julia farr association

tell us 1
survey report

Disability funding – where should it go?

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

A JFA Publication

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INTRODUCTION

It is essential that people living with disability are asked about what their lives are like so that we understand what is important to them.

The Julia Farr Association (JFA) developed the **tell us** survey to gather this information 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 through asking respondents to talk about their lives and identify what they think could be different.

One particular focus of the **tell us** survey was to collect information about the views of the disability community on the areas they felt Government should be directing additional disability funding.

This report highlights the key areas identified by respondents, including discussion on how this relates to the allocation of resources by Government for people living with disability.

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 throughout the disability community. Initially the survey was circulated at the Disability Expo held in Adelaide in October 2006. It was then made available on Julia Farr's website followed by a comprehensive distribution of surveys to disability support agencies in South Australia. Surveys were collected until the end of February 2008.

RESULTS

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).

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

Demographics of **tell us** Survey Respondents

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

The responses provided in the **tell us** survey identified that people have 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

Responses to Question 10 of the tell us Survey

Question 10 of the **tell us** survey asked respondents:

If you could choose three areas that you would give more government money to, what would they be?

Respondents were provided with 20 categories to choose from including the option to highlight other areas not listed (see Appendix).

The categories ranged from support services such as various accommodation options, advocacy and information services, Service Coordination, counselling, medical care, to employment and access to public transport and public spaces.

Based on the responses provided in Survey A and Survey B, three key priority areas were identified.

PRIORITY AREA 1

Support to people living in their own homes, by themselves or with family/friends

This was highlighted as the key area that required additional government funding by both Survey A and Survey B respondents, with 26.72% in Survey A (163 of 610 respondents) and 26.67% in Survey B (44 people of 165) giving this area their first preference.

The total number of respondents who highlighted this area as being either their first, second or third priority was 255 people of 610 in Survey A and 65 of 165 in Survey B.

PRIORITY AREA 2

Support to younger people so that they don't have to live in aged care facilities

This area was ranked as second highest in priority in Survey A and third highest in Survey B with 134 people in Survey A and 28 people in Survey B giving this area their first preference.

The overall number of respondents who highlighted this area as being either their first, second or third priority was 237 people of 610 in Survey A and 53 of 165 in Survey B.

PRIORITY AREA 3

Support to people living with other people who have a disability, in ordinary houses

This was the second priority area for Survey B respondents with 19.39%, or 32 of the 165 people who completed this survey rating it as their first preference. Of the 610 Survey A respondents, 55 also ranked this as a priority area for government funding.

A total of 108 people of 610 in Survey A and 46 of 165 in Survey B highlighted this area as being either their first, second or third priority.

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

DISCUSSION

The three priority areas emphasise a common theme to the allocation of more government money; to support people living with disability to live within the community independently or with family and friends, as opposed to living in larger residential facilities.

This emphasis on the need for appropriate community-based living options for people living with disability also aligns with the UN Convention on the Rights of Persons with Disabilities which was recently ratified by the Australian Government in July 2008 (McClelland, Smith & Shorten 2008). The UN Convention under article 19, recognises that “persons with disabilities must be able to live independently, to be included in the community, to choose where and with whom to live and to have access to in-home, residential and community support services” (United Nations Enable 2008).

Not only is there widespread support for the rights of people living with disability to live within the community, evidence suggests that living in community-based accommodation can produce positive outcomes (CRU 2008; Epstein-Frisch, van Dam & Chenoweth 2006). In comparison to people living in larger residential facilities, people who live in smaller community-based housing arrangements are more likely to experience greater choice, increased social networks and more involvement in activities within the community (Epstein-Frisch, van Dam & Chenoweth 2006).

This focus on the importance of providing community-based accommodation for people living with disability is given further credence by the Government of South Australia’s commitment to double the number of people living with disability who are appropriately housed and supported in community accommodation by 2014 as part of its Strategic Plan, and based on the view that all people living with disability “should be included in, and valued by, our community” (Government of South Australia 2007, p.36).

