A Better Deal for People with a Disability and their Carers

Submission by the Client Guardian Forum Inc.

A parent/guardian organization in the Australian Capital Territory

The summary of our submission is included on the first page. It is structured as follows:

- Disability and the ageing population;
- Services for Carers of people with an intellectual disability and our recommendations;
- Services for people with an intellectual disability and our recommendations;
- Recommendations in relation to the written CSTDA agreement; and
- Summary of our recommendations
- Case studies (as appendices)

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***A Better Deal for People with a Disability and their Carers**: A submission to the Senate Community Affairs References Committee Inquiry into the Funding and Operation of the CSTDA*

Introduction

1 The Client Guardian Forum Inc (CGF) is an ACT parent/guardian organisation which proactively supports systemic issues within the field of disability. It does not receive any ongoing financial support from Governments. Our members are primarily family carers of people with an intellectual disability.

2 The services available to our family carers and the people with a disability that they look after are totally inadequate to provide for their needs in relation to accommodation support services and the transition from the family home to independent living for their sons and daughters, for respite care, and for the ongoing support needed for ageing carers of people with a disability.

3 Improvements are also needed in the delivery of other service types, including Employment, Community Access and Community Support. These service types receive less attention in this submission because we believe that the total inadequacy of Accommodation Support services is the major issue to be addressed in respect of Australian disability services. There are nevertheless important issues to be addressed for the other service types, and we do point out some of them.

4 In this submission we emphasise the situations faced by people with intellectual disabilities and their families because we feel they are consistently overlooked or undervalued. Most of the recommendations we make nevertheless seek assistance that would be available to all people with disabilities.

5 Our submission is made in principally response to Term of reference (b) of the enquiry, and parts of it are relevant to the other Terms.

Summary of our submission

6 This paper picks up the June 2005 Report of the Senate Community Affairs References Committee Inquiry into Quality and Equity in Aged Care (the June 2005 Senate Report) and outlines the main concerns of family carers of people with an intellectual disability. While the CGF is an ACT-based organization we know these concerns are not restricted to the ACT. They are national issues.

7 The paper and its recommendations are structured under three headings - about the situations faced by family carers and by the people with disabilities themselves, and some other key issues for the next CSTDA agreement.

8 The best way of summarizing these sections of the paper is to refer to the recommendations that they make. These are presented together under “Summary of Recommendations” at the end of the submission.

9 In the conclusion we point out that if there were a single outcome from this Review that we would value above any other, it would be the establishment of properly funded transition programs which prepare people with intellectual disabilities to move from their family home to their own home, which help them to actually make the change, and which link smoothly into ongoing accommodation support programs that are also properly funded.

Disability and the ageing population

10 The Australian population is ageing, and many parents of people with a disability are reaching an age at which they can no longer support their adult children with a disability in their family home. Nevertheless, in many cases the person with a disability remains in the family home because there is no alternative, leading to a consequent fall in the quality of life of both the person with a disability and the parents, until the parents inevitably die. The amount and type of respite care available to these parents is wholly inadequate. The services available to transition sons and daughters from the family home to independent living are woefully inadequate and poorly funded. The amount and type of accommodation support services both within the family home and outside it are extremely limited and poorly funded.

11 Many families are in crisis or a near-crisis situation in caring for their intellectually disabled son or daughter. This situation is exacerbated as family carers age. Many family carers worry about what will happen to their son or daughter as they age and can no longer provide the necessary support. Many family carers worry about what will happen when they die. Many families are in a constant state of stress without access to adequate respite services.

12 To quote the June 2005 Report of the Senate Community Affairs References Committee Inquiry into Quality and Equity in Aged Care : “**4.14** As well as evidence about young people already living in aged care facilities, much evidence was received by the Committee concerning people with disabilities living in the community who face the prospect of becoming residents in aged care facilities because no other suitable accommodation is available. As noted above, it is not known how many people may fall into this category but a number of groups at risk were identified including those people who are cared for by ageing parents and those whose medical needs cannot be supported by community based services.”

13 At the same time, advances in medical research have meant that more and more children with substantial disabilities who would once have died at a young age are surviving to adulthood, albeit with considerable necessary support.

14 These factors put enormous pressure on both government and non-government services to provide the range and volume of services that meet the recognized needs of people with a disability and their carers. This includes the need for an increase in in-home support services, improvements in transport options for people with a disability, increasing accommodation options for those unable to remain in their own homes, an increase in respite options, and better provision of community access and community support services.

