

DRG DISCUSSION PAPER #2

Strengthening Support To Individuals And Families – The ‘Front Face’ of the System

Anne Cross developed this paper as part of the work of the Disability Reform Group. It combines her input, discussions of the DRG, input from individual members of the DRG and issues raised in the literature.

1. The System of Support for People with Disabilities

The vast majority of people with disabilities receive most of their support from their families and other ‘natural’ supporters. Both the empirical and anecdotal evidence demonstrates this convincingly. Only a relatively small number of people are fully dependent on residential and accommodation services. Even though there has been some improvement in support and ‘respite’ for families the focus and major resources of the present formal ‘system’ of support for people with disabilities is substantially focused on residential and accommodation options, not on flexible personal and family supports. Indeed it is predictable that the demand for residential options will continue to increase exponentially if there is not better focus and attention on supporting individuals and their families and other natural supporters.

If the ***main system of support for people with disabilities is their families and other natural supporters*** it would be logical to direct substantial effort towards re-designing and refocusing the system so that people with disabilities and their families and other supporters are assisted, supported and strengthened. It would seem far more sensible to proactively support individuals and their families so that it is easier for people with disabilities to have the kind of life or lifestyle that is optimal for them.

2. Some Other Key Issues

Individuals and families continue to report on the fragmentation and inflexibility of the system. Furthermore they report feelings of being disempowered, and experiences of not being given the information they need in a timely manner, not getting the help they need when they need it, being left to manage, being case-worked and seen as the problem. They also experience discrimination in accessing the ordinary facilities of the community.

Consistently people with disabilities and their families and supporters indicate that their core needs include:

- Recognition and respect for their roles
- Recognition of their competencies and strengths
- Control over their own life/ lives re: decision-making, planning, and problem solving
- To be as self sufficient as possible – not be dependent
- Recognition of the importance of relationships in their lives
- Opportunities to know what is possible, to imagine “better”
- Flexible support that is tailored to their needs

If this is what individuals and their families consistently tell us, then it would be ethical and sensible to develop systems and approaches which respond directly to these preferences and issues.

In addition to the issues raised by individuals and families, there are some other ‘systems’ issues. These include:

- No clear pathways to assistance
- ‘Poor’ reach – substantially reactive, rather than proactive support to individuals and families; little capacity to reach out to people who are not ‘in touch’ with the system
- Difficulties in distributing resources in an efficient and fair manner
- Resources locked into (inflexible) service models
- Limited capacity to respond to ‘underrepresented’ constituencies
- Relatively small portion of the system directed into flexible personal and family support
- Weak capacity to encourage consumer and family initiatives
- Limited ‘grass roots’ strategies for encouraging change or for supporting the advocacy of individuals and families at the community level and in mainstream systems
- Poor planning data that reflects the ‘grassroots’ experiences of people with disabilities and their families

3. Some Relevant Principles for Development of the 'System'

In any development and re-design of the 'system', it is proposed that the following principles guide the development of the system. These include:

- **Outreach to *all* People with Disabilities and their Families across all Life Stages**
- **Clear Point(s) of Access and Support for individuals and families**
- **Access to Relevant and Timely Information**
- **Recognition that People with Disabilities and their Families and Supporters have a Legitimate Authority in their own Lives**
- **Support to individuals and their families include opportunities to Imagine "Better" and to plan the ways in which goals might be pursued**
- **The Importance of Informal Supports, Natural Social Networks and Mainstream Services**
- **The Adaptation and Responsiveness of Mainstream 'Generic' Services and Supports**
- **Access to flexible 'Formal' Personal and Family Supports which Complement and Strengthen Existing Arrangements**
- **Access to 'Specialist' Disability and Health services**

While these principles have implications across the whole system, they are particularly important for what the Disability Reform Group has come to call the '**front face**' of the system. *Many of the principles speak directly to the support that is available to assist people with disabilities and their families and supporters to be as self-sufficient as possible, to maintain the integrity of their own lives and their family life, to engage the support they need and to pursue their life goals.*

They also propose that a basic principle of the system should attempt to address the issues of 'reach' across the system and people falling 'through the gaps'.

