

# **People at the centre - Seeing new possibilities**

## **Report on Community Consultation for the ACT Disability Reform Group**

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RPR Consulting

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# 1 Introduction

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## 1.1 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 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 engaged RPR Consulting to consult with the community on its behalf. The purpose of the report of this consultation is to inform the advice that the DRG gives to government regarding reform of disability policy, services and support in the ACT.

## 1.2 The consultation process

The consultation project was divided into two stages. 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 in a series of forums and focus groups as listed below:

- 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 guardians
- 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.

It was also planned to hold a focus group with families of people with disabilities from other culturally and linguistically diverse backgrounds. Despite considerable liaison and discussion with organisations working in this area, it was difficult to locate families that would be involved in a specifically convened group. A significant number of people from culturally diverse backgrounds did attend the public forums and focus groups and their views were heard through these processes.

The process was also intended to involve families of people with disabilities from Indigenous communities. Many attempts were made to organise a group through local providers but timeframes and the fact that Indigenous families do not appear identify themselves strongly as having “a disability” made it hard to reach these families. Future consultation processes need to allow for time and different methods of reaching Indigenous families. This is taken up further in the final section of the report.

A full description of the issues raised in this stage of the consultation is provided in the discussion paper – *Having our voices heard - A discussion paper based on Disability Reform Group Community Consultations July 2002*<sup>1</sup>.

The second stage of consultation was designed to focus on future strategies and change. The discussion paper and a draft vision and values statement developed by the DRG provided a framework for this task. Stage 2 involved a future directions workshop (repeated three times). The workshops brought together people from across the sector - including people with disabilities, parents, guardians and unpaid carers, and government and non-government organisations. Approximately 125 people participated, many of whom had also been involved in stage 1.

### **1.3 Overview of outcomes of the consultation**

The consultations strongly supported the need for reform in the disability area. While the workshops did not seek to arrive at specific recommendations or proposals there were a number of significant messages and themes about which there was broad consensus and support. The key messages are summarised below and detailed in the body of the report.

#### **Support for a shared vision and values**

- A vision statement will only be meaningful if backed by action.
- Community ownership and engagement is important.
- The vision and values need to reflect the importance of inclusion.

#### **Need for strategic planning**

- A 3-5 year strategic planning framework for disability is needed in the ACT and should be a driver for the reform process.
- A priority is to strengthen the capacity for long term resource planning based on demographic analysis.
- Government leadership and accountability is critical to the reform process.

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<sup>1</sup> This paper is available from Disability ACT  
People at the Centre – Seeing new possibilities  
RPR Consulting, 28 August 2002

- There needs to be partnership and collaboration in the work of planning and reform.
- Public accountability requires a clear performance and reporting framework.

### **Improved community awareness and attitudes**

- Change is needed in the wider community to address community fears and stereotyping
- Media and education strategies are needed to create positive community attitudes and to promote positive images and diversity of people with disabilities

### **Service improvement and quality**

- More systematic ways to ensure good standards of service are needed.
- Service users are critical in any assessment of quality and good practice.
- Standards need to be put to work in service improvement, evaluation and staff education.
- Better guidance, processes and systems are needed that provide quality assurance for people with disabilities and families this assurance.
- Sector development strategies directed to building good practice and innovation are needed.

### **Reduced fragmentation of services**

- There are high levels of frustration due to lack of certainty and continuity of services.
- There are significant gaps and limitations in the current system.
- The consultation found some support for rationalising the number of services.
- Broad level planning needs to focus on achieving an optimal service system.

### **Improved collaboration among those involved with disability issues and services**

- Building opportunities for joint work on new initiatives and in driving the reform process.
- There is strong support across the service system for more joint training, staff exchanges and mentoring opportunities.
- New service approaches should promote more joint case planning and management.
- Better links between specialist disability and mainstream services such as education, health and employment are supported.

### **New service approaches and improved quality**

- There was strong support for development and expansion of person centred service approaches.
- Whole of life planning was identified as important – in conjunction with a person centred approach.
- New approaches should be piloted with the lessons shared widely.
- There were calls for a stronger focus on and more resources for early intervention.
- Promote current understandings and experience of good practice more widely.

## **Improved access to information and services**

- There was strong support for a centralised information service that has a capacity to link people with services.
- For others, the issue was better information as a key element of a person-centred approach.

## **Supporting and investing in people working in disability services**

- The paid carer role is deserving of stronger valuing and recognition.
- Paid carers and other staff would benefit from improving training, career development, support and remuneration.
- Reform should aim to create a culture of learning in organisations and across the sector.

## **Resource allocation**

- People should be recognised as a major resource in the system.
- Resource allocation should be guided by long term planning.
- There is a need for increased transparency in resource decisions.
- For consumers, the availability of discretionary and individualised funding is needed to ensure choice and flexibility in service provision.
- Additional resources will be needed to support the reform process in areas such as planning, innovation, ongoing consultation, new service approaches, research and evaluation.

## **Sustainable reform process**

- There is a need to balance a longer-term planned approach that assures accountability with some short term and tangible action that achieves results.
- The Government needs to develop a governance framework for monitoring and communicating the progress, impacts and results of reform.
- Change champions and leaders should be nurtured and supported.
- Ongoing participation and consultation should be hallmark of future planning, service delivery and the reform process.