Services for Carers of people with an intellectual disability

15 The June 2005 Senate Report, and many of the submissions put to it, make it quite clear that the above issues were raised vigorously with, and were considered by, the Senate Committee. The CGF reminds Committee members of the evidence given by one parent in the June 2005 Senate Committee which is reproduced in Attachment A to this paper. That parent has eloquently expressed many of the feelings of our members. To add to this, Attachment B gives accounts of the experiences of two of our family members. While the accounts are provided anonymously in this submission, representatives of the families would be very happy to speak with you about the difficulties they are encountering in providing adequately now and in the future for their child with an intellectual disability.

16 The key statement relating to carers in the Senate Report was:

"4.16 In November 2004, the Minister for Family and Community Services announced that State and Territory Community and Disability Services Ministers had accepted a plan to help ageing carers of disabled people. A working party of officials is to provide advice as to the steps governments will take to:

- consult with older carers of people with disabilities to understand the present unmet needs for support and future needs for care of their sons and daughters;
- provide more transparent planning for future service provision and allocation of resources;
- provide greater confidence amongst older carers that, with cooperation between the Australian, and State and Territory Governments, the needs of their sons and daughters will be better met; and
- enable increased personal/family provision for future care."

17 One of the only two formal recommendations in the Report about carers follows this up:

"**Recommendation 28:** That the Commonwealth and State and Territory Governments give priority to the efforts of the Working Party established in November 2004 to examine succession planning for ageing carers of people with disabilities and appropriate support for respite for carers."

18 However, this recommendation is relatively weak as compared to the important recommendations made about the release of young people from nursing homes to more appropriate accommodation (which we support wholeheartedly). It is therefore not surprising that now, a year later, there are no concrete outcomes from the planning process mentioned in recommendation 28 above. We think it is reasonable to say that the Report did not take a strong stand on the issue of needs of ageing carers, and we urge the Senate Committee to take much stronger steps now by building appropriate requirements into the next CSTDA.

19 The other carer related recommendation in the June 2005 Senate Report was:

"**Recommendation 47:** That, while welcoming the increases in Commonwealth funding for carer-specific programs over recent years, the Commonwealth increase funding for these programs through the National Respite for Carers Program and the Carer Information and Support Program."

20 The CGF is unaware of any improvements to the funding of programs for carers of people with disabilities in the ACT that have been made consequent to this recommendation. Perhaps this is because the National Respite for Carers Program is funded through the Department of Health and Ageing rather than through the CSTDA. We urge that CSTDA respite care programs are better funded, as the existing arrangements still do not provide sufficient support for carers of people with a disability.

21 The Mature Carers Program is an essential source of support for some older carers. But even though its formal target group and service scope are quite wide, agencies that use its limited funds have to adopt prioritisation rules like: *carers over 70 can have 4 weeks of respite a year , and carers 65 – 70 can have two weeks respite a year if they have been hospitalised*. This sort of assistance is of course far better than none, but it is wholly inadequate to address the underlying circumstances of the ageing (and younger!) carers. It does not make a contribution to preparing people with a disability to leave home before their parents die, and sustaining them there. If such assistance were available from any source, then some of the above described respite would no longer be needed and would become available to other carers. We understand from discussions held when preparing this paper that some funds allocated under the Mature Carers Program have been returned by agencies due to insufficient take up by carers. We find this both extraordinary and distressing when there is clear unmet demand. If this has happened because of access restrictions at program or agency level, these arrangements should be changed.

22 Another program that is both of value and of concern to family carers of people with a disability is the Flexible Family Support Program. While we understand the program is truly flexible in seeking to provide the kinds of

assistance that families need most, and we applaud this approach, our experience is that the assistance available from it is in practice temporary, and is usually small. It does not seem to be readily available to families caring in the long term for a person with an intellectual disability. While it does provide valuable respite care for family carers in a crisis, it does not provide ongoing respite care for families who have an ongoing need, and it does not help carer families to establish and sustain their people with a disability in their own homes. As in the case of the National Respite for Carers Program, perhaps this is because it is funded through the Department of Health and Ageing rather than through the CSTDA.