4. Consideration of Some Models and Approaches for the “Front Face” of the System

4.1 Local Area Co-ordination

In response to issues similar to the ones raised in this paper, the Disability Services Commission in Western Australia operates a Local Area Co-ordination Service throughout the State. The Charter of the Western Australian Service is:

“To develop partnerships with individuals and families as they build and pursue their goals and dreams for a good life, and with local communities to strengthen their capacity to include people with disabilities as valued citizens”

The overall aim of this statewide service is to support people with disabilities to live within accessible, welcoming and supportive communities. Each LAC operates as a service co-ordinator rather than a service provider and, as such, is there to help the person with the disability and their families/carers where appropriate to plan, select and receive needed services. Key elements of the role include:

- Information and support,
- Planning with individuals and families,
- Assistance to access and engage needed supports,
- The use of small levels of direct funding,
- Assistance to apply for funding via various funding programs,
- Assistance to access generic or mainstream services and build community connections, and
- Advocacy support.

The scheme has been reviewed and evaluated on many occasions. These evaluations show amongst other positive results a high level of satisfaction from individuals and families and good ‘outreach’. The work of LAC’s is safeguarded through training and support for LAC’s, a supportive management framework, and regular reviews and evaluation.

Local Area Co-ordination has been adopted in other jurisdictions in Australia and overseas. In Queensland, the aspirations of the much newer Local Area Co-ordination scheme are captured by this statement.

"Once connected to a local area coordinator who lives and works in their own community, individuals and families have access to information they need, they have someone to assist them think and plan about the future, to assist them over time to build supportive networks and relationships, to connect them to services in their own community and if required, apply for any funding and service support that may be available."

An evaluation of the initial nine sites in Queensland has just been completed and this evaluation shows very promising outcomes that are consistent with the above principles.

All people can be assisted by Local Area Co-ordinators on a one-off or short-term basis (Level One eligibility). As well Local Area Co-ordinators work with people on an on-going basis where there is need for on-going support. (Level 2 eligibility) LAC also provides a mechanism for people who wish to self-manage funds they receive for support.

4.2 Wide Range of Flexible Personal and Family Support

There are many examples especially in the US of Family Resource Centres that have a broad mandate to support and strengthen families in their parental roles. They typically combine a range of services and supports. Many would incorporate principles such as

- ◆ Support directed to the family as a whole, as well as individual family members
- ◆ Support that is flexible, individualised, and responsive to the changing needs of families
- ◆ Recognition of family integrity and respects the personal and cultural values of the family
- ◆ Mobilises the flow of resources to the family
- ◆ Builds and strengthens the social support networks of the family
- ◆ Builds the competencies of the family, especially the parents
- ◆ Minimises intrusion upon the family
- ◆ Maximises the family's control over the amount, time, and methods of provision of support, resources or services.

Many of these family resource centres would be mandated to be there for all families, who have a family member with developmental disabilities. Most of these agencies have been set up to work with families, and are less well positioned around adults with acquired disabilities or adults with developmental disabilities who have married, etc.

Likewise, in Australia there are examples of service providers who undertake the range of support functions with families, not just the provision of direct services. Increasingly in the last decade, however, their contracts have more been more prescriptive with respect to the provision of direct services alone.

There are also some compelling arguments that the support to individuals and families around decision making and planning is best separated from the provision of direct services. This is to assist in overcoming the in-built conflicts that exist between the provision of independent advice and the provision of direct services.

4.3 Self-help and Family Support Groups

There is a long history of people seeking information and support from people who are in similar circumstances to themselves and this has led to the emergence of various self-help groups. This is no less true in the disability area where self help groups have made an important contribution. Some have relinquished their self-help 'roots' and grown into major service providers. Others continue to substantially reflect the principles of self-help and are either internally focused on maintaining members or undertake a range of educative, advocacy and community activism. Consumer and family governed services, that retain their grass roots connections, are further examples of self-help groups.

In the disability area, many self-help and support groups have been diagnostically based. Thus they have tended to perform narrow rather than broad functions. They are likely to have a core membership of long standing and contact with other members on a shorter term basis.

4.4 One-stop Service Access and Information Centres

Many jurisdictions have implemented Service Access and Information Centres as an entry point to the 'formal' system. Various examples of these exist in the UK, Canada and the US. New Zealand has a national needs assessment service implemented nationally but operated via contracts with non-government providers. Needs assessment and case management are separated in the system from direct provision of services.

