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

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Response to NSW Government Inquiry into Transition support for students with additional or complex needs and their families.

Prepared by
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About Network

Network of Community Activities represents 1000 OSHC Services in NSW. Approximately 700 of those Out of School Hours Services (OSHC) in NSW services and ACT, are current financial members of the organization.

Established in 1974, Network provides resource, support, training, advocacy and advice to communities and OSHC services throughout NSW.

Introduction

Networks response will cover the following age group of 5-18 year old children and the issues related to their access to suitable child care arrangements.

In compiling this submission Network drew on the information provided by OSHC service providers across NSW. The information collated reflected similar themes and services were able to provide many examples to illustrate the issues they are facing.
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We have not attempted to go into a high level of detail, preferring instead to allow our case studies illustrate the challenges.

Network has included these examples as a snapshot of the issues and would welcome the opportunity to discuss solutions to ensure that the needs of all children are met through the provision of suitable, adequately resourced and funded, age appropriate services.

**Current Situation.**

There are approximately 1100 Out of School Hours services in NSW. These services cater for 5-12 year old children and offer child care for families before school, after school and during holiday periods. Whilst the services are aimed at 5-12 year olds there is a growing number of children with a disability accessing these services up to the age of 18 years.

Whilst Network supports the right of children 12-18 years to access a service we believe that the services providing this access are inadvertently complicit in shielding Government from the lack of adequate service provision for this age group. As a result we are seeing an increase in numbers of teenage children accessing services designed for primary age children. This access is placing unrealistic pressure on services, staff, children and families.

This issue is further compounded with frequent examples parents of children with additional needs threatening services and staff with legal action and discrimination. The bullying of services into taking children with high level of complex needs and retaining them at the service is not an isolated incident. In a number of situations Network has had services report to them incidents of bullying and harassment. Some of this harassment has come from disability advocates rather than the parent themselves adding a complicated dimension to collaborative work that meets the best interests of children. The only need being met in this instance is the needs of parents with an “instant fix” for affordable childcare.

As a result, fear of litigation often keeps services hostage to a system that is not meeting the needs of the child with high and complex needs, particularly in adolescence and to the detriment of the services and other service users. In addition there appears an incentive for some funded agencies to place children with high and complex needs into OSHC services due to the ready access to some form of Government funding.

“We will often find that when we talk to the parents of these children about our concerns and inability to meet all of their child’s needs we often are told that we are discriminating against them due to their disability. This often evokes fear

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amongst the staff particularly when they get threats about getting legal action or getting the media involved.” OSHC Service South West Sydney.

Network believes there is an urgent need to address the issue of provision of school age care services aimed at youth in particularly those with complex and additional needs.

**Trends**

“There is an expectation amongst many of our parents with children with additional needs that their child will be able to attend the service until they finish high school at which time they qualify for other care.” OSHC Co-ordinator.

Whilst OSHC services are already struggling to meet the demands of primary age children with additional needs, the additional demands of an expectation that this care will then be extended into care for high school students with complex or additional needs is unreasonable.

Services report there has been a steady increase over the last five years in the number of families calling centres investigating and requesting care for their children with special needs. In 2011 a number of services reported an ‘explosion’ in care needed which includes children attending secondary schools.

With the changes in trends, staff find it most difficult to cater for the growing number of high school children and their specific needs. The following is a snapshot of one school age care service providers current enrolment of children over 12, all of whom have additional or complex needs;

- **J and L** – 15 year old twins diagnosed with Down Syndrome, ADHD and hearing impairments. L has issues with his kidneys which is stunting his growth and causing further medical issues. Both attend 3 afternoons.
- **T** – 13 years old assessed as having Autism, ADHD along with Developmental delays. He attends five morning and five afternoons.
- **B** – 13 years old assessed as having Autism. Attends five afternoons a week.
- **J** – 13 years old assessed as having Autism. Attends five afternoons and each day in Vacation Care.
- **A** – 13 years old diagnosed with Down Syndrome attends Vacation Care daily.
- **K** – 14 years old assessed as having Autism. Attends Vacation Care daily.
- **J** – 14 years old diagnosed with Down Syndrome. Attends daily in Vacation Care daily.
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- A – 13 years old diagnosed with Klinefelter Syndrome. Attend Vacation Care daily.
- J – 15 years old assessed as having Autism. Attends Vacation Care daily.