23 In summary, the three programs discussed above do provide valuable support for some families of a daughter/son with an intellectual disability, but they are generally not targeted to provide the level of sustained respite care that many such families need until their children with a disability move to their own home, nor to facilitate their transition to their own homes. The recommendations below are designed to provide adequate support under the CSTDA to these families.

24 It is very difficult for us to state here just what “adequate support” is, as the circumstances of each person with a disability and his/her family carers are different. But we can say that restrictions like a few weeks a year (see para 21 above) are quite inappropriate. Many families are under sustained daily pressure arising from the nature of their son/daughter’s disability which is highly unlikely to ever change. They need weekly access to age appropriate respite care on a permanent basis, provided by a single agency so they don’t have to “shop around” to put together several contributions from different agencies, and provided in a way that suits the circumstances of each individual family. The range of these circumstance means that in home, in other peoples’ homes, centred based and other forms of respite are options that should all be available. The family experiences outlined in Attachment B illustrate these points.

25 The CGF requests that the Senate Committee in its Inquiry into the Funding and Operation of the CSTDA re-visits recommendations 28 and 47 quoted above to take account of all carers of people with a disability not just aged carers; to ensure planning processes are concluded; to implement changes that assist carers; and to make more specific recommendations about how to assist carers. Action is needed in the short term, as was taken to remove young people from nursing homes, so the families do not collapse under the weight of their carer responsibilites.

Recommendations

1 ***That the Senate Community Affairs Reference Committee Inquiry into Funding and Operation of the CSTDA refreshes the recommendations 28 and 47 about carers made by the Senate Committee's previous Inquiry into Quality and Equity in Aged Care and adds within them:***

   - ***consideration of all carers of people with a disability, not just aged carers;***

   - ***early timelines for concluding the planning process referred to in the Senate Committee's previous Report, and for implementing changes that assist carers; and***

   - ***much more specific recommendations about how to assist carers.***

2 ***Establish programs that assist family carers of people with a disability to prepare their adult children for moving from the family home to their own home, and then actually make the transition. Funding of these programs must reflect the number of families supporting a child with a disability and the level of assistance they need for effective transition.***

3 ***Provide family carers of people with a disability with access to programs which enable their adult children to have sufficient support to live permanently in their own homes after transition. This support must be available to all families with adult people with a disability, with special priority to families where the parents are approaching, or over, 60 years. This support must also be available in the family home to those families who decide it is in the best interests of their child to remain in the family home until the point is reached where this is not possible. Funding of these programs must reflect the number of families supporting a child with a disability and the level of assistance needed to support the child in his/her own home.***

4 ***Provide under the CSTDA adequate in home support for families caring for a person with an intellectual disability. This includes regular access to age appropriate flexible respite care on a permanent basis, provided by a single agency, and provided in a way that suits the circumstances of each individual family. (For families with older parents, this may best be achieved through development of the Mature Carers Program. For younger families, some other mechanism is needed.)***

Services for people with an intellectual disability

26 All the above discussion about carers is important, but the core issues are more about the people who themselves have an intellectual disability. Only a small proportion of them have access to adequate accommodation support programs. To quote the June 2005 Report of the Senate Community Affairs References Committee Inquiry into Quality and Equity in Aged Care:

"4.18 There are many people with severe disabilities who live at home. They do so with the help of family members and government and community funded support services. The Committee was provided with many cases where families have gone to extraordinary lengths to support their family members at home."; and:

"4.20 …The Cerebral Palsy League of Queensland indicated that family breakdown sometimes resulted in children being placed in aged care facilities: *…the reason sometimes children with disabilities end up living in nursing homes is that there is a family breakdown because of the high support needs around the child. They just cannot cope. They cannot get enough support when the child is younger and then as the child gets beyond adolescence they grow heavy to lift and some of those sorts of things occur. They do not have enough support and there is a lot of stress put on the family unit*."

27 The solution to prevent such breakdowns for family carers and the people with a disability themselves requires not only better support for the carers, but better accommodation support for the people with a disability.

The shortage of Accommodation Support

28 There is a profound shortage of funded accommodation support programs in the ACT, and we believe nationally. This has been partly alleviated by some people with a disability being fortunate enough to be granted an Individual Support Package (ISP). But only a small number of ISPs are large enough to allow people to move to, and be supported in, their own home.

29 It does not matter a lot to the person with a disability whether it is accommodation support or ISP programs that are targeted for substantially increased funding, as long as vacancies are provided in one program or another that allow them to reach the very normal outcome of moving to and remaining permanently in their own home. The funds available now cover only people who have reached a crisis point in their lives. Most other people are forced to remain with their parents as they age, until the crisis point is inevitably reached.

30 While the Bureau of Statistics and Institute of Health and Welfare provide important broad data about disability in Australia – eg that in 2003 2.6 million Australians under 65 years were affected by a disability, 1.25 million were affected by a profound or severe core activity limitation, and only 187,806 service users accessed CSTDA-funded services - there are nevertheless no official statistics of the unmet need for assistance in preparing a person with a disability to move out of the family home, to physically make the transition, and to provide the support they need to sustain

them in their own homes. Disability ACT did, however, conduct a study of applications for ISPs made in Sept 2004 that were not funded, which provides an estimate of the minimum number of people with unmet need for accommodation support (and of the unmet need for other types of services). These data have not been publicly released. We suggest the Committee obtain them for their consideration. We believe the best way detailed statistical information of the unmet need for disability services can be obtained is as a by product of open calls to the public for applications for support funding. The internal Disability ACT data are a unique source of information on this social issue.

31 The Client Guardian Forum is aware of many examples of unmet need that would be best addressed through access to a better funded accommodation support programs or to ISP programs that have regular vacancies. We know that in the ACT ISPs only become available occasionally, and we understand the position is no better in other States/Territories. The need to substantially expand supported accommodation programs seems to us to be ignored by the funding authorities. Some small steps have been taken, but the large majority of families of a person with an intellectual disability are left with challenges they cannot meet to provide a reasonable life for their adult child. Rather they are left to sweat it out until a crisis is reached for the parents, or for the child when the parents die.

Recommendation

5. ***Policy and programs are developed that address the substantial shortfalls in accommodation support programs and individual support packages (ISP).***

Other support services

32 While in our judgement Accommodation Support is the service type that exhibits the greatest gap between the need for, and availability of, support for our constituency of people with an intellectual disability, there are also substantial shortfalls in the provision of Employment, Community Access and Community Support services. If ISP funds were increased sufficiently, the problem with Community Access and Community Support would be reduced, as ISPs are typically available for the recipient’s basic needs of living, development of living skills and participation in the community generally. But not everyone will have an ISP, so each of these service types needs large improvements.

Recommendation

6 ***Policy and programs are developed that address the substantial shortfalls in Community Access, Community Support and Employment services.***

A minimum service level

33 The words ”*Substantially increase the funds*…” in the last two recommendations reflect our inability to quantify just how much increase in funding is needed. It depends on just what the level of unmet need is, and our views on measuring this are given in para 30 above. An indication of the true meaning of “substantial” could be derived from the Disability ACT internal data referred to there. But not being able to quantify the unmet need must not in any case be allowed to block progress in addressing it. We shall therefore come at this issue from another direction in this paper.

34 We believe that any person with an intellectual disability should be given a level of support which reflects their dignity as members of the Australian community and which allows them to lead as satisfying and as independent a life as can reasonably be achieved in the context of their disability. This requires a “minimum level of support” with qualities like the following:

- Accommodation support to allow people to live in their own home, or in the family home if that is their own preference;
- Supported employment opportunities for people who are able to undertake paid work;
- Support that allows people to meet the basic needs of living, develop their living skills, and participate in the community to the degree they wish;
- Consistent access to all relevant information, and the support of a personal advocate when needed;
- Respite and the other support that carers need, when they need it and before a crisis develops; and
- All the above is readily available for each person with a disability through a single agency that negotiates with multiple service providers where more than one is needed, and without delay. In particular, services should be available for school leavers from the time they leave school.

35 These simple words are doubtless subject to interpretation and will conflict with some people's valid opinions, but we believe they summarise what a just minimum level of support would provide. We urge that the next CSTDA contain an obligation on the Commonwealth and States to meet a target like this within three years.

Recommendation

7 The Commonwealth and States adopt a formal three year target of providing a minimum level of support with the qualities described in paragraph 34.

