

Advocacy for Inclusion Inc



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Dear Reader...



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The rally outside Parliament House on Tuesday 25th September was well attended and we heard some inspiring and passionate speeches from people whose lives are affected by the CSTDA, such as carers and people who have a disability.

We also have an interesting biopic of our new Individual Advocate, Ian Goodacre, who is working in tandem with Sheryl.

Happy Reading

Deborah, Ian, Justin A, Justin R, Sheryl and Stephanie

“providing individual and systemic advocacy to improve life for people who have a disability”

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From The Executive Officer

National Day of Action

Advocacy for Inclusion together with People With Disabilities organised what is thought to be the largest rally in the ACT of local people with a disability. The rally for the CSTDA National Day of Action was held at the Federal Parliament on Tuesday 25th September. About seventy people gathered to raise the issues of unmet need in the disability field and called for more funding for essential services for people with disabilities and their carers and families.

The rally was addressed by Senator Gary Humphries, Annette Ellis MP and Greens Senate candidate Kerry Tucker as well as by many of those assembled.



The rally called on the Federal Government and the Opposition to accept the recommendations of the Senate review of the Commonwealth State Territories Disability Agreement that called for all governments to commit to substantial additional funding to address identified unmet need for specialist disability services, particularly for accommodation, accommodation support services the transition from the family home to

independent living, respite care, employment services and the ongoing support needed for ageing carers of people with a disability.

I would very much like to thank those of you who took time out of your day to come and support the Rally. It was terrific to have such a large crowd on the day and reflects, I think, the level of concern there is about the inadequacy of funding and service delivery and support.

I will keep this short as further in the newsletter you will find an article “A Fair Go For People With a Disability and Their Carers” written by John Thorn the President of the Client Guardian Forum in the ACT for the National Action Day. Recommended reading!

Deborah Hamilton
Executive Officer

Key Advocacy Issues in this Newsletter

A fair go for People with a Disability and their Carers

The unmet need for disability services in Australia is massive and growing but the services available are inadequate and poorly funded and targeted. An ageing population will only exacerbate the problems unless urgent action is taken now.

Critