

Submission No. 1031

(Inq into better support for carers)

AOC 28/7/08

SUBMISSION TO THE INQUIRY INTO BETTER SUPPORT FOR CARERS – 4 July 2008

Person making the submission: Kerrie (mother of Magenta, an 11 year old intellectually disabled daughter with autism). This submission, apart from our contact details, is not confidential.

Summary of main points of the submission.

Based on my experience as the parent of a child with multiple disabilities, and living in both Sydney and a regional country location, I offer the following observations about what support was, or would have been helpful to our family, and share our concerns for the future as our child grows to adulthood, and my husband and I become older carers.

1. Importance of family-based local or regional early intervention with CONTINUITY of intervention.
2. Adequate funding of community preschools, which are an excellent early childhood setting for young children with disabilities.
3. Income support to assist with the severe financial impact that follows the arrival of a disabled child.
4. More aide support for special school teachers to cope with additional demands of challenging students or high numbers of wheelchair bound students.
5. Support to find and access suitable recreational opportunities and sports for our daughter, who finds most of the activities on offer to disabled groups overwhelming.
6. The value of occasional family-based recreational support for siblings and other family members.
7. Our concern to find and access suitable post-school recreational care for our daughter, whom we find increasingly dissatisfied and bored with long periods at home.
8. The importance of the availability of flexible respite for carers; we spent ten years with NO respite from family or friends – none felt confident about looking after our daughter.
9. Our concern for the future living arrangements for our daughter when we are too old to look after her; my husband would prefer an institutional setting with grounds for her to a group house arrangement or the totally unacceptable prospect of inclusion into an aged care setting for our daughter. At present there is inadequate provision for fulltime care for disabled people, so most places are used for crisis situations. Parents need more confidence in the timing and the kind of care to be provided than this.

SUBMISSION IN DETAIL

1. Importance of family-based local or regional early intervention with CONTINUITY of intervention.

Finding yourself with a new baby with a disability, especially for a first-time mother, I found an isolating and bewildering experience. We were not referred to early intervention for a year, and there were many medical visits in the first twelve months. The early intervention team with DADHC was good, but when my daughter was also found to have hearing loss, we were referred to the Shepherd Centre.

The difference was stark:

- intervention was weekly and ongoing; there were no waits for intervention blocks; we could bring our other children to the play-based therapy sessions;
- there was a weekly play group, with a parent discussion group hosted by a social worker fortnightly;
- they assisted with transition to school and hearing examinations;
- there were some home visits, but most of the intervention took place at their premises;
- we felt supported as a family.

In contrast, state-based early intervention involved waits for service, blocks of intervention followed by 'closure of our file' on a regular basis.

Noah's Ark in Nowra offers a centre based playgroup and therapy, but they have nothing like the level of resources that we enjoyed at the Shepherd Centre.

2. Adequate funding of community preschools, which are an excellent early childhood setting for young children with disabilities.

We moved from Sydney to Kangaroo Valley because the small community preschool seemed a better setting for our daughters (now 4 and 2) and the city was much harder to cope with for the family with a disabled child.

The range of ages and family composition of the preschool made it much easier for our younger daughter, Lauren. She has grown up with all of her friends accepting her sister and making no fuss about her disability. However, inadequate funding was a nightmare; I had to make appeals to the Minister to fund an aide (this had been automatic at the federally funded long day care centre she had attended previously) and all the parents had to undertake constant and stressful amounts of fundraising just to keep the doors open. My family would have been better served if I had been looking after them!

3. Severe impact on family incomes following the arrival of a disabled child, and the importance of income support and assistance for additional outlays that having a disabled child entails.

When my first child was born, my husband and I had been working fulltime, and we on the way to paying off a second home. We have run through all of our savings since the birth of our second and third children; this is partly because of the major changes we made to accommodate Magenta's needs, the inability of both of us to work fulltime anymore, and the impact that shifting to a regional location has had on the ability of either one of us to find work.

4. Concern that NSW Department of Education funding for teacher's aides does not reflect the level of need experienced in some school classrooms.

We carers rely on the schools to assist in the independent living skills of our disabled children, and they can't TEACH properly if the funding ratios can't be altered to reflect pockets of greater need. This has been an ongoing problem at Havenlee SSP, where the current enrolment of wheelchair bound students with cerebral palsy is high, and students like my daughter need careful attention.

5. Difficulty we experience finding suitable sport and recreational activities for our daughter.
Most of the team sports and group activities provided in our region don't work for Magenta (she has no speech, limited use of Picture Exchange Cards, highly mobile and very strong, and limited in time she is happy to be involved with activities – maybe an hour), so we usually need one-to-one assistance for her and have to carefully select physical recreation that can suit her (e.g. teams sports are out, but special gym or horse-riding may be suitable).

However, we need to find something suitable, as she is clearly not getting sufficient stimulation during weekends and school holidays at home.

6. The value of having some family-based recreational support through a regional centre with the flexibility to meet parents' expressed needs.

We have enjoyed some sibling and family-focused recreational days organised through Noah's Ark. As Magenta's brother and sister get older, they will naturally object more to the constraints that having a disabled sister place on them and our family. These recreational camps and outings are designed to help our family deal with this issue, and we have been very grateful for the opportunities afforded to us to date.

7. Our concern for finding and being able to access suitable post-school recreation and day-based care.

Most of the Havenlee school leavers have been able to access Atlas funding for post school recreation or study. Magenta is a more difficult child to place in such activities, and we would need some transport support as well to make participation, should we be able to find suitable recreational respite, possible. We can care for her at home for many years; but as she gets older she clearly needs more stimulation than we can provide.

8. The importance of the availability of flexible respite for carers.

For the past year, for the first time, we have had access to a weekly respite allowance from Interchange at Nowra, which we have the flexibility to use in a variety of ways. Prior to this (that is, for the first ten years' of our daughter's life), we had NO respite at all from family or friends or provision for emergency care; none of our family or friends have felt confident about looking after our daughter. This has proved valuable, not only for my husband and I, who have been able to go out at night for the first time in years, but also for our other children, who attend Saturday morning sport and other activities, which are otherwise hard to handle for us.

9. Our concern for the future living arrangements for our daughter.

It is our intention to look after our daughter as long as we can. However, we need the assurance that appropriate care will be available when we are no longer able to care for her. My husband would prefer an institutional setting with grounds for her to a group house arrangement or the totally unacceptable prospect of inclusion into an aged care setting for our daughter.

In any case, we have been advised by other parents to continually insist that we want her taken into full-time care NOW at annual DADHC reviews (even though we do not want this) on the basis that time in the queue is an issue and there is inadequate provision for her needs. Parents need to have confidence that THEY can make the decision to put their child into full-time care and that suitable accommodation will be available when that time comes; we do not want to find ourselves in any crisis handover and do not wish to make false statements in a bid to avoid a possible future crisis.

Thank you for giving me the opportunity to make this submission. If you have any questions, do not hesitate to contact me.

Sincerely,

Kerrie