## 2 A shared community vision and values

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### 2.1 Principles emerging from consultation

The first stage of the consultation asked people to identify principles that were important in relation to future thinking about disability services in the ACT

The most commonly expressed themes to emerge were:

- 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.

### 2.2 Feedback on the DRG vision statement

One of the tasks of the DRG has been to develop a vision and values statement to guide future planning and service delivery for people with disabilities and families in the ACT. A draft vision and values statement was provided to participants in the joint future planning workshops with a view to getting feedback. Even though different language was used in the draft statement, it was seen to have close correlation with the principles that had emerged through consultation.<sup>2</sup>

#### General support for the vision and values

In the joint consultation workshops, participants were asked to comment on the DRG values and vision directly. Overall, although several people thought the statement was too long to generate the necessary energy and focus, the consultations affirmed that a common vision and values across the disability sector would be useful. While there was some wordsmithing, people at the workshops felt that DRG version was philosophically in the right direction and generally that it was a good start. The critique also raised other useful points as indicated below.

#### Backing the vision and values with action.

The first and perhaps the most important is that the best vision and values in the world is only a piece of paper unless it is backed by action which demonstrates a commitment to the values and which delivers results. Delivering results raises the question of who owns the vision and values and who monitors performance against them. This is not just a rhetorical question. If the vision and values are not owned by the sector – as a minimum in the first instance - they will have very little power to guide behaviour and build the collaboration that many people feel is essential to reform. A range of mechanisms will be required if

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<sup>2</sup> These are described in greater detail in the discussion paper generated from the first stage of the consultation – *Having Our Voices Heard*.

they are both to guide the development of a new disability culture and become imbedded in it.

Some people commented that the vision and values statements were little different to the principles contained in the disability legislation and the current disability standards. For some this was a concern since the existence of these principles had not been a driver for how the service system has operated. Others felt congruence with legislation and standards was important and having them expressed in a new vision for the ACT would be helpful to focusing the reform.

The workshops also concluded that the values should be part of the framework for monitoring the success of the reform process, although they would require further interpretation and translation through policy and service approaches. Monitoring performance against the framework of the vision and values could also form part of any organisational reporting and accountability mechanisms – government or non-government.

### **Community ownership of the vision**

Others took a broader approach to implementation of the vision. They argued that broad community ownership was important and to be really effective, a vision and values would be integrated into the way *all* parts of the community operate. They would be supported by an education program to have them understood and adopted across the community, not just in the disability sector. If they were a truly operational document they would be demonstrated not only in the government's strategic intent and actions with respect to disability, but in the way it delivers its *general* community services eg with respect to transport, employment, housing, health etc. They would be seen in the way the government and non-government parts of the service system collaborate with each other. They would be seen in the way the business sector employs people and sponsors community activities involving people with disabilities. They would be seen in the way respite care is delivered or how decisions are made in a group house. Community attitudes would be predicated on inclusion rather than difference.

### **Using the language of inclusion**

Some felt that the language used in the vision and values perpetuated exclusion of people with disabilities. As reported in the discussion paper, the very fact that we have a conversation about 'inclusion' or 'access' for people with disabilities perpetuates their definition as 'other' and as having to fight for the rights of a citizen rather than having them automatically. While agreeing with this in principle, a larger group of people felt that we were so far from this ideal situation, that the vision and values statement was needed as an interim step to guide the behaviour not only of the disability sector, but of the whole community. Extending the vision and values statement to be a whole of community statement rather than one pertaining only to the disability sector would require some further work on the statement by the DRG. It is an important change of focus that would at least partly address some of the concerns raised here.

Some other issues such as safety and equality also generated a lot of discussion. With safety this related to the subtleties of the inclusion argument outlined above about why it is necessary to specify the general rights of a citizen for people with disabilities. Issues associated with the dignity of risk were also raised here. The latter probably cannot be resolved through a statement of values, but needs to be addressed in another forum through debate and discussion about standards of care and management systems. Equality raised a concern that people with disabilities may not have equal ability to access opportunities and

that equality should not rule out the need to provide support and assistance to them and even positive discrimination in some circumstances.

### **Putting the vision and values to work**

The draft vision and values statement generated some rich discussions and, despite the challenges of accommodating the diversity of views across the sector, adoption of a broad vision that has strong recognition and ownership across the community was seen to have many advantages. Without restricting diversity of approach and individual preference, it would provide a philosophical guide for setting future directions and policy. It could also guide the development of community education, service approaches and resource allocation. It can help to determine a framework for evaluating the outcomes of current practice as well as for assessing initiatives undertaken in the future. Above all, it steps beyond the deficit model so often applied to the disability area and articulates aspirations in a proactive and positive way.

## 3 Broader systemic change

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Many ideas ranging from the micro to the macro level have been put forward during these consultations, but it is clear that there are some systemic drivers of change that must be put in place if sustainable reform is to be achieved. Some of these could have an impact almost immediately and others are medium to long-term projects.

