

Standing Committee on Social Issues
Legislative Council
Parliament of NSW
Macquarie Street
Sydney NSW 2000

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LEGISLATIVE
COUNCIL

Dear Committee members,

Inquiry into Services provided or funded by the Department of Ageing Disability and Home Care

Thank you for the opportunity for The Futures Alliance to appear before the Standing Committee on Social Issues on 3rd September 2010, in regard to the Inquiry into Services provided or funded by the Department of Ageing, Disability and Home Care. I am writing in response to your questions on notice, as below:

Response to Questions on Notice

1. Evidence presented at the Committee's earlier hearing suggested that there were approximately 460 NGO's providing disability services in NSW. It was debated whether there is a need for such a large number of organisations.
 - a) In your opinion is the current number of NGO's viable? And would you consider the notion of there being a 'right mix' of large and small NGO's?
 - b) Have your individual organisations noticed any cost savings or other efficiencies since forming the Futures Alliance?
 - c) Would you recommend other organisations form similar alliances?

Response

- a) The Futures Alliance does not have an opinion as to the viability of the number of NGO's in the NSW Disability Sector. Nor would we proffer a view as to the 'right mix' of large and small NGO's. We would however assert the following principles
 - **Choice** A range of options must be available for people with a disability and their families/carers to meet their needs. This is of paramount consideration when determining the optimum size and number of organisations in any given geographical location or service type.
 - **Quality** People with a disability and their families are entitled to excellent services and support options that meet their needs within high standards.
 - **Access** People with a disability and their families deserve access to the supports they require to lead a good life, no matter where they live.

- **Partnership** Services are more effective when they work in genuine collaboration with people with a disability, their families, other providers and the community.

b) The Futures Alliance is a cooperative of community representatives from disability and aged care providers in NSW which includes representation from consumers, academics and peak bodies. The Futures Alliance has been formed and has grown via a network of professional relationships with a shared vision of influencing policy pertaining to people with a disability who are ageing and ultimately improving outcomes for this group of people.

As such our group is concerned with knowledge exchange, research, policy development, advocacy and lobbying. It is self evident that the pooling of our collective wisdom has borne results that may not have been achieved via one person or organisation acting alone. In particular, the cross pollination of knowledge and ideas between service providers and academics in both the Ageing and Disability sectors, combined with the input and expertise of the Peak body reps and the wisdom and experience of people with a disability and carers has produced a rich and creative exchange.

The Futures Alliance is not in a position to comment on cost efficiencies as the Alliance exists upon the good will and resources of its members. The Futures Alliance does not provide a service delivery function and receives no formal funding from any source.

c) The strength of the Futures Alliance is in its single focus on maximizing resources for people with a disability who are ageing. The organisations we individually represent have had a stake in this issue over a long period and many of these have made individual representations to government and policy makers in the past. By uniting with a single voice on this issue, we have achieved the following:

- **Purpose** A clear sense of who we represent and what we are working toward, has enabled the Futures Alliance to maintain its single focus and not be distracted by other equally important but competing issues that we individually confront in our daily working lives.
- **Clarity** Through the exchange of knowledge, research and practice experience we have developed a clear sense of the issues and solutions and have clarified our key messages for change
- **Recognition** By acting with a single voice the Futures Alliance is being recognised by government, service providers and policy makers as playing a key role in informing policy and practice in relation to people with a disability who are ageing.


Our experience in forming the Futures Alliance has been both positive and productive and we would recommend this approach for organisations and interest groups to maximise their resources and extend their influence.

Case Studies

In response to the request for a case study we have taken the opportunity to provide the Standing committee with a selection of examples. People with a disability experience a range of issues as they age and this is influenced by a complex interaction of factors including but not limited to the nature of their disability/ies, their family circumstances and support networks, the nature and type of service they are currently accessing and whether this is flexible and able to respond to their changing needs. Therefore we have attempted to reflect a range of experiences in the examples attached. Some of the people highlighted in these case studies have indicated that they would be willing to appear before the committee if requested.

Once again, we thank you for the opportunity to give evidence in this inquiry and would be pleased to assist further if required.

