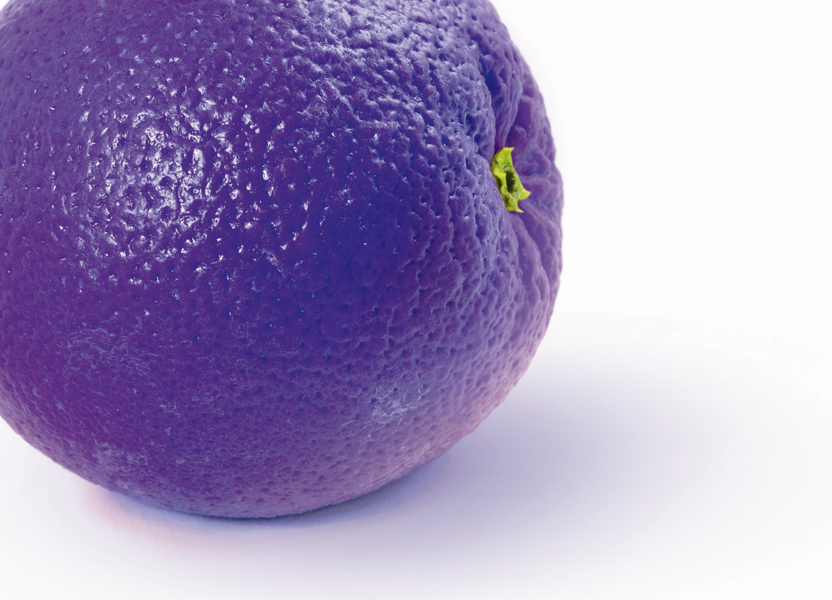

julia farr association

tell us 2
survey report

Having choice and control

This is the second in a series of reports from
the **tell us** disability community survey

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TABLE OF CONTENTS

1.0 PURPOSE

The purpose of this second **tell us** report is to help inform policy and decision-makers about some of the key areas for consideration that impact on the lives of people living with disability.

2.0 SUMMARY

The **tell us** survey contained a range of questions about the lifestyles of people living with disability. Based on nearly 800 responses, the survey results raise concerns, especially in regards to issues of choice and control in housing and support. Around one quarter of total respondents reported they did not have a say in their housing arrangements, and nearly half of relevant respondents reported they did not have a say in their support arrangements. Around one third of respondents reported they were not treated with respect when accessing services.

The report discusses these findings in the context of the UN Convention on the Rights of Persons with Disabilities, and notes the benefits of access to ordinary housing, person-centred planning, and the building of natural networks within the community.

This paper also notes the advantage of Individualised Funding, and the importance of a respectful and ethical relationship between people living with disability and those providing paid support.

3.0 INTRODUCTION

It is essential that people living with disability are asked about how they live their lives so that we understand what is important to them. This is an important prerequisite, for example, for the effective use of disability support funding, so that people living with disability can live lives of choice as active citizens in the wider community.

The Julia Farr Association (JFA) developed the **tell us** survey to gather this information and thereby to promote awareness within the community about the key issues felt by people in the disability community. This is based on the possibility that not enough is known about the daily lives of people living with disability. The survey focuses on painting a picture about people's lifestyles by asking respondents to talk about their lives and identify what they think could be different.

This report draws on these experiences, highlighting key areas identified by respondents including discussion on why these issues need to be considered and addressed by policy-makers.

4.0 RESEARCH METHODOLOGY

The questions for the **tell us** survey were derived from the Q50™ Framework[1] and cover key areas such as participation in family and community life, healthcare, employment, housing and access to services and support.

The **tell us** survey was widely distributed through the disability community and surveys were mainly collected over an eight month period until the end of February 2008.

5.0 DEMOGRAPHICS OF TELL US SURVEY RESPONDENTS

The **tell us** survey was completed by 775 members of the disability community: 610 people living with disability (Survey A) and 165 people who know a person living with disability (Survey B).

The demographic of the people who completed the survey are summarised below.

