Submission to the Disability Care and Support Inquiry

I would like to express my sincere gratitude to everyone who has worked so hard, for so long, to get to this stage where we can discuss the much needed reforms for people with disabilities and their families. I have a three year old with complex special needs. In our journey with her we have met many families of young children with special needs and it is very clear that under the current system families are completely on their own, financially and in practical terms, in caring for a disabled child. This has enormous financial, health, employment and wellbeing consequences for all involved and is grossly unfair. Planning for a child’s future under the current system is frightening and very difficult.

I believe that comprehensive reform is needed, with an NDIS being central. The specific issues that I would like to raise are grouped under the broad headings of: eligibility for services; funding and financial issues; service provision; service planning; parent/carer choice; and accountability. Due to the age of my child most of the points made concern the needs of families with young children with disabilities. However, I have read with great concern the submissions of individuals and parents regarding adolescents and adults with disabilities. I believe that many of the underlying themes in my submission (increased funding, greater accountability, increased flexibility and transparency) must also be present across the lifespan.

Eligibility for Services

- Funding for early intervention services needs to be extended to ALL children with a registered disability. At the moment, and under policies currently proposed by the Labor Party, only children with a specified disability/diagnosis will have access to funding for early intervention. This would exclude many children, with very similar needs and potential to benefit from therapy, from funding for early intervention. This is complete discrimination, with no possible empirical or other defence. I strongly support funding for early intervention, as this is an enormous cost for families, but it must be equally available to ALL children with a disability.

- Organisations which provide services to people with disabilities should not be allowed to change their eligibility criteria at whim and without consultation. Our child has had her name down on a waiting list for an early intervention program run by the Education Department. Her application was accepted for the coming school year and the application deadline has since closed. However, we have been advised that the Education Department may now be changing the criteria for the program which would make my daughter ineligible. It is astonishing that this is allowed to occur at this very late stage and it greatly disadvantages children. Services, particularly government services, should be required to be far more accountable in the way that they make decisions regarding eligibility for services and these decisions should be made in consultation with those who will be affected.

- Eligibility for early intervention services should never be linked to a requirement for children to attend a particular form of schooling. In our situation the best form of education for our child is an early intervention unit for several years and then to transition into a mainstream school. However, she is only able to attend the early intervention unit if we agree that she will attend our local government school when she leaves the program. If she accesses the early intervention program she will not be permitted to later attend a religious school (which is consistent with our faith and is where her sister will attend school). This is completely discriminatory and indefensible. We should be entitled to choose the most appropriate form of schooling for our child, just as any other parent can.

- An NDIS should not be limited to people with a severe or profound intellectual disability. A person with a moderate intellectual disability still has very significant needs and requires a full range of services to enable them to participate in society. Our daughter is projected to have a moderate intellectual disability and she has multiple, complex needs requiring extensive support and intervention both now and in the future.

Funding and Financial Issues

It needs to be properly recognised, across all levels of government, that parents/carers of people with disabilities incur very significant expenses in caring for their family member. These expenses are even more problematic as they usually occur alongside reduced or no workforce participation for the main carer. Families desperately need substantial ongoing assistance in meeting these expenses. Some specific ideas are as follows:

- All out of pocket expenses for early intervention, medical and equipment services need to be fully tax deductible.

- Parents/carers should be able to pay only the gap amount for services, rather than the current system of paying the full amount upfront and then claiming back the rebate. Where parents are unable to meet the full cost of the service upfront, the child misses out on a much needed service. This problem would be reduced if any rebate was automatically deducted from the account and the parent only needed to pay the gap amount.

- Any form of funding to people needs to be indexed to the CPI and increase if the real costs of services are increasing beyond CPI. The costs of services should be regularly reviewed by the government to ensure that they have accurate data as to the real world costs of things such as therapy and equipment.

- In purchasing services or equipment, parents should always have the option of ‘cashing out’ the benefits of a basic service/equipment to use the funds as a part payment for more appropriate service/equipment. Families should have maximum control of these decisions and the system surrounding this should be as flexible as possible to ensure that the diverse needs of individuals with disabilities can be most appropriately met.

- Where money has been allocated to an individual for aid/support staff these funds should be able to be used by the family to directly employ staff (rather than being required to go through an agency) in order to ensure the best possible value for money.

- Any parent contribution to services should be means tested and lower income families should not be expected to make contributions. All family contributions to services should be fully tax deductable (not just 20% of the cost as per current health costs).

- Money allocated for services, equipment and staff for people with disabilities should be done in a completely transparent way so that parents know what funding is available to them both now and in the future. Families need to be able to budget and make long term decisions regarding commencing therapy or purchasing equipment with a full knowledge of what funding is available for this over time. Families also need to have complete control over how they choose to spend funding rather than being constrained to choices that may not be useful or relevant to them.