These trends are by no means limited to the metropolitan areas and one small rural service reports that they currently provide care for 6 diagnosed children with high support needs and another 6 with challenging behaviour. This service caters for 31 children in total with a maximum daily participation of 26. Therefore, 46% of the children have additional support needs in this small centre. This level of service delivery is managed with 2 staff members and one additional disability worker. It could easily be said that the service staff have unrealistic demands placed on them to meet the standards of service delivery required by Government.

Impacts on Service provision

Financial Implications

“Attracting disability specific trained staff due to the hours and the wages. Funding is limited to the number of hours the children are attending and capped at $16.49 per hour. This is below the award rate for the type of staff member that you would employ for their qualifications or skills and experience to work with some of the high needs we are encountering. This therefore becomes an ongoing loss for centres that can place a financial burden on its viability, particularly when they may be more than one ISS staff member per centre. The wage that we would be paying a staff member in this situation would be around the $21 mark per hour. Using the example of J and L from the above list we would pay out a further $40.59 per afternoon to cover staff direct cost (not taking into consideration insurances etc). For the week the loss stands at $121.77, for the term it equals $1217.70 for the year it totals $5114.34. That is a large financial loss considering that is only looking at the twins from the above list.”

“With the financial costs even for the 5 to 12 year olds we get about 16.00 an hour for the so called funding, yet we have to pay staff a minimum of 23.00 an hour so it costs the service a lot of money each week to support the special needs kids, and I know at the end of the day its not about the money its about the child but it certainly takes a lot out of the budget when you have 5 special needs carers every afternoon. “

“In our Vacation Care program we extend shifts for permanent team members or employ casuals for the care to be shared. In 2008 the VC weekly wages deficit was from $81.60 to a maximum of $255/child, to now being from $125 to $320/child. We
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currently have 3 funded children in VC, if they all attend for the full day (8’) for a week (40’), this equates to a maximum weekly shortfall of $375 to $960.”

“I have three children and we must find an extra $14160 a year to fund this, not that easy for a not for profit organization.”

The examples provided sum up the dire situation facing OSHC services in NSW. Provision of children with high and complex needs requires adequate funding. Services are suffering financially in order to assist families access care.

This has been raised with the Federal Government consistently over many years and remains an unresolved issue for services. The examples speak for themselves. The current finding model is not sustainable, we are heading for a crisis in care provision for children with additional needs.

**Provision of Age Appropriate Provision**

“We currently have a boy who is now 16 years old enrolled in our service four days a week for after school care who has very high support needs. He is in a wheelchair and is both intellectually and physically disabled. He is tube (PEG) fed every afternoon by our staff as he is unable to feed himself. He is also not independant with toileting and is normally changed using a hoist and change table but we don’t have these facilities. The decision was made by his parents at the time of enrolment that they were happy for him to go unchanged while in our care (the hope is that school will do one last change before he leaves for the afternoon and then he is only with us for 2.5 hours or so). We were pressured by the local inclusion support service to take on the enrolment as the family were in desperate need of care and the support service’s after school care service for children with high support needs was at capacity and could not take him. The staff have built a wonderful relationship with this child and his family and do not begrudge the extra work we have taken on but he is not in the appropriate setting for either his age or his disability.”

OSHC services designed for children 5-12 years of age are not appropriate settings for children in their teenage years. Despite the mental age of children there are
significant factors in regards to a child’s development that makes provision unsuitable.

Due to the size of some teenagers services report that if they have challenging behaviour that is of a physical nature the degree of injuries inflicted on other younger and smaller children and the staff is more substantial. Staff also reported that adolescent children often start to display sexualised behaviour towards the other children and the staff as they move through puberty.

Access to appropriate equipment for use to meet individual needs of teenagers (i.e. hoist for toileting) is challenging in OSHC as often the children are much larger than primary age children with additional needs. The size of teenagers requires two staff for undertaking caring duties due to manual handling requirements. This results in compromised staff: child ratios in the centre. All children are placed at risk when ratios are compromised.

Due to ratios and the part time nature of OSHC service provision, specific staff rostering is not always possible in a traditional OSHC Service. This will often leave staff feeling uncomfortable particularly with toileting and assisting teenage girls who are menstruating.

