

 A.C.T. LEGISLATIVE ASSEMBLY COMMITTEE OFFICE	
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**SUBMISSION TO THE ACT LEGISLATIVE ASSEMBLY
COMMITTEE ON HEALTH, COMMUNITY AND SOCIAL
INQUIRY INTO RESPITE CARE SERVICES IN THE ACT**

I am submitting this report in my capacity as Executive Officer of Noah's Ark Resource Centre Inc. Noah's Ark is a not-for-profit community organisation that has been providing services to families in the ACT and surrounding regions for over 37 years.

Noah's Ark has a long tradition of providing services for families of children with additional needs. We have a solid reputation within the early childhood, community and disability sectors for delivering quality programs and support.

Service Gap

Early in 2008, we identified a gap in after school care services for teenagers with a disability. On graduating from primary school, families no longer have access to school based care, as there is a community perception that high school students are capable of going home on their own. This creates an additional stress for parents of students with a disability as they need to make alternative care arrangements for their children. This often means one parent having to forego participation in the workforce to care for their teenager, with obvious financial and wider implications for the family.

Although there are a couple of community services run out of local Youth Centres, these inclusive programs have lengthy waiting lists. In addition, the environment within which these programs are delivered does not suit all children.

Our Program

In July 2008, we commenced operation of our after school and holiday program for teenagers with a disability. This service was originally funded through the Commonwealth's Non – Government Centre Support Element, administered by the ACT Department of Education and Training.

The program is delivered from our Centre at Rivett and is staffed by Disability Support Workers, Youth Workers and Childcare professionals. We cater for a maximum of 8 children per day, between the hours of 3.00pm and 6.00pm and have a student to staff ratio of 1:3. The school holiday program operates for half of all the holidays between 8.30am – 5.30pm.

The program aims to meet four key learning objectives:

1. self-help and independence skills
2. healthy nutrition and physical activity
3. homework and IT tuition
4. socialisation skills

This unique Centre-based care, delivered in a nurturing, safe and secure environment has been highly successful in achieving positive outcomes for the families and children who have participated. The heavily subsidised cost makes the program accessible to most families. In addition, the significant



costs associated with transporting the students from school to Noah's Ark are met by the service provider. The attached testimonials are evidence of the enormous value the families place on this program.

Late in December 2009, we learned that the program would not be funded in 2010. This caused significant stress to our families, particularly given the late notice over the Christmas holiday period. After negotiations with the ACT Department of Education and Training we were given one-off temporary support to assist with the cost of operating the service until alternative funding can be secured. Without funding, this program is not sustainable.

Late in 2009, FaHCSIA called for applications for after school services for teenagers with a disability. There was only one service in the ACT whose application for funding was successful – the Wheelies program run by Marymead at Black Mountain School. This program only caters for children in wheelchairs.

Recommendation

It is our strong belief that the ACT Government needs to provide funding for localised, centre-based after school and holiday care programs for teenagers with a disability.

The program offered by Noah's Ark clearly supports the Strategic Priorities outlined in 'Future Directions: Towards Challenge 2014' document. Our service is appropriate, timely and accessible. It has defined educational objectives that aim to increase the students' capacity to make a successful transition from school to the wider community. We provide an opportunity for students to learn valuable socialisation skills and form friendships with their peers. Our program has evolved in response to the needs of families.

In addition, the families utilising our service have expressed the need for a coordinated response to the provision of respite and support services. The dissemination of information about available services is at best ad-hoc and parents frequently complain about the lack of timely communication and cohesive service delivery.

Contact Details

I am happy to be contacted to discuss the issues raised in this paper in more detail. My contact details are as follows:

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12 January 2010

Mr Andrew Barr MLA
Minister for Education and Training
Minister for Children and Young People
GPO Box 1020
Canberra ACT 2601

Dear Mr Barr,

**RE NOAHS ARK AFTER SCHOOL CARE PROGRAM FOR TEENAGERS
WITH A DISABILITY**

We are writing to express our frustration with the ACT Governments decision to withdraw funding for the above program. It is an essential part of our sons life and also "our life". Without this program one parent would have to work part-time as it is not feasible for [REDACTED] to travel home from school on his own.

This program means that not only can we both work fulltime which is necessary both for financial and emotional reasons but that [REDACTED] is in a safe environment learning necessary life skills. Our son [REDACTED] has numerous medical conditions which mean regular visits to specialists in Sydney and lots of medical costs which are very hard to fund without both of us working fulltime. [REDACTED] also loves the social interaction and contact with the other teenagers and the program staff. He has been attending the program since its inception in 2008 and the independent living skills the staff are teaching them are also very important as [REDACTED] learns differently from other kids.

There is no suitable alternative care for [REDACTED] as other after school care programs finish when the kids leave primary school. The cancellation of this program means that one of us will have to go back to part-time hours (if acceptable to the companies we work for) and [REDACTED] will lose the social contact which is important for his emotional development. It also means a drop in income which affects our family as a whole.

Life is hard enough living with a teenager with a disability without this program being cancelled.

As parents directly impacted by this decision we would like answers to the following questions:

- Why this funding has been discontinued? and
- What (if any) alternative services will be available in February 2010 to replace this program?

Do the people making these decisions:

- have any understanding of what impact such changes make on these already over stressed families? and
- The constraints and the additional burden (time and money) experienced by families caring for a person with a disability?

We look forward to your response.

