

DRG DISCUSSION PAPER #1

Service Reform, Development and Renewal

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.

The challenge of service development and renewal essentially revolves around the question of whether services offered to individuals are potent and relevant. This is a "state of the art" question insofar as it is desirable to have the capacity to render service in such a way that the individual concerned has access to all the advantages of evolution of the field.

It is apparent that many individuals and families who are currently receiving service in the ACT are satisfied with those services. Many people are concerned that services not be reduced or changed. This paper is directed at making it possible for more people to get services, which are relevant to their needs and consistent with their aspirations for themselves. So what is proposed is further development and modernisation of the system so that more possibilities are available to people with disabilities in the ACT.

The DRG considered a number of issues in arriving at the following recommendations.

First, it developed a set of criteria for ascertaining the importance of any particular reform. These are listed at Appendix 1.

Secondly, it conceptualised the *system*, and named some of the core overarching reform issues. This is represented diagrammatically at Appendix 2.

Thirdly, it reviewed a summary of the issues from the literature that specifically pertain to accommodation support/ supported living. See Appendix 3.

Fourthly, it considered the relative merits and issues involved in "*top down*" and "*bottom up*" change. This diagram is at Appendix 4

These discussions also influenced the work it did on "front face of the system" (**Paper #2**) and its work on Quality (**Paper #3**).

The Disability Reform Group recommends the following strategies to Government to improve the options available to people with disabilities. These need to be read in conjunction with the recommendations in the other papers produced by the DRG.

1. Creating more options and the development of more “person centred” arrangements.

The DRG believes the government should adopt a programme over the next five years that focuses on the *modernisation and renewal* of the system. Such modernisation should focus on

- Making flexible personal and family supports the core modality of the system, and
- Any service expansion for the foreseeable future should be undertaken principally within innovative personalized support arrangements.

A **first step** would be to establish the principles and policies that will guide service improvement, development and renewal. This implies a strong role for government in working with stakeholders.

2. An ongoing strategic leadership, renewal and innovation training/education plan for staff, people with disabilities and families.

It is improbable that any measurable progress on any of these agendas can be expected without the accompanying *“people investments”* of education, leadership development, networking, project environment, etc, as these are the core predictors of human performance. While it is true that some forward movement can be expected in the case of exceptional individuals this does not hold true for most consumers, families and providers. These should be thought of as sector wide resources and should include and be available to people with disabilities, families and workers in the field.

Some investments could include:

- a) An annual progress and change conference for the field that focuses on *Living Well*.
- b) Leadership level events for people with disabilities, families and providers that would support and equip them to take on the many leadership roles that are necessary if progress is to be made on the modernisation and renewal of the system.
- c) Opportunities for people in the ACT to hear from innovators within and outside the ACT.

- d) A programme of values based training that would encourage people to think critically about how services and supports are developed and arranged for people with disabilities.
- e) An opening up of training across the field, for example the *Certificate* /// basic training.

3. Establishment of “grass roots” or “mini” projects of innovative Consumer/ Family Partnerships with Providers and Disability ACT

A sensible way to “break new ground” is to do this through small projects aimed at both innovation and improving partnerships with consumers and families. This enables people involved to try out new ideas in manageable steps. Small projects have the advantages of being more responsive to people who are directly involved, and corrections and modifications are more easily made.

- a) These projects should not be time-limited “pilots” unless it is apparent that this suits the particular matter or issue. They might be developed using current funding, new monies or small grants from the innovation fund or a combination of any of these or other sources of money. Innovation in itself may not require additional money.
- b) The priorities for service innovations should be developed in collaboration with people with disabilities, families and providers. It should develop priorities based on the established principles (#1 above) that will guide service improvement, development and renewal.
- c) Innovation will not occur unless there is a clear focus and priority given to it. Thus it is important that a small percentage of funding resources are always directed to innovation in an ongoing manner.
- d) Innovative projects should be accompanied by an evaluation strategy so that the learning from them can be shared across the field.

4. Creation of *Technical Capacity* for the creation of more flexible and personalised supports within the system

It is predictable difficult for people who are used to one way of doing things to shift to another. The transformations proposed in the Gallop Report are such major shifts, and these will obviously proceed with higher quality if consumers and their supporters, providers and departmental personnel are provided ongoing ‘hands on’ technical advice and assistance

in learning how to optimally develop new arrangements and transform existing service models and into desirable personalized support arrangements. The training component is covered by the "investments in people" (#2 above) but this leaves the question of targeted technical assistance, since its presence would have considerable strategic importance. Badly implemented personalized supports help no one. The risk in these new arrangements can be greatly minimized by building up service design expertise and connecting aspirant and novice service designers with more experienced people both within and outside the ACT.