Broader systemic change issues raised in the joint workshops fell into the following categories:

- Developing a strategic plan for disability in the ACT
- Raising the awareness and involvement of the whole community around disability
- Developing a framework for service improvement and quality
- Reducing fragmentation of services
- Promoting collaboration across the sector

### 3.1 Strategic planning

#### **Government leadership and accountability**

While the whole sector needs to take ownership of the reform process, the workshops concluded government has an important leadership role in key areas. Following the reviews, consultations and reports of the past few months, the disability community will look to government for commitment and a statement of strategic intent, which can be used to provide a framework for the strategic planning which the sector believes is a high priority in the reform process.

The consultations suggested that a 3-5 year strategic plan for disability in the ACT is needed if there is to be continuity of well targeted service and support for people with disabilities and their families. Taking its cue from the vision and values, a strategic plan would provide the link between these aspirations and the practical objectives and tasks which can make them happen. A published plan can also provide a vehicle for monitoring progress that is clear and accessible to the whole community. An annual report to the community on disability would be another way of doing this. (This could be similar in concept to the Urban Services Report to the Community, but with a stronger focus on qualitative issues).

Most participants in this consultation saw the strategic plan with associated resource allocation as critical to developing a sustainable service system that provides security, flexibility and quality of support. Without this tangible sign from government they were not convinced that the kind of adhocery that was perceived to exist in the past would not continue. Strategic planning was also seen as an essential framework for deciding priorities and mapping the ongoing reform process.

Participants in this consultation also wanted to see longer term more general planning (beyond five years) that was informed by demographic data on congenital and acquired disability. This could be an ongoing role of government and would enable broader service

and resource planning to match known whole of life needs now and in the future. In turn, this would help to build client confidence that services would be there when needed.<sup>3</sup>

### **Sector ownership of reform**

While many people see that the strategic direction must come from government and that it has a major role to play in driving reform, they do not want to abdicate their own responsibilities or negate the contribution they can make to the change process. Despite many years' involvement and various frustrations, many of those consulted recognise that change has to be a whole of system effort. They still have much to give and they want to be involved. It will be important to have a range of formal and informal mechanisms to cater for this in developing and implementing a strategic plan for disability in the ACT.

## **3.2 Community awareness**

As indicated earlier in this report, the aim of the reform process is not to segregate people with disabilities from the community, but to promote inclusion and participation. This is not a quick fix area. It is a long term issue which nevertheless needs to be tackled and the sooner the better. It is also a two way affair. People with disabilities must have courage and sometimes take risks and have support to make this happen; and the community must be helped to see people with disabilities in less stereotypical ways, as individuals that it can welcome and accept as fully participating members.

Many people – ranging right across the field from people with intellectual disabilities to government workers - want a community awareness and education strategy which puts forward positive and varied images of people with disabilities. They do not want people with disabilities to be portrayed with special status or pity, but as a diverse range of people with different strengths and abilities, as citizens with many things to offer the community, as human beings with stories to tell. If an education or media campaign is to be attempted, it must be done well and at this stage the most likely source of sponsorship would be from government.

While image is one aspect of community awareness, simple information is another and this can be done at the personal level as well as at the large-scale program level. For example one mother spoke about the informal talks on disability that she gives to her son's mainstream school class to help her son's classmates feel more comfortable with him. Her dream 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.

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<sup>3</sup> 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.

### **3.3 Framework for service improvement and quality**

The consultation found there is a need to look at a more systematic approach to planning, encouraging and assessing improvements in quality within individual services and across the service system as a whole.

Participants in the consultation argued that part of the framework for this is already there in the form of legislation and standards, but these have never been seriously put to work in terms of guiding or evaluating effectiveness and quality of services.

People with disabilities and families will experience quality, or the lack of it, first hand and they are a key to any ongoing monitoring and evaluation approaches. Consumer feedback mechanisms and participation in thinking about new service approaches and improvements to existing services should be a part of any strategy in this area.

People working in the disability field and consumers want the reform process to deliver guidance, processes and systems that offer greater assurances about the quality of services. This is partly about translating the proposed values and existing standards into explicit guidance about how services should be operating at the practice level and how the service system as a whole might work together.

While specific proposals in this area were not forthcoming, the process has confirmed that priority given to improving quality and being able to better evaluate the extent to which services are delivering the outcomes that people with disabilities and families want is given high importance. The goals of service improvement and quality underpin other strategies canvassed through the consultation including proposals regarding innovation, learning, investment in disability workers and research and evaluation. These are discussed elsewhere in this report.

### **3.4 Reducing fragmentation and building collaboration**

#### **Addressing fragmentation**

Putting boundaries around services may be administratively convenient, but it can create difficulties for people with disabilities and their families and it can waste resources. There were indications 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.

It was mentioned at one workshop that approximately 90 organisations dealing with disability in the ACT. While this could represent choice for consumers it also - even if it is an overestimation - has the potential for fragmentation of service. Some participants thought consideration should be given to rationalising the numbers of organisations involved on the grounds that there are significant inefficiencies in the current system as well as failures in terms of people getting the type and continuity of support they need.