Gender and age group of those who completed the ***tell us*** *survey.*

Age Group	Survey A			Survey B		
	Female	Male	Not Stated	Female	Male	Not Stated
Under 18	6	13		5	8	
18 - 25	18	18		8	12	1
26 - 35	42	27	1	17	12	
36 - 45	69	42		9	10	2
46 - 55	77	47	1	22	13	
56 – 65	74	35		17	8	
66 - 75	55	27		2	6	
Over 75	32	22		5	1	
Not Stated	2	1	1	3	1	3

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[1] The Q50™ Framework is a proprietary tool that provides a mechanism for mapping, planning and measuring people's lifestyles.

The responses provided in the **tell us** survey identified that people have a lived experience of a wide range of disabilities and health-related factors.

Out of the 610 people who completed Survey A, the five main categories identified were:

Multiple Sclerosis	140 respondents
Parkinson's Disease	78 respondents
Arthritis *(includes Osteoarthritis & Rheumatoid Arthritis)*	77 respondents
Intellectual Disability	68 respondents
Acquired Brain Injury	40 respondents

Out of the 165 people who completed Survey B, the five main categories identified were:

Intellectual Disability	37 respondents
Down Syndrome	15 respondents
Multiple Sclerosis	9 respondents
Parkinson's Disease	8 respondents
Cerebral Palsy	8 respondents

6.0 NOTICEABLE STATISTICS

A number of noticeable statistics emerged from the **tell us** survey data which highlight some of the issues experienced by people living with disability.

6.1 DAILY LIFE

- Over one in five Survey A respondents stated that they did not choose where they lived. The percentage of Survey B respondents was even higher, with over 43% stating the person living with disability did not have a choice.

6.2 INDEPENDENCE AND SUPPORT

- Over 37% of Survey A and nearly 59% of Survey B respondents stated that they received help with their personal support needs like using the toilet, washing and dressing.
- Of the participants who received help with their personal support needs:
  - Over 34% of Survey A and nearly 28% of Survey B respondents stated that they were not treated with respect;

    - Over 24% of Survey A and 45% of Survey B respondents stated that they did not choose who provided them with personal support.
- Of the participants who received disability support services, less than half of all respondents (43.44% of Survey A and 42.42% of Survey B) stated that they had been given the opportunity before receiving assistance to say what they wanted.

7.0 DISCUSSION

A number of key themes emerge from the noticeable statistics that illustrate the importance of people living with disability having choice and control of how they live their life.

Although the surveys were gathered on an ad hoc basis, and so cannot be declared with certainty to be a representative sample of the disability community of SA, the sample size of 775 does suggest that the highlighted views may be reflected more broadly.

The results suggest that people living with disability are not enjoying sufficient choice and control in respect of accommodation and personal support.

The significance of these themes is strengthened by the UN Convention on the Rights of Persons with Disabilities (UN Disability Convention), which views people living with disability as holders of rights "who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society" (United Nations 2008, p. 1).

Countries that ratify the UN Disability Convention make a commitment to ensure that the rights of people living with disability are promoted, protected and implemented (United Nations n.d.). In July 2008 Australia ratified the UN Disability Convention and commenced the process of developing a National Disability Strategy to "ensure that the principles underpinning the *United Nations Convention on the Rights of Persons with Disabilities* are incorporated into policies and programs affecting people with disability, their families and carers" (Commonwealth of Australia 2008, p. 11). More information on the UN Disability Convention can be found on the following website:
http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

Given the Australian Government is currently developing a National Disability Strategy, it is important to maintain dialogue on the areas that can impact on the lives of people living with disability and how governments and others can help ensure that people living with disability get a fair go at active citizenship. The following discussion on the key themes identified through the **tell us** survey makes a contribution to this dialogue.

7.1 HAVING CHOICE AND CONTROL ABOUT WHERE YOU LIVE

Over 20% of Survey A and 43% of Survey B respondents living with disability reported they did not have the choice about where to live.

Having a home is something that is considered important within society. Having the freedom to choose where to live in the community and who to live with contributes to this sense of home. Making such decisions usually occurs periodically throughout a person's life as needs and personal situations change (Beer & Faulkner 2007; Dyke 2005). The importance of people living with disability having this choice and control about where they live throughout their lives is reinforced by the UN Disability Convention under article 19, where it states that people living with disability are to "have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement" (United Nations n.d., p. 13).

