

Disability ACT  
Department of Disability, Housing and Community  
Services

## **Issues raised in the *Future Directions* Consultation May-June 2004**

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*'There is no reason why the ACT should accept the pressures for bureaucratic mediocrity when it comes to people with disabilities. If Disability ACT sets its sights on becoming a stand-out example of innovation and quality, then everyone wins – people with disabilities, the community, departmental people, workers in disability – even the Minister and the Chief Minister.'*

*Consultations on Future Directions, June 2004*

RPR Consulting would like to acknowledge the contribution of Phillip Gleeson to the writing of this report and the contribution of Patsy Muggeridge, Phillip Gleeson and Kerry Reed-Gilbert to the conduct of the consultations.



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# 1 Executive summary

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## Part 1: Issues raised in consultations

*Future Directions for Disability ACT 2004-2008* was released by Disability ACT for public comment over the period May-June 2004. This paper reports on outcomes of the consultations in Part 1 and provides an evaluation of the process used for the consultations in Part 2.

### Comments on the approach taken in developing the plan

Overall comment on the approach taken to developing the plan emphasised:

- The need for better qualitative and quantitative data to inform needs analysis and monitoring of progress
- The importance of linking the plan closely with other government policy initiatives such as the *Social Plan* and *The Canberra Plan*, the *Caring for Carers Policy*, the *Access to Government Policy* in particular

Participants in the consultations also suggested streamlining the final plan so that it contained only strategic directions, outcomes or objectives and strategies. They wanted it written in plain English with sensitivity to the use of language which empowered people with disabilities rather than doing things ‘for’ them.

The consultations also revealed that people had a strong interest in the action planning phase which is the next step of the Disability ACT planning process and that they were keen to see a monitoring and reporting regime introduced.

### Overall comments on content

The strategic directions in the plan covered these general areas:

1. Improving policy and culture to promote an inclusive society
2. Improving government and community responses to people with disabilities, their families and carers
3. Improving planning and funding to better meet the needs of people requiring ongoing support
4. A responsive and sustainable service delivery sector

Feedback received in the consultations endorsed these general strategic directions, albeit with some comment and suggested refinement, which are discussed later.

In relation to the disability vision and values statement which underpins the philosophy of the plan, people consulted acknowledged that the vision and values apply to everyone with disabilities, but they also wanted recognition that for some people with disabilities this will be through the choices that others, such as families and carers, make for them.

The consultations also showed that people wanted more attention given to funding and funding policy in the plan in a range of areas:

- More funding for more services
- The policy framework which guides how funding is allocated between individuals and services
- The issue of equity of funding between individuals and what equity means in reality when the diversity and intensity of need varies so much

- Possibilities for alternative sources of funding.

Some other general issues which people wanted in the plan included:

- using all forms of technology to maximise independence
- promoting citizen and self advocacy
- embodying a partnership approach between people with disabilities, government services and policy makers, and non-government service providers in implementing the plan
- ensuring a whole of government approach.

Accommodation was a major concern for many people and they did not feel that the plan provided sufficient emphasis on provision of respite and long term supported accommodation.

Employment was seen as a flagship issue for inclusion and participation which also did not receive enough attention in *Future Directions*.

Brief comments on each of the strategic directions follow.

### **Strategic Direction 1: Influence policy and culture to promote an inclusive society**

The strategies here were generally supported along with these new ones:

- promoting inclusion through including awareness programs in the education system from preschool to college
- working to influence Commonwealth policy to be more person centred and increased interface between Commonwealth, NSW and ACT governments in relation to disability policy and programs
- positively supporting the employment of people with disabilities in all employment sectors and in mainstream volunteering
- developing and implementing a media campaign.

### **Strategic Direction 2: Improve community and government responses to people with disabilities, their carers and families**

The emphasis on access, referral and early intervention was strongly supported. However it was pointed out that there was a discrepancy between a strategic direction which focussed on response and the strategies which focussed on improving access. These are related, but not necessarily the same thing. Nevertheless the importance of improving access, information and referral was strongly endorsed.

The link with the *Caring for Carers* policy was seen as extremely important, but the issue of carer choice, which is fundamental to the Carers' policy, was seen as problematic when services which provided an alternative to family care were not available.

Research was seen as important to identify good practice and as an evaluation technique to test that what is done is the most effective use of resources.

### **Strategic Direction 3: Improve planning and funding to better meet the needs of people requiring ongoing support**

The consultations revealed concerns about the six areas of particular focus identified under Strategic Direction 3. The first four related to ages and stages of life:

- Families with young children to the age of 14 years

- Young people from 15-25 years
- Older adults from 55 years
- Mature carers from 65 years.

People accepted that transition stages, eg school to work, were times requiring particular support but were unhappy with the rigidity of the age categories. They felt that the age categories did not reflect the reality of the lives of people with disabilities who may take longer to move into adulthood or may age earlier than 55. They were also unhappy that adults were not included as an area of focus. The consultations suggested a need to acknowledge that, while there are some similarities for all people at each stage of life, the diversity of individuals combined with a range of disabilities means that people at similar life stages may have vastly different needs.

Two groups for whom service access can be especially difficult were also identified in *Future Directions* as requiring particular focus under Strategic Direction 3. They were Aboriginal and Torres Strait Islander people and people with high and complex needs. Both were strongly supported by the consultations as requiring particular attention.

The consultation with people from an Aboriginal and Torres Strait Islander background underlined the critical importance of developing general cultural awareness and specific awareness around the meaning of disability in Indigenous communities. Relationship building and developing credibility with the Indigenous community will be essential first steps before effective planning and implementation of strategies to enable Indigenous people to access culturally appropriate support can be achieved.

With respect to people with high and complex needs, the consultations emphasised the great diversity of people, needs, disabilities and circumstances which fall within this group and the need to ensure that the strategies recognise this.

While some people with disabilities from culturally and linguistically diverse backgrounds do access services, people consulted felt that there are likely to be many ‘hidden’ people from culturally and linguistically diverse backgrounds who do not and that this group should receive more attention in the plan.

More detailed comment on each focus area is included in this report. (See page 21)

#### **Strategic Direction 4: Develop a sustainable and responsive service sector**

This strategic direction was strongly supported in the general consultations without much comment – except about low pay rates in the sector and the need for skilled staff imbued with the vision and values. It generated most discussion in the service agency meeting. Here it was felt that, while the intent was worthy, there was insufficient emphasis on a partnership approach as embodied in the *Social Compact*. The comment was also made that the strategies focussed on sustainability, eg through quality systems, but not so much on responsiveness. Many agencies advised that they already operate under at least one set of standards and they queried the value of introducing another.

While there is widespread support for the intent of this strategy, there is also a need for Disability ACT to nourish a partnership approach by responding to sector feedback and offering opportunities for the sector to be closely involved in the action planning phase.

## 2 Introduction

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### 2.1 Background

*Future Directions for Disability ACT 2004-2008* is a whole of government strategic planning response to support the aspirations and address the needs of people with disabilities in the ACT, their families and carers, as well as the service providers who support or assist them.

While Disability ACT has primary responsibility for actioning this strategic plan, other agencies responsible for mainstream programs and services, the business and community sectors and the broader ACT community also have a role to play in ensuring the plan is effectively implemented.

The strategic plan is part of an overall planning process that commenced following the release of the Report of the Board of Inquiry into Disability Services in early 2002. It also is linked closely with subsequent whole of government planning initiatives such as the ACT government's *Canberra Plan* and the *Social Plan*.

### 2.2 Purpose of the consultations

The plan identifies the directions and areas where policy, program and service development attention will be focused over the next four years. Consultations were undertaken over May and June in 2004 to test whether the draft strategic plan addresses those areas and issues that are most important to the ACT community and in particular, to those with a disability, their families and carers. The outcome of these consultations, reported here, will inform the final drafting of the plan.

### 2.3 The consultation process

The consultation process comprised:

- 4 public forums attended by a total of approximately 38 people excluding Disability ACT officers
- 6 focus groups attended by a total of approximately 51 people excluding Disability ACT officers
- Presentations by Disability ACT on *Future Directions* to the executive of all government departments
- A meeting of across government services attended by 10 people
- Written responses from 5 government agencies
- A meeting with service agencies attended by approximately 35 people
- In invitation to provide written responses
  - 11 submissions were received from individuals or organisations
  - 5 informal written comments were received
  - 21 standard feedback forms were received
- 2 private interviews were conducted on request. (Comments from these interviews are incorporated where appropriate in the report.)