The dignity of the children with additional and complex needs and their right to an age appropriate service should be respected. Currently, despite the best efforts of all parties involved, this is not the case in the provision available.

**Absence of Options for Families**

“We have a young man who participates in our programs, he has been coming to us since 2003 and is now 14. His Vacation Care participation is ISS approved but coping with his changing needs as a teenager whilst continuing to deliver service to primary age children is increasingly difficult. We have discussed transitioning him out but to where????”

The major issues facing families and OSHC services is that there is no or limited provision of services for children with high and complex needs once they reach high school age. Many children currently using OSHC services have no access to another service to allow for transition to occur into a more age appropriate service.

The lack of age related care results in waiting lists for younger children in OSHC services designed to take the younger child. So the effect is twofold – it restricts access to a suitable service for younger children with additional needs and it places stress on services to provide care outside their scope.
A service in the St George area, estimated that they referred at least 4 families every term to other agencies and services in relation to Vacation Care as they were unable to stretch their resources further. The referrals were to other mainstream services which may have vacancies or are suitably resourced for inclusion. Once service stated “we are currently reviewing our practices in relation to inclusion as being ‘too inclusive’ is creating issues and concerns. We are compromising the quality of care we provide to include more children than we should as there is very little choice for families”.

The lack of provision also provides families with issues in relation to transport. Children with high or complex needs are frequently not able to be accommodated in mainstream schooling however due to lack of provision are transported back to OSHC services located in schools. This places children at an additional risk and services have reported a lack of supervision on the transport can result in children being offloaded at the OSHC service location without a staff member present to take responsibility for them.

**Staff Recruitment and Retention**

“In the past we have had a number of older special needs children at our service for both ASC and VP, it has been very challenging for all involved as the majority of our special needs staff are uni casuals as we cannot afford to put on a fulltime disability worker as that child may only be with us for one year or six.”

“What do we do about staffing? All our good disability workers leave for fulltime work as we can only offer them a casual position of 3hrs a day as long as that child keeps coming or is not sick. This year I have had to turn away four families from the local ASPECT school due to not being able to accommodate the children with both staffing and funding with ISS.”

The rate of pay and the casual nature of disability support work makes staff retention and recruitment challenging in OSHC services. Services complained of being stretched to meet some of the support needs of the children attending with examples of tube feeding and changing nappies increasingly being required in services whilst concurrently providing play and leisure activities for 5-12 year olds on ratios of 1:15 in venues not designed for high level support needs.

Questions regarding legal implications, occupational health and safety and duty of care have been largely overlooked in the quest to meet the burgeoning demands of care provision. There is an absence of legal advice available to services and staff to assist them make informed decisions about their ability to provide care and their liability if an issue arises.

Services cited examples of finding it difficult to recruit and roster staff in OSHC services.
that are able to take on the additional requirements of a child with an additional needs. Lack of training and the nature of OSHC service provision makes it difficult to support staff with these tasks. This is particularly common when staff are required to assist teenage girls who are menstruating which requires last minutes rostering changes that may not always be possible.

"I have had one child run down the aisle at the cinema and start to strip off and another break a tail light of a car in the street and then try to run on the road because he wanted to die. Again I go back to the issue of not being able to employ trained disability staff members due to lack of hours and job security as the child could leave at anytime."

Current finding arrangements do not support services being able to fund adequate staff and child ratios nor do the service environments allow for modifications to make them more appropriate as they are not purposed built and lack in most cases many of the features required for the provision of high support care.

**Solutions:**

- Development and funding of services for 12-18 year olds to meet child care needs of families.

- Incentive grants / financial support for establishment of OSHC services in schools for children 5-12 years with additional and complex needs.

- State Government to liase with Federal Government regarding increasing the current level of Inclusion Support subsidy for OSHC services.

- Exploration of legal liability for services and child care staff in provision of care to children with high and complex needs that require additional services such as tube feeding.

- Education of services and families regarding the nature of discrimination – right and responsibilities including appropriate “discrimination” to ensure that other groups are not significantly disadvantaged.

- Disability workers appointed to support a child and family on a long term basis across the different transitions to guide families in choices of service delivery and negotiate
issues of access to services and funding.