Since the 1980s across Australia there has been a strong focus on people living with disability moving out of institutions into community-based accommodation, with an initial emphasis on people moving into group homes (AIHW 2008; AIHW 2007; AIHW 2001). From this period of time up to 2003 there have "been consistent increases in the number and rate of people living in households and decreases in the number and rate of people living in institutional settings" (AIHW 2007, p. 195). The reported benefits of people living with disability moving from larger institutions into smaller community-based accommodation include experiencing greater choice, increased social networks and more involvement in community experiences (Epstein-Frisch, van Dam & Chenoweth 2006).

Although there may have been positive developments and outcomes for people living with disability resulting from the provision of community-based accommodation such as group homes (especially when compared to people's previous experiences of institutional life), it is strongly suggested from the **tell us** survey results that people living with disability are not necessarily being provided with the opportunity to make the choice about where in the community they want to live.

Some of the identified key factors that can influence why people living with disability are not often offered the opportunity to live in a home of choice are:

- A lack of available and suitable housing;
- The existence of funding constraints;
- Inadequate support networks and relationships
  (Bostock et al. 2001; Dyke 2005; AIHW 2007).

Consideration about how best to respond to these barriers is essential to ensure that people living with disability are afforded the right to make the choice about where they live.

7.1.1. CONSIDERATIONS

People living with disability need to have access to the same range of common housing options as other community members as this will create greater choice and opportunity.

The benefits of offering common housing options to people living with disability are twofold. Not only do people have increased opportunities to develop their social networks and community involvement when they are living within their local community, there is also evidence to suggest that the cost of providing such community-based options is less than larger congregate accommodation arrangements. For example:

> "Research literature and anecdotal evidence strongly indicates a consistent pattern of better outcomes and lower costs where housing is integrated into ordinary neighbourhoods rather than larger grouped facilities,… [and] where the size and composition of the group is more akin to ordinary home living…" (CRU 2008, p. 23).

There needs to be person-centred planning which places people living with disability at the centre of making decisions about where they want to live.

Person-centred planning is an ongoing process that gives people living with disability the central role in determining what they want to do now and in the future. There is a focus on assisting people living with disability to identify their aspirations and needs in the context of not only what is currently available but what is possible (Helen Sanderson Associates n.d.). Person-centred planning also encourages their family, friends and members of their local community to work together to achieve these goals that "helps to build the person's place in the community and helps the community to welcome them" (Helen Sanderson Associates n.d., p. 6).

The use of person-centred planning with its emphasis on self-determination, shared action and social inclusion would not only assist in ensuring that the social networks, needs and interests of people living with disability are met through responding to what they want to achieve, but it would encourage people to creatively plan for the future through looking beyond what the current accommodation options are (CRU 2008; Fidock & Williams 2008).

A good process, at its heart, will have fundamental regard for the person's wishes, strengths, qualities and potential, and will always assume the person's capacity to be a participating citizen in the life of the local community.

Encouraging the involvement of personal networks in community-based accommodation arrangements, to maintain and develop the natural links people living with disability have in their wider community.

According to Kendrick (2008, p. 15), "[p]art of making a home of one's own is to integrate one's home life with one's web of relationships and one's lifestyle". Maintaining these links and expanding the involvement of family and personal networks can increase and diversify the supports available to people living with disability. A range of models encourage the establishment of informal networks which can support people living with disability to live in their home of choice with the personal assistance they require, for example, circles of support, co-tenancy arrangements (Supported Accommodation Task Group 2006) and microboards (Vela Microboard Association 1997).

The development of such networks are best anchored on the person's potential to be an active citizen in the life of their local community.

7.2 HAVING CHOICE AND CONTROL ABOUT WHO SUPPORTS YOU

According to Kendrick et al. (2006, p. 7), "[n]eeding support is an ordinary human condition, most people are both dependent and interdependent on others". When support is required there is the expectation that this help is provided to meet our needs. This view is supported by article 19 of the UN Disability Convention which states that "[c]ommunity services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs" (United Nations n.d., p. 14).

It is the experience of many people living with disability that that they do not receive the support they require resulting in people feeling discouraged, dissatisfied and restrained (JFA 2009; Kendrick et al. 2006; Williams et al. 2008).