The *Future Directions* document was also available on line and several hundred hard copies were distributed.

While not directly part of the *Future Directions* project, the consultations are also informed by the consultant's attendance at:

- two meetings conducted by Housing ACT and Disability ACT which were attended by a total about 60 people on a proposal to offer individual tenancy agreements to people who live in Disability ACT's group homes; and
- two planning meeting of the Workforce Reform Working Group which was set up by Disability ACT and comprises community and government members who have been working on sector workforce issues for the last eighteen months.

### **2.3.1 Use of co-facilitators**

Three co-facilitators were engaged to assist with the consultations – a person with a disability, a family member of a person with a disability and a facilitator from an Indigenous background.

## **2.4 About this report**

The report is an overview of general issues raised in the consultations about the *Future Directions* document.

The report attempts to provide the flavour and content of the conversations, written feedback and submissions that comprised the *Future Directions* consultation. Some quotes are provided in italics throughout the report, however names have been omitted for privacy reasons. Some quotes are taken directly from written comments received and sometimes they are derived from notes taken at focus groups or forums. In the latter case they have been adjusted slightly to take them from note form to sentence form. Where people have submitted a signed written submission, their comments are attributed. Some aspects of the report are directly relevant to writing the next draft of the plan. Others will be useful in the action planning phase or in designing future consultations and some simply provide valuable feedback.

This report commences with comments on the plan and the planning process. General comments on the content of the plan come next and these are followed by some more detailed comments on each of the four strategies. It concludes with some suggested next steps.

Disability ACT would like to thank everyone who took the time to provide comments and suggestions on *Future Directions*.

## 3 Comments on plan design and planning process

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### 3.1 Quantitative data for planning

Several people had concerns about use of the ABS data from 1997/98 or use of ABS data at all for specific planning. Even though the latest ABS data does include disability status related to main condition, assistance needed and received, use of aids, use of public transport and employment restriction,<sup>1</sup> it was still seen as a rough indicator of the incidence of disability and not a real indicator of need in the ACT.

Others felt that more defined information on disability in the ACT could be obtained through the Australian Institute of Health and Welfare. In any case, many people consulted felt that for planning purposes better data was required and that Disability ACT should attempt to acquire it. At a specific level, a number of young families were concerned about the statement of 'relatively low growth in the need for services for children and young people with disabilities' and quoted various studies to show otherwise.

The point of all this is that the consultations indicated, as have those conducted previously, that sound data is needed for planning purposes. The credibility of that data is very important for families who are not just concerned about the next four years but are in it for the long haul.

### 3.2 Qualitative data for planning

The idea of a customer needs analysis came up frequently in different forms during the consultations. Someone said that if there was a strategy 'to identify the extent of the need among Aboriginal and Torres Strait Islander communities and the range of family and community specific support programs they prefer' (p19 *Future Directions*) could this not also be extended to the rest of the community?<sup>2</sup> As an adult who has lived with disabilities for many years stated at the consultations:

*No one has ever asked me what I need.*

*Strategy 3 discusses the implementation of strategies to better meet needs without any mention of needs assessment. This is an issue that is constantly raised in disability fora. Many of the sub-strategies mentioned under strategy 3 would have much greater meaning if a needs assessment was conducted.<sup>3</sup>*

### 3.3 Explicit links with the other government planning frameworks

While there is reference to *The Economic White Paper* and *The Social Plan*, feedback indicated that links with the other government policies and frameworks could be made more explicit. As discussed later in the report, the service agencies also felt that Strategy 4 did not reflect the spirit of documents like *The Social Compact* and the *Service Funding Policy*.

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<sup>1</sup> Submission from a parent, dated 16.06.04

<sup>2</sup> Ibid

<sup>3</sup> Submission from a community organisation

## **3.4 Planning terminology**

### **3.4.1 Strategies, strategies, strategies**

Several people with expertise in strategic planning attended the consultations. They pointed out that each of the four strategic directions, its outcomes and the lower level strategies could be seen as simply three sets of strategies. This contributes to a sense that the document is a little too much about what is going to be attempted but not a lot about what is going to be achieved.

#### **Generic strategies**

A number of people pointed out elements of repetition in the sub-strategies of the focus areas of Strategy 3 in areas such as information, peer support, sibling support etc. They suggested that these could be presented as generic strategies at the start of Strategy 3 and did not necessarily need to be repeated. This would give a sharper focus to each of the specific areas identified in Strategy 3.

#### **Too many strategies?**

While no strategies were removed and a few suggestions were added, some people thought that when the action planning phase starts there will be too many strategies and it will not be possible to do them all. Some consolidation could be useful in finalising the document and some prioritisation will be necessary in the planning phase.

#### **Order of priority**

Several people commented on the order of priority of the strategic directions – arguing coherently for retaining the status quo or some reordering. Disability ACT advised that the intention of the plan is that the four strategies are interconnected – the achievement of one will assist with the achievement of another and vice versa. The numbering from 1 to 4 is for convenience, it is not intended to imply an order of priority or an order of sequence.

## **3.5 Structure of the plan**

### **3.5.1 Keep to the essentials**

By including discussion and achievements to date, people felt that the document attempts to do too much. It becomes long and dense and difficult to read at a single session. It was suggested that a simple version based around the four strategic directions might be better. A version including the discussion could be retained for reference and made available to those who wanted it – or the discussion could go with the action plans which are to be developed later around each strategy.

#### **Reporting on achievements**

People felt that reporting on achievements should be separated from the plan itself as these will change over time. However they are very interested to know what has been achieved and these could be included in the reporting regime developed around *Future Directions*.

#### **A further comment on achievements**

During the consultations, some of the achievements mentioned in the document were queried by participants. Disability ACT staff were able to clarify and confirm that the achievements had been begun but perhaps not completed. However, it is better to be very clear when describing achievements, as this sort of discrepancy contributes to a feeling of distrust and cynicism about the worth of documents of this sort.

## 3.6 Language

### 3.6.1 Plain English

Some people commented that the document was comprehensive and well written, but for many it was a hard read. Not everyone thought

*Pseudo intellectual tosh! Whatever happened to plain speak?*

but most people would prefer plain English. A shorter sharper version would have more impact. Acronyms should be avoided wherever possible. A glossary of terms may help.

### 3.6.2 Empowering language

While it was not general feedback, one submission cautioned against paternalistic language. The implicit messages in a document such as *Future Directions* can be as important as the explicit content. The capacity of language to empower is illustrated in this description of the social model of disability.

The Social Model of Disability understands disability as a problem created and imposed by society. It recognises that it is not the impairments of people with disabilities which cause the problem but rather the way in which society fails to make allowances for differences. The Social Model takes the view that disability is the result of society's failure to accommodate the needs of people with disabilities. The Social Model focuses on the barriers people with disabilities face on a daily basis. It establishes that everyone is equal and demonstrates that it is society which erects barriers that prevent people with disabilities participating and restricts their opportunities. The social model empowers people with disabilities to challenge society to remove those barriers.<sup>4</sup>

## 3.7 Interest in the action planning phase

It is important for the credibility of the plan and of this first phase of the consultation process that the arrangements for the action planning process are announced soon and implemented as promised. Many people saw this as the place where their contribution would be most important.

## 3.8 Monitoring, evaluation and reporting progress

Many people who attended this consultation are sophisticated in the use of planning documents such as *Future Directions*. They will remain somewhat sceptical until they see an accountability framework established around *Future Directions* and until they receive their first report on progress. They would like to see customer satisfaction measures included if possible and monitoring of the practice of government as well as non-government agencies.

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<sup>4</sup> Extract from the preamble to Women with Disabilities Australia's strategic plan, provided by one of the participants

## 4 General comments on content

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### 4.1 Support for the four strategic directions

The outcomes of the consultation generally supported the four strategic directions and many people recognised the hard work and hard thinking that had gone into the plan. The standard feedback form asked people to rate the appropriateness of the four strategic directions on a five point scale with five being the optimum. The average response was 4.5.