The written CSTDA agreement

36 The Client Guardian Forum notes that the Report of the Senate Community Affairs References Committee Inquiry into Quality and Equity in Aged Care made strong recommendations about properly caring for young people inappropriately accommodated in Aged Care facilities. The 2006 Federal Budget made new financial allocations that will enable important progress to be made with the Committee's recommendations. It also notes that in the current CSTDA, the bilateral agreement between the Commonwealth and the ACT Governments contains a strategy to address: "….the inappropriate placement of young people in aged care homes" (3.4). Clearly the 2003 CSTDA documents laid groundwork for an adequate response to this issue.

37 The Client Guardian Forum requests that the next CSTDA contains a strategy that enables the adult children of aged (and other) carers to move to and successfully live in their own home.

Recommendations

8 The documentation of the next CSTDA Agreement, including the bilateral agreements between the Commonwealth and each State/territory, should ensure the <u>implementation</u> of the CSTDA Review's recommendations.

9 The documentation of the next CSTDA should contain a strategy for all Governments to follow to increase to adequate levels the funding of programs that support family carers of people with a disability, and of Accommodation Support and ISP programs for the people with a disability themselves.

38 The Client Guardian Forum supports the existing strategies in the ACT/Commonwealth bilateral agreement, but believes more needs to be done to meet desired outcomes.

Recommendation

10 The existing four strategies in the ACT and Commonwealth Governments' CSTDA bilateral agreement should be strengthened by stating outcomes more explicitly, and by adding specific progress reporting requirements with timelines.

39 The CSTDA agreement places the administration of most disability service types (eg Community Access and Respite Care) in the hands of the States, and keeps disability Employment services with the Commonwealth. This split of responsibilities has not worked well for the families of people with an intellectual disability.

40 To take a specific example, when our people leave school they in nearly all cases seek Employment assistance or Community Access assistance or both. Some people with a mild intellectual disability may need assistance with employment but are otherwise independent; some may have such a level of disability that employment is not an achievable target, so they rely on Community Access services for their daily activities; and in many cases the person can sustain some form of part-time employment but also needs Community Access support for living skills development and to participate in the community generally.

41 This latter group has a hard time arranging both Employment and Community Access because they have to obtain it from organizations funded by two separate governments. Employment services funded by the Commonwealth are particularly inflexible as they have rules that are designed for FACSIA's and DEWR's administration, not to meet the needs of the people with disabilities. Neither FACSIA nor DEWR has any provision in their supported and open disability Employment services for making positions available in a timely way for school leavers.

42 The splitting of disability Employment services in 2005 from one Commonwealth department to two has made service access harder for our group. Further, DEWR imposes on its open disability Employment program constraints from its vastly wider Job Network that work to the disadvantage of people with an intellectual disability. These people are not in a position to rip off a government program by exaggerating their disability.

43 Looking at the situation globally, disability service administration is very fragmented. It involves multiple arms of both State and Commonwealth Governments. To give another illustrative example, a non-government organization operating in the ACT in the interests of people with an intellectual disability has four different government funding sources, each with its own requirements that have to be met for the same people.

44 The next CSTDA should reduce this fragmentation. We considered recommending that the administration of disability Employment services is transferred under the next CSTDA to the States, or that the administration of all other disability service types be returned to the Commonwealth, so that all disability services are administered by a single government. We decided that such changes would be very difficult to implement, involving issues that we find it difficult to assess, so have instead made a recommendation that puts the onus on both the Commonwealth and the States to solve the coordination issue that families face. We do not feel so sanguine about the splitting of the administration of open and supported Employment services, and recommend that they again be administered jointly by FACSIA.

Recommendations

11 The next CSTDA agreement contain conditions that force the Commonwealth and States to coordinate the services they administer so that clients can negotiate packages of the services they need from a single agency.

12 The Commonwealth reverses its 2005 decision to split disability Employment services between FACSIA and DEWR, and returns the administration of all Commonwealth funded disability Employment services to FACSIA at an improved level of funding than existed at the time of the split.

Conclusion

45 To help the Senate Committee have a comprehensive understanding of the situations faced by families caring for people with a disability, the Client Guardian Forum would like to arrange for Committee members to visit in their homes some ACT carer families who are in a variety of circumstances.

46 The CGF's recommendations are principally designed to provide the environment and funds that are necessary to enable people with a disability to move to and successfully live in their own home before this is forced by family breakdown or the age of the parents. They also address other important aspects of these peoples' lives. People with intellectual disabilities are among the most deserving and needy small groups of the Australian population, and parent carers of people with a disability are one of the backbones of Australia's community care system. In our society people with a disability have a right to be supported in a way that gives them a fair chance of leading a safe and reasonably fulfilling life.

