

Having Our Voices Heard

A discussion paper based on the Disability Reform Group Community Consultation

RPR Consulting

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Table of Contents

1	Introduction	3
2	Acknowledging the diversity of people with disabilities	8
3	Common principles and values	9
4	Future directions	15
4.1	Service approaches and models	15
4.2	Broader systemic change	19
4.3	Use of resources	23
5	Issues around consultation.....	25
	Attachment 1: Disability Reform Group: DRAFT Vision & Values Statement	28

1 Introduction

Background

The Disability Reform Group (DRG) was set up by John Stanhope, Minister for Health, in response to the Board of Inquiry into Disability Services Report (Gallop Report). Its task is to work with Disability ACT (formerly the Office of Disability) to provide advice to government on the findings and recommendations of the report.

The Gallop report strongly endorsed a person-centred approach to planning and delivery of services and included findings and recommendations about:

- amendments to disability legislation
- government structures and arrangements
- individualised service approaches and models that promote integration in the community
- engaging people with disabilities and their families in decision making about the services
- government structures for policy, purchasing and delivery of services
- good practice guidelines pertaining to the disability standards
- external evaluation or auditing processes to assess quality
- contracting between government and non-government service providers
- strengthening complaints and appeals procedures
- allocation of resources, including resources to non-government providers.

The DRG has met regularly and often in its first months of operation and has given priority to advising government on new structural arrangements for disability services, developing a draft vision and values statement, and considering complaints and monitoring mechanisms for disability services in the ACT.

About this consultation

The DRG is committed to providing advice to government which reflects the aspirations and concerns of people with disabilities, their families, guardians and unpaid carers. It is also committed to tapping in to the experience and ideas of people working in government and non-government services, advocacy organisations and peak bodies in the disability field. As part of this commitment, the DRG has engaged RPR Consulting to consult with the community on its behalf. The consultation project has been divided into two stages.

Stage 1

The first stage aimed to elicit views in two broad areas:

- a future vision and strategy for improving participation, services and support of people with disabilities and their families.
- how people organisations and existing community networks can play a role in ongoing consultation, planning and advice to government.

To cover these issues different stakeholder groups were asked three questions:

- How would they like things to be for people with disabilities and their families?

- What would need to change or improve in order to achieve what people with disabilities and their families want and need?
- How can people with disabilities, families and organisations be involved in the ongoing process?

These questions were explored through the following processes:

- sixteen interviews with key informants in the disability sector
- two public forums for people with disabilities
- five focus groups with people with disabilities
- three public forums for parents, carers and guardians¹
- interviews with service providers to Indigenous families with a disability²
- a forum for non-government organisations involved in the disability sector
- meetings with government services
- a small number of written submissions provided directly to the consultants and some telephone conversations with the consultants.

Stage 2

The second stage of the project will comprise three workshops. Participants will be drawn from across the sector, including people with disabilities, parents, guardians and unpaid carers and government and non-government organisations. Material provided through the first stage as outlined in this paper and a draft vision and values statement developed by the DRG will provide a framework for the tasks of the workshops.

The workshops will be solution focussed and future oriented with participants being asked to identify the priority changes needed to better meet the needs of people with disabilities and their families in the ACT. They will then explore the implications of translating the vision in three broad areas:

- service approaches and models
- the broader service system
- resource allocation.

The workshops will also focus on consultation mechanisms and issues, including barriers and enablers, which could be associated with implementation of change.

The outcomes of the workshop will be included in RPR Consulting's final report to the DRG. This report will help to inform the advice that the DRG gives to government regarding reform of disability policy, services and support in the ACT.

About this discussion paper

The first stage of the consultation was structured to hear from different parts of the sector in separate groups. The process involved many hours of conversation with approximately 200 people. This paper is a scan of major themes and key ideas expressed in this part of the DRG consultations. It is not possible to do full justice to the many individuals who

¹ Originally, it had been suggested that a focus group should be held for people from culturally and linguistically diverse backgrounds. Unfortunately, within the timeframe of the project, it was not possible to locate families able to be involved in a specially convened group. However, a significant number of people from culturally diverse backgrounds did attend the public forums and focus groups. Hearing from the 'hidden' group of families from culturally and linguistically diverse backgrounds who also have a family member with a disability and who may not be currently accessing services is a more complex issue, which is beyond the scope of the current consultation project.

² While initial discussions have been held, this meeting is planned to occur shortly.

spoke eloquently on so many different issues. The paper aims to provide a flavour of the range of views expressed at these meetings, but cannot detail every single issue raised. It draws on areas of consensus, good thinking and as wide a range of views as possible. Questions raised by the issues discussed are included as an introduction to some of the work which will be required in the Stage 2 workshops.

As an introduction to the more detailed discussion later in this report, the differences in emphasis which emerged across the different groups and the shared nature of the major issues raised across the consultation are presented in summary below.

An overview of views presented by the different groups

Different perspectives on similar issues

In general, people with disabilities placed an emphasis as consumers on issues which frustrated them in their daily lives such as transport, personal care, working with carers, stability of services, consistent quality of care, access to employment etc. However, they also linked these issues closely with bigger picture issues such as the need for an individualised approach to care and support, greater transparency in resource allocation and the need for more sensitivity and awareness from the community.

Parents, guardians and unpaid carers raised similar issues and also emphasised the need for early intervention, individualisation of care, stability of care and whole of life planning. Some recognised that these were also system issues and wanted less fragmentation of services, better long term planning at an overall sector level, and commitments to resource allocation over the longer term. Members of this group also saw the importance of building a continuous improvement evaluation system around this reform process and the longer term management of the sector. As well, they recognised that the role and expertise of paid carers is critical to reform and were supportive of better training and career opportunities for them.

Non-government organisations supported similar themes to those outlined above, but also talked from their own perspective about creating dialogue and collaborative approaches across the sector, including with government. Many talked about wanting to encourage the development of a way of working which enabled the person with disability and their family to be located at the centre of the service and support system, rather than maintaining a silo approach where the program itself was the centre of the service system. They were interested in innovation, bringing in new knowledge and flexible approaches. They saw themselves as having much to contribute to reform particularly if they worked together more closely.