The following comments give a more qualitative indication of the response:

*[A disability community organisation] applauds Future Directions for outlining a raft of strategies and actions which start with changing cultural and community attitudes and continue through all levels of the social structure to the support of the individual in the home.<sup>5</sup>*

*I would like to congratulate you and your staff on the development of your plan and acknowledge the many challenges you face in preparing and implementing such a plan.<sup>6</sup>*

Some people who have been involved with the system for a long time found a sense of déjà vu in the document, even quoting from previous plans from some years ago that had said very similar things.

*We agree with all the strategic directions promised in the paper, but please don't make commitments that you cannot honour.*

*There is a concern that a new form of words is merely substituted for the old one and that people will still have to fit the service rather than having a true person centred approach.*

There is also a sense that a good document is still only a good document -

*When will we move from motherhood statements to action?*

*All the visions, values and strategies are good but need to be converted to real person centred support.*

Service agencies agreed:

*The community will continue, as it has for the years since Gallop, to ask for action not words. An improvement in the lives of those we work with, live with, know and love is the true indicator of progress, as important as documents, policies and words are, they're the easy part!*

Many people stated that while they were pleased to be able to comment on the strategies, their real interest lay in the action planning which is to be the next phase of *Future Directions*.

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<sup>5</sup> This is a direct quote from the submission of a disability community group. However it should be noted that this group also provided significant critique of several other aspects of the document.

<sup>6</sup> Submission from a parent

## 5 Comments on issues affecting the whole plan

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Major overall areas of concern or emphasis are listed below and discussed in this section.

- Recognition of diversity of perspectives and need
- Transitions rather than age categories
- Gaps in the focus areas
- Funding issues
- Too much change or not enough?
- Importance of a spirit of partnership
- Whole of government approach

### 5.1 Recognition of diversity of perspectives and need

#### 5.1.1 A vision and values for all?

While a closer reading of the vision and values (particularly the values) recognises that for some people the vision and values will be achieved through the choices that others such as families and carers make for them, there is still a sense that the vision is only for some -

*We are so far away from [our child] being able to choose how he wants to live, that the vision and values seem meaningless and to exclude us. I just want him to be able to wipe his own bum.*

*The vision and values statement says 'live how they choose to live'. Well, we choose a group home, but I don't think that is seen as acceptable any more.*

#### Use of age categories and person-centredness

It was also argued that the use of an age-based approach was not person centred because it did not take account of the individuality of people with disabilities or the differences between different types of disability. For example, the practical needs of a person with quadriplegia trying to get a book published and the needs of a person of a similar age with a moderate intellectual disability trying to establish independent living arrangements require quite different approaches. What they share is that they may both come up against similar barriers to participation.

While people clearly did not want to be categorised by their disability, the extent to which a person has the ability to make choices for themselves can make a difference. For some families dealing with highly challenging behaviours in a young person with a severe intellectual disability, the strategies for young people focussed on inclusion, education and post-school options seemed almost to mock their struggle just to survive day to day. For planning purposes it is practical to use some categorisation of need. However, the emphasis on person centredness remains fundamental. It was suggested that a less rigid focus on age, along with an acknowledgement that people with high and complex needs cover all stages of life and a wide range of disabilities, could maintain a sense of the individual within the planning document.

#### Gender

It was argued in one submission that women with disabilities are significantly under-resourced, largely because of the differing types of disability that (statistically) men and women experience. They stated that it is usually young men who require high and complex support, while women with disabilities are more likely to develop chronic conditions requiring a medium level of support. This means that resources are inequitably allocated by

gender. They hope that this will be considered in prioritising resources. Specific support for women with disabilities could be addressed in the action planning stages of this project.

### **5.1.2 Transitions rather than age categories**

Transitions were recognised as periods of high stress, and there was support for focussing on them. However, the age categories around the transitions were perceived to be too rigid and often irrelevant to the reality of the lives of people with disabilities.

*The transitions can take longer. Our kids don't leave school till they're 20.*

*I think the young person age range is too narrow. If you look at the way the young person transition is described [in the appendix] hardly anyone – even if they don't have a disability – would have finished all that by 24.*

*People with disabilities may begin ageing much earlier than 55.*

*I am not over 65, but I have been caring for my daughter for 32 years, that feels like mature to me.*

*The Council on the Ageing starts at 55, so why do we have to wait till 65 to be classified as mature?*

## **5.2 Gaps in the focus areas**

### **5.2.1 Adults**

In reading Strategy 3, most people gained the impression that the lack of focus on the age group from 25-54 would result in a lack of attention to this stage of life over the period of the plan. This is particularly evident in feedback forms filled out by people who did not attend a meeting. However, even at meetings where it was explained that these were areas of particular focus and that attention would still be given to other areas, it was clear that people were not comfortable with having some age groups left out.

*So many people cannot see themselves in the document. An attempt could be made to write a document where every person with a disability can see themselves somewhere in the document, and of course this would help to make the system be – or at least appear – person centred.*

#### **Consultant's comment on omission of adults**

The omission of the age range of 25-54 as a focus area in the consultations means that issues of great significance to this group and to the disability community as a whole eg employment, transport, accommodation and discrimination may not have received the emphasis which they warrant. It would be seen as a positive response to community input if Disability ACT were to include this group in *Future Directions*.

### **5.2.2 People from culturally and linguistically diverse backgrounds**

The inclusion of Aboriginal and Torres Strait Islander people as a target group triggered a query about why people from culturally and linguistically diverse backgrounds were not also being targeted. While some people from culturally and linguistically diverse backgrounds do access disability services and some did attend the consultations, there is a perception that many people in this group do not access support because of the different cultural dimensions to disability in different ethnic groups and significant language barriers.

## 5.3 Funding

Several people were concerned about the statement that implementation of *Future Directions* would be achieved within the existing budget. Disability ACT officers responded to this by indicating that better allocation of existing resources could achieve better service outcomes. The early experience of the pilot Community Access and Linking Program is that much can be achieved without any additional cost, but there is still a degree of scepticism about funding issues. This particularly related to expectations that more supported accommodation, respite care and supported employment opportunities may be required – all of which are seen to use real resources.

*The notion of 'person-centredness' must not become rhetoric that allows government to dilute the level of service.<sup>7</sup>*

Many people were sceptical about links with the *Caring for Carers* policy, which states that carers have the right to decide whether to take on or continue the role of care and are supported in their choices. This was because they saw few alternatives to the care they already provided and did not feel confident that funding would be made available to develop more care options.

### 5.3.1 Equitable and transparent funding

This was mentioned as an issue related to funding levels and funding policy including:

- the straightforward request for more funding for more services
- the issue of the policy framework for balancing funding provided to individuals and block funding provided to services

*There is an assumption that funding to individuals will flow through to organisations. I don't think this is a good enough base for funding.*

- the issue of equity of funding between individuals
- the complex relationship between equity and need

*I am concerned that equity of funding may mean that people with very high and complex - and costly - needs may miss out.*

Funding and the policies around it were regarded as fundamental issues which did not appear in *Future Directions*. Some people are aware that the Access, Equity and Eligibility Working Group, set up as part of the disability reform process, is addressing some of these issues, but there is a need for greater clarity around them.

### 5.3.2 Alternate sources of funding?

One person suggested that alternate sources of financing (eg low interest loans, shared equity etc) for the support, development and accommodation (and perhaps employment) of people with disabilities should be investigated and that Disability ACT could take a representational role in this.

## 5.4 Using all forms of technology to maximise independence

This issue was raised by one person, and was not extensively discussed at the consultations. However, technology is transforming living arrangements in all sorts of ways for many people and the potential benefits for people with disabilities should not be

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<sup>7</sup> Submission from one community organisation in relation to the description of person centred approaches in *Future Directions*, p10 which emphasised family and informal support networks and the notion that planning and funding are usually best directed at supporting them rather than replacing them with formal and specialist disability services.

overlooked. It could perhaps be used as a principle to guide thinking in the action planning phase.

## **5.5 Self advocacy and citizen advocacy**

This issue was raised by one person and was not extensively discussed in a direct sense. However, many of the issues raised in the consultations about inclusion, could be at least partially addressed by such an approach.

## **5.6 Too much change or not enough?**

Some groups talked about their sense of change exhaustion. Explorations indicated that this was generally change in personnel, process and philosophies.