For people with disabilities, their families and carers, the issue of fragmentation means a great deal of frustration, time and energy is spent negotiating and renegotiating the support they need. This is made more complex by their having to deal with mainstream services such as education and health, as well as specialist disability support services. Planning for

disability in the ACT needs to formulate a plan for an optimal service system design at the broad level as well as within specific services.

### **Collaboration within the sector**

This process has suggested there is a strong will to build stronger collaboration across those organisations working in the disability sector and between specialist and mainstream organisations. Bringing people together has the potential to release positive energy in the reform process to work together for improvements and change.

Service providers strongly suggested there is potential gain to be made - without necessarily requiring additional resources - through collaborative approaches and sharing creative ideas and learning across the sector. The responsibility for this change does not rest only with government. Each organisation within the disability sector can make a contribution to reform through collaboration. 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 a set of quality standards across the whole sector.
- Developing joint ventures and collaborating on projects.
- Joint case planning and management.

As a unifying theme, organisations will need to have a shared understanding of the reform goals, how they impact on the service provided by their own organisations and on their relations with other organisations with whom they share clients. United by a common vision and values, they can be part of the process of breaking down service silos and helping to make things simpler and more accessible to people with disabilities.

### **Collaboration with other sectors**

While there are opportunities within the sector there are also other opportunities outside the sector that may not have been fully explored. Two areas in particular were noticeable during these consultations. Mental health networks were quite strongly represented in consumer forums and while some of the issues are different, there are also many similarities and potential for learning from each other. Another area which clearly plays an important role for families where there are children with disabilities is the education system. The potential for working more closely with education and its networks was not fully explored during these consultations, but it is an area which is worth investigating. Developing relevant links with other government departments such as Urban Services may also have potential for raising community awareness and reducing some of the barriers to participation that are faced on a daily basis by people with disabilities.

Mainstream services also represent a largely untapped area for collaborative approaches and this can be quite separate from issues raised in the debate about integrated or specialised services. One planning workshop talked about community sponsorship ranging from a long term goal of seeking corporate sponsorship from the big end of town to the individual sponsorship and friendship that can be offered on a one on one basis by ordinary people in the community.

## 4 Service approaches and quality

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These discussions ranged across many issues that can be categorised into five broad areas:

- Introducing person-centred approaches
  - Piloting person centred approaches
  - Whole of life planning
- Early intervention
- Better access to information and service
  - Central information sources
- Investing in staff in the disability sector
- Creating a learning culture in services.

### 4.1 Person centred approaches

The focus groups, forums and workshops generally agreed that moving from a program or service centred approach to a person centred approach was critical if real change which improves the wellbeing of people with disabilities and their families is to be achieved. These words are easy to say and they can be mere window dressing - just a new piece of jargon to describe wider choice from a broader range of services.

#### **A fundamental shift or tinkering at the edges?**

A fully developed person centred approach would drive profound and far reaching change across the disability community. It would affect the way people are treated because they would not have to define themselves through a deficit model of need in order to access service. There is a big difference between asking people with disabilities what they want and need and asking them whether they meet the eligibility requirements for a defined service. The way decisions are taken and who takes them would change - the person with disability would make the decisions (or the family or advocate on their behalf where this is necessary). The types of support would be different, the way staff are trained and the type of staff may be different. The way the support itself is structured, managed, funded, delivered and evaluated would change, as would all the organisational systems associated with those functions. While many people in the consultations 'talked the talk' of the person centred way, there was not time for more in-depth discussion about the real impacts on the structures, cultures and services that already exist.

Making a commitment to move toward a person centred approach has major implications for other aspects of the reform such as our view of what a future service system might look like, how services are resourced and staffing issues. For some people, even discussion about expanding the range of options and services is threatening. Some fear was expressed that in the search for new models and approaches, current service arrangements that are perceived to be working well might be lost. For some, choice means keeping the services they are happy with rather than trying something new or different.

#### **Piloting person centred approaches**

Adopting the person centred approach is a fundamental lever of disability reform and, while acknowledging the fears around change in some quarters, it should be given due attention. There are a number of ways of moving forward on this. There does need to be a lot more discussion about what this kind of approach looks like in practice across the sector, but words are not enough - the person centred approach has to be demonstrated. It

has been suggested that some pilot projects on the person centred approach be undertaken and evaluated, including cost benefit analysis, as soon as possible. This would only be a small start but, in reality, change to service approaches is likely to be incremental anyway. However, apart from the hoped for benefits to the people involved in the pilot, it would allow the testing and learning to be done in a manageable way and then shared across the sector. It would not be radical whole scale change which destabilises, but it could show that change is possible and allow people to see what person centred service looks like. It would give hope to those who earnestly and urgently desire to try a new way and it would demonstrate that it is OK to try something different. At the same time a well-run pilot would reinforce that evaluation is an intrinsic part of innovation and the learning from it could be shared across the sector.

As well as piloting new approaches, a key to the forward strategy should be identifying and promoting what is already working well and identifying why it works well so that these principles of this good practice can also be shared. While these initiatives can be taken anywhere in the sector, government would be best placed to play a facilitating role. This would include specifically funding innovative pilot projects on condition that the learning is reported on, shared across the sector, and, where applicable, publicised in the wider community. In the early stages of reform, government will need to strongly support this, and in doing so it would signal that it is giving 'permission' for innovation to occur in other areas.