Yours Sincerely

Mr Andrew Barr MLA
Minister for Education and Training
Minister for Children and Young People
GPO Box 1020
Canberra ACT 2601

Dear MR Barr,

Re: Noah's Ark after school care program for teenagers with a disability

We are writing to you to express our anger and frustration at the ACT Government's decision to withdraw funding of the after school care program for disabled teenagers at Noah's Ark. My son has been attending this program since it was first established in 2008 and loves it. He also participates in all the school holiday programs.

This service has allowed me (mother) to return to meaningful employment. This is not only of financial value to our family, but more importantly it offers me the opportunity to carry on meaningful employment beyond that of being a carer for [REDACTED]. The intangible benefits of having a career, which in turn supports my self esteem and happiness helps me cope with the emotional strain of living with [REDACTED] day to day. As much as we love our son, he is emotionally draining to deal with day to day and socially isolating for the family.

[REDACTED] also benefits enormously from the supportive learning environment provided by this service. He has learnt additional social and independent living skills and made friends through attending this service. [REDACTED], despite his disability loves the additional friends and contact he receives through this service.

To my knowledge there is no such suitable alternative care for [REDACTED] after school. The loss of this service will be disappointing for [REDACTED] and will mean I will have to renegotiate my hours employment, with long term consequences such limiting status and promotion within the organisation. For some parents I understand that this will mean the complete loss of employment, as many jobs are not flexible in regard to hours of service.

As parents directly impacted by this decision we would like answers to the following questions:

- Why this funding has been discontinued? and
- What (if any) alternative services will be available in February 2010 to replace this program?

Do the people making these decisions:

- have any understanding of what impact such changes make on these already over stressed families? and
- The constraints and the additional burden (time and money) experienced by families caring for a person with a disability?

We look forward to your response.

Yours Sincerely

Mr Andrew Barr MLA
Minister for Education and Training
Minister for Children and Young People
Member for Molonglo
GPO Box 1020
Canberra ACT 2601

Dear Minister

I am writing about the out of school hours care program for teenagers with disabilities which has been run by Noah's Ark Resource Centre during 2009. I have been advised that the ACT Government has terminated funding (provided through the Commonwealth Non-Government Centres Support Element and administered by Student Services, ACT Department of Education) for the program for 2010. The service provider has not been advised of any options for ongoing funding beyond 2010.

Our daughter, [REDACTED] who has Down Syndrome, has utilised the program every day after school and during school holidays during 2009. We had planned for [REDACTED] to utilise the program again this year. We see it as a key element of [REDACTED] ability to participate in secondary education. Transport from The Woden School has also been provided as part of the program.

We are very supportive of the program run by Noah's Ark. It has provided a safe and supportive environment for [REDACTED] and other teenagers with disabilities. I am not aware of any equivalent service. Indeed, for [REDACTED], we are not aware of any out of school hours care that would enable myself and my wife to both continue in our current employment.

Out of school hours care is not a discretionary service for children like [REDACTED]. It is a core part of the daily care required for her to participate in a normal school routine.

It is unfortunate for parents that there appears to be no services of this nature coordinated by the ACT Government. Parents such as ourselves rely on a piecemeal ad-hoc approach to service provision that means we lurch from provider to provider with no apparent coordination or communication from the ACT Government or its departments. We learnt of the decision to terminate this funding from Noah's Ark and have received no communication from either the ACT Department of Education or Department of Disability.

In the short term we are seeking your urgent reconsideration of funding for the Noah's Ark out of school hours care program for 2010. In the longer term a more coordinated approach to provision of this type of service would assist teenagers with disabilities to stay engaged in their schools and communities.

Yours sincerely

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Mr Andrew Barr MLA
Minister for Education and Training
Member for Molonglo
GPO Box 1020
Canberra ACT 2601

Dear Minister

Further to my letter of 12 January 2010, I am writing about the out of school hours care program for teenagers with disabilities which has been run by Noah's Ark Resource Centre.

Firstly I would like to express our gratitude for the representations from your office which have resulted in the Department of Education extending funding for the program to 30 June 2010. The original decision, communicated days before Christmas, to terminate funding immediately, caused great distress among the 13 families of teenagers with disabilities who are depending on the service this year.

Our daughter, [REDACTED], who has Down Syndrome, has utilised the program every day after school and during school holidays during 2009 and over the last two weeks of the January 2010 holidays. We are relying on [REDACTED] being able to utilise the program again this year. We see it as a key element of [REDACTED] ability to participate in secondary education. Out of school hours care is not a discretionary service for children like [REDACTED]. It is a core part of the daily care required for her to participate in a normal school routine. The limited vacation care program run by Noah's Ark has also been critical in allowing us to cover the 12 weeks of annual school holidays. The care needs of teenagers with disabilities in many ways are similar to those of primary school children who have a range of options for after-school and vacation care.

The decision to fund Noah's Ark until 30 June is appreciated but you will understand that what these teenagers and we families now need is certainty about support for the program on an ongoing basis. This is a modest program for a very vulnerable group of people. Families are contributing to the program but some government support is needed.

The ACT Education Department has explained to Noah's Ark that it doesn't see itself having an ongoing role in this area. Whether the support is coordinated by the Education Department or DHCS is not so important; what is important is that parents are given some certainty about the program going beyond June 2010.

We seek your support as our local member and as a senior minister of the Government in providing an ongoing commitment from the Government to Noah's Ark to continue to provide out of hours school care for teenagers with disabilities.

Yours sincerely