*Because of the never ending changes to disability services the impact on families is actually maximised. Processes are changed and families are forever fighting for their disabled family member's cause without really knowing what the process is.*

*Family members need a more stable environment.*

*Each new initiative gives you a feeling of - What are they doing to us now? What is going on?*

At the same time there is a perception that nothing much really changes.

*There is a lot of talk and not much action. I have been to so many of these meetings but where are the results?*

## **5.7 Importance of a spirit of partnership**

At the service agencies meeting, concern was raised that the plan reflected a 'doing for' approach rather than a 'doing with' approach. The essential message here is also reflected in this comment:

*It is important that the department and all workers in disability believe that people with disabilities are part of the solution, and not a part of the problem. This is far more than a clever and often used play on words. People with disabilities should be involved on the issue of disability as far as possible. A very tangible way of ensuring the health and improving the functioning of the overall system for disability services is to increase/enhance the self-esteem and confidence of people with disabilities and to enable them to participate.*

The spirit of partnership also extends to the relationship between the government and non-government sectors and this aspect is discussed in more detail in the comments on Strategic Direction 4 later in this report.

## **5.8 Whole of government approach**

*Future Directions* was circulated to each government department for comment and presentations have been given to all departmental executives. As well, a meeting was held for government representatives as part of these consultations. Participants at the meeting came from Chief Minister's, Treasury, Office for Children, Youth and Family Support, Education and Training, CIT and Disability, Housing and Community Services. There was recognition of the need to take a whole of government approach on disability and also to cooperate and coordinate approaches across departments at the operational level so that a more person centred approach to service delivery is achieved.

This comment from the Chief Minister's Department submission sums up importance of a whole of government approach and the challenges involved in achieving it:

*Ensuring people with disabilities receive a higher standard of support and assistance requires an across government approach, as identified in the document. The challenge lies in developing governance structures and processes that will produce better outcomes for people with disabilities. These areas include more holistic approaches to, for example, funding arrangements, early intervention strategies, life transition support, community partnerships, transport issues and broader issues of social inclusion for people with disabilities. ...developing processes for building a collaborative, whole of government culture around the Future Directions for Disability ACT 2004-08 is a challenge and one that this document and future work could address.*

## 6 Specific areas requiring more attention

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The issues which emerged as generally requiring more attention in the plan were

- Accommodation
- Employment
- Reaching Aboriginal and Torres Strait Islander people with disabilities

### 6.1 Accommodation

Accommodation is a worry for many people who attended the consultations and they were concerned that there is not a strong emphasis on it in the document. For some, a sense of political correctness seems to have developed around accommodation. They see this as preventing the real issues from being discussed.

*If they would just say to us, there isn't enough money to keep the group homes going, perhaps we could sit down together and talk about what to do, but somehow we are made to feel that we are in the wrong for preferring this option.*

The consultations indicated that people did not yet have confidence in the policy options being developed to replace expansion of the group home model:

*Accommodation is our biggest concern, but it hardly gets a mention in the plan, because we are meant to talk about options. What on earth does this mean?*

*Overall the 'future directions' indicated leave me with doubts about what type of accommodation support will be available when my daughter reaches adulthood. It does not provide confidence that the type of support her parents want for her will be available.*

*The mature carers section talks about short term assistance in crisis situations for carers who are unable or unwilling to continue to provide live in care for those with disabilities. [This person then referred to the principle of choice in the Carers Policy] ...Long term accommodation options also need to be included. Caring for a person with an intellectual disability should not be a life sentence, especially where difficult behaviours are concerned.*

*There needs to be an immediate commitment to improved housing and support models that cater for the wide range of disabilities in this community, as well as preferences for location, tenant mix and housing style chosen by people with disabilities.<sup>8</sup>*

*At the moment the availability of these options [ranging from regular respite to full time care] is not readily apparent and people feel pressured and trapped.<sup>9</sup>*

#### 6.1.1 Respite

Many people said that if they could access more respite, they could keep going longer in their caring role. In any consideration of accommodation, access to respite is clearly an important consideration. Regular respite and even a week on week off arrangement was

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<sup>8</sup> Community organisation submission of June 2004

<sup>9</sup> Submission from an individual of 18 June 2004.

also seen as an important component in making a transition from at home care to full time care outside the home.

#### **Consultant's comment**

When Disability ACT officers from the new Community Linking and Needs Assessment Service attended meetings there was considerable interest from participants in what they were doing. While it is recognised that this is a pilot program, it may be useful to provide more information about the practical outcomes of this approach when they occur. This issue of security of care and support for their offspring with disabilities in the future is the major concern of parents of all ages, but particularly older parents. For them an 'option' needs to be much more concrete if it is to give them peace of mind.

## **6.2 Employment**

This is recognised as a difficult issue, but a fundamental one. Change here would make a critical difference to the lives of people with disabilities and their families.

*The employment of people with disabilities is a core issue, which can be a litmus test for the health, or state of disability in the ACT. People with disabilities who want to work (regardless of hours, or needs for assistance) are a resource not only to fill jobs, but also to add value to the workplace through diversity and experience. The numbers of such people who are unable to find work is a sad comment on the level of humanity and compassion in the ACT.*

ACTCOSS challenged Disability ACT to become an example of a good practice area in this field.

*Empowerment for people with disabilities should be reflected in the decision making process, including having people with a wide range of disabilities as part of the employment base of the organisation.*

More broadly, considerable interest was expressed in the consultations about the potential of the ACT Government's role as an employer of people with disabilities.<sup>10</sup>

## **6.3 Reaching Aboriginal and Torres Strait Islander people**

Aboriginal and Torres Strait Islander people were already included in *Future Directions* as a group requiring more attention. This was because, despite statistical and anecdotal evidence that rates of disability are high in this community, the rate of accessing support services is disproportionately low. To the consultant's knowledge no Indigenous people contributed to the general consultation. People who did participate in the general consultations said in a respectful way that they did not feel they could comment on the strategies specifically for Indigenous people.

The reason for including this group again is to emphasise the need for engagement. The consultation, undertaken with a very small group of Indigenous people – mainly from organisations - and facilitated by an Indigenous person, indicated that it is not discussion of the strategies, but actually connecting with this community that should be the first area of focus. These beginning conversations gave to the white people present a glimpse of the complicated cultural framework through which disability is viewed by many Indigenous people. It showed how cultural beliefs and shame can combine with the 'institutional

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<sup>10</sup> The Chief Minister's Department in partnership with Disability ACT is currently developing a new whole of government employment strategy for people with disabilities in the ACT public service.

racism' described below to exclude Indigenous people with disabilities and their families from accessing the support and assistance that they need.

While the draft strategies in *Future Directions* were well meaning they were developed from a white perspective and around white models of care.

There's not just a difference between cultures, it's a clash, and reflects the fact that the nature of white Australia today is very much based on the individualism of neo-liberalism. Aboriginal culture is traditionally and remains, much more community focussed and there is a desire for mutuality, reciprocity, sharing. We would argue that health services are first and foremost social institutions built on the cultural stance of the population they serve ...Mainstream health services in Australia are driven by individualistic western values and not the community values of Aboriginal people.<sup>11</sup>

A simple example of this was given. A mainstream organisation might employ an Indigenous worker to work with Indigenous communities. This is good, but often along with the mainstream job will come a subtle expectation of a 9 to 5 office based mode of operation. However, more flexible community based approaches which may involve long absences from the desk focussed on relationship building - which does not look like 'work' in the white model – are more culturally appropriate and more likely to have long term benefits.

Until a relationship of understanding is established between Disability ACT and the local Indigenous community it is hard to plan for what could really make a difference for people with disabilities who are from an Aboriginal and Torres Strait Islander background. Disability ACT will need to engage with the Indigenous community and work with them to develop strategies that are culturally appropriate.

More issues associated with engaging with Indigenous people with disabilities are discussed in more detail in Section 8.7 of this report and in Section 3.3 of Part 2.

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<sup>11</sup> Dr Gavin Mooney, "Institutional Racism in Australia", Medical Journal of Australia 17.5.04. (Quote provided by a participant).