People with disabilities and families must be partners in designing, trialling and evaluating new service approaches. They can also become advocates for change with other people in the community and services that might be slower to embrace change.

## **4.2 Whole of life planning**

The issue of whole of life planning was consistently mentioned through forums, focus groups and workshops. In emphasising whole of life planning people did not mean linking a client to a service for life. They meant there needed to be a whole of life focus for people with disabilities rather than a service focus per se. People would have some knowledge of what opportunities may be available for them in the next stage of life, in the same way as every other person in the community. People with disabilities and families want greater certainty about the availability and continuity of service over time. Support during and across transition points is of critical importance. Many people said how helpful it would be to have a consistent case manager/advocate/mentor/guide who would be there for them to assist with whole of life planning and to help them negotiate the transition points.

The need for a whole of life approach was also an issue raised by service providers. They identified that the way the service system is currently organised with 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.

## **4.3 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. 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.

#### **4.4 Central information sources**

In every forum, focus group and workshop people complained about the difficulty of getting the right information at the right time. This difficulty in finding comprehensive information is often a symptom of a fragmented service system, and in this circumstance part of the solution must be to address that fragmentation.

However, many people consulted saw setting up a 'one stop shop', 'a Canberra Connect for Disability' as the preferred solution. They argued that consumers and others working in this system would benefit from having one agency that was playing a role of maintaining and providing centralised information and helping people link with and connect to the right points in the systems. This option is seen as a way of alleviating the frustration and time and energy taken by people trying to negotiate the service system.

In a more collaborative integrated system adopting a person centred approach, clients should be able to enter the system at any point and be directed to the information they need. The supports are developed and fitted to the person, it is not a matter of having to shop around to find a service that the person is eligible to access. The need to have access to information on a range of service options may become less of an issue.

Specific solutions in this area warrant further debate and discussion and should be thought of in relation to where we are trying to take the service system, not just designed to address problems in the system as they are currently experienced.

Experience elsewhere with attempts to centralise and facilitate better access to information indicates that it is not the information itself so much as the way it can be coupled with support and referral mechanisms that are tailored to the person's needs that creates the positive experience. It also shows that we need to be mindful of people's behaviour – who they reach out to help them understand and access services. Friends, relatives, doctors and other first to know agencies (such as schools and hospitals) are usually critical players in any information strategy.

#### **4.5 Skills development, training and career paths for paid carers.**

Issues around staff in the disability area were 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 need to have a lot of casuals was perceived to be because it was hard to retain permanent staff for a range of reasons. The view that carers often seemed to be under trained and were not well paid was prevalent.

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 sharing practice experience and increasing professional development opportunities for workers in the disability field.

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.

It was also suggested by a number of people that sensitivity to disability 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.

Overall, there was strong and widespread support for a much greater investment in the training and career development of people working in the disability field. This is not merely an issue of fairness to the staff involved, it is a critical factor in quality and

consistency of care. It is a fundamental of service improvement. The extent to which people want to work in the disability field in the ACT will be a longer-term indicator of the success of the reform agenda.

#### **4.6 Creating a learning culture in services**

What is clear from the consultation is that trying new things involves risks and learning – for people with disabilities and families, as well as for service providers. An important theme in the consultation was creating a culture around the delivery of services that actively encourages learning by all involved. In the reform process this will be a goal in whatever changes and improvements are being planned.

In the joint workshops there was clear evidence of learning through the conversations between professionals and people with disabilities, between people with disabilities and parents, between staff in non-government and government services. More opportunities for this kind of learning have strong support.

Equally, strategies discussed in other sections dealing with innovation, investing in skilled staff, frameworks for quality improvement and evaluation are also about building a culture of learning within organisations, across the disability sector and in the wider community. Becoming learning organisations requires the breaking down of barriers between people, the building of trust, using action research and reflection and actively encouraging participation at all levels.

## 5 Resource allocation

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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
- sustainability of services and support - providing better for people over their life stages and through transitions
- resourcing the reform process.

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.

### 5.1 Resources – planning issue

It is not possible to address resourcing issues in isolation from other matters raised in these consultations. People are aware there is not a bottomless pot of gold available. On the other hand they would identify current gaps, inequities and inefficiencies in the use of resources. In the end priorities will have to be set and agreed. In some quarters there is a perception that very little priority setting has been done to date and that funding decisions have been somewhat reactive.

People consulted feel there has not been a great deal of transparency around the reasons for funding decisions and they think that squeaky wheels might get priority. There is also a common perception that accommodation services take the lion's share of available funding and that other areas are not sufficiently resourced.

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. For example it can be very difficult financially to access resources or support to engage with mainstream services and opportunities including education, transport, employment and social activities if you must always take a taxi. 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. There is some awareness that planning resource allocation should include a re-examination of how existing resources are being utilised, not just looking at how new monies can be directed.

## **5.2 Funding programs or people?**

People with disabilities and their families are looking to play a greater role in determining what resourcing options will work best for them. This assumes some capacity for choice of funding options and for people to become more comfortable with greater choice over time. As with many issues in disability, it is not an either or situation, but an either/or/and situation

### **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.

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.