This kind of resource is rarely covered in routine program budgets as it is often "assumed" that the competency of the provider is sufficient. Such an assumption may be less risky to hold if the task at hand is a routine one that is widely mastered in the system, as individuals needful of consultation and advice can readily get it as a casual and informal element of their networking. The support proposed here is of a different order, as it can safely be assumed to be limited in availability, given the relatively modest levels of experimentation in the ACT with flexible personalized support arrangements.

5. Creation of a Contracting/ Purchasing Environment that would permit more flexible and personalised support arrangements.

- a) The Government should review existing contracts with providers with a view to permitting and encouraging funds currently held in established and fixed models to be used more flexibly and wholistically on behalf of individuals.
- b) There should be developed a set of desirable outcomes for consumers as a key ingredient of the contracting system. (See paper on Quality & Standards)
- c) Contracts should be reviewed and the desirability of including in all contracts a responsibility for community development should be explored.

Criteria for Judging Service Reform Proposals

Vision Significance

Will the action progress the intent of the vision that people with disabilities have an ordinary life with the same opportunities as other people as other people in the ACT?

Values Significance

Is the action consistent with the articulated values?

Relevance

Is the reform relevant to the needs of people with disabilities?
Will the reform have a breadth of impact – for whom, how many, etc?
Does the reform address known gaps?

Potency

Will the reform, if addressed, bring strong advantages for people with disabilities?

Long term Significance

Will the reform have an enduring impact?

Capacity Building

Will it enable rather than constrain?
Will it support problem solving and creativity?

Feasibility

Is it realistic to address this at this time?

Economic Viability

Is it financially viable now?
Is it economically sustainable over time?

Foundational Primacy

Does it resolve primary matters first and build success?

Right Relationship

Does it progress in a way that ensures that the relationship with people with disabilities and their families accords them the appropriate influence?

Strategic

Will the matter if addressed now bring greatest advantage?

System Design – Conceptualising the ‘system’

Main (primary) System of Support (Private Domain)

- *Individuals*
- *Families*
- *Community*

(What strengthens these primary systems?)

Mainstream Generic Systems

- *Education*
- *Health*
- *Housing*
- *Transport*
- *Justice*
- *Etc*

*Issues: Access
Adaptation of
generic systems*

‘Formal’ Disability Systems

- *DSP - \$34m*
- *HACC*
- *FACS – employment,
etc*

*Issues: Moving from ‘fixed’
models to more open menu
Quality issues*

Government Roles

- *Legislation*
- *Planning*
- *Funding Priorities*
- *Workforce planning*
- *Cross – govt*
- *Monitoring gaps in
service delivery*
- *Care & protection of Very
vulnerable people*
- *Ensuring adequate
safeguards*

Formal Corrective & protective Safeguards & Services – complaints, advocacy, service monitoring and evaluation, guardianship, standards, community visitors, etc

Shared Responsibilities (Shared Business)

Vision, Values, Public Policy, very vulnerable people, capacity building, qualities of the system, Service development & Innovation, priorities

Issues identified in Literature & Practice – Accommodation Support and Supported Living

The following summary is directed at identifying those factors which lead to better outcomes within small group home settings and to identify the qualities of the new breed of 'supported living' arrangements.

While the overall superiority of newer, smaller, community-based services (group homes) over institutions and medium sized units has been established through research and evaluation, ***there are significant differences in service quality within small community residential units.*** It is apparent that physically closing institutions has provided no guarantee against the re-emergence of "institutional" practices or sustained improved client outcomes over time. Low engagement of residents in meaningful activities has persisted in community housing, and increased staffing has not automatically increased resident activity. Long term studies of deinstitutionalisation have reported a plateauing effect after initial gains. Clearly where there is provision of service to a group, the major challenge is to preserve individualisation, resist 'group management' practices, and protect and safeguard vulnerable individuals.

The research has now moved to an analysis of the variables, which contribute to improved outcomes for residents. Several issues emerge in the literature as key contributors to quality. Longitudinal studies of group homes have been undertaken in both the UK, and in the USA. A number of variables interact and influence quality within group home models. Some of them are also pertinent for lifestyle support and accommodation services more generally. Within group homes, no single determinant seems to influence strongly better outcomes, but rather an interaction of variables is the key to better outcomes for individuals.

1. Size

There has been considerable debate within the literature as to whether 'size' is a key variable in successful and unsuccessful living outcomes. Generally size *alone* is not considered to be the powerful determinant of outcomes, however there is substantial evidence that size is a factor. Several major studies show that reduction in 'institutional' practices (by staff, and consequently by clients) is most likely to occur when size is small. In some studies this is considered to be 3 or less, in others 4 or less.