47 If there were one outcome from this Review that we would value above any other, it would be the establishment of properly funded transition programs which prepare people with intellectual disabilities to move from their family home to their own home, which help them to actually make the change, and which link smoothly into ongoing accommodation support programs that are also properly funded.

48 Finally, our last recommendation alludes to the long term nature of the required support.

Recommendation

13 These initiatives must provide funding for ongoing, long term support. The nature of almost all intellectual disabilities is such that while the person's support needs and those of their carers may change over time, it is highly unusual for the needs to be eliminated.

49 We request the opportunity to speak with the Senate Committee about this submission.

Summary of Recommendations

About carers of people with a disability

1 *That the Senate Community Affairs Reference Committee Inquiry into Funding and Operation of the CSTDA refreshes the recommendations about carers made by the Senate Committee's previous Inquiry into Quality and Equity in Aged Care and adds within them:*

- *consideration of all carers of people with a disability, not just aged carers;*
- *early timelines for concluding the planning process referred to in the Senate Committee's previous Report, and for implementing changes that assist carers; and*
- *much more specific recommendations about how to assist carers.*

2 *Establish programs that assist family carers of people with a disability to prepare their adult children for moving from the family home to their own home, and then actually make the transition. Funding of these programs must reflect the number of families supporting a child with a disability and the level of assistance they need for effective transition.*

3 *Provide parent carers of people with a disability with access to programs which enable their adult children to have sufficient support to live permanently in their own homes after transition. This support must be available to all families with adult people with a disability, with special priority to families where the parents are approaching, or over, 60 years. This support must also be available in the family home to those families who decide it is in the best interests of their child to remain in the family home until the point is reached where this is not possible. Funding of these programs must reflect the number of families supporting a child with a disability and the level of assistance needed to support the child in his/her own home.*

4 *Provide under the CSTDA adequate in home support for families caring for a person with an intellectual disability. This includes regular access to respite care on a permanent basis, provided by a single agency, and provided in a way that suits the circumstances of each individual family. (For families with older parents, this may best be achieved through development of the Mature Carers Program. For younger families, some other mechanism is needed.)*

About services provided directly to people with a disability

5 *Policy and programs are developed that address the substantial shortfalls in accommodation support programs and individual support packages (ISP). (An indication of the true meaning of "substantial" could be obtained from the Disability ACT internal data referred to in paragraph 30.)*

6 *Policy and programs are developed that address the substantial shortfalls in Community Access, Community Support and Employment services. (An indication of the true meaning of "substantial" could be obtained from the Disability ACT internal data referred to in paragraph 30.)*

7 *The Commonwealth and States adopt a formal three year target of providing a minimum level of support with the following qualities:*

- *Accommodation support to allow people to live in their own home, or in the family home if that is their own preference;*
- *Supported employment opportunities for people who are able to undertake paid work;*
- *Support that allows people to meet the basic needs of living, develop their living skills, and participate in the community to the degree they wish;*
- *Consistent access to all relevant information, and the support of a personal advocate when needed;*
- *Respite and the other support that carers need, when they need it and before a crisis develops; and*
- *All the above is readily available for each person with a disability through a single agency that negotiates with multiple service providers where more than one is needed, and without delay. In particular, services should be available for school leavers from the time they leave school.*

About the written CSTDA agreement

8 *The documentation of the next CSTDA Agreement, including the bilateral agreements between the Commonwealth and each State/territory, should ensure the implementation of the CSTDA Review's recommendations.*

9 *The documentation of the next CSTDA should contain a strategy for all Governments to follow to increase to adequate levels the funding of programs that support family carers of people with a disability, and of Accommodation Support and ISP programs for the people with a disability themselves.*

10 *The existing four strategies in the ACT and Commonwealth Governments' CSTDA bilateral agreement should be strengthened by stating outcomes more explicitly, and by adding specific progress reporting requirements with timelines.*

11 The next CSTDA agreement contain conditions that force the Commonwealth and States to coordinate the services they administer that clients can negotiate packages of the services they need from a single agency.

12 The Commonwealth reverses its 2005 decision to split disability Employment services between FACSIA and DEWR, and returns the administration of all Commonwealth funded disability Employment services to FACSIA at an improved level of funding than existed at the time of the split.

