needs, or a capacity payment in recognition of the impact of this on an educator/carer
- supports the participation of children with ongoing high support needs in child care programs with typically developing peers. It does not duplicate other forms of support, such as specialist child care services, nor does it provide one-on-one support for children with ongoing high support needs

The Inclusion Support Subsidy, is a flat hourly rate (currently \$16.19), which is paid as a contribution towards the cost of engaging an additional child care worker when a child care service includes a child with ongoing high support needs. The subsidy applies for up to 25 hours per week and there is a gap of approximately \$8 per hour (up to 25 hours) in the real cost to provide additional supports to enable participation.

Feedback from both for profit and community preschools has identified that this cost is absorbed by them, and in some cases services are not able to absorb this additional cost and is a barrier to the inclusion of children with disability. Feedback from preschools around transition to school indicated a varying response. In some circumstances supports having been organised and in place for when the child starts school and in other circumstances this not being the case despite proactive planning by families and preschool providers.

Transition from Secondary School

Community Participation is one of two ADHC funded services targeting school leavers. The other is the two year Transition to Work program. Ability Options provides both services. The focus of this submission is largely on the issues arising from the Community Participation perspective. Ability Options has been running a self-managed Community Participation program since 2007. During that time we have supported 92 people through this service.

Young adults with disability and their families participating in the self-managed Community Participation Service are people who want a better life for themselves and are prepared and able to be involved in the management and determination of how their life post school is to unfold. Through the self-managed service we have seen young adults develop their dreams and goals and to achieve success beyond

even their own expectations. Attached are a few individual stories from our self-managed Community Participation service that highlight some of the key ingredients enabling people to achieve their goals and transition into adulthood.

Unfortunately, a smooth transition into adult life is by and large still subject to chance and many services and links are still missing to ensure that the transition into adulthood of young adults with disability is one comparable to those without disability.

There has been some improvement in the pathways post school via the community participation and transition to work programs, in being assessed for suitability to either of these programs. However, there is significant inconsistency in the quality and abilities of Support Transition Teachers within the Department of Education and Training. In our work we found Student Support Teachers who are focusing on and strengthening people's ability and we found Student Transition Teachers with exactly the opposite focus. Therefore, the choices offered to students are more likely determined by the outlook and focus of a Student Support Teacher, rather than by the student's level of disability (or, better, the level of functionality) and their own goals and dreams. This in turn impacts on the information and options that are made available to people with disability. This is evident in that we have many inquiries from one school, while none from another, although the number of schools leavers and their levels of disability might be similar. In addition, in our experience, Student Support Teachers frequently make assumptions about the capabilities or otherwise of families in relation to their ability to self-manage funds. Despite some attempts by DET and ADHC to address this issue, our concerns remain. We have received direct feedback from families about being actively discouraged from exploring non centre based options that families expressed a preference for.

Equally, there continues to be issues with ADHC case-managers having limited understanding of self-managed models and, like DET Student Support Teachers, continue to make assumptions about both young people's abilities and the abilities of their families.

Some of the current options for school leavers include Transition to Work or Community Participation. Ability Options remains concerned that people are assessed for their suitability for either one of those programs through an assessment that continues to focus on functionality only. This assessment is focused on deficit not ability and ignores other factors that might aid people's ability to participate in and contribute to community.

Furthermore, the Transition to Work program is only available as a two year program and is not available as a self-management service. Therefore some people are 'choosing' the self-managed Community Participation program, rather than trying out for Transition to Work (because it gives them greater levels of control, more funding and funding for a longer period of time). In this context it is interesting to note that in

our self-managed Community Participation program we have individuals that attend university, have set up their own business and are employed- most of these outcomes are not seen as likely or even possible for people assessed as being eligible for the Community Participation program.

We also suggest from our experience that the transition process and in particular the transition conversations should occur at least 2 years before people leave school. People should be able to access Transition to Work or Community Participation programs earlier (for example, once a week for a 6 week period), people should be encouraged to trial the different options and explore what might be possible for them. Having early access to information is critical to provide the opportunity for people with disabilities and their families to explore the options available and to make an informed decision for their future.

Finally and most importantly, there is a major lack of any options available for young adults with disabilities wanting to move out of the family home and live lives similar to those of their non-disabled peers. Support for independent living is virtually non-existent (unless there is a crisis). We find it extremely difficult and disappointing for the young person, that while we work with individuals with disabilities and their families on creating dreams and goals beyond what might have seemed possible, those goals cannot include an ordinary adult life lived away from ones parents.

It is pertinent to refer to the Productivity Commission Inquiry into Disability Care and Support for people with disability. The final report highlights that the disability services sector is underfunded, unfair, fragmented, inefficient and provides little choice and no certainty. The establishment of a National Disability Insurance Scheme as suggested by the Productivity Commission recommends individually tailored support to people over their lifetime with choice and control being key features to that individuals and their families can determine the who, what, when, where and how of supports are delivered. It is hoped that a National Disability Insurance Scheme (NDIS) will address issues identified by this Inquiry around coordination and responsiveness between agencies (through memorandum of understanding), better resourcing and information to increase the adequacy and accessibility of appropriate supports from an early age and facilitating post school life in line with other community members.