



30th August 2011

The Director  
Standing Committee on Social Issues  
Parliament House  
Macquarie St  
Sydney  
NSW 2000

**Re: The Inquiry into Transition Support for Students with Additional  
or Complex Needs and their Families**

Dear Sir/ Madam,

On behalf of the Management Committee and members of the Learning Difficulties Coalition of NSW Inc. I am pleased to lodge the attached submission for the above named inquiry.

The Learning Difficulties Coalition NSW Inc is the peak advocacy group for the 1:5 young people who learn differently. The LDC represents parent support groups across the state encompassing ADHD, Aspergers Syndrome, Learning Difficulties, Autism Spectrum Disorders, Velocardiofacial Syndrome (VCFS) and Tourette's Syndrome. The LDC runs a Parent Helpline from the Children's Hospital at Westmead and also provides a quarterly newsletter for members and regular education seminars.

We congratulate the Hon Minister Piccoli MP for initiating this inquiry to examine the issues raised by consumers around the transitional support required by students with complex needs and their families.

We would welcome the opportunity to contribute to the hearings.

Yours sincerely

Jude Foster  
President

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

## **Terms of Reference**

*1. The adequacy and accessibility of appropriate support for children and their families;*

### **Some of the Issues**

There is inadequate support for children with complex needs and their families during periods of transition. Calls to our Parent Helpline and anecdotal reports from families indicate a high level of distress by families trying to access support for their child.

Common transitions which cause concern occur during:

- Entry to daycare or preschool
- Entry to primary school
- Entry to out of school care
- Entry to high school
- Entry to Post Secondary Education
- Entry to Adult services e.g moving from Paediatrician to Adult Mental Health Services
- Completion of Pilot programs which have raised the expectations of families for services, which then cease at the end of the program

Each of these periods have specific challenges. Transient families and children who have experienced extreme trauma have different transitional needs.

1. Many young people with complex needs, do not have a defined disability or receive any additional funding. They may experience a range of challenges that impact their educational, psychological or social success which, in turn, impacts their families/ carers, siblings and teachers. The UK Government sought to address some of these educational issues in a recently funded a project to investigate Complex Learning Difficulties and Disabilities: Developing Meaningful Pathways to Personalised Learning<sup>1</sup>. Engagement was found to be the single best predictor of successful

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<sup>1</sup> Complex Learning Difficulties and Disabilities Research Project: Delivering meaningful pathways to personalised learning. Specialist Schools and Academies Trust – Wolverhampton Office Technology House, Glaisher Drive, Wolverhampton Science Park, Wolverhampton West Midlands, WV10 9RU

learning for children with learning disabilities<sup>2</sup>. Engagement is often compromised during periods of transition and the family members are often the messengers between many professionals. In addition, the new wave of children with special needs encompassing chromosomal disorders, children who survived extreme prematurity or multiple disabilities at birth, and others affected by prenatal drug and alcohol abuse need different support.

2. The global difficulties experienced by young people with complex needs are not well understood by the many professionals involved in their care. Increasingly this results in their marginalisation within the education system and general community. Currently many interventions appear too random, and in isolation.

Parents and carers are the constant support for children with complex needs, so it is essential that they have the support they need to continue to advocate for their child for as long as required. There are considerable additional costs to the families for medicines, professional interventions, respite and remediation.

3. Quality Respite Services are in very short supply, especially in rural areas.

The stress of moving on children, may carry negative effects on mental health and happiness in adulthood. When children move to different places, they are forced to leave their friendships behind and make new ones, which isn't always easy. Introverted children may have a harder time joining a new social circle and developing close relationships than more outgoing kids, meaning the shy ones may have more of a negative experience adjusting.

## **Solutions**

1. The NSW Government needs to appropriately fund a similar project to that established in the UK to determine an evidence base for funded interventions for the educational, psychological and social issues affecting young people with complex needs.

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<sup>2</sup> Lovannone, R., Dunlap, G., & Kincaid, D. (2003). Effective educational practices for students with Autism Spectrum Disorders. *Focus on Autism and other Developmental Disorders*, 18, 150-168.

There needs to be a systematic connection and integration between the early intervention programs and the next stage for the child, whether it is transition to school or to another therapeutic or special educational setting. Parents, teachers and therapists need to collaborate in preparing the child for transition<sup>3</sup>.