Both government and non-government service providers raised similar issues to the other groups. As would be expected, they also had a particular interest around staff issues. They saw many opportunities for greater collaboration across the sector and they were particularly interested in strengthening the sector by seeking out opportunities for staff from different parts of the sector to work together by sharing expertise, training and experience.

Being involved and being heard

One point that came through clearly from all groups was that consumers, their families and staff do want to be involved in the issues and decisions that affect them, both on the day to day level and over the longer term. Many times, people complained about ‘not being

heard'. It is important to think about what this consistent message might mean. It does not appear to mean that more consultations are necessarily required. In fact, several people also complained about 'more consultations'.

However, while developing more systematic and regular ways for consumers, their families and the staff who care for them to have their say in organisations, in the sector and at government level would be beneficial, the message behind 'not being heard' seems to relate more to the second stage of good communication - the response. A good response acknowledges that the message has been received and checks to see if the meaning has been understood. When the message has requested action, a good response gives reasons why the requested action either is or is not going to occur. Even where the requested action cannot be implemented and the person may be disappointed, the fact that a response has been made generally enhances communication and trust, while consultations that go into a 'black hole' have the opposite effect. While these may seem minor 'soft' issues, developing the habit of response across the whole disability system is critical for the credibility and success of the reform process.

Key messages from across the consultations

The key messages are developed from areas of general agreement across all the consultations. While they represent a high level consensus, the discussions which follow in the body of the paper reveal also some of the differing dimensions and perspectives underlying them. In summary, the key messages relate to:

- Acknowledging and respecting the diversity and individuality of people with disabilities.
- Identifying common principles and values pertaining to disability including:
 - Community awareness and respect
 - Participation and inclusion of people with disabilities
 - Equity and access
 - Access to information
 - Person centred focus and individualised services
 - Choice and flexibility of service options
 - Safety
 - Security of service and support
 - Recognition of the role and support for families.

At the service delivery level, the consultations identified the need for:

- Adoption of person centred and strengths based service approaches with
 - emphasis on early intervention
 - whole of life planning with particular support at transition points
 - increased stability and security of service.
- Access to a wider range of service approaches and models
- Better training, career paths and remuneration for people working in disability
- Need for sensitivity to disability as a pre-requisite for staff selection
- Piloting new approaches and spreading the learning
 - including learning about those areas of current service delivery that are working well.

At the systemic level, the consultations identified the need for

- Translation of the vision through legislation, strategic planning and clear policy
- Change management processes for the reform
- Reducing fragmentation of services
- Support for innovation
- Stronger collaboration and joint work among service providers
- Structures to support, monitor and evaluate service improvement
- Ongoing consultation and involvement of stakeholders.

In the area of resource allocation³ the consultations supported the need for:

- Strategic planning to ensure resources are targeted effectively in the short and longer term
- Resource allocation that supports choice, flexibility and person-centred approaches
- Long term sustainability of services and support for people with disabilities.

³ Although this issue came up in general discussion, it was not addressed directly in the first stage of consultations with consumers and their parents, guardians and unpaid carers. This area will be more strongly emphasised in the workshop phase of the consultation.

2 Acknowledging the diversity of people with disabilities

Participants in all meetings and focus groups talked about issues related to diversity and the importance of individualised responses to need and respect for different life situations and aspirations. People with disabilities come from all social spheres and family circumstances. The disability itself can cross the physical, intellectual and psychiatric spectrums.

*'Disability is not just something some people are born with. Any one of us could become disabled through illness or accident at any time.'*⁴

The impact of the disability on the person, their family and their way of living differs in every circumstance. This means that the detail of what people need in order to participate as fully as possible in the community and to have a fulfilling life varies enormously.

This diversity needs to be recognised and acknowledged. It has meant that the public forums for people with disabilities often ranged over many issues and were unable to go into great detail in specific areas. Even within one so-called category of disability, such as intellectual disability, many factors may come into play. For example, the comment was made that with respect to people with an intellectual disability the ACT is still dealing with de-institutionalisation. Consequently the focus is on people with high support needs. Those with lower support needs receive very little, and yet this is a group which is over-represented in jails and among homeless populations so that a small amount of support at the right time could have disproportionate personal and social benefits. Another example relates to group houses. A number of families strongly support the current group homes model provided under the Disability Services Program, while others, whose situation may appear ostensibly similar, are looking for quite different options.

Clearly one size does not fit all and one voice does not speak for all. This truism takes on greater resonance in the disability context where two common complaints are that the individuality of people with disabilities is not recognised sufficiently in service provision and in community attitudes, and that the voices of people with disabilities and their families are not heard. At the same time common issues, which can best be addressed across the sector, do exist. This tension between individuality and the power of a common voice underlies many aspects of support and service provision in the sector and is a challenge when developing future ongoing consultation mechanisms.

⁴ The words in italics throughout this document are taken from ideas provided by participants in the consultations.

3 Common principles and values

The consultation has affirmed the need for a common set of values and principles across the disability sector. Development of a broad vision that has strong recognition and ownership was seen to have many advantages. Without restricting diversity of approach and individual preference, it would provide a framework for setting future directions and policy. It could also guide the development of community education, service philosophy and resource allocation. A common framework would also provide a structure for evaluating the outcomes of current practice as well as for assessing initiatives undertaken in the future. Above all, it would enable the sector to articulate its aspirations in a proactive and positive way.

Despite differences associated with different kinds of disabilities, different life circumstances and different approaches, on the basis of these consultations at least, there are common views among people with disabilities, families and people working in the sector (paid and unpaid) about the principles and values which are fundamental to enabling all people with disabilities to live satisfying lives. They are outlined in the following sections and seem generally compatible with those developed in draft by the DRG (See attachment 1). The DRG's draft will be tested more fully during the workshops.

Community awareness and respect

People with disabilities and their families deal not only with the physical, emotional and economic aspects of the disability itself, but they often still struggle with the unnecessary hurt of stigma and exclusion.

'There is so much fear in the community about disability.'