General

13 These initiatives must provide funding for ongoing, long term support. The nature of almost all intellectual disabilities is such that while the person's support needs and those of their carers may change over time, it is highly unusual for the needs to be eliminated.

Client Guardian Forum
ACT
August 2006

Attachment A: an extract from the June 2005 Report of the Senate Community Affairs References Committee Inquiry into Quality and Equity in Aged Care

4.15 Many ageing carers have provided care for family members for years, if not decades. This length of caring takes its toll on ageing carers: physically, financially, socially and emotionally. At a time when others have enjoyed a long retirement, carers face the anxiety of what will happen to their children once they require aged care. For many people with a disability, and indeed their carers, one of their biggest fears is that if community services are unavailable, there will be no option but to enter a nursing home. One parent told the Committee: Probably the most important thing that I would like to mention today is our fear for the future. While we love looking after Paul at home, we will not always be here to do this. I am terrified about what will happen to Paul after we have gone. I would never expect my other children to take over this responsibility. They deserve a life of their own. There has to be somewhere in the future for our young people to be accommodated for either respite or long-term care. This problem affects us all: it is our kids that we are talking about, and it could happen to anybody's family. I really hope and pray that things will change for the better in the future.

Attachment B: the experiences of two families caring for a person with an intellectual disability

FIRST CASE STUDY

A brief background to our daughter

Our daughter became ill at 13 years of age and after months in hospital had developed a form of epilepsy which is intractable and intellectual regression occurs. After 10 years of testing, analysis and experimentation we have no causal reason for the epilepsy and limited control whereby seizures have never stopped but severity is manageable. She has multiple types of seizure activity.

We have seen our daughter slowly decline in mental capability from someone who could attend normal school, converse and look after her own health, ride horses, take part in representative athletics, to someone who must be monitored 24*7, bathed, dressed and sometimes fed. We have not seen stability in her condition yet at 32 years of age. There are days when she can partake in her community activities with a carer like Meals on Wheels, shopping for people in a local nursing home, delivering magazines and newspapers to patients in the hospital. Other days she is unable to function because of non convulsive seizure activity and is unable to speak, feed herself or take part in any activity. Every day is different and is impossible to plan for.

While my wife and I still provide the 24*7 care, this must come to an end sometime. However we do not believe any existing service can provide a reasonable substitute for what is her current lifestyle and comfort level unless we are able to train carers using our experience. Our daughter spends two nights a month in respite and for that short time we can be assured of staff who have become familiar with her and her needs. It is not an option to have her cared for by people who are unaware of the total picture.

The lives of all the family over the past 18 years revolved around our daughter, not because we wanted it to but because her condition required us to do so. Our daughter has grand mal seizures on average 3/4 nights a week and usually does not wake until about 11.00 am so the mornings are impossible to plan for. What is apparent to us is that our daughter can only be managed through personal experience so that her various conditions can be identified and strategies developed.

What intellectual disability has meant to our family

My wife had to cease working some 16 years ago denying her potential to hold a rewarding career.

Our son clearly had to deal with watching his sister regress and the lost time together as a family.

I stopped full-time lucrative executive employment some 5 years ago to assist my wife with the 24*7 cars and to allow her some freedom to follow her interests. While I have worked limited time as a consultant from home over the past 5 years to supplement our income this is becoming increasingly difficult. Clearly the family standard of living must suffer.

Holidays are now somewhat restricted as flying must be after 2.00 pm (not more than 2 hours or so) and accommodation must allow us flexibility similar to home. Driving in a car for extended periods induces sleep for our daughter leading to seizures, somewhat restricting car holidays.

We are trying to preserve what financial capital we have to allow some additional quality of life for our daughter when we are deceased. This obviously denies any sharing of inheritance with our son.

I would emphasise the time consuming nature of Intellectual Disability on families must be experienced to be understood. The effect this has on the health of parents is an unknown but unlikely to be beneficial.

What we want for our daughter?

There are 2 principles we focus upon –
1. That if we die suddenly there is a plan in place to look after our daughter which maintains some quality of life, and
2. We can move our daughter into acceptable accommodation before we are not able to look after her ourselves

To meet our preferred approach we see there are 3 stages in our daughter's life
A. Access to accommodation and care for greater time away from home – say 2-3 days per week
B. Extend time away for home to 5 days a week
C. Move full time into accommodation when we are too old or death intervenes.,

How can we achieve our wants?