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 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.

## **5.3 Long term sustainability of support and services**

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.

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.

## 5.4 Resourcing the reform process

Finally, the joint workshops concluded that the reform will have little chance of success without an investment of resources. Such resources will be needed to support several of the proposals emerging as priorities – for example.

- Information and service access
- Investment in early intervention
- Individualised funding packages
- Policy development
- Planning, research and evaluation
- New processes and systems for quality
- Participation of people with disabilities and families
- Innovation, research and evaluation
- Training
- Ongoing consultation

In addition management of the reform process itself will require resources. This will be the case for government agencies and community organisations and advocates. Structures such as the DRG, with its new emphasis on partnership and collaboration, involve significant costs (people's time, agency time, consultation costs, information dissemination, secretariat costs).

## **6 Sustaining the reform process**

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Many people have heard what is being said in this consultation before. This time they want action, and they want a role in seeing that the action does happen. The issues they raised around sustaining the reform process fall into five broad areas:

- A planned approach
- Accountability in the reform process
- Supporting leaders and change champions
- Innovation, research and evaluation
- Ongoing participation, communication and consultation.

### **6.1 A planned approach**

Elsewhere this report captures the strong conclusion that strategic planning is critical to improving the lives of people with disabilities and their families in the ACT. Stakeholders in the consultation seek to be a part of this ongoing planning and have emphasised the importance of wide ownership of the reform strategy. Government is seen to have a particular responsibility for putting such a planning framework in place with strong participation from people with disabilities, families and organisations in the community.

At the same time there is a strong desire and high expectation for immediate action. Part of the challenge in managing the reform process will be to keep a balance between getting on with some change and taking a planned and strategic approach to reforms so as they will be sustainable and able to show results over time.

### **6.2 Accountability in the reform process**

Many people have been through a similar well-intentioned consultation to this one many times over many years. They hope for change this time, but they remain to be fully convinced. They want a governance structure around the reform process which enables progress and achievements to be measured and reported to the community. One workshop group talked about an ‘Accomplishment Framework’ which could be used for this purpose.

The workshops called for precise action plans with clear responsibilities and performance milestones that allow for review and reporting what has been achieved. Again Government was seen to have an important responsibility for achieving results from the reform process. But the consultation also emphasised that there has to be a wider responsibility embedded in all organisations playing a role (specialist and mainstream) and in the community if the reform process is to be successful.

### **6.3 Supporting leaders and change champions**

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. Anyone in the sector can take on this function, and everyone in the sector will have a role in supporting them in promoting positive change and innovation. However such leadership needs to be encouraged, supported, rewarded and resources if it is to have a positive impact over time.

## **6.4 Innovation, research and evaluation**

Quality standards were regarded as a being important in building objective structures and systems to support staff and others in making changes in the right direction, with strong input from clients. 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.

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 also 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, their families and organisations working in the disability sector.

If continuous improvement is to be sustained, a culture of research and evaluation will need to be developed and resourced in the disability sector. Routinely seeking client feedback and developing expertise in tools such as action research and incorporating this into the way business is done will be important.

## **6.5 Ongoing involvement in decision making and consultation**

This consultation suggests that a multi-layered and flexible approach is needed if effective participation and consultation involving all parties is to be achieved. As well, the commitment to participation and 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 formal consultations around high-level government policy. Consultation and involvement can be formally organised and time-limited or spontaneous informal and ongoing. It can be online or face to face. It can be based around recognised networks, organisations or individuals. The sector needs all of these.

While all who participated in the current consultation would support these general statements, implementation of suitable approaches is not straightforward. It needs to be acknowledged that many people in the sector did not come forward with their views in this process. A range of other longer term and more creative strategies and approaches will be required to engage people with disabilities who have difficulty in speaking out, people from Indigenous backgrounds, and those who are just busy, weary and cynical.

The consultation found people wanted opportunities to come together with others with whom they have something in common. Sometimes people with a similar disability will welcome the opportunity to speak in depth about their issues. Parents or carers may like to talk together. Organisations involved in advocacy as distinct from service delivery may want to discuss developments in thinking about advocacy approaches. Consultation may be around specific issues such as transport, physical access, accommodation, building a satisfying social life, relationships with carers, parental involvement or ageing. Identifying issues and focusing processes around them will bring together people with common concerns so that solutions can be explored.

At other times more will be gained from bringing players with different interests and viewpoints together. The joint workshops in this process were well received and powerful in their capacity to create better understandings and build bridges between people who may have come with different perspectives and interests. Many people said they would welcome more opportunities of this sort. However, the planning workshops covered a broad range of issues and it was not possible to develop concrete proposals across the range of issues identified.

The consultations showed that people do want to have their voices heard, they do want to be involved in decisions that affect them, and that they have many ideas for improvements. However, while ideas were put forward about how best to ensure that this happens, no clear overall direction emerged about the best way to develop and maintain consultative processes and participatory mechanisms across the system. Some new ways of doing things are needed, but it is again clearly a case of one size does not fit all.

## **7 Report supplement – participation and consultation**

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Part of the consultancy brief was to offer advice based on the consultation about future processes and structures for consultation. The following section draws on RPR's own thinking about consultation processes based partly on experience in this process and from wider experience.