'When people come to our house, they say hello to everyone except my son. It is like he doesn't exist.'

One person talked about not being served in a bank without his support person present, even though he manages his own money. He found this patronising and humiliating.

'I have confidence, but people wear you down when they tell you that you can't do it all the time.'

In the consultations many people thought that changing community attitudes was fundamental to ensuring that they or the person with a disability whom they are close to had a rich and fulfilling life. One person said,

'If we could get this right, everything else would flow from it. We would have the money and resources. Working in the disability sector would be prestigious. Our kids would have access to a normal life.'

The people who raised these matters were not naïve. They recognise that changing community attitudes is a long term and difficult goal, but they know that it can be done. The dream of one mother was to see a disability curriculum developed which would be

introduced in pre-school, and continued through primary and secondary school, with tertiary options available. Before dismissing such an idea as too ambitious, it is salutary to think about how introduction of new curricula in the education system has supported changes in areas such as environmental awareness. Changes in attitudes to smoking and drink driving are other examples of changes in community attitudes and behaviour which have been deliberately fostered.

People working in disability services also saw community awareness and respect as a major issue and emphasised their role in promoting positive perceptions and integration.

‘If there was better understanding and attitudes toward people with disabilities there would be a higher value placed on services and supports that enable people with disabilities and their families to participate in community life.’

While individuals can play their part in raising awareness, and the sector can support initiatives aimed at changing community attitudes to disability, government can have a very powerful role here through legislation, policy and community education and awareness initiatives. This change in attitude is fundamental to the quality of life of people with disabilities and their families. It would also help to address the fear of parents – frequently expressed during the consultation - about what will happen to their child when they (the parents) are no longer around to advocate on their behalf.

‘I want my son to be imbedded in the community. That is the only real security he and I can have.’

Participation and inclusion of people with disabilities

There is consensus that a major goal for the future is to strengthen the participation and inclusion of people with disabilities in community life and to enable them to have choice and influence in decisions that relate to their lives including choices about the services and support they need. Responses in this consultation suggest wide acceptance of this principle but much room to improve the practice. This was true at many levels:

- full participation and involvement in community life
- involvement in decisions about future life opportunities and plans
- involvement in decisions and having influence over the services and supports they use
- input to broader service planning policy that relates to people with disabilities.

Equity and access

The fact that words like equity, access, self-determination are talked about as principles that have to be expressly articulated for people with disabilities is a prime indicator that they do not exist for them as a matter of course in our society at present.

‘Exclusion [of people with disabilities] starts from birth. Being part of the community is a given, it should not be something you have to struggle to attain.’

Equity is fundamental not only to the person with a disability but also to their families. It applies both at two levels - access to the rights of a citizen in the broader community and equal access to the services which are currently available for people with disabilities. A

forum response to a question about how things would be in the ideal situation illustrates the access to citizenship issue:

‘There would be an underlying attitude in the community that people with disabilities are equal citizens with those who don’t have disabilities. Their rights and ability to access services and opportunities would be equal to those of other citizens. If these conditions prevailed it would make the life of aging parents much less anxiety ridden.’

Many stories were told about perceptions of inequity in access to services for people with disabilities. There is a perception that eligibility criteria for services may be unevenly applied and that even complying with them offers no certainty that services can be accessed because of uncertainty around funding. People with disabilities and their families often feel they have to have to fight to get the basic services and supports they need. A common theme was that the loudest are often heard at the expense of others who may be more needy. While understandable, this can create tensions for service providers who are also committed to ensuring equity of access to services, but who must also balance urgency of need with funding limitations.

Sometimes there are barriers to accessing both the general community and the services provided specifically for people with disabilities. While everyone in our society would agree that equity is a fundamental human right for all people, often for people with disabilities access to equal treatment is seen to be dependent on many factors including community attitudes, the appearance and behaviour of the person with a disability, the availability of enabling services and supports, attitude of staff, removal of physical barriers and access to affordable transport.

‘Our daughter cannot use public transport independently and we cannot afford \$35 a day for her to use taxis to go to work, so she has to stay at home.’

The reality is that many people with disabilities will never drive a car. Taxies are costly. Public transport can be difficult to negotiate and lacks the flexibility that people with disabilities often need. This means that many people with disabilities are prevented from participating in community activities and become socially isolated. This can create a vicious circle.

‘I just wish my son could have a friend, but it’s so hard for him to get about.’

Accommodation raises similar issues. Many people wanted recognition that people with disabilities had an equal desire for and an equal right to have a home just like anyone else.

‘The group house is my son’s home. It is not just someone’s workplace.’

In the consultations, the issue of accommodation as ‘home’ were seen largely in terms of group houses. Other options mentioned were hostels, cluster housing, individualised supported accommodation (owned or rented) and retirement villages. Family governed approaches seemed to be of more interest to families whose children had not reached the stage of leaving home. However, if family governance becomes more evident in other areas of service over time, people who do not necessarily want to adopt the model may still

begin to see the variety of options that it opens up. This could mean that consumers and families begin to consider other more mainstream accommodation options for people with disabilities such as individual home purchase.

Access to information

Information is another enabler of access to service. There was a general belief that it is hard to get information on what might be available and who was eligible for what.

'We went through a long invasive and painful assessment for a service only to be told at the end that we weren't eligible. We were devastated and we would never have put ourselves through that if we had known.'

At the consultation meetings, a number of parents and carers picked up new and useful information from other participants whom they had never met before. There is also a perception that even within different parts of the government system service providers may not be aware of what other government providers can offer. Fragmented service contributes to fragmented availability of information. If the service system itself was based on holistic and cooperative approaches and was sufficiently informed to sustain this, client access to the system at any point would also give access to the whole system. However, this is a longer term goal and it would seem that some more tangible action in response to information access is required by families.

People talked about the value of creating a single point of access for information, one-stop shops and the like. Variations of this theme have worked well in other states, where information has been made available, assistance with referral is provided and support is provided to assist people to navigate an appropriate path through the system. The support issue is a most important component of information provision. Some examples illustrate this. Families who have just received a diagnosis of disability can be in a state of shock and grief. At the very time when they need information, they may not be in the best state to find or assimilate the information provided. While it is important to have the information easily available, this may not be enough in these circumstances. Support is needed to help people take the information in and to use it effectively. Even when it is not a crisis situation, accessing useful information available can be difficult.