What is needed is funding to form a joint home with another 1 or 2 other persons so that the 24*7 level of care can be achieved at sensible cost and that a "family" atmosphere is developed in the home. We want to have this funding in sufficient time to put in place the structure and training of carers before we are unable to do so. As a minimum, a target should be made by governments for all families to be eligible for funding to enable transition by the disabled person into their own accommodation before parents reach the age of 65.

On applying for funding or discussing our situation with government representatives we are told there is no funding - we are not a priority!

Does our daughter have to wait for our death to become a priority?

We see ourselves as part of the unmet need in disability services but why?

SECOND CASE STUDY

J is a 20 year old young man, the third of four sons, who has a unique chromosomal abnormality. This manifests as profound intellectual disability, autism and suspected but unconfirmed bi-polar disorder. He is non-verbal, doubly incontinent and totally dependent on others for his every want and need.

2006 is his final year at school and what the future holds for him, and hence us, his parents, is unclear. The only thing that is definite is that he will be always be totally vulnerable and that he will need full support for the rest of his life.

At present we are ‘lucky’ enough to be able to work; his father full-time and his mother part-time. We are both contributors to the economy and development of this country. After this year, however, one of us may have to give up work entirely or both of us reduce our hours of work so that J can be supported. We then become much lesser contributors to the economy and development of this country.

We will be applying for Post School Options (PSO) funding but, as yet, no parent whose son or daughter is finishing school this year knows what funding is available, when they need to apply or what their chances are of receiving any. We do know that there has been no growth money for disability from the ACT Government in the 2006 budget except for young people in nursing homes. There is, (and this is August already) no indication of what will be available for him when he finishes school in three and a half months time.

If we are successful in receiving some PSO funding, we can then start the long, arduous, frustrating ordeal of approaching services to see which one doesn’t have a waiting list. We can try to cobble together some support from a number of disparate services; this support will be fractured and inadequate and J will be spend bits and pieces of days here, there and everywhere depending on which service can fit him in and when. This is the good story remember and wholly contingent on our receiving some funding. You can’t imagine the bad story. We can!

Like many other people in the ACT, we have no family support at all and so are forced to rely on governments to provide funding for services to support J for the duration of his life. It seems to us that if medical technology ensures the survival of so many people with disabilities (as it did our son) and that all life is valued (as our society professes), then to deny our son, and by default us, a life of interest, dignity and care is a gross denial of our so-called culture of respect and rights for all people.

As J’s parents, our future looks like this. J will finish school with, at the moment, no prospect of community activities, employment or care of any kind other than that he receives from his parents or what we can create for him.

One of us has a history of bi-polar disorder that initially manifested in the first few extremely stressful years after J’s birth. We are both ageing and starting to develop a number of health problems that will eventually directly impact on our ability to adequately care for our son. Our other three sons have moved interstate and so it is just the two of us. As Carers, we are unable to do even the simplest thing, such as see a film together or go for a half day bushwalk, without major organisational feats.

As we move into our 60s, 70s and 80s we will be in exactly the same situation - struggling to care for our, by then, middle-aged, totally dependent son with very little support from anywhere. There will be no prospect of him moving out of home as there will be no bricks and mortar for him to move into and no Individual Support Packages and hence no funding to pay for his support. We face a life of caring for him until we reach the inevitable crisis that is waiting for us. We could become totally physically incapacitated, senile, mad or dead.

And then what will happen to him?

J is a young man who is human. He deserves a life that honours his humanness and existence because his existence is worth honouring. He deserves to be loved, respected and treated with care and dignity. He contributes to our society not in an economic sense but in the sense of reminding us that the human condition is fragile and comes in a myriad of forms. He contributes by being the person he is: a thrill-seeking, gentle young man with a great sense of humour who brings out the best in people and encourages us to be compassionate, accepting, giving and tolerant of difference. He is a great teacher if we are open enough to learn from him instead of treating him as a person to be ignored and feared, chucking him the merest crumbs of life and expecting him to gratefully accept them.

And don’t forget, that for every person with a disability who needs financial, government and community support there is one, two or more Carers or family members who are also needing that support.

If we can’t treat our vulnerable people and their Carers better than we do now, it speaks pretty poorly of us as a society.

It isn’t good enough.