Some of the factors that can contribute to people living with disability not receiving the support they require are:

- Not having choice and control over the type of support provided;
- Not having choice and control over who provides the help;
- Being restricted in regards to having to plan life around staff availability (Kendrick et al. 2006; Williams et al. 2008).

This is reinforced by data collected from the **tell us** survey which identified that over 24% of Survey A and 45% of Survey B respondents stated that they did not choose who provided them with personal support, and over half of all survey respondents (56.56% of Survey A and 57.58% of Survey B) stated that they did not have the opportunity before receiving assistance to say what they wanted.

In addition to such factors, another key element that can impact on the quality of support provided is the extent of respect and consideration people living with disability are afforded by those providing the support. In the case of **tell us** survey respondents, only 65.57% (Survey A) and 72.12% (Survey B) stated that they were treated with respect when receiving support with their personal needs. Basically this means that up to one person in three were concerned they were not treated with respect by those supporting them. Considering the fact that being treated with respect is one of the fundamental principles of the UN Disability Convention (United Nations n.d.) ratified by the Australian Government in July 2008, it is worrying that so many people feel this is not happening for them. This highlights an urgent need to look at ways of changing the relationships between people providing support and people living with disability "as it is not easy for people to build a decent life for themselves if the main gatekeepers/providers of paid support leave them feeling doubtful, fearful and unvalued" (JFA 2008, p. 16).

It is essential that considerations are made about how to ensure that people living with disability feel empowered to have control over the supports they require and who provides this support because otherwise the problem is only going to grow. After all there is an increasing need for the provision of supports to people living with disability due to Australia's ageing population "leading to increasing numbers of people with disability and a severe or profound limitation…" (AIHW 2007, p. 164).

7.2.1. CONSIDERATIONS

Introducing Individualised Funding packages which provide people living with disability with control over the decisions about the supports they receive needs to occur.

Individualised Funding (also variously known as Self-Directed Funding, Individualised Budgets, and so on) gives people living with disability the control over the types of support they require and who should provide this support. This control can have “a positive impact on quality of life, as reflected in areas such as making choices, achieving goals, participating in the community, and growing relationships” (Williams 2007, p. 20).

Instead of having an allocation of service, the person gets an allocation of funding and there is much greater flexibility about the way that funding is used. In essence, the person (with assistance where requested) gets to choose how the funding is spent, so that it provides the best possible support for the lifestyle the person wants. Notably, the Individualised Funding methodology is inclusive of people with cognitive impairment, because people can choose a variety of ways for how the allocation is managed on their behalf.

In order to ensure that people living with disability are treated with respect by those who support them, the development of valued relationships needs to occur.

There needs to be a strong emphasis on ensuring that those providing support to people living with disability acknowledge the valued role that people living with disability can play in our society. People living with disability are more than service recipients, they are citizens who like everyone else in society are “integral to their community;… whose uniqueness is not only recognised but is also considered a valuable contribution to a rich and dynamic societal fabric” (Knox 2006, p.3).

Support providers need to ensure that their systems and staff embrace the importance of respecting people living with disability through actively encouraging their involvement in making decisions about the supports they receive. Kendrick (2003) refers to this as establishing the “right relationship” and further highlights that, “[c]hoosing the right pathway begins with the recognition that there needs to be a fundamentally respectful and ethical relationship between services and the people they assist…” (Kendrick 2003, p. 1).

8.0 CONCLUSION

It is of paramount importance that people living with disability have choice and control about where they live and the supports they receive. These rights are recognised through the UN Disability Convention and it is essential that people living with disability are encouraged and supported to enact these rights in pursuit of the life they want, to actively contribute to society and to develop and maintain links with their social networks and the wider community.

Keys to this are:

- Genuine ‘ordinary life’ choices about where to live and who with;
- Person-centred planning;
- Development of natural networks within the community;
- Flexibility in funding, for example through Individualised Funding;
- Reframing the relationship between the people living with disability and those providing paid support.

9.0 DISCLAIMER

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10.0 REFERENCES

AIHW – *see* Australian Institute of Health and Welfare

Australian Institute of Health and Welfare 2008, *Disability in Australia: Trends in prevalence, education, employment and community living,* Bulletin 61, June, AIHW, Canberra.

Australian Institute of Health and Welfare 2007, *Australia's welfare 2007,* Cat. No. AUS 93, AIHW, Canberra.