2. Grouping / compatibility issues

In the earlier literature there is considerable guidance and theory about grouping issues. Apart from size of the group, attention is paid to group dynamics that affect motivations of each resident to enhance their competencies and the capacity of workers to constructively manage the group. There is a rich body of knowledge on these issues, which seem to be largely unknown or lost in the field today. Some recent work has been done on the development of compatibility indices.

3. Client / staff ratios

Size is strongly related to the issue of staff: client ratios. However studies show that the amount of staff time available to individuals has been shown to be unrelated to the number of carers, unless people were supported in small groups of 1-4.

4. Vocational, avocational and recreational activities away from the 'home'

In the literature key variables in overall measurement of quality relates to the opportunities for residents to work and participate in demanding vocational and avocational activities, and to have leisure and recreational opportunities away from the home and outside of the 'group'.

5. Loss of the 'mission' of home

One of the many conflicts and tensions in group homes is the tension between a 'workplace' for the staff, versus the 'home' of the people who live there. This is an ongoing problem in group homes, and requires attention and resolve to overcome.

6 Loss of 'focus' on the individual

Even in quite small groups, it has proved difficult to retain consistently a focus on individuals. This is exacerbated by staff arrangements and staff turnover.

6. No forward planning and involvement of the person's life

After initial planing with individuals, the evidence is that once arrangements are in place, then this is maintained for lengthy periods unless there are difficulties. Thus people remain in the same patterns with little opportunity for advancement.

8. Nature of support provided – loss of a developmental approach.

Inadequate staff support results in low activity in clients. However increasing staff alone does not fix this issue. The quality and nature of the interaction between staff and residents is crucial. The degree to which staff are actively

involved in prompting clients, demonstrating and providing guidance to do an activity, teaching and instruction and the provision of "Active Support" is key variable. Liking grouping principles, many of the pedagogies for teaching seem to be largely unknown or underdeveloped in our current services. Minding and managing clients is far more dominant in many services today.

10. Loss of autonomy & rights

The quasi-institutional nature of many group homes, together with the loss of mission about 'home' has brought with it loss of clarity about client's rights and has left people with disabilities very vulnerable to exploitation and abuse. Vigilance and safeguards around all these issues are just as necessary as in institutional settings.

11. The Lack of Involvement of families, advocates and ordinary citizens.

12. Financial Status of clients

13. Organisational leadership

Leadership has been shown to be crucial in establishing internal structures, policies and procedures, motivating staff to implement practices, which support better lifestyles for people, and to preserve a clear focus on the individual.

This list of issues alone would provide ample challenges and guidance for a Group Home Improvement Project. While interrelated, each of these issues provides some clarity about directions and actions that would be required. However, whilst the group home is the dominant form of housing and accommodation support in many places, there is also substantial development of more personalised models of long term support for people with disabilities.

Contemporary Models of Supportive Living

During the 1990's, there was considerable development in thinking and practice in the provision of support to people with disabilities, including in the area of accommodation support. While there is considerable amount of material available, it is probably true that evaluation and theory development is lagging behind the practice. Nonetheless it is evident in places all around the world that while the group home remains dominant, there are more and more examples of other options emerging to challenge the group home as the best model of support for people with disabilities and other vulnerable people.

The *Major Features* of these emerging approaches and models include:

- Expanded use of more personalised support arrangements – person centred services
- Wide range of solutions, including home sharing with non- disabled
- Use of ordinary housing
- Separation of housing and support
- Clear mission of 'home', not just accommodation
- Developing solutions around an individual, rather than fitting them into a fixed model
- Service User and supporters entrusted with sufficient authority to influence the character of the supports they receive
- Flexible Individualised Funding
- Strong emphasis on relationships with non- paid people – supporting personal, neighbourhood and community connections.
- Strong emphasis on having 'meaningful things' to do; 'enriched lives'
- Personal control over one's own income
- Increased influence of service user in decision making
- Safeguards developed individually consistent with the vulnerabilities / risks for that person
- Arrangements change with the person's development & changing life circumstances
- Strong emphasis on community inclusion
- Clarity about 'Who' is directly responsible for decisions about individuals who need supervision, especially to prevent them being harmed or from harming others
- Targeted Supports for High Risk Individuals
- On-going emphasis on *people capacity* – values, leadership, skills
- Strong interweaving of the 'agency' or 'provider' with the broader community.

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Appendix 4

CHANGE