'If you know what you want then they give you the exact information. The frustrating thing is that for a lot of the time as a parent you never know exactly what you want only that you need more advice – and often less information – to try and work an issue out.'

Another example relates to older parents who may have had a support system in place which has worked well for many years until some change occurs either in family circumstances or in the services available which means that they must renegotiate the supports needed. They too may find the situation upsetting and confusing. A little bit of support at the right time can make all the difference in these situations. From the consultations, it seems that development of an integrated information service with support available would be well received.

Person centred focus and individualised service

Across the consultation the theme of seeing and responding to people with disabilities as individuals was emphasised as a fundamental goal.

'My child is an individual, she is not a diagnosis or a group.'

'People are not a problem to be solved by the service system.'

This goal is easy to articulate, but individualising service under the current system is not easy to do and there were many examples of how current service arrangements work against this. There was a sense that well-intentioned 'programming', particularly where it is group-based, works against a person-centred approach. From the stories shared through the consultation, practice and access to service options appear to lag a long way behind the rhetoric of person-centred service. Not only personal attitudes but organisational policy and government guidelines would need to become more flexible to accommodate even small changes which would make a difference in many lives.

'I realise that some people need advocates but my husband could manage his own support package. It would mean he would feel more in control of his own life. It would give him something useful to do.'

'I appreciate what my carers do for me, but I wish that one day I could just have a shower or go out when I felt like it, not when the service is available.'

For service providers it is not always easy to determine what an individualised approach looks like and the extent to which this approach resides within a given service or defines a package of support that individuals can access. In the consultation many people spoke of the importance of flexibility, choice and self-determination. At the same time they identified a range of practical constraints that made these things almost impossible to deliver such as resources, current service models and staff attitudes.

Choice and flexibility of service options

This consultation has found there is still a strong element of fitting the person to the available services rather than fitting the service to the person. For individualised and person centred services to be the standard, there need to be a wider range of service options available and capacity for more people to choose, arrange and manage their own package of support. This doesn't always mean more resources, although many participants saw more resources as a fundamental issue. It means taking a different approach to involving people in decision making and being able to respond to their ideas and strategies for addressing the issues presenting in their lives.

This shift has major implications for the way in which services are conceptualised, funded and managed. In consultations with services, there were apparent tensions between wanting to provide greater flexibility and choice on the one hand and managing the services on offer within the current eligibility and procedural guidelines and available resources.

Safety

The issue of safety was a recurring theme ranging widely across several areas. For people with physical disabilities it may have been to do with pavement design or negotiating the

barriers imposed by street cafes. For others, it may have been to do with the attitude, skills and accountability of carers in the home or in group houses. Other parents mentioned fear around the behaviours of other people who lived with their family member in a group house. The point here is not to list all of the specific concerns but to recognise that ensuring the safety of the person with a disability is a priority. The challenge is to see that safety measures do not impose unnecessary restrictions on the person with a disability but enable them to participate more fully in community life.

Security of services and support

Concern about the security and stability of services and support was mentioned often. In some cases the concern related to changes within a given service and the impact of these on the person with a disability and their families. In other cases it was concern about life stage transition points and the difficulty of gaining access and negotiating for new and appropriate services at these points. One example relates to how staff in group homes are managed. From the client's point of view constant staff changes are seen as random and illogical and they work against ongoing relationships and the development of a good understanding of client needs.

'I would like to be assured that where a house is working AI, that the staff or 75% of them are not moved in one stroke of a pen.'

Staff in group homes also expressed a high level of frustration and concern about the impact of movement and rostering of staff on clients, a practice that is exacerbated by a growing reliance on casuals and contract staff. One example given was where quality and experienced staff can be moved to model better practice in a different group home. Although on the surface this arrangement has some merit, the move has the effect of destabilising a home that is working well and breaking positive relationships with residents and teamwork among staff. It is often not appreciated by staff who are then expected to improve the quality of a home that is working less well. This scenario does not work positively for clients or staff.

The second concern relates to having greater certainty and predictability of services and support through different life stages. Some people said that they were unable to make longer term plans because they were uncertain what kind of support would be available in the future (from their current service provider or under a different arrangement).

In some forums Individual Service Plans were criticised for their short term orientation. Uncertainty about the future is a major preoccupation for many people with disabilities and their families. The consultation found there is a lack of whole of life planning and that current service and funding arrangements can exacerbate rather than reduce anxiety for people with disabilities and their families.

4 Future directions

As indicated earlier, the consultation confirms that it won't be hard to achieve broad agreement about the broad principles and values that should guide future thinking about participation, support and services for people with disabilities in the ACT. The consultation also concludes that there remains much room for improvement if people with disabilities and their families are to experience service and support systems in a way that is consistent with the vision. In the various forums and focus groups, there were good news stories as well as examples of shortcomings, and this section of the paper touches on some of the views expressed under three broad headings:

- Service approaches and models
- Broader systemic change
- Use of resources

4.1 Service approaches and models

The consultation found that people with disabilities, families, guardians and unpaid carers and people working within current services all see that a wider range of service approaches and responses is needed. However there was also fear expressed that in the search for new models and approaches, current service arrangements that are perceived as working well will be threatened. For some, choice means keeping the current services that they are happy with rather than trying something new or different. Common themes in the consultation relating to service approaches and models are discussed briefly below.

Person centred and strengths based approach

Already in this paper, the importance of individualisation as a fundamental principle which underpins a person centred approach to service has been discussed. The need for stronger involvement of people with disabilities, guardians and family members in service planning and case management emerged strongly as a related theme.

'I would like someone one day to ask my daughter what she needs rather than telling her what the service provides.'

The consultation outcomes suggest that more discussion is needed about what a person centred, individualised service means in practice and what changes would be needed within organisations to support better practice. Disability is so often seen through a deficit model, yet nowhere is it more important to focus on the strengths of the person and a positive strengths based approach is being sought by many stakeholders. Based on the views expressed in the meetings there is not a lot of confidence that the system can change in this direction, despite many people advocating such a change and the increasing knowledge in the ACT and elsewhere of new service models that could be further developed here.

Early intervention

Early intervention was seen as a high priority. Whether the disability is present at birth or is acquired in later life, the nature and experience of early intervention can set the scene for many years ahead or even a life time.

Right at the start when the family is dealing with the birth of a child with a disability or with serious and permanent injury to a family member, the right blend of 'normal' community support, formal services and 'technical' (such as medical or therapeutic) support at the right time is needed to ensure that the family has access to information, service and support which enables them to remain integrated into community life.

Some forums talked about how too much technical support or formal intervention when it is not needed, or is without a balance of normal community support, can result in the 'person' merely becoming a 'case' to those working with them. Keeping the person and the family at the centre of the service response and actively involving them in planning services and support is important at all times, but early intervention responses are even more critical. Not only can they provide much needed practical and emotional support to the family, but they can set the foundations for the family's expectations about what support is available to them and how it can be used. At the same time it has to be recognised that during this period, family members may feel grief stricken, confused, and unable to take in too much information.

While getting the right information at the right time can be difficult, it can also be hard to access service.

'Unfortunately in Canberra the biggest problem is the lack of therapists and the frustration of trying to get appointments when you want them... We all know that when dealing with children, advice is needed sporadically because the children suddenly have a growth spurt and questions come up unexpectedly. When this happens it causes stress to everyone, parents feel neglected and therapists are frustrated with their inability to squeeze you in.'

Several families and a number of service providers from both the government and non-government sectors emphasised that high quality early intervention services would pay dividends both at the time and in later life both for the family and for the community. Families would be less frustrated in their attempts to provide for their family member because they would draw support from a range of options designed to meet the particular personal needs of themselves and their family member. From the start they would assume their rightful place at the centre of the service.

Overall, on the basis of these consultations, the reality appears to fall short of this. There is a sense of frustration around early intervention from families, and from government and non-government service providers. Everyone agrees it is a high priority, but the service systems currently in place do not appear to be geared to support that level of priority.

Whole of life support and transition points

Support during and across transition points is of critical importance to people with disabilities and families. It was also an issue raised by service providers who identified that the way the service system is currently organised with the need to set boundaries around eligibility and target groups can set up rigid barriers that leave people with disabilities and families without support or having to continually renegotiate support for the next phase of life. Once again people felt that they entered a new information vacuum at these times. If they didn't have the contacts or didn't know the right questions to ask, working through these transitions was even more difficult. These quotes from the forums speak for themselves.

'It's the transition points that are tricky – when you might be going from, one service system to another – or from one service system to nothing.'

'When you finish with CHADS, if you don't go on to the special school system, you just don't get anything.'

'Young people with disabilities should be allowed a 'youth' i.e. to be teenagers (not assigned to health, medical aged or infancy models).'

'Where are the recreational and social things for him to do on the weekend?'

'It has taken us eighteen months to get plans in place for when our child leaves school. I have learnt a lot that could help other parents going through the same thing.'

'It would be such a relief if someone could help me plan for my child's life a little way ahead – like what he is going to do when he leaves school.'

'When I came out of hospital there was no written information about what supports I could get at all.'

'I am trying to get work, but I feel like the system punishes me for my disability rather than helping me.'

'What are the options for someone who can't work? Do they just stay at home forever?'

'My son is now over 40 years old and he is aging too – like me. Where will he go? Where is the retirement village for him?'

Mainstream or special services?

This issue recurred throughout the discussions particularly in relation to schooling. There was consensus that inclusion was a fundamental right and a desirable objective. However the right community attitudes and the right supports were needed to assist it to happen well. In the case of schooling, it was recognised that unless the supports were available for it to happen respectfully, inclusion in mainstream education was not always in the best interests of the person with disability. Choices that families make about mainstream or special schooling can also impact on access and availability of support post-school and can shape expectations concerning future life opportunities regarding accommodation, work and further education.

Stability

Some certainty about the availability and continuity of service was an issue for many families and people with disabilities. The comments below express the importance of stability and security of care to parents who may have reached the end of their own resources in very difficult circumstances, such as caring for a person with a dual diagnosis.

'This is not ideal but it is where I am at - desperate. I want an institution for stability and security and ongoing care in all situations. Ideally there is much greater flexibility to deal with changing circumstances ...'

People with disabilities also talked about the difficulties of dealing with changing carer relations and funding arrangements. Often the funding available for critical services such as respite care changes from year to year. The fact that family members and unpaid carers do reach the end of their tether and their capacity to provide further support strengthens the

case for early intervention and involving the families in contributing to the planning for long term support.

Recognition and support of parental role

Parents and family members care about the person with a disability and are there for the long haul. As one parent said

‘Let’s face up to the fact that the system will never meet all people’s needs. The service system needs to recognise its position and place, which is not in a dominant role.’

At the same time, the physical, emotional and financial costs of caring for a person with a disability may be too large for families to take on by themselves. One parent suggested that respite care arrangements should be set up automatically whether or not the family chooses to use respite at the start or not.

‘I cannot stress how important it is that families have [respite] strategies in place before the family unravels and falls apart... It is vital that people in charge of policies realise that all people regardless of age or type of disability cannot survive in this society without consistent and yet flexible support systems.’

Another parent voiced a view that was strongly supported.

‘Families [should be] listened to. After all we have cared for a child for a number of years and feel we know at least a little bit.’

While these are fundamental principles in practice it may not always be so straightforward when, as happens in every family, the views of parents and other family members do not coincide, or when there is a general perception or the view of an advocate that the best interests or rights of the person with a disability are in jeopardy. This adds another layer of complexity to service provision.

‘One of the things we find very difficult as service providers is when the person with a disability and their parents do not see things from the same perspective. We have to keep asking ourselves - who is the client?’

Skills development, training and career paths for paid carers.

The issue of paid carers was raised many times during the consultation. The attendant or paid carer role, which may be quite intimate and personal, is critical to the quality of life of many people with disabilities. The change of carer can be a major anxiety particularly as people reported varying standards of quality and training from different agencies. Because the carer relationship itself is part of the service, many people were very uncomfortable with the idea of many casual staff in the carer ranks.

The view that carers were not well paid and they often seemed to be under trained was raised many times. While some people saw the carer role as a privilege which should not be driven by remuneration, others recognised its complexity and difficulty and thought that both training and remuneration needed to be improved. Many were not aware of the CIT training available and of the extent to which it is being used by people employed as

disability workers. Some felt that this training should be an entry point requirement not an optional extra.

Without foregoing specific training in their own organisation, opportunities for some common training right across the sector were also raised as a way of promoting a shared vision and values and to increase professional development opportunities for workers in the disability field.

Frontline staff – a part of the change process

Another related theme was that frontline staff are critical to any future reform and quality process. Service provider staff involved in the consultation identified valuing, support and recognition of staff as a key plank of any future quality strategy. They need to be seen as a major part of the solution with opportunities to contribute ideas for service improvement, to expand their understanding of emerging directions and to be valued for their contribution.

Sensitivity to disability as a prerequisite for all disability staff

It was suggested that this factor should be given high priority in staff selection for all people who work in this field. One person went so far as to say that priority for employment should be given to people with a disability or people who have a family member with a disability. While this is an extreme view, it represents a more widely held one that generalist skills are not enough. Familiarisation with the reality rather than just the theory of disability is a critical part of the training of all staff in the disability field.

Piloting new approaches and spreading the learning

Change to service approaches and models is likely to be incremental. The consultation identified that there is value in piloting new approaches and models on a small scale so that experience can be built and lessons learned ahead of wider implementation. A key to the forward strategy should be identifying and promoting what is already working well and publicising the lessons and implications of any new models piloted as widely as possible to people with disabilities, families and organisations working in the disability sector.

4.2 Broader systemic change

While practice and service approaches can be changed within specific services and in the interaction between services and people with disabilities and families, it is also clear from some of the views expressed that change will be required at a broader systemic level. Change is required at a wider community level, in mainstream services and in the disability services sector. Issues raised through the consultation are discussed below.

Translating the vision - legislation, strategic planning and clear policy

If the new vision is to make a difference it will need to be strongly reflected in legislation and government policy impacting on people with disabilities. Beyond that it will need to be embedded in community attitudes and in the way both mainstream and specialist agencies operate. Agreement on a common vision and values, which has already been discussed earlier in this paper, can drive a policy direction which helps to promote useful cohesion which is focussed for the overall good of participants in the system.

‘Policy makers compose big picture concepts or put problems into words for the individual departments to interpret. It is this interpretation that is the most important final product for the users of the system. Good clear easy to read policy

makes for good clear consistent services. Variation in interpretation leads to frustration confusion and unnecessary stress.'

Consultations with service providers indicated that there is potential gain to be made - without necessarily requiring additional resources - through collaborative approaches and sharing creative approaches and learning across the sector. The responsibility for change does not rest only with government. Each organisation within the disability sector and each person within the disability community can make a contribution to the reform agenda.

Once the vision and values for the approach to disability are agreed strategic planning can assist by linking the vision to practical objectives and tasks. A longer term strategic plan for disability in the ACT is generally supported although the consultation did reveal some scepticism about the capacity of governments (which may have a short term life) to achieve change that by its very nature requires a long term commitment and process.

Participants thought that better use could be made of existing demographic data on congenital and acquired disability to ensure service planning matches known needs now and in the future. This would help to build confidence among people with disabilities and families that services would be there when needed. For example, it is likely that the children currently at Cranleigh School will be requiring particular kinds of support to leave school in the next ten years or so. Another example is that there is a known cohort of middle-aged people with intellectual disabilities in the ACT. Consideration could be given now to planning for the sorts of support and services which may assist them to live a fulfilling life in their later years.

Several participants in this consultation saw the strategic plan with associated resource allocation as critical to developing a sustainable service over time. Strategic planning was also seen as an essential framework for deciding priorities and mapping the ongoing reform process.

Reducing fragmentation of services

Putting boundaries around services may be administratively convenient, but it can create difficulties for people with the disability and families. There was evidence that many people with disabilities experience the service system in a fragmented way. They may have differential levels of information and knowledge about what support is available and, depending on which service providers they are in contact with, they might or might not get access to other resources and supports.

'When you don't fit the requirements of the service, you just feel like the door is slammed in your face. It feels like somehow you have failed, and then you have to start the search again or you don't get any help at all.'

Future planning needs to address how mainstream and specialist services are directed and how the service system as a whole operates, particularly for those people with disabilities and families that have ongoing support needs. They ought to be able to see pathways in the system that are going to meet their needs over different life stages.

Increasing flexibility and choice will not necessarily make things simpler for people working in the system - although it could make their work more satisfying. They will need to have a broader understanding of the reform goals, and how they impact on the service

provided by their own organisations and on their relations with other organisations with whom they share clients. They need to be part of the process of breaking down service silos and helping to make things simpler and more accessible to people with disabilities.

Supporting innovation

Encouragement of innovation is a sign of a system interested in continuous improvement, and several people wanted innovation to be more strongly encouraged in the ACT.

‘Create a culture where its OK to move outside the square. Families can be brave but this “ permission” needs to come from government.’

‘We [parents of people with disabilities] need the same choice and freedom to mistakes as anyone else and to learn from them. It’s OK to try something else if it doesn’t work.’

‘Staff need to have permission to do things differently. They need to understand the possibilities and why they are important to people with disabilities before they can change what they do.’

Supporting this commitment to innovation with action research methodologies, as recommended by a participant, provides the system with a structured way of monitoring new approaches and learning from the participants about what works and what doesn’t.