Yours Sincerely



Jo-Anne Hewitt
Chairperson
The Futures Alliance

September 23rd, 2010

Case Studies

April

April is a 78 year old woman with an intellectual disability who works in a supported employment setting three days per week. April has expressed a desire to stop working as she gets very tired and has been doing the same thing for a long time. April has a person centred plan in place which acknowledges her dreams and aspirations for her future including stopping work. The organisation supporting her is unable to provide her with support during the hours of 10 am and 2 pm as they are not funded for this and has also been told that there are no other types of program funding available to support her at the moment. April is not regarded as a priority by either ADHC as she is in good health and able to work. April is content to keep working because at the moment nobody can tell her what life will have to offer if she is able to retire and she is looking for some reassurance from the organisation that she won't just sit at home and do nothing. April says enjoys the working as it is the only real social contact she has with others.

Elizabeth

Elizabeth is a 44 year old lady with a bright personality and a love of music and socialising. Until June 2009, she was living alone in the family home with daily support for 1.5 hours and weekly housing cleaning for 2 hours a week and one meal per day delivered by meals on wheels. She also had regular contact with her siblings, extended family and her network of friends. Since her mother died, she has been on medication for depression had been drinking heavily and had experienced harassment from neighbours.

Elizabeth had been active in community activities with Salvation Army and would often access a disability recreation service one evening per week. Elizabeth had just started accessing a centre based day program for up to 18 hours per week. She was there for 4 weeks when she got pneumonia. It took her several months to recover. She returned for one week until she had a fall. She had a number of falls over a two year period. The last time she fractured a vertebrae in her neck and was hospitalised for 4 weeks. An ACAT assessment was completed which concluded that she required 24 hour high level care. Elizabeth now lives in a nursing home as this was the only option available.

The average age in the nursing home is 83 and Elizabeth shares a room with 3 others.

Elizabeth organised for her day program funding to be transferred to a self managed option. Elizabeth accesses her funding to provide her with support to engage in community activities throughout the week, using formal and informal supports and to pay for a weekly massage. Elizabeth maintains her interests and social connections and age appropriate activities outside of the nursing home. She chooses her own staff and manages her package with support from her sister and a case manager.

Having lived independently she is used to living her own life. The nursing home is a much more restricted environment and their duty of care places restrictions on her freedom of movement. She is unable to go out without someone with her. Elizabeth is hoping that in the future she will be able to live in her own unit/space within a supported environment, with access to staff support and people her own age to socialise with.

Adrian

Adrian is a man in his late 60's who has cerebral palsy. The cerebral palsy significantly impacts on his physical capacity, mobility and speech. Adrian requires a powered wheelchair for mobility as well as personal and domestic support.

Adrian has led a full life with regular contact with family and involvement in his community and church activities. As Adrian has grown older his support needs increased and these were being met through his community group home and work place. Whilst enjoying employment Adrian expressed his desire to retire. The practicality of this request was difficult due to the nexus between his daily support needs and the inflexible funding criteria of his support services.

The barrier to Adrian actioning his goal was the lack of transferability of funding between State and Federal disability programs. Hence Adrian was destined to remain at his employment option as the funding for his group home did not extend to providing support during normal working hours. Nor was Adrian eligible for day option funding under the Community Participation program. Adrian was therefore unable to plan for the next phase of his life due to inter-governmental funding boundaries. Adrian was not the only adult with a disability who faced this scenario.

Over a period of 10 years The Spastic Centre consulted with a number of adults who were growing older and their families. They were seeking additional support to respond to their changing needs and life phases. These adults were also experiencing dissatisfaction with the restrictions and limitations of the traditional group home model. This included lack of space, shared facilities, physical design/access and limited opportunities for privacy other than in their bedroom.

In partnership with Department of Housing, a housing model known as Lifestyle Apartments was constructed for 12 adults over the age of 50 years who had constant and increasing support needs that were not able to be met by their existing group home environment. The proposal was presented to ADHC and given approval.