It was clear from the consultations that people with disabilities and their families in the ACT do want to be active participants in decisions that affect them. This is true at the level of planning and delivery of individual services and at the broader policy level. In addressing this topic, it is important to recognise that there is a range of ways people can be involved. A prerequisite in planning for greater involvement is to be clear about the parameters of what we are talking about and to acknowledge that different people will seek different levels of involvement at different times. The important thing is that there is a culture in the overall system which encourages involvement and it is accepted that people can choose to be involved in different ways.

This section outlines issues associated with consultation, participation, partnership and collaboration, formal advisory mechanisms. It also identifies the importance of using existing organisational structures for making links, seeking advice and keeping people informed and finally it talks about some ways of keeping in touch with the disability community and beginning to structure information and contact to suit individual preferences for the level of involvement they are seeking.

As some of the ideas and issues presented here did not come from the consultation directly, it is hoped that they will provide a stimulus for more discussion about these matters in the context of the particular needs of the ACT disability sector.

### **7.1 Processes and structures for involvement**

#### **Differentiating participation and consultation**

In the context of involvement in decision making, consultation is a narrower concept than participation. It generally refers to processes of gathering information and views so that these can be considered in the decision making process, with the decision making usually being a separate process that draws on other information (such as research and expert advice).

Yet these two concepts, participation and consultation generally get used in an undifferentiated way. Consultation often becomes overburdened in terms of what it is expected to deliver, particularly where the processes draw together stakeholders with different and sometimes conflicting viewpoints and interests.

#### **The place of consultation**

Consultation can be used to assist decision-making at multiple levels. It is most helpful at two points in the decision making process:

- to gather information and views at the front end to scope what the community is thinking or experiencing around certain issues and to gather ideas for what action might be taken;

- to obtain feedback on proposals that have already been shaped by other processes (for example through joint working groups, by the DRG or by government, through for example research and evaluation exercises).

There is a range of consultation methods and it is usually sensible to offer more than one way that people can contribute their views, as was the case with the DRG consultation (Focus groups, surveys, workshops, written ideas, phone-ins and one on one interviews). Choice of methods will depend on who is the audience and what is most likely to work for them. It will also be influenced by the subject matter of the consultation and what stage the decision making is at (initial scoping or getting feedback on proposals).

### **Basis for effective consultation**

The ACT has an established Consultation Protocol that is Government policy. It provides guidance on how consultation should be undertaken: In RPR's experience the most important ingredients are that the consultation is:

- well-planned
- has had good publicity
- has adequate timeframes
- provides a good briefing ahead of time to assist people understand the context and scope of the consultation and to prepare their thinking and contribution. This briefing should indicate what is up for discussion (and what isn't if there are already established parameters)
- processes are appropriate to the audience (running focus groups with clients of services will be different from talking with academics and established organisations, including consumer organisations)
- there is support to participate, good location and amenity
- people receive feedback on the outcomes of the consultative process that helps them to see how the differing contributions (including their own) have been synthesised and considered.
- people are kept informed of what decisions and actions flow from consultation processes.

### **New forms of participation - partnership and collaboration**

At the Commonwealth and state and territory levels, we are seeing increasing emphasis on partnerships and other forms of joint structures being used to achieve direct participation in decision making. The DRG is one such example as it seeks to build partnership and joint development of responses to Gallop and the future reform process.

These examples are concerned more with direct participation in decision making processes, or bringing parties together to work through differences and come up with a common viewpoint and strategy that draws on the collective expertise and reconciles different interests. Such partnerships may then consult with a wider group of people or interests to help them formulate their thinking and decisions.

There is scope in the ACT disability reform process to use partnerships and joint ventures to much better effect in a range of areas:

- planning and monitoring reforms
- drawing in expertise to develop detailed proposals and direction within a broad plan
- working on new policy
- building a pool of reform champions

- developing new services (including through more joint ventures).

Joint workshops of the kind conducted in this consultation can be considered as a way to facilitate wider participation in this kind of work. It may be that the DRG or Disability ACT could plan 3 or 4 such joint forums over the year that have a specific content focus linked to the reform agenda.

### **Formal advisory mechanisms**

At the same time Governments have traditionally established advisory structures to provide for direct input to policy making. These may be expertise based or representative, or more commonly these days a mix of the two.

If the DRG is established as a permanent advisory group, its relationship with existing advisory structures such the Disability Advisory Council will need to be clarified. At the same time, there are advisory mechanisms that deal with other population groups and or issues (women, youth, indigenous affairs and multicultural). It could be worthwhile to establish links with these other groups and to encourage some of them to take an interest in the disability reform agenda as they can provide valuable pathways into both mainstream and marginalised community networks.

### **Peak bodies and organisational networks**

In the ACT there are a number of established peak bodies (specialist and other) that play a role on disability issues. These include bodies representing consumers, self help groups and service providers. Such bodies can play a useful role in linking into the communities and tapping different constituencies, providing expert advice, as a vehicle through which consultation might be undertaken and as partners in the decision making processes through, for example, joint working groups.