## 7 Comments on Strategic Direction 1<sup>12</sup>

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### 7.1 Influence policy and culture to promote an inclusive society

Generally these outcomes and strategies around changing community attitudes were accepted as being very important. As one person said

[If there was an inclusive society] *Would this mean we wouldn't have to fight for things all the time?*

It was recognised that these are long term initiatives – way beyond four years in most cases - and that it is difficult to measure progress. However, they also believed that establishing some indicators of change in community attitudes was needed to see if the suggested strategies were working. Many people acknowledged their own role in making it happen.

*When my son first started going down to the club after his accident, people didn't know how to approach him or what to do. We had to help them feel comfortable. Now they do a lot to make it easier for him. They have even undertaken some modifications to improve access for people with disabilities.*

There was strong support for the Access to Government policy, a more proactive role for the ACT government in providing employment opportunities for people with disabilities, and establishment of the Disability Services Commissioner. A whole of government approach is also seen as essential because of the impact of government policies in areas such as health, housing and education on people with disabilities.

#### 7.1.1 Suggested new strategic areas

- Support the educational system to promote understanding and positive attitudes among students and teachers from preschool through to college
  - Some younger participants told us that it is now unacceptable in schools to make a racist comment, but that it is still generally acceptable to call someone a 'retard'.
- Work to influence Commonwealth policy to be more person centred as, particularly through the Commonwealth State and Territories Disability Agreement, the Commonwealth has a big influence on what can be done in the ACT.
- It was also suggested that there should be an increased interface between Commonwealth, NSW and ACT Government responsibilities – particularly with respect to options and policies related to employment, accommodation and day activities.<sup>13</sup>
- Positively promote and support employment of people with disabilities in the government and non-government sectors, including as service providers, and in the private sector.

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<sup>12</sup> This is a summary of feedback on *Future Directions*. A 27 page report detailing feedback was also provided to Disability ACT to assist in redrafting the plan.

<sup>13</sup> Submission from a community organisation

- Work with Volunteering ACT to develop strategies to support people with disabilities to access mainstream volunteer participation in the community and to remove barriers to volunteering.
- More emphasis on community partnerships eg foster families to share care with the family of a disabled child.<sup>14</sup>

### **7.1.2 Suggestions for the action planning phase**

- A media campaign could be undertaken perhaps engaging the creativity of media students working in cooperation with people with disabilities (as in the recent anti-smoking advertisement).

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<sup>14</sup> Submission from an individual participant

## **8 Comments on Strategic Direction 2**

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### **8.1 Improve community and government responses to people with disabilities, their families and carers**

#### **8.1.1 Overall comments**

##### **Access or response?**

People pointed out here that although the strategic direction appeared to be about responding, many of the strategies related to access, information and referral. They saw this as having significant implications as indicated by this comment.

*Increase the capacity of the sector to respond through a better resourced sector – OK; more pamphlets and training – No.*

##### **Acknowledging good practice**

It was also seen as important to develop new community education and support models, but in doing so people felt that attention should also be given to what is working well, so that learning can be shared and acknowledged. The point was also made that a similar outcome could be achieved by improving and expanding existing models that are working well, rather than always developing new ones.

### **8.2 Comment on specific strategies**

#### **Information and referral**

There is strong support for improved access to information and referral services, noting that these services need to be flexible and individualized. It was also noted that people often seek help when they are at their lowest point and at that time their personal resilience and resources may not be up to taking up complex information or difficult tasks. It is also not just giving the information, it is helping people to use it (as in the Local Area Coordination model).

The emphasis on early intervention was strongly supported, and it was noted that early intervention does not only refer to childhood intervention but can apply at any stage of life when the disability is acquired. There was also support for a focus on crisis avoidance, coupled with some scepticism about how the inevitable crises of living with a person with a disability could be avoided.

#### **Community networks and natural supports**

People felt that these networks were critical for people with disabilities, whether onset was from birth or later in life. Everyone involved with disability, including doctors, should understand the importance of helping people to stay connected to the community. However, it was also noted that alternate supports may need to be developed when natural supports are unavailable or depleted.

The comment was made at the service agencies meeting that there is unused potential in community networks, which could be developed more, but that this should not be seen as a way of substituting for a paid workforce. It was suggested that Disability ACT should work with Volunteering ACT to ascertain what sort of support volunteers and volunteer organisations are needing. Volunteering ACT has also raised elsewhere the issue of working to remove barriers to people with disabilities accessing roles as volunteers in mainstream organisations if they choose to do this.

The comment was made that because few adults with disabilities attended the consultations the issues of isolation, loneliness, loss of hope, and loss of confidence were not given sufficient emphasis. The development and maintenance of natural supports – including through meaningful work which is a major mainstream source of social networks and self esteem - can be one way of helping people with disabilities stay connected to the communities to which they belong.

### **Link with the *Caring for Carers*' policy**

While one submission argued that as carers had their own policy, reference to carers in a strategic plan about disability diluted the rights of each group, this was not a general view. Almost everyone else saw the link with the carers' policy as needing even more emphasis.

*I think it is very important to link this strategy with the new Caring for Carers strategy, I didn't get a strong sense of this from either... In many cases it is difficult to separate the needs of the individual and their carer...*<sup>15</sup>

People would like to see implementation work on the Carers' Policy cross-referenced with the action plans flowing from *Future Directions*. However, few people felt they had real choice about caring (as indicated in the Carers' policy) because they see so few alternatives to the care they provide to their family member.

### **Research**

This was seen as a high priority by some participants in the consultation and the community sector would like to be involved in research undertaken. A stronger evidence base may give initiatives a greater chance of success. Some people found it difficult to comment until they knew what areas of research were being considered.

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<sup>15</sup> Ibid.

## **9 Comments on Strategic Direction 3**

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### **9.1 Improve planning and funding to better meet the needs of people requiring ongoing support**

As reported earlier, there was concern about implementing the plan within budget. In this context it was felt that this strategy might be better expressed as ‘Improve planning and use of available funding ...’. Taking account of previous comments about discomfort with the age categories, the following strategies had strong support across all stages of life.

The earlier general comments on greater emphasis on accommodation and employment are also relevant across this whole strategic direction.

### **9.2 Strategies relevant to all stages of life**

#### **Improved access to information and peer support arrangements at disability onset**

People would like to see access to information ‘promoted and advertised’. Others noted that ‘onset’ is often not a one-off event in time. It could take place over quite a lengthy period, and people’s capacity to hear and take in information changed over time.

*Sometimes we need some space and too much information can be as bad as too little.*

Simply having access to information is not enough, people may need a guide to help them find the appropriate pathway through the system.

It was suggested ‘fostering peer support arrangements’ was a completely different strategy and should be separated. People would also like to see some models of peer support developed and tested. At the same time, already high demands on families were acknowledged and a more formal peer support model would need to take account of this.

#### **Flexible family support models which identify the most effective and least intrusive service delivery models that promote self determination for families**

This was supported. It was also stated that parents often don’t have enough information to know the right questions to ask about different models of support and that this should be addressed as part of the action planning associated with this strategy. They also wanted access to respite to be included here.

#### **Pilot and evaluate sibling support and self help models**

To the consultant’s knowledge only three siblings of people with disabilities attended the whole consultation and only one of these was a young person still living at home. Another person suggested that the sibling support model should be expanded to include support and self help for the children and spouses of people with disabilities.

#### **More inclusivity from mainstream providers of recreational activities and sporting organisations**

Parents indicated that this was not just a matter of social inclusion, but of physical health. They felt that young people (and other age categories) need exercise to maintain health and fitness. As for any other member of the community, their level of fitness affects their general wellbeing. This was often difficult and expensive to arrange. Parents felt that for some young people specialist services were still required.

Sometimes attitudes were right in mainstream organisations but access was restrictive. One family had to change their young family member on their car bonnet as a large change table was not available at a sports facility. The group also felt that there was a need to build relationships with these organisations first before influencing strategies would be effective.

**Forge relationships with peak bodies to raise awareness of the issues experienced by people with disabilities in that age group**

This was suggested for young people and ageing people, but is relevant to peak bodies associated with all age groups.

**Whole of government and community initiatives that promote awareness and the needs of people with disabilities at all stages of life**

This was accepted but regarded as a motherhood statement, which fitted more appropriately under Strategic Direction 1.

