

30 November 2006

STRATEGIC DEVELOPMENT

Survey of People with a Disability

About The Respondents

Responses to the **DISTSS Developing the Disability Workforce, Questionnaire for People with Disabilities and Families and Carers** were received from 129 people. 107 of these people identified themselves as having a disability with the remainder being family members and/or carers. Twice as many responses were received from females (71) than males (36), and a small number did not indicate their gender.

Questionnaire responses and comments were contributed in hard copy, electronically and via the free-call telephone facility. Two people with disabilities provided lengthy comments and insights, but did not complete the questionnaire – their comments are included in this summary of responses.

29 responses were received from people older than 55, 44 from those aged 35 to 55, 28 from younger adults aged 20 to 35, and 8 people aged less than 20 years of age responded. Twenty people did not indicate their age.

Although 28 people said they did not receive any formal support, 85 received support from workers at least in their home, with the remainder using support in their workplace, the community and in planning their support needs.

Almost half of respondents said they needed help from someone with self-care activities (59) and used aids or equipment (57). 34 said they needed help with body movement activities such as moving around the house, and 44 required assistance at least sometimes with communication activities.

What People Said

Overview:

Overall, the key issues for respondents were the attitudes of workers, the available labour pool (selection and recruitment), and the investment required for on-the-job or in-home training.

Attitudes and skills repeatedly mentioned were:

- *“Positive attitude”*
- Being treated with *“dignity”, “I need a worker who treats me like an adult, not a two year old.”*
- *“Understanding”, “compassion”, “empathy”*
- *“Respect”, “friendliness” and “politeness”*
- *“Honesty” and “trust”*
- *“Talk to me”, “ask me”,*

- and “being listened to”.

Attributes of workers valued by many people with disabilities using support were “common sense”, “practicality” and the ability to work “efficiently”, as well as people who were “unafraid of disability, open to challenges and learning”.

There was also recognition of constraints imposed by limited time and money; *‘there is a lot to do in very little time’* and wages are relatively low. Several respondents commented on the labour pool for support workers; one respondent observed:

“The pool of available labour has changed, particularly in the last 10 years - ‘welfare reform’ has squeezed people and we are now seeing people with diagnosed psychiatric illnesses and histories of hospitalisation as support workers.”

“University drop-outs” were identified by another person with a disability as unsuitable, and a few people said there should be “more males involved” or “more young males”. A carer also expressed concerns with the labour pool:

“Not people off the street without a job. People who cannot care properly for themselves cannot successfully care for others.”

It was reported that training for both the person receiving support, and the worker, does not adequately address the labour pool characteristics, and the perception (if not fact) that there are “better wages in aged care – we get what’s left”. As part of attracting and keeping a skilled and ‘good’ labour force, there were suggestions for minimum qualifications/criteria and a career structure for workers - “they should have Disability III before starting”, and “offering career paths” -while many suggested wage increases.

Training was seen as an investment in “keeping good workers” and respondents commented that there is a cost-benefit to the agency in training but the “dollar value to the agency (and the service system) of the training provided by people with disabilities is not recognised.”

Another observation was that the connection between the requirement for training and the outcome for the person with disability was tenuous:

“The measurement of the effectiveness of training needs to be directly linked to the outcome for the person with a disability in receipt of the workers’ service. The question needs to be asked; is the person with a disability’s quality of life any better for the training provided to the worker?”

This respondent was fearful that course-based training was seen as a ‘bludge’ or just something to be got through in order to earn an income.

Responses to Survey Questions:

Respondents were asked both whether it was 'important to have things in common with their support workers', and if they felt they 'did have things in common with their support workers'. Despite only 14 respondents saying that it was **not** important, just less than half (63) of respondents felt they had things in common with their support workers.

However, when asked 'how good their support workers were at doing their jobs', just over half of respondents (70) indicated they thought their workers, or at least some of them, were good or excellent. Some respondents noted that there was great variation between individual workers and found it difficult to generalise their response.