Need for better working relationships across the service system

The forums and meetings with service providers all emphasised the importance of building better relationships and opportunities for joint work across different organisations. There were major benefits identified in stronger collaboration and exchange between the government and non-government service agencies. Ideas included:

- More joint training across the disability sector
- Staff exchanges and mentoring opportunities
- Developing joint ventures and collaborating on projects
- Joint case planning and management

Supporting, monitoring, and evaluating systemic change

The consultations included several people with expertise in change and quality improvement processes. They recognised that a commitment to change is not enough to sustain improvement over the longer term. Structures need to be set in place.

‘We need a governance system to support the changes.’

These participants sought to build a culture of evaluation into the disability sector. Relevant quality standards and external monitoring were regarded as a way of building objective structures and systems to support staff and others in making changes.

Linked to this, many participants acknowledged that quality improvement and reform of services requires a substantial cultural shift for some organisations and the people within them. It may also represent a significant shift for some clients of services and their families. Sensitivity will be needed, as well as good communication and education to ensure people can move forward and take ownership of the change.

As with any change process leaders or champions will be needed. They will be drawn from the ranks of people with disabilities, family members, advocates and people working in the government and non-government parts of the system. Everyone in the sector will have a role in supporting them in their role of promoting positive change and innovation.

4.3 Use of resources

The issue of resources was raised often during the consultation. Not surprisingly many people considered there is a need to provide more resources to address service gaps, to ensure greater equity in access to available services and to provide for a wider range of service options. However it was also raised in the context of:

- ensuring resource allocation decisions are based on good planning
- developing resourcing models that support flexibility and individualised services
- providing better for people over their life stages and through transitions.

A further resource issue related to the need to invest more in people working in the disability system, via improved remuneration, support, education and development.

Matching resources to priorities

There is a perception in some quarters that very little priority setting has been done to date and that funding decisions have been somewhat reactive, or at least that there is not a great deal of transparency around the reasons for funding decisions. A common perception is that accommodation services take the lion's share of available funding and that other areas are not sufficiently resourced.

'I think there is an imbalance with accommodation clients getting the bulk and those not already in the service getting very reactive access to services.'

Participants also raised the difficulty of accessing resources or support to engage with mainstream services and opportunities including education, transport, employment and social activities.

People with disabilities and their families also have differing economic capacity to directly pay for supports and resources that can improve their quality of life. Those with poor financial means may often be disadvantaged in other ways such as less flexible access to accommodation, more difficulty in accessing information and less experience in negotiating service systems. This can be a contributing factor to further ongoing inequity in life opportunities and needs to be considered in discussions about resource allocation.

There was a call for more transparency in resource decisions and better strategic planning to ensure resources are directed to areas of need across the disability spectrum. More inclusive consultation and sharing of information about the basis of resource allocation decisions would go a long way to addressing any misperceptions. Participants in the consultation are mindful that funding is not unlimited and funding decisions will have to be made on the basis of priorities.

Funding programs or people?

While a number of Independent Support Packages are available in the ACT, the major part of funding is program based. Some people would welcome greater availability of personal funding and some are quite satisfied with the status quo. Family governance was mentioned but more as an idea than an option relating to managing resources. As with many issues in disability, it is not an either or situation, but an either/or/and situation. People with disabilities and their families are looking to play a greater role in determining what resourcing options will work best for them. More choice in the system will enable this to happen and for people to become more comfortable with greater choice over time.

Resourcing models to support flexibility and individualised services

The way the system is currently funded and resourced can be a barrier to individualised services. Most funding is directed to either government or non-government services which in turn offer specific services or programs. The major cost of most services is staff, and once services are contracted to deliver services on behalf of a certain target group, it can be hard to move resources within or across programs.

In addition to the issue of individualised funding, many examples were given where it has been difficult to gain access to resources to support particular service responses and practical assistance outside of what is included in the current service arrangements. There is no point asking people what they want if there is no flexibility in how resources can be used to meet requests and preferences of clients. This is a major challenge for reform and one which warrants more discussion in the workshops and in forward planning.

There will be a need to maintain visible support arrangements within mainstream services and specialist support services and to make these widely available. However, access to discretionary funding within and across services may also be needed to help provide the choices and flexibility of response that people are looking for even where the resources continue to be managed by a given service provider.

Long term sustainability of support and services for people with disabilities

Providing for the future resource needs of people with disabilities and their families is a major issue for future planning and reform. In many ways sustainability of support and services for people with disabilities is much more than a resource issue. Because it is linked to the level of community awareness and acceptance around disability, it is also a measure of the health and strength of the community itself. In one participant's words:

'When the ordinary person in the community has a better understanding of what it's like to have a disability and try to participate and live an ordinary life, perhaps we will see more resources for disability services and support.'

Many of the factors mentioned in the consultations need to be operating well and in conjunction with each other if there is to be longer term resource allocation to sustain the whole system. It is not just a government issue. Listening to the voices of people with disabilities and their families will identify need and preferred responses to those needs. Community attitudes will influence political will and the range of supports available beyond government and through the community itself. Strategic planning will help to identify longer-term priorities and address gaps and emerging issues. The skill, commitment, care and advice provided by people working in the sector will help to sustain people with disabilities and their families. The creativity and bravery of people with disabilities and their families can inspire further innovative responses from the broader community.

5 Issues around consultation

The outcomes of this stage of the consultations suggest that a multi-layered and flexible approach is needed if effective consultation involving all parties is to be achieved. As well, the commitment to consultation needs to be acknowledged as a fundamental value which underpins the approach in all parts of the sector. This would include involvement at many levels ranging from a person living in a group house being involved in household decisions to consultations around high level government policy. While this view would be supported by all who participated in the current consultation, implementation of suitable approaches is not straightforward as expectations and need for information and involvement differ. It also needs to be acknowledged that many people in the sector did not come forward with their views in this process.

Expectations of consultation

One complexity of the consultation process is that participants approach the consultation with different histories of involvement and different expectations. While people who participated in this consultation shared their aspirations and gave freely of their ideas, it is fair to say that there is some scepticism about whether anything will really change. Others, because of the circumstances leading to the Gallop report and the publicity it has had, have a heightened expectation that this time things will change for the better. At the same time some parents are concerned that as a result of new ideas circulated through the Gallop Inquiry they will lose valued services and supports which they have fought to obtain over many years. All of these perspectives have validity. The consultation needs to be able to work with and respect these different viewpoints as well as providing consultation mechanisms which enable different parts of the sector to be involved in ways that are most effective for them. Several suggestions were raised in the forums and focus groups and some are presented here to illustrate the issues involved.