2. The Carer Allowance funding is often not accessible by families of children with complex needs, particularly if the student does not have a recognised diagnosis. There are currently 2.6m carers in Australia, many of whom care for children with complex needs. It is essential for carers to be on an equal footing to professionals involved in care. There needs to be an assessment of the needs of carers so that appropriate support can be provided for them. At present there is funding in place for professionals, agencies and some peak bodies to provide support for individuals with disabilities but there is no funded voice for carers. These families are then often dependent on social security and public housing sometimes raising a child with complex needs and other siblings in a high density dwelling. If support and respite were provided earlier the families possibly would not suffer the isolation and despair and the family units would have a better chance of survival. Raising children is demanding for any parent but the pressures on families bringing up children with special needs is overwhelming.

Carers deserve the same opportunities as other Australians to participate in work and the community, and live a meaningful life<sup>4</sup>. As the parent of two children with Autism stated: *"Women who choose to be a carer or have it put on us, we have to lose our careers. We need a concrete, sustainable system that is going to ensure that we are able to secure work in our own professions."*<sup>5</sup>

Fund the training and support of an interdisciplinary case manager for each child through funding from the Departments of Education; Family Community Services; Juvenile Justice; Health and Medical Research using the established infrastructure of school

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<sup>3</sup> Roberts, J. M. A., & Prior, M. (2006). Early Intervention for Children with Autism Spectrum Disorders: Guidelines for Best Practice

<sup>4</sup> National Carer Strategy, 2011

<sup>5</sup> The Age. August 4, 2011. Carers cautious over \$60m deal.

communities. Their role would promote the centralising of information about young people which is often fragmented across different sectors. e.g. psychological assessments completed on young people in primary school often do not travel with the student to the high school setting and this results in duplication of services. A case manager would overcome this issue.

In addition, ensure that consistent, simple and easy to access information is also accessible from the websites of the above Departments using diagrammatic (and text) guidance for families to assist their navigation between the available services. Guidelines for best practice of specific conditions and presenting behaviours should be accessible from all the websites.

## *2. Best practice approaches to ensure seamless and streamlined assistance during transitions;*

### **Solutions**

- Encourage families to hold copies of all assessments /reports completed on their child
- Develop a navigation guide for families to assist them in advocacy
- Provide funded opportunities for handover from case manager to case manager or for an overview to be provided for all staff/carers at the new setting
- Promote engagement of students with problems with written language through the use of voice activated software.
- Promote engagement of students through offering of different learning pathways and special exam provisions.

## *3. Any other related matters.*

LDC would like to refer the Commission to the previously completed Inquiry into Early Intervention for Children with Learning Difficulties completed by the NSW Standing Committee on Social Issues in September 2003. The conclusions and recommendations of that Inquiry, that learning difficulties and issues are best treated by early intervention still has great merit and many of the stakeholders mentioned above are represented in

that Report and very few of the recommendations have been carried out. It would be an excellent point of reference for your research and be an economical way of reviewing problems extant today as in 2003.

Access to Allied Health services is very restricted. My experience is that the public system cannot meet the demand and many staff are inexperienced in dealing with these children. Access via GP's is significantly limited if TCA Care Plans are the only route available. Many OT's are not eligible for access via Mental Health Plans (e.g. Coffs Harbour has only one).

The ASD programs that Paediatricians can refer to is good, however, if young people who don't have significant autism don't qualify.

Most GP's require both education and incentive to be involved. The slashing of the Mental Health Item Number fees will undermine GP ability and incentive to help these children. Thus most GP's will continue to just pass these kids on to already busy Paediatricians. This problem would presumably be much worse in rural and regional areas.

Royal Far West continue to do an excellent job in trying to help these young people. RFW are perhaps the best option for complicated cases from rural areas. The new videoconference item numbers could radically change things. RFW have also got a new bus for travelling out west. If that works out well then maybe more buses is one answer?

Bus travel to and from school seems to be an ongoing issue. The kids with most challenging issues get put in a taxi. The rest have to battle it out with some pretty cruel kids. Changing buses can be a nightmare for some.

Case Conferences at school continue to be extremely useful. Incentives to further encourage these should be considered. The fee structure isn't really adequate. Given that there is not much utilisation the fees should be reviewed.

Paediatrician recruitment to regional areas is an important issue. Many rural areas have aging specialists and for a range of issues it is more and more difficult to attract quality people to the country.