### **9.3 Strategies for families with young children up to 14 years**

#### **Work with Therapy ACT to improve mechanisms for referral to supports and services that address a child's development**

People recognise the importance of early intervention. They want greater responsiveness from Therapy ACT and there is concern that the resources are not available there to provide the required level of service.

*A focus needs to be directed at appropriate referrals to appropriately qualified professionals. If unavailable within Therapy ACT, then a rigorous recruiting and retraining strategy needs to be developed, implemented and promoted in the sector so referrals are timely and support is ongoing, not just a pre-set amount of time.*

Even though a world wide shortage of therapists was acknowledged, the perception that Therapy ACT has difficulty attracting and retaining staff generates frustration.

*I thought a child had a right to appropriate treatment, therapy and early intervention.*

*Where is the strategy which aims to prevent a worsening of the disability because the treatment wasn't there at the right time?*

Several parents talked about buying therapy from the private sector for their children, but being unable to continue because of the cost.

Parents acknowledged that collaboration between Disability ACT and Therapy ACT works quite well, but there is a need for monitoring this to ensure that the service is responsive and that families do not fall between the two services. They also believe there should be a crisis response capacity in Therapy ACT.

#### **Closer relationships with education services to support families to plan for their future and develop sustainable pathways for realising their goals and aspirations and**

#### **Appropriate resources to assist families to identify their needs and to plan for the immediate, short term and medium term needs of their child**

The consultations indicated that developing sustainable pathways needs to begin in early childhood if children with disabilities are to be prepared for life after school. People believed that preparation for post school – either employment or other adult style activities - needed to commence when the children were quite young. Innovative approaches should be tried: –

*Why are we struggling to teach our kids to write when it would be more productive to teach them to use a computer?*

Participants also felt Disability ACT could have a role in influencing educational systems and resources to be more flexible and person centred. A three way partnership between Disability ACT, Therapy ACT and the education system is needed – and any other organisations involved, eg Deafness Resources Centre and Canberra Blind Society. Another person said appraisal of children with disabilities needed to be more student centred with teachers actually reporting on their learning. (These are matters which could be taken up later in the context of a close relationship partnership between Disability ACT and Education and Training).

### **Pilot a specialised support programme for children with autism.**

This would be an action rather than a strategy in the redrafted plan. They would like to see an outcome attached to this strategy – eg ‘to improve their integration and autonomy’. It was suggested that autism needs clinical intervention as well as support. (This would require a partnership approach with Therapy ACT.)

Generally there was wariness of the term ‘pilot’ wherever it was used as they felt pilot programmes would be tried for a while and then let lapse.

#### **9.3.1 Suggested new strategic area**

Develop and introduce a model for person centred service in the disability area when multiple services are involved.

## 9.4 Strategies for young people from the ages of 15-24

### **Future planning identifies ongoing education / employment / vocational / recreational and relationship aspirations of young people with disabilities**

This was supported with the important proviso that accommodation aspirations and needs, which parents saw as a very high priority, were included in the planning.

### **Close relationships with education employment services increase opportunities for young people with disabilities to access higher education and vocational training**

Preparation for post school life – either employment or meaningful activity – was an area of strong interest and concern for parents. Again it is not just a matter of working with specific services but of looking at the whole circumstances of the person.

Parents were disappointed that this strategy did not talk about the outcome of higher education and training – which they hoped would be employment. They also felt that the issue of transport, which was often a significant barrier to participation in educational or employment opportunities, needed to be included.

### **Collaboration between Disability ACT, Therapy ACT and the Child and Adolescent Mental Health Services, to support young people with disabilities whose behaviours may socially isolate them and place them at risk**

The need for mental health crisis teams to have expertise in the field of disability was very strongly supported. Stories were told of families in extreme crisis being passed from one agency to another without any specific help being provided under the current system. It was also suggested that ‘and to support their carers’ should be added to this strategy.

### **Alternative independent living arrangements for young adults with a disability**

This was seen as the issue of highest concern to parents in this age group and to parents of adult offspring with disabilities. Parents who once expected that their children would live in a Disability ACT provided group home need to see some of the alternatives proposed happening in action. Evaluation and feedback are important here as there is uncertainty about whether more flexible models can deliver the sense of security that parents are seeking, particularly with long waiting lists at Housing ACT. Many parents want to see some bricks and mortar options.

### **Strengthened post-school options program offering a more diverse range of support options for school-leavers**

A submission advocated that the age range for this group should be extended to a minimum of 29 or 30 and indicated that the actual transitions undertaken by young people with a disability are much more complex than ‘model transitions’. It described two key stages in the transition to adulthood for young people who have a disability:

- from school to post school options such as further education, employment, community living skills and/or community participation; and
- from post school options to the ‘rest of their life’, including living more independently from their family in the community and making choices regarding important ongoing relationships.

The submission continued:

*Whilst the post school options programs may offer excellent opportunities for experimentation and flexibility, an apparent lack of ongoing support means that*

*there is considerable pressure to be allowed to receive post school support options for an indefinite period of time. A focus on supporting young people who have a disability to move from post school options to the 'rest of their lives' is likely to result in both the young person and their family experiencing an enhanced quality of life.*

*...Failure to address [these] issues [proactively] ...is likely to result in a continued reduction of the quality of life experienced by people who have a disability and their family and friends, a continued incidence of families under stress who are having to simultaneously address issues associated with a dependent adult who has a disability and his/her ageing parents, and a continued demand for crisis driven support options that are more likely to be high cost, low quality, segregated options.<sup>16</sup>*

Another submission agreed:

*The [post school options] program operates on a three year cycle, but the end of that period does not coincide with the end of services or responsibility. In most cases the 'problem' will not go away after the three years is completed.<sup>17</sup>*

The latter submission also included a number of detailed comments on how the program should operate which will help to inform the action planning phase related to this area.

**Expanded recreational and day activities for young people unlikely to find employment, with a focus on vocational and life skill development including the development of social and intimate relationships.**

This is very strongly supported, particularly by parents whose children may have limited employment possibilities. One family explained that they had managed to care for their son who had high and complex needs when he was at school for six or so hours a day five days a week. Now that their child had left school, he went to an activity for one day a week. As they were getting older themselves, the burden of their child's care was increasing not decreasing, and they wondered how long they could keep going.

There is a perception that not enough emphasis has been placed to date on development of life skills and independent living skills and that this needs to start early.

**9.4.1 Suggested new strategic areas.**

- Expand the range of supported accommodation options.
- Increase public sector employment of young people with disabilities
- Investigate alternate and cheaper transport options for young people, including at night.

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<sup>16</sup> Submission from a community organisation

<sup>17</sup> Submission form a community organisation

## **9.5 Strategies for older adults from 55 onwards**

### **A broad framework for planning individual services and coordinating aged care and disability service programs**

The framework should recognise that people with disabilities often experience early onset of ageing. It should include retirement planning for people with disabilities who may need to stop work earlier than the norm and assist them to engage in other activities which are suitable for them and appropriate for their age, physical capacity and personal preferences. It was also suggested that coordinating or even combining funding arrangements between the aged care and disability area could be useful in this area.

### **Appropriate needs assessment standards for people with a longstanding disability who are ageing**

This was agreed and it was noted that training will be needed for people to cope with the range of disabilities.

### **Review accommodation and housing for people with a disability who are ageing.**

This was seen as an important priority. It was suggested that there should always be a role for a government provider in this area, but that as far as possible people with disabilities should not have to move just because they are ageing. People at the consultation would have liked the strategy to be amended to go beyond 'review' to 'provide access to...'

#### **9.5.1 Suggested new areas**

- Given that ageing and disability come together here, investigate the possibilities of thinking more laterally about funding arrangements between the two funding bodies.
- Develop a close partnership with the area in Health which deals with ageing (just as for young people there is the aim of linking closely with Education).

## **9.6 Strategies for Mature Carers aged over 65**

### **9.6.1 Initiatives with strong support**

**Planning arrangements for carers and people receiving their care to prepare for a sudden or anticipated change in circumstance**

**An emergency short term response service for carers who care for people with episodic conditions or who are experiencing crisis**

People at the consultation indicated that they would like to see a care plan in place which could be activated in a sudden change of circumstance (such as their own hospitalisation) or a crisis. They also supported the need for longer term planning for the time when they were no longer able to care for their family member.