Talking to people with similar disabilities.

Publicly advertised forums such as those conducted in this project have the benefit of being open to all and they have their place, but the diverse circumstances of people who respond to the invitation often mean that issues cannot be pursued to the necessary depth. Several ideas were raised in the consultation in response to this dilemma.

It was suggested that future general consultation processes could address the need for specific focus by working more closely with support organisations and peak groups for people with particular types of disability. While this approach may address details, it does not really address the needs of people with multiple disabilities. It also does not use the strength derived from a dialogue between people with different experiences and the power of a united front on common concerns. For example in the consultation, some people in the consultation who use wheelchairs talked about their frustration when parking spots for disabled people were taken by able-bodied people.

‘If people could just live our lives for a day, I think they would be more understanding. It takes me so long to get ready and then if I can’t find a disabled car spot I may have to turn round and come home again. If able-bodied people really understood, they would never park in a disabled spot again. I think the government should raise the fines for that.’

This is a particular issue for this group of people but it has its roots in the broader issue of physical access for all people with disabilities. It needs to be addressed at both levels and will be more powerfully addressed at the broader level if the whole sector is involved.

Issues based consultation

Another way to enable in-depth consultation to occur could be to supplement general forums with concurrent issues workshops which focused on ideas and solutions around issues such as transport, physical access, accommodation, building a satisfying social life, relationships with carers, parental involvement or ageing.

It was also suggested by one group of parents that there should be an elected representative group of parents of people with intellectual disabilities to act as a consultation forum to government. Others felt that this could represent only one segment of the sector, and as such had its limitations.

Streamlined consultation

Other people sought a more streamlined, co-ordinated and outcome focussed consultation.

‘Because we have a family member with a disability, our time is even more constrained than most families. We are always being asked to come to meetings to give our opinion yet we never hear or see any result from it. This meeting could well be the same.’

Electronic forms of communication were seen as efficient by many people even though they have their limitations particularly in an area as complex as disability. Some people felt that more use could be made of email and websites as a supplement for face to face contact. For example the development of the central distribution list may already be having an impact. Of those who attended the consultations, many people had heard about the process from multiple sources – the newspaper, via electronic message and from their school or other organisation. However at least one person said the consultation had been poorly advertised, and it is not possible of course to know whether people who didn’t attend were not there because they did not know it was happening or for some other reason.

The DRG is providing a focus for consultation and communication at present and the second stage of this consultation will provide more detailed recommendations around consultation mechanisms for the future. The lesson so far is probably to keep communicating and seeking feedback via as many mediums as possible. The lesson for the future may be to encourage a range of different mechanisms both formal and informal which are driven by a shared vision and values but which use a variety of ways to pick up the different parts of the disability mosaic.

Most people seemed to accept that consultation does not mean necessarily that the decision goes the way they want it to go. However, regardless of what approaches are taken to consultation and what decisions are made, one of the critical things is to maintain the feedback loop. This means that if people take the trouble to participate, they receive feedback on the outcomes of the consultative process. The DRG is committed to this approach and it is an important way of strengthening trust in the sector over time.

Gathering views on an ongoing basis

One-off large scale consultations are useful in some circumstances, as are formal consultative bodies, but in the current environment these need to be supplemented by less formal systems which gather views in an ongoing way from a variety of sources. These could include channels provided by service providers and advocacy groups. Much information could also be gathered under the auspices of peak bodies. The systematic monitoring of complaints is another rich source of information about the health of the system. This is a two way process. Service providers and government gain information on whether consumers are satisfied with the support, participation and service they are receiving. By the answers they get, consumers will also be monitoring the good will, health and responsiveness of the service system.

Attachment 1: Disability Reform Group: DRAFT Vision & Values Statement

Vision

All people with disabilities achieve what they want to achieve, live how they choose to live, and are valued as full and equal members of the ACT community.

Values

Inclusion

All people with disabilities are recognised and respected as valued and contributing members of society.

Family Involvement

The roles of families, guardians, friends, carers and significant others in the lives of people with disabilities are supported, valued and promoted.

Community

All people with disabilities have opportunities for personal relationships and for full involvement in the ACT community in positive and creative ways, building on their individual capabilities. This in turn enhances the skills, perspectives and diversity of the ACT community as more people have the opportunity to be involved in the lives of people with disabilities.

Self-determination

All people with disabilities are free to make or influence the decisions and choices that affect the course of their lives. This empowers them to realise their self-worth in every aspect of life.

Equality

All people with disabilities enjoy equal rights, responsibilities and opportunities with the rest of society.

Equity

Resources for people with disabilities are distributed strategically to best meet their overall needs, taking a holistic view of the community.

Access to Public Places

All people with disabilities have full and direct access to all public places in the ACT.

Access to Information

All people with disabilities and/or their representatives receive accurate, timely and understandable information that enables them to make appropriate decisions.

Transparency

Principles, priorities and processes for service provision for people with disabilities are public and clear.

Partnership

All people with disabilities have the opportunity to work collaboratively with government and the community to set agendas where appropriate and to be leaders and decision makers, particularly in the development and reform of relevant services. All parties have a clear understanding of their relationship and share relevant information with each other.

Consumer Power

Consumers of disability services enjoy the same rights as any other consumers. Consumer power involves protection, choice, information and redress.

Excellence

Services that support people with disabilities, their families and friends are flexible and innovative, and aim for, and continue to be at world best practice levels.

Creativity and Development

All people with disabilities have the opportunity to enrich the community through their own growth and development. Research and recognition of the unique life experiences and skills of people with disabilities, their families, friends and carers, provide ongoing opportunities for learning.

Safety

Acceptable levels of safety for all people with disabilities are determined in consultation with the person with a disability, their family, guardian and significant others.

Representation

All people with disabilities are empowered through advocacy support and representation of their needs and rights where necessary.