The focus for most of these centres is on access to formal services, and often incorporate assessment and service co-ordination functions. They would provide information and undertake assessment for funding and

services, establishing eligibility for long term services. They are the main 'gatekeepers' to the resources of the formal system.

Typically they are reactive to people finding them, or being referred to them. There is usually little emphasis given to planning apart from funding and services, and little emphasis on community building and community change. In this sense they have few strategies to deal with the reality that many needs of people cannot be met within specialist disability systems. Nor have they much to offer if funding is not available. Typically they would have short-term relationships with people with disabilities and families.

4.5 Information Services, including one-stop shops

One-stop shops are primarily designed as information services. They typically have 'street' visibility, and develop data bases about what exists. Typically they do not have a referral role or responsibility to help people navigate the system. They simply assist people with information about what may be available. These are closely associated with the "Community Advice Bureau" model from the UK that has been implemented in various ways in Australia, especially in conjunction with community centres, neighbourhood centres and the like. In Australia they have also been tried as government information services. In the ACT various information services currently exist. As well, part of the rationale for the establishment of the regional officers of Disability Programs was to provide a local 'point of access' for people with disabilities and their families.

While information is clearly an important need of individuals and families, most experience would suggest that one-stop shops per se have been quite limited in assisting people to get what they need. Incorporating easily accessible sources of good information into system is a crucial issue, it may be more useful to combine it with some other functions, rather than limit the role to information only.

4.6 Brokerage agencies

Brokerage agencies originally developed in British Columbia to support people with disabilities and their families to have greater control over their arrangements and more independent advice than might be available from any particular service provider. They have strong links with individualized funding approaches. They were also designed to assist people to navigate the system. Their basic role is to assist people to develop plans, submit for funding, and then purchase the supports the person requires once

funding is made available. They will assist people with service co-ordination to the degree that this is needed. Brokerage agencies are likely to have long term relationships with the people for whom they 'hold funds'.

Unless they have been deliberately designed to be the 'front face' of the system, many people with disabilities and their families would not know to go to a brokerage agency. In many jurisdictions brokerage agencies mostly have contact with people at the time funds are allocated, rather than before.

Clearly this is a model with which the ACT is familiar and the current role of these agencies would need to be considered in any re-design of the "front face" of the ACT system.

5. Recommendations Regarding the "Front Face" of the ACT System of Support for Individuals and families

- 5.1 ACT government should place high priority on assisting individuals and families to get the information and assistance they need to maintain control over their own lives and pursue their goals. This should be provided in ways that support individuals and families as much as they want.
- 5.2 ACT Government should take steps to develop an proactive model of support in the ACT that is based on the following principles:
 - ❑ Outreach to *all* People with Disabilities and their Families across all Life Stages
 - ❑ Provides Clear Point(s) of Access and Support
 - ❑ Provides Access to Relevant and Timely Information
 - ❑ Recognises that People with Disabilities and their Families and Supporters have a Legitimate Authority in their own Lives
 - ❑ Recognises the Importance of Informal Supports, Natural Social Networks and Mainstream Services
 - ❑ Technical assistance that enables individuals and families to Imagine "Better", and to Pursue their Goals
 - ❑ Assists people to access the ordinary Mainstream 'Generic' Services and Supports that are available to all citizens of the ACT, and supports them in their advocacy as necessary.

- ❑ Assists people to Access 'Specialist' Disability and Health services
 - ❑ Assists people to apply for funding for which they might be eligible
 - ❑ Aggregates information and data that will assist the ACT to plan effectively.
- 5.3 ACT government should incorporate into a model for the ACT the elements of the role of Local Area Co-ordinators in West Australia and Queensland but adapt this to the circumstances and existing infrastructure of the ACT. Work should be undertaken to examine current roles, and scope of those roles, whether the roles should be expanded or redefined, whether new roles should be combined into one scheme or built into the system overall, and whether this support should be located within or outside government.
- 5.4 ACT government should support the existence of self-help and other consumer and family initiatives that support individuals and their families.
- 5.5 ACT government should examine its contracts and pricing to encourage all service providers to support families to get the information that will help them access the support they need.