### **Links to other structures and processes**

Consumer organisations, peak bodies and specialist and mainstream service providers participate in a wide range of advisory and consultative structures and processes. Due to the size of the ACT, these processes can make heavy demands on the existing resources in the system. With the changes in the departmental arrangements and introduction of the DRG model, it may be timely to have a stock take of existing structures and processes to ensure that there is a clear rationale, coherence and efficiency in how these will operate in the future.

### **Learning from what's happening in the service system**

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 how any service system is working. 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. We need to tap into the ideas and wishes that are expressed at the service interface, both those that can be met and those that are beyond the system's capacity at this point in time.

Staff are another key source of input and ideas. Most organisations have processes (staff meetings, training and forms of supervision and support) that are directed to tapping into what staff think is working and how things might be improved. We also need to find ways to capture this thinking within and across organisations in a more systematic way.

### **Reaching marginalised people and those not in contact with services**

A further issue is ensuring that processes of consultation reach beyond the people who are easiest to reach or those who are connected with formal service or consumer networks. A key to this is being able to access data that helps us understand who to target and using processes that engage people with least effort on their part.

More could be made of qualitative research as a strategy for finding out about the views and experiences of people who are marginalised and not in contact with services.

Increasingly government and community agencies are choosing to pay people for the time they contribute to focus groups and other research processes. Another strategy that is occurring more often is for interviews and focus groups to be undertaken by people who are already in contact with and trusted by the target audience. This approach could be particularly useful in engaging people with disabilities from culturally and linguistically diverse backgrounds may be seen as a 'hidden group'.

There are also opportunities for use of mass media, phone-ins and Internet technology to reach people who aren't likely to want to attend meetings or otherwise participate in group processes.

### **Consultation with Indigenous people and communities**

Consultation with the Indigenous community in the ACT who are concerned about disability issues, including people with disabilities, families and organisations supporting them, is likely to require different processes to the usual format of consultative workshops, forums and focus groups. Gaining access to the community is the first step. Approaches should be through Indigenous organisations and community leaders. Those seeking to hear the community's views need to take advice on the best way to reach people and how the issues should be canvassed, noting areas that may be culturally sensitive. Experience in other areas suggests that processes for taking with families and staff of organisations may need to be more informal and flexible.

In our experience, Indigenous organisations and communities prefer their own process, rather than participating in large forums where they are in the minority and feel their views are hard to get across. A common failing in consultation with Indigenous communities is the tendency to tack the process on to a community wide process, rather than take a planned and culturally sensitive approach to the issues and process.

Another problem can be that the very small number of Indigenous organisations get called upon to assist with access to the community or direct involvement in consultations across a wide range of policy and service areas. The resources available limit their capacity to respond and participate, particularly given the tight timeframes that can sometimes apply.

### **Promoting a culture of participation**

A range of consultative processes and participatory mechanisms can be put in place, but in the end it requires a culture change to make them work well. If the reform process generates that culture change it would mean that formal mechanisms are only part of the

process. People with disabilities and their families would feel free to provide feedback and input to any part of the system and would have confidence that they would be heard; it would mean that staff working in the system could raise ideas for improvement and have them acted upon; government and non-government service providers would feel able to talk freely with each other.

## **7.2 Keeping in touch – data and regular communication a key**

### **Register of interest and expertise**

The DRG has specifically sought advice on establishing a register of interest and expertise. While this could have value, there needs to be a specific purpose or opportunity that people are responding to in registering their names and contribution. If registrants are subsequently not approached to participate, they will become frustrated over time.

Such a register is more likely to be helpful in selecting people with expertise and interests to sit on working parties, rather than as a method to determine invitations to a consultation process. Consultations are usually quite targeted or broadly based. In either case they will need to go beyond those that have previously expressed interest.

### **Data base for communication**

Disability ACT could maintain a database of people who wish to be kept informed of developments in the reform process. This could also serve as a list for publicising consultation opportunities. Peak bodies and other networks are likely to have data bases that should be used to publicise consultation and distribute information.

## **7.3 Matching choice of process to purpose and task**

The DRG should be considering how participation can be strengthened at the service and policy and planning levels. Ultimately there will be a range of processes that are needed and each needs to be designed around a purpose, target audience and choice of strategy or process.

There are probably six broad strategies that need to be kept in mind that would help build the culture of participation and involvement that people with disabilities and families are looking for. These are over and above the formal structures like the DRG, Ministerial advisory bodies and peak bodies.

- Keep the broad-based communication flowing regularly, including use of the media and other short communiqués using plain English and user-friendly formats to engage interest.
- Have joint working groups that extend beyond the DRG membership to work on substantive issues or planning. Ensure that people with disabilities, families and interested organisations can play a role in these.
- Have more structured and broadly based consultation processes that bring people from different areas together to share experiences and shape ideas and strategies for reforms (2-3 times per year).
- Have a series of more structured and targeted consultations with people who are unlikely to participate in broader consultation processes.

- Encourage government and non-government service providers to give priority to keeping their clients and constituents informed about developments in the reform process and encouraging their active involvement in decisions that affect them.
- Embark on research to learn more about the groups who are hard to reach or unlikely to be in touch with services and networks.