- There needs to be formal recognition that caring for a person with a disability permanently compromises a carer's ability to participate in the workforce, undermining their current and future financial security (and therefore impacting on the person that they are caring for). This must be addressed.

Service Provision

- In our State there is an emphasis on providing 'consultation' to families regarding early intervention, so that the family itself can provide the early intervention. Disability services do not seem to be funded adequately to actually provide therapy, so the burden of doing so falls onto families who are not trained or equipped to do so. This greatly affects the quality of intervention that the child receives and their ability to benefit. I am not a physiotherapist, occupational therapist or speech therapist yet I am expected to perform early intervention in all of these areas with my child, with little knowledge of how to do so and only sporadic support from the relevant professional. This is grossly inadequate. On the surface some of the philosophies behind this practice appear sound, for example children learning best in naturalistic settings and within real world situations. However, in reality, this is window dressing for the burden of early intervention being placed solely on family members who are not equipped to carry it out. Adequately resourced professionals need to deliver therapy, with parental support, not the reverse.

- Home based therapy should be supplemented by a multi disciplinary one stop shop that parents can access as needed, such as an early intervention day care or playgroup.

- Families should be able to select the most appropriate early intervention service for their child rather than being required to access whatever is available in their immediate geographical area.

- Respite is such a key need and an important way to support families. Respite needs to be far better funded, more flexible and not left to the not-for-profit sector or charities. Families should always have the option of in home or out of home respite depending on their need.

Planning

- It is essential that services are funded in such a way that they can take a long term approach to service delivery for families.

- Services should be required to be joined up and coordinated, it should not be up to a parent/carer to have to perform the role of the coordinator or case manager.

- Families need to have a choice in the allocation of a key contact person or coordinator, rather than being ‘assigned’ a person whose background or professional group is less relevant to the client than another that is available.

- Families need very specialist advice regarding education and employment options for their child at multiple points in their life (ideally from a person or agency with a long term relationship with the family). This advice should be provided by an independent party, with no affiliation to any one service, who has a detailed knowledge of all of the available options. The current system in our State, of having a Local Area Coordinator who is attached to a geographical area and is responsible for providing information to people of all ages within this area, is not adequate for this role.

- I believe that services such as PIN in WA who facilitate the formation of a network of support around an individual with a disability have a great deal to offer and should be government funded to provide services for all families.

Parent/Carer Choice

- As has already been highlighted above, parent/carer choice needs to be upheld as much as possible in all situations as families are best equipped to make decisions for their loved ones. One specific example of this is that parents should have the option of accessing services in another state in situations where their child has a complex/rare condition and where expertise in this area exists in another state. Services in the child’s home state and the other state should be required to cooperate and communicate in the child’s care. Our child was born with a rare presentation of a serious medical condition. There is a team at the children’s hospital in our state who works with this condition. However, they had not seen a case like our daughter and had not performed many of the specific type of operation that she required. We found a specialist team in another state who had enormous expertise in the type of surgery required. However, because our daughter’s surgery could theoretically have been performed in our home state we were not supported in any way, practically or financially, in our choice for our daughter to attend the specialist team. We decided to go interstate as we assessed that this would ensure the best care for our child. This has been proven, many times over, to have achieved the best possible outcome for her (and incidentally the most cost effective for the tax payer as the specialist team was able to perform the surgery in one operation whereas two operations were scheduled in out home state). However, this decision was, and continues to be, enormously expensive for our family and would have been impossible for many families (we have had to travel interstate on eight occasions in three years, with one visit being 31 days in duration). In addition, the hospital in our home state continues to maintain the stance that our daughter is not their patient and will not even provide basic assistance such as letting her have routine scans there.

Accountability

- Any disability service should have to collect and present consumer feedback in order to receive ongoing funding and there should be a significant minimum percentage of consumers required to be surveyed. There should be some obligation on the service to respond to consumer feedback to ensure that people’s needs are being appropriately met.

- There should definitely be a Disability Ombudsmen appointed as soon as possible. I am not aware of any affective mechanism whereby families can have issues addressed/resolved or any independent means of appeal. I have written to my local Federal Member in relation to disability issues on two occasions, on each occasion he did not even acknowledge my correspondence much less provide any assistance.

As I look towards the future for my child I am filled with the same fears that so many parents have, namely what will happen to my child when I can no longer look after her. Although I am not able to make specific comments regarding this at this time, I would like to support the other submissions that have highlighted the importance of people with disabilities being meaningfully employed and having a range of accommodation options available to them. It is clear that a great deal of work and funding is required in these areas.