*Our biggest concern is what will happen to our family member with a disability when we are no longer around to care for them.*

They felt this process might also include assistance to help them let go, which can be extremely difficult after many decades of providing care.

**Increased options for mature carers by providing support to people with disability who are ageing**

As one person put it simply:

*Provide accommodation and support for the offspring of mature carers so they can die peacefully.*

**Understanding and addressing barriers affecting uptake of carer support services**

This was seen as very important by the people who attended the consultation not only for themselves but for a number of mature carers that they know and who do not attend meetings.

*At consultation meetings you see the tip of the iceberg. Some mature carers are in their eighties or older. They cannot get out to a meeting easily and they may have difficulty in expressing their views – particularly when the documents are written in bureaucratic language laced with ideological jargon.*

*We need to address the barriers put up by parents who were told right at the start that their child should or would eventually go into an institution. This is what they expected and they are now very protective and may not be aware of the other options that are possible. Older carers fear being let down.*

Discussion indicated that this was also a generation of carers who saw themselves as having had to fight for everything they had achieved for their family member with a disability and that this in itself may constitute a barrier to using services.

It was felt that strengthening the links with Carers ACT and other agencies conducting Mature Carers Programs would be beneficial – both to gain a better understanding of the concerns of this age group and to enable more co-ordinated support to be provided.

### **9.6.2 Areas requiring more attention**

There should be more emphasis on long term accommodation options and respite.

## **9.7 Aboriginal and Torres Strait Islander people**

This is an area of particular focus because it is known that the incidence of disability is high in this community and engagement with support is low. Some of the cultural complexities around this were briefly outlined in Section 5.3 and issues related to the consultation process itself are discussed in Section 3.3 of Part 2 of this report.

### **9.7.1 Beginning to talk at Boomanulla**

There are no specific comments about the strategies suggested in *Future Directions* because the limited consultation undertaken indicated that it was not yet time to consider specific strategies. The consultations took some tentative first steps along the path to planning culturally appropriate approaches. As with many conversations about disability, this one ranged from issues of immense philosophical complexity to matters of concrete and practical need. An Aboriginal Elder gave her view of the three highest needs:

- a strong support centre
- an outreach service (quick, and as required with good follow up)
- appropriately trained departmental workers.

There was also discussion on the value of advocacy workers in this field.

It seemed to those present that many more conversations of this sort will be required and that, if Disability ACT is to be equipped to participate in the conversations with full understanding, cultural awareness training will be needed.

### **9.7.2 Suggested enabling actions**

It may well be that enabling actions are needed for this focus area before any of the suggested strategies can be attempted. These could include:

- Provide cultural awareness training for key members of Disability ACT to enable them to gain an understanding of disability from an Indigenous perspective.
- Engage a person with an understanding of disability and with credibility in ACT Indigenous communities to work with the communities and Disability ACT to plan some practical next steps and develop longer term strategies to address the needs of people with disabilities in the ACT Indigenous community.

## 9.8 Strategies for people with high and complex needs

This was strongly supported as an area requiring specific focus, particularly where challenging behaviours are involved. The point was also made that this area covers a very wide range of ages and stages of life, as indicated by the definition in *Future Directions* -

The needs of people within this category are diverse - they may require intensive 24 hour support from several people at any one time, they may exhibit complex behaviours which place them at risk of harming themselves or others. People with the highest support needs commonly require cross agency responses, high levels of resources and/or carers with specialist skills. (p22)

While this definition was in the plan, most people missed it. In the redrafted version it needs to be more prominent. Many people took the mention of 'people under 50 years of age in nursing homes', mentioned in the first strategy, as the definition.

### 9.8.1 Comments on specific strategies

#### **A single crisis response team or other arrangements to respond to people in crisis**

This was strongly supported particularly by those families who are caring for a person with challenging behaviours:

*They changed his medication and he was out of control. We called the mental health team, the police, the hospital, but no one could do anything. In the end we took turns at physically restraining him. It was exhausting and terrifying and we felt as if we were on our own.*

There was some concern expressed that if there was only a single response team that some families could be blacklisted, but generally it was felt that having a crisis response team was a good first step.

#### **A single needs assessment and planning process, and community-based care co-ordination service for those people with multiple needs**

One group who discussed this saw 'single' as representing a standard tool (as in some educational assessments) which would not take account of individual needs and circumstances. This may need to be re-written to avoid confusion.

#### **Options for individualised and locally-based care support and treatment programs for people with dual disabilities and complex and challenging behaviours**

The needs here are certainly high and urgent, the demands on families are very great, and the crises, when they occur, are severe.

*I am sick of being in the too hard basket.*

As a general comment on this strategy it was suggested that families should be included in this exploratory phase.

#### **Attraction of appropriately qualified and skilled staff**

Continuity, right attitude (including punctuality, reliability and trustworthiness) and practical skills were seen to be as important as formal qualifications. However there were also stories of pleasant staff not having basic skills eg in lifting which meant that the care was not satisfactory. Fear was expressed that some people might leave the industry if stringent qualification requirements were enforced and that better pay and conditions might not lead to better care.

## 9.8.2 Areas of concern

### The extent and nature of the need

It was suggested that research was needed into the numbers, characteristics and needs of people with high and complex needs in the ACT - including unmet need.

### Role of government

‘Strengthening the role of the government service provider, Individual Support Services in Disability ACT, in the planning, development and delivery of services and responses to the needs of people with high and complex support needs’ was seen as very non-specific and quite meaningless. People asked whether this refers to ‘the provider of last resort role’ referred to in Gallop, and whether it included real bricks and mortar responses to supported accommodation and respite needs. More access to respite was also seen as very important.

*We are so mentally tired as well as physically, that we just can't think beyond the day to day. We need a break to give us the energy to be able to think and plan for the future. We have heard about something called shared care in Queensland where the person lives away for the week and comes home for the weekend. As we are getting older, this is something we could manage.*

### Single person care?

One person suggested allowing the choice of single person care (as in NSW) as an option which would lead to increased quality of life for them:

*As a person with a disability I am concerned about the restrictions placed on service provider organisations that do not allow for a single carer to undertake the provision of ALL services (eg personal and non-personal) for the individual. This type of restriction is a major impediment to providing additional services from existing funding levels and one that causes extra administration demands that are also a waste of funds that could be better used to provide direct services. This restriction also means that individuals must have multiple persons entering their private lives to provide their care.*

*... the Future Directions being proposed lean heavily towards maintaining the same methodology used to develop disability services ...[which] evolved through demand and allocated funds provided direct to service provider organisations. Hence we have many services being provided ...based on an assumption by the service provider on their perceived understanding of the user's needs. A change to a single person approach to provide all care needs would certainly save staff, training and administration costs.*

## 9.8.3 Suggested new approaches

- Pilot a single carer approach for people with high and complex needs (modelled on the approach taken by NSW Paraplegic and Quadriplegic Association).<sup>18</sup>

The consultations also indicated that more options are needed for:

- Supporting children and spouses of people with high and complex needs.
- Increased access to respite for carers of people with high and complex needs.
- Longer term supported accommodation needs of people with high and complex needs who are unable to live at home or who choose not to do so.

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<sup>18</sup> This is discussed in detail in the submission from an individual participant, dated 5 June 2004

## 10 General comments on Strategic Direction 4

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### 10.1 Develop a responsive and sustainable service delivery sector

There was support over all the consultations for the importance of this strategy. However, as it is of direct relevance to service agencies, it was in this meeting that most debate about the detail and nuances of Strategy 4 was generated.

#### 10.1.1 Need for a partnership approach

The most fundamental critique from the service agencies was that it did not sufficiently reflect the spirit of *The Social Compact* which sets out the relationship between the government and non-government sectors. Some people felt the document read as if things were being done ‘to’ rather than ‘with’ the sector.

*It feels like a watching, monitoring policy rather than supportive.*

*The wording is inconsistent with partnership. It discusses what Disability ACT will do to NGOs eg assess, review, implement etc. In the same way it lacks recognition of the role that all elements of the community had in the achievements so far.*

*The flavour of the document does not reflect the history, expertise, influence, knowledge, etc of people with disabilities and organisations and the crucial role they have played in getting us to where we are now.*

They also saw the Social Compact as crucial for guiding the relationship with the sector – as *Future Directions* will only succeed if there is a united effort. This suggested rewording of Strategic Direction 4 which reflects a stronger sense of partnership illustrates the point that many organisations were implying.