When asked 'what could be improved about support workers' and what they 'wanted workers to be good at doing to support them', respondents said:

- Attitudes, including respect and empathy:
 - *"Workers who have the right attitude and give a damn"*
 - *"Seeing a problem from the point of view of the person with a disability"*
 - *"Too tough", "more emotional support", "not grumpy"*
 - *"Just a job and they don't really seem to care about what might be going on inside us"*.
- Understanding of non-disability issues e.g. *"aging"* and *"community networks"*.
- *"Efficiency"* of the support workers, and acknowledgement that it is *"difficult for people living on pensions to live decently and have money for necessities like medications, toiletries and clothing"*.
- *"Communication"* and *"talking"* were also seen as areas for improvement.
- Some people, particularly those receiving attendant support in their home, observed there were sometimes *"English language and other skills issues"* with support workers.

One such respondent was very careful, however, to emphasise that language or other support needs of workers should not be used as reasons to exclude them from this work. However their participation placed extra responsibilities (not always taken up) on agencies and coordinators, and assistance was required for people with disabilities to *"handle or manage"* this situation.

- Some people also suggested improvements to supervision, coordination and management of support workers.

When asked about training, just over half of respondents (69) said they knew their support workers did get training to do their job, and most (94) thought that training helps workers to do their job.

The sorts of training respondents were most frequently aware their workers had undertaken were:

- Certificates in Disability Studies (including Certificate IV),
- Induction or “council” training,
- First Aid, and
- Occupational Health and Safety training.

Respondents also mentioned numerous specific training their workers had undertaken such as: *‘manual handling’*, *‘hoist’*, *‘behaviour management’*, *bus driving*, *‘First Start’*, *‘aged care’*, *‘counselling’*, and *‘epilepsy training’*. Some noted their support workers were students.

Asked about ‘the best ways for support workers to learn how to support’ them, overwhelmingly respondents said *“on the job”*, in their (respondents) homes and taught by the person receiving the support; *“ask me”*, *“get to know me/my body/what is possible for me”*, *“listening to me”*, *“understanding”*, *“shadowing good workers”* and *“respecting me”*.

Many said this personalised training – on the job and in-home - should be in addition to basic training already provided. Mostly, these respondents had to *“use my own hours”* or *“it costs me my emergency hours”* to provide this training. This use of their scarce resources was seen as unfair; resources for training and providing support should not be confused. A few respondents said that they felt they had to re-train workers in the home environment. However, respondents generally had a commitment to supporting their workers as part of ensuring good service/support.

When asked about training for themselves, ‘to get support workers to do what they want’, less than half of respondents (51) said they would like training, and 45 definitely did not want training for themselves:

“No – I know what I need and want. Workers need training and education.”

Of the many who were unsure about training for themselves, most said it depended largely on what the training was and who was paying for it.

Throughout responses, there was an undercurrent of recognition of the human relationship central to the role of providing and receiving support. People with disabilities said, when asked about ‘what they want workers to be good at doing to support them’, that they want to be recognised *“emotionally and treat us like human beings”*. In turn, many recognise their workers have their own needs. Some suggested workers would benefit from a greater understanding of their own needs (personally and professionally) in context of this role. In the end, however, people with disabilities want to *“be listened to”*

and expect *“they (support workers) are there to do a job”*, it must be done *“properly”*, *“efficiently”* and with *“kindness”*, *“compassion”* and *“politeness”*.

Many respondents emphasised the necessity of *“common sense”* and *“practical(ity)”* and questioned whether this could be ‘trained for’, instead being a selection and work trial issue.

Asked about ‘the most important things to do to get a good support worker’, apart from attitudes and skills, responses most often related to the selection and *‘matching’* (for *“compatibility”*) of workers to people requiring support. This was viewed as a very individual process and nearly all respondents wanted to be personally involved in selection via *“meetings”*, *“interviewing”*, and *“having a way to gauge the person”*. Being able to select for positive attitudes was most frequently mentioned, and ensuring that you get *“people who want to work in the job, for the job, not for making money as the only reason.”* ‘Trials’ were also suggested by a few respondents.

Overall, respondents suggested they could ‘get good support workers’ by being involved in both selection and on-the-job/in-home training, with the required resources for this to be made additionally available rather than for them having to *“use my hours for this”*.