The model consisted of modern one bedroom apartments with the following characteristics:

- Fully accessible environment
- Bedroom
- Accessible en-suite toilet
- Private living room
- Internal and external access apartments
- Automatic doors and ceiling hoists
- Digital technology capacity
- Emergency call systems
- Common areas (internal/external)
- Access to 24 hour support
- Capacity for friend/family to visit and stay over

Adrian moved into his private apartment in 2009. Access to an accessible environment with guaranteed support, enhanced amenities and privacy, has allowed Adrian to achieve his goal of

retiring from employment. Over the last 18 months Adrian has continued to actively participate in his community and has plans to write a book about his life.

Access to reliable support and an enhanced accessible environment has allowed Adrian to participate in a lifestyle that adds quality to his life. The critical element of the Lifestyle Apartments was to allow the efficient and effective utilisation of the pooled DSP funding to increase the responsiveness and range of support services to the residents who were ageing. The increased level of support provided the reassurance and flexibility to the adults and their families.

David

David is a 62 year old man with a mental illness living in a Housing NSW unit in Sydney's Inner West, where he receives in home and community support from UnitingCare Disability Supported Living. Previously David lived at Lyndhurst House (licensed Boarding House) for 20 years. David has spent most of his adult life in boarding houses and hospitals, including Rozelle. Whilst living in Lyndhurst, his access to the kitchen was restricted and he relied on other people for meals. The common areas were crowded, as there was only 1 TV to share and he slept in a dormitory.

When Lyndhurst House closed, David moved into emergency accommodation in Lilyfield at a facility also run by UnitingCare Disability Supported Living. Whilst at this facility David was given the option of where and how he would like to live, and it was here that David identified he wanted to live in the community with support. David says that he is happy now living in his flat, as it is a warm place to live. He has a Support Coordinator to help him with daily living skills like grocery shopping and he has found that he likes living by himself as he can make choices and decisions regarding his life.

David also has a variety of connections and social activities within his community that he likes to do. Every Monday he visits the Hannaford Seniors and Community Centre for lunch and entertainment, and enjoys attending this every week. David also enjoys walking along the water at Balmain, where he stops and watches the pelicans. David also visits the local flower shops, where he buys flowers that are in season for his flat. David is very interested in flowers and plants, and enjoys looking at the range of flowers available. David has also made a connection with his local café Poppy's, where he regularly goes for coffee and cake.

David is also living in close vicinity to his friends that also used to live at Lyndhurst, and as such he can regularly get in touch with them and plan activities. David often meets his friends for coffee or lunch, attends movies with his friends, goes out to places like Circular Quay and the Botanical Gardens, and celebrates events like birthdays and Christmas. David is also a member of a Self Advocacy Group, which he attends monthly. At these meetings he is learning about the concept of self advocacy and the skills required to self advocate through training and experience.

David feels that compared to his life in the boarding house, he is now very active, can plan lots of activities and can try many new things. David is currently planning to visit the flower shows and gardens that they often have on in spring, and is even talking about planning a trip away to see some gardens. David is also planning to enrol in a course on social interactions and friendship, to further develop his social skills and make some new connections. These are all activities and connections he had never considered before he moved into his unit in the Balmain community.

Teresa

Teresa is a 44-year-old woman with a diagnosis of Schizophrenia and an Intellectual Disability. From the age of 6 years Teresa lived in institutionalised hospital settings. She was removed from her family as there was substance abuse and domestic violence in the home and she was a victim of physical abuse at the hands of her family members.

Twenty years ago, at the age of 22 Teresa became a client of Ability Options. She was given a place in a group home. When she arrived at the group home, she had clear aims and ambitions of becoming more independent. Ability Options facilitated this ambition, using an individual planning process.

Teresa excelled beyond everyone's expectations and was able to move into her own home supported by our independent living team within 6 months. All these years later Teresa is still a client of Ability Options, although the support she now requires is minimal. One of our social educators visits Teresa once a fortnight to help out. Teresa can pay all her own bills, cook, do the grocery shopping, she works three days a week, maintains a long term romantic relationship and travels on public transport independently.

Our flexible approach to accommodation assisted Teresa in making the transition from institution to group home and finally to independent living. Teresa states that she is very happy, gets along well with her neighbours and loves her dog Suzie and cat Tubby more than anything in the world.