*Work with the community sector to assist with the development of quality, responsive individual options for people with disabilities and their families.<sup>19</sup>*

### 10.2 A sustainable and responsive sector - service agency perspectives

As an introduction to this part of the consultation, service agencies were asked to brainstorm what a sustainable and responsive sector would look like. Later analysis showed that a sustainable and responsive sector would have impacts for the sector as a whole, for clients and for staff.

#### 10.2.1 For the sector as a whole

##### Planning and responsiveness

- Able to plan proactively with available information and not reactively.
- It does what the community wants.
- One that meets what people want and need (responsive).
- A sector that can meet needs as they arise.
- Responsive to client needs.

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<sup>19</sup> Submission from a community organisation

- One that can identify gaps in service types needed by individuals, and cause them to be filled.
- Individual services can expand and contract in response to demand.

#### **Adequate funding**

- Adequately funded/resourced by government and community.
- Funding that is available, responsive and reflects need.
- Adequate funding.
- Good sustainable programs. Funding reflects costs of service delivery.
- Facilities that grow with the service.

#### **Sector relationships**

- Communication throughout service system (reliable).
- Genuine partnerships.
- Transparency.

### **10.2.2 For clients**

#### **Programs that empower**

- Funded programs that focus on developing community networks and individual networks in the community (relationships and connections).
- Programs focussed on building self esteem.
- [Working towards] An integrated society.
- Programs focussed on self determination.
- Flexible – different models choice.
- Inclusive (consumer participation - including Boards of Management).
- Reflects community that it serves (inclusive employment).

#### **Quality services**

- Good quality framework – training, education, systems.
- All services meet understood and practical service standards.
- Clients receiving high quality care and support.
- There is a co-ordinated system of access by individuals to each of the services they need.
- Less layers in the service system.

### **10.2.3 For staff**

#### **Work environment**

- Staffing is stable (compared to the community generally).
- A good place to work.

#### **Work conditions**

- Decent career path – long term careers.
- Portable entitlements (Long Service Leave etc).
- Parity with ACT Government in IT, training, wages, conditions.
- Adequate remuneration.

#### **Recognition**

- Respected for expertise and skills.

- Recognising and utilizing skills – valuing.
- Volunteers valued and not there to replace paid staff.

### **10.3 Insufficient emphasis on strategic responsiveness**

As can be seen above, when people at the meeting were asked to describe a sustainable and responsive sector, they gave a good deal of attention to assessing needs, planning, and flexible person centred responses. This balance seemed less evident in Strategic Direction 4.

*I think the outcomes [in Future Directions] do relate to a sustainable sector, but I am not so sure that there is enough in there on responsiveness.*

*Where is the emphasis on creative and innovative responses to people's needs?*

*This is more about audit than strategy.*

*There is nothing in there about innovation and encouraging different ways of providing support.*

### **10.4 Need to define the disability sector**

The sector appears to be defined as specialist disability services in the government and non-government sectors but it may need to be made more explicit.

*In talking about a service system, we need to include NGOs not funded by Disability ACT and Disability ACT itself.*

*I would like to see groups such as the ACT Leadership Development Group acknowledged as an important part of the sector.*

It was also suggested that workforce sustainability issues for volunteers – who could be people with disabilities or people who support people with disabilities - should also be included in this strategy.

### **10.5 Comment on structure of Strategic Direction 4**

The structure of this strategic direction differs from the others. There are only three main strategies mentioned, those related to a Quality Improvement Framework, a Workforce Development Strategy and New Service and Funding models.

However in the discussion part of the paper many more strategies and actions are included. It is unclear whether these are strategies are a formal part of the plan.

These extra strategies appear to reflect the product over the last eighteen months of the Quality Working Group, the Workforce Reform Working, the Access, Equity and Funding Working Group and the Accommodation Working Group. For some people at the consultations, this had the feel of a fait accompli to which they had had little input – and there was insufficient time at the meeting to give this range of matters their due attention. The status of the strategies mentioned in the discussion part of the paper needs to be clarified. More consultation and engagement is needed with the sector to ensure that actions agreed in the action planning phase have ownership from the people involved.

## **11 Specific comments on Strategic Direction 4**

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### **11.1 A Quality Improvement Framework**

While there is support for quality service, the comment was also made that many services are already responding to multiple quality frameworks (eg HACCC, Mental Health, the generic standards - *Raising the Standard*). There was some questioning about whether setting up another set of standards was a high priority. The specific inclusion of ‘incentive based performance agreements’ caused some confusion as people were not sure what it meant. Depending on how the incentives were defined, they were concerned about the potential conflict between a focus on incentives and a focus on quality.

### **11.2 A Workforce Development Strategy to attract, train and retain staff**

There is general support for these approaches from all groups consulted.

*A first level public servant gets paid more than a support worker, yet we ask so much of them*

One person with a disability said:

*Our support workers become like family. Making too many changes or having casuals come in is just horrible.*

The sector also supports the general approach set out in this strategy, but they recognise the hard part is the how. There is also interest in the outcomes of the recent review of staffing arrangements in the sector, which is seen as useful baseline work which can underpin future strategies with hard data.

Another person suggested that it was necessary to be more up front about the stress factors that go with work in this field. This would mean that ways of dealing with the stress, such as debriefing and other forms of worker support, could be more overtly factored in to work practices.

### **11.3 New Service and Funding Models to expand the range of services and improve accountability and transparency in Government decision making.**

This is an important and sensitive area which requires more thinking, more consultation and perhaps some hard decisions. The earlier discussion on funding issues (Section 4.4) applies here.

#### **11.3.1 Supporting a sustainable sector**

This area generated the most discussion at the service sector meeting, as people were unsure about the nature of Disability ACT’s role with respect to this. For example the rationale and purpose of assessing the current future accommodation needs of non-government providers in relation to occupational health and safety requirements and accessibility was unclear.

#### **Review of governance**

The review the governance arrangements of non government disability service providers also generated concern from several agencies.

*An autonomous and independent community sector is important to a civil society. Surely this form of oversight is the Registrar General's responsibility?*

*Under what charter does the Department have authority to review governance arrangements?*

But not all had this point of view:

*Our organisation feels strategy 4 is not intrusive and the outcome can only ensure best practice is achieved. Isn't that why we are here?*

### **Contribution of volunteers to service delivery.**

Volunteering ACT suggested that Disability ACT should work with it to

- survey organisations and volunteers to identify need for volunteers and identify the shortfall in demand
- ensure that organisations involving volunteers in the support or provision of services to people with disabilities have sufficient funding to recruit, train and properly manage volunteer staff and that
- all volunteers and managers of volunteers have appropriate training ie Volunteer management Training and Active Volunteering Certificate 1.

While recognising the important contribution of volunteers, other comments emphasised that volunteers should not replace paid staff.

## **11.4 Conclusion**

In summary, there is support for the strategic direction, but the need for greater engagement with the sector to refine the strategies, clarify detail, and develop the action planning phase.

## 12 Suggested next steps

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1. Develop overall design and interrelationships of planning documentation to include
  - the structure of *Future Directions* which could focus on the strategic directions, outcomes and strategies only
  - the action planning process and format
    - this is likely to include some of the content in the discussion part of the current draft of *Future Directions*
  - the monitoring and reporting framework for the community
    - this may include performance indicators and some of the content included as achievements to date in the current draft of *Future Directions*.
  
2. Redraft *Future Directions* taking account of community concerns and feedback particularly in relation to
  - inclusion of adults in the stages of life
  - flexibility of age categories and focus on transitions
  - stronger focus on supported accommodation and employment
  - need for outreach strategies with the Aboriginal and Torres Strait Islander community and for culturally and linguistically diverse groups
  - maintaining a strong focus on high and complex needs, recognising the diversity of need
  - an approach to data collection and management and needs analysis; and
  - increased emphasis on partnership, particularly in Strategic Direction 4.
  
3. Report back to the community on outcomes of the consultation and advise on arrangements for the action-planning phase of the consultation as soon as possible.
  
4. Review the consultation process and consider trialling some new options for connecting with a wider spectrum of the disability community, including the Aboriginal and Torres Strait Islander community.