Australian Institute of Health and Welfare 2001, 'Deinstitutionalisation: the move towards community-based care', in *Australia's welfare 2001,* Cat. No. AUS 24, AIHW, Canberra, Ch. 4, pp. 96-138.

Beer, A & Faulkner D 2007, *The housing careers of people with a disability and carers of people with a disability*, Australian Housing and Urban Research Institute, Southern Research Centre, Melbourne, Victoria.

Bostock, L, Gleeson, B, McPherson, A & Pang, L 2001, *Issue 002: Meeting the housing needs of people with intellectual disabilities:* Australian Housing and Urban Research Institute, Sydney, NSW, < http://www.ahuri.edu.au/publications/projects/p70015>.

CRU – *see* Community Resource Unit

Commonwealth of Australia 2008, *Developing a national disability strategy for Australia*, Commonwealth of Australia, Canberra, ACT.

Community Resources Unit 2008, 'If only our service system had these qualities: seven strategies likely to help people who have a disability to have 'a home'', electronic version, *Crucial Times*, issue 40, pp. 22-25, <http://www.cru.org.au/crutimes/CT40/CT40.doc>.

Dyke, J 2005, *A home of my own. Right, rhetoric or reality? Considerations for housing and a sustainable future for people with disabilities*, Queensland Disability Housing Coalition, Stones Corner, QLD.

Epstein-Frisch, B, van Dam, T & Chenoweth, L 2006, *Presenting the evidence: Accommodation and support for people with disability*, Institute for Family Advocacy and Leadership Development, Epping, NSW.

Fidock, A & Williams R 2008, *Tell us survey report 1: Disability funding: Where should it go?*, Julia Farr Association, Unley, South Australia.

Helen Sanderson Associates n.d., *What is person centred planning?,* viewed 18 May 2009, electronic version, <http://www.helensandersonassociates.co.uk/PDFs/WHAT%20IS%20PERSON%20CENTRED%20PLANNING.pdf>.

JFA – *see* Julia Farr Association

Julia Farr Association 2008, *Why is it so hard to speak up and be heard? Views from the Loop conference 2007*, Julia Farr Association, Unley, South Australia.

Julia Farr Association 2009, *Getting a good life: Taking control of what's possible. Views from the Loop conference 2008 (DRAFT)*, Julia Farr Association, Unley, South Australia.

Kendrick, M 2003, 'The role of personal integrity in upholding "right relationship" in organisations', electronic version, *Crucial Times,* issue 28, pp. 1-8, <http://www.cru.org.au/crutimes/CT28/ct28fa.htm>.

Kendrick, M 2008, 'How genuinely supportive persons, agencies and systems can enable people to have real homes of their own', electronic version, *Crucial Times*, issue 40, pp. 13-15, <http://www.cru.org.au/crutimes/CT40/CT40.doc>.

Kendrick, M, Petty, R, Bezanson, L & Jones, D 2006, *Promoting self-direction and consumer control in home-and community-based service systems: Third of three papers on unlocking the codes of effective systems change*, Independent Living Research Utilization, Houston, TX.

Knox, M 2006, 'He's more than just a service user, you know', electronic version, *Crucial Times,* issue 36, pp. 3-4, <http://www.cru.org.au/crutimes/CT36/ct36.pdf>.

Supported Accommodation Task Group 2006, *Consultation paper. Accommodation and personal support for people with disabilities in South Australia*, Government of South Australia, Adelaide.

United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, United Nations, viewed 3 February 2009, <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.

United Nations 2008, *Convention on the rights of persons with disabilities,* United Nations, New York, USA, viewed 3 February 2009, <http://www.un.org/disabilities/default.asp?navid=12&pid=150>.

Vela Microboard Association 1997, *Microboards*, Vela Microboard Association of B.C. Surrey BC Canada, <http://www.microboard.org/PDF/velabrochure.pdf>.

Williams, B, Copestake, P, Eversley, J & Stafford, B 2008, *Experiences and expectations of disabled people – Executive summary: A research report for the office for disability issues*, Office for Disability Issues, London, UK.

Williams, R 2007, *Individualised funding. A summary review of its nature and impact, and key elements for success*, Julia Farr Association, Unley, South Australia.

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