As part of the SA State Budget for 2008/09 a commitment has been made to match the $72.9 million funding to be provided by the Commonwealth Government over the next four years. The total of $72.9 million of SA Government funding is to be made up of $26 million in new spending, $46.9 million committed over four years from last year's budget and $11 million provided by the State Government in 2007/08 (Estimates Committee A 2008). This increase in funding will be directed towards a range of service areas such as providing supported accommodation to 92 people who are urgently waiting, 102 packages of intensive home assistance so that individuals do not have to live in nursing homes or group homes, and providing 650 individual care packages (Estimates Committee A 2008).

In previous years, funding has also been allocated by the SA Government to provide community-based accommodation to people living with disability resulting in the creation of 101 new supported accommodation places from 2003 to 2006 and an investment of $18.4 million with the Commonwealth Government "to prevent people under the age of 50 being admitted to nursing homes because of their high needs" (Government of South Australia 2006, p. 15).

The SA Government has acknowledged the need for better planning to provide community-based accommodation as part of its Supported Accommodation Strategy and has identified one of the ways of achieving this is through providing "services based on people's support needs, not diagnosis" (Government of South Australia 2006, p. 6). People living with disability need to be at the centre of this planning process and be actively supported to make the decisions about how they want to live and who they want to live with, as this will not only ensure that the choices made meet their support needs but enhance their quality of life and experiences within the community (CRU 2008; Kendrick 2008).

Focusing on maintaining the links people living with disability have with their family and personal networks is also important as these "relationships are an integral part of home life and personal lifestyle..." (Kendrick 2008, p. 14). The available community-based accommodation arrangements currently used, such as group homes, "do not offer sufficient choice and rely on paid care, without sufficiently incorporating family or community resources where these are available" (Supported Accommodation Task Force 2006, p.19). There needs to be a focus on alternative community accommodation arrangements where involvement of key personal networks are encouraged and maintained.

Some of the models that would assist people living with disability to live on their own or with family and friends (as identified as priorities for **tell us** survey respondents) are circles of support (Russell 1995), co-tenancy arrangements and microboards (Vela Microboard Association 1997).

CONCLUSION

It is encouraging to see that the SA Government's financial commitments and its development of a strategy to provide community-based accommodation to people living with disability in South Australia align with the views of the **tell us** survey respondents about those areas more Government money should go to.

However, providing people living with disability with appropriate community-based accommodation requires significant thought and planning and involves more than the provision of the 'bricks and mortar'.

Therefore in order to ensure that this funding is spent in the most effective and beneficial way, and is responsive to the individual needs of people living with disability, the support systems put in place need to be flexible and have regard not only for a range of alternative community accommodation arrangements, but also for the ease with which a person can remain in contact with family and friends and build natural associations within the wider community.

As is suggested by the findings of the **tell us** survey, many people living with disability have strong feelings regarding accommodation, reflecting values of personal authority, a sense of home, family, friends and community; in short, values that are common to many people.

It seems apparent, therefore, that funding for disability support be prioritised so that people living with disability are supported to exercise these values in their daily lives.

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APPENDIX

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10. Money If you could choose three areas that you would give more Government money to, what would they be? *(Please mark the three boxes you choose, with a 1,2 and 3 according to your preference)*	
Service coordination (also known as *options coordination*)	☐
Support to people who wish to purchase and/or manage their own support	☐
Support to people living in their own homes, by themselves or with family/friends	☐
Support to people living with other people who have a disability, in ordinary houses	☐
Support to people moving out of long-stay institutions	☐
Support to younger people so that they don’t have to live in aged care facilities	☐
Respite and holiday opportunities	☐
Self-help support networks	☐
Information and advice services	☐
Advocacy services	☐
Changes to laws and regulations so that there is less discrimination in jobs, buildings, transport and so on	☐
More accessible public buildings and spaces	☐
More accessible public transport	☐
Regular jobs alongside non-disabled people	☐
Regular jobs alongside other people who also have a disability	☐
Recreation services	☐
Therapy	☐
Medical care	☐
Early childhood development	☐
Counselling	☐

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