Loneliness, Isolation and Not Belonging

Workshop Communiqué

While we may be heading towards a civilization which may have little further use for the “social”, for the time being it seems as though this problem is the cause of considerable pain and suffering.

Professor Adrian Franklin

On Wednesday, 17th October 2007 the Australasian Society for the Study of Intellectual Disability and the Department of Disability Studies, Flinders University, conducted a workshop “Loneliness, Isolation and Not Belonging”. This workshop, conducted to address what has been described as the “emerging crisis of loneliness” within Western societies and, in particular, the effect on people with disabilities, attracted 52 participants from a broad background.

Dr Lorna Hallahan, Lecturer from the School of Social Work in the Faculty of Social Science at Flinders University and recently appointed Chair of the Ministerial Advisory Committee on Disability, was the keynote speaker. Lorna set the scene for the workshop by describing the role seemingly assigned to people with disabilities in our societies and how our attitudes exacerbate the isolation of people with disabilities. Lorna also spoke on the need for community development and systems that put people more in control of their lives and destinies.

Dale Hassam, who recently retired after 45 years in the field of Intellectual Disability, spoke of his experience of managing the Department for Community Services’ relationship with the boarding house sector. He spoke of lives impoverished by a lack of friends, plans and hope for the future. Rather than homelessness being a cause of the problems in an individual’s life, it is much more likely to be a manifestation of “lives without hope”. Dale spoke of the need for new ways to include people with disabilities and
the limitations of the service system which often had a preoccupation with accommodation, not recognizing the sustaining capacity of friendships and a purpose in life.

He also spoke on the “Wraparound” model which has been successful in Canada in bringing these important components into a holistic view of the individual.

Mr Ross Womersley, Executive Officer of the Community Living Project, spoke on his organisation’s experience in implementing a “Circles of Support” program. This program entails finding significant people in the life of an individual who will meet with the individual to develop a friendship group and support the development of future plans. Ross showed a film that had recently been developed to demonstrate what the “Circles of Support” could offer to people with disabilities. There is no doubt that this initiative has insured that people with disability, that have participated in this process, have a group of people who are interested in supporting them on a long-term basis.

Ms Carrie Quigley, Teen Companion Coordinator of Interchange, spoke of the Teen Companion program. In this program, a young person with a disability is matched with a young person without a disability who shares the same interests. The two then meet on an agreed basis to do things that are of interest to both of them. Carrie mentioned that although they are able to recruit about 50 teen companions a year, they currently have a waiting list of 250 people with disabilities who are seeking a companion.

The discussion at the workshop ranged across a number of topics but some key issues emerged:

- There is a need to find out the degree of isolation amongst people with disabilities. As this has generally not been ‘on the radar’ of service providers, it will be necessary to ask people with disabilities themselves.

- The situation of people living in institutions needs to be examined. There is a view that many people with disabilities have a rich and varied range of relationships with other people in institutions and that when down scaling projects occur, these relationships need to be taken into account.
• There is a need to support people with disabilities to speak for themselves and to talk about the things that are important to them. Such organisations as “Our Voice” (a self advocacy group) should be supported so that the actual views of people with intellectual disabilities can be obtained.

• Community development initiatives are imperative. We need to find out where communities gather and work out strategies as to how those gathering places can include people with disabilities. It is interesting to note in passing that some venues are already very inclusive of people with disabilities e.g. football clubs.

• We need to recognise that if people with disabilities are truly integrated within the South Australian community then they have to have opportunities to contribute to the community. Many already do this through service clubs, their employment and through volunteering. These programs need to be supported and expanded.

• Developing the infrastructure to support these options for people with disabilities is well worth funding. Many are essentially volunteer models and do not require a high outlay of funds for a significant benefit to a potentially large number of people with disabilities. For example, once established, “Circles of Support” can be potentially self-sustaining.

• There is no panacea for the accommodation crisis or the overall substantial underfunding of disability services. Group home models of service are not cheaper than institutions. There have been a number of attempts recently, e.g. home boarding, that have not only been more cost-effective but have also given the individual an alternative family.

• The underpinning of addressing loneliness and isolation in people with disabilities will also address this growing problem in the wider community. We don't live in neighborhoods in a way that we once did. The majority of people drive to most places because public transport is not user-friendly. Children are transported to school and even if the supermarkets are close by, which is not likely in many of the newer housing estates, we invariably take our cars. These are all issues that will need to be addressed as we move to a society that has to pay more for its energy and transport.
• There are real economic costs to social isolation not only for people with disabilities but indeed all vulnerable people. It is those people who are usually unemployed whom we see as not making a contribution to the community. These people will be at greater risk of mental illnesses such as anxiety and depression. They will add to what epidemiologists call the community's “burden of disease”. These are the people who are more likely to find themselves vulnerable to a gambling addiction, substance abuse and exploitation by others. These are also the people who are most likely to find themselves before the courts on minor charges such as shoplifting and disorderly behaviour.

• Some participants expressed concern at the attitudes of other workers in this field often alienating families and controlling the person's contacts. Such programs as “Community Visitors” could have a substantial effect in ensuring that there are substantial other people in the lives of an individual.

SUMMARY

Loneliness and isolation are emerging problems in South Australia and not only for people with disabilities. The emphasis on the need to be first and foremost consumers rather than citizens has resulted in many in our society being disconnected, lonely and unhappy. Our “new toys” seemingly do not give us the happiness the “market” promised us in its seductive messages. These problems will be exacerbated when those living in ill-planned and infrastructure-poor suburbs are hit by the effects of the looming energy shortages and price increases.

The issues raised in the forum and documented in this communiqué present a significant challenge to all people who are concerned about the circumstances of people with disabilities and their families. The range of constraints (e.g. budgetary) on the responsible public sector agency - the Department for Families and Communities - appears to result in the department responding in a way that is more reactive (responding to crises) rather than putting in place proactive programmes that may address issues causing and resulting from isolation and loneliness. Strong leadership is required.
The Australasian Society for the Study of Intellectual Disability (SA) and Flinders University’s Department of Disability Studies recommends some urgent activities by the South Australian Government including:

- Research on the causes and nature of loneliness and isolation.
- Research on the effects of fuel shortages on our communities.
- Talking to people with disabilities about their lives.
- Providing opportunities for people with disabilities to contribute to our community.
- Giving high priority to community development initiatives.
- Research on the social cost of isolation.
- Some innovative programmes that demonstrate how people with disabilities can be included in the fabric of the community.
- Research on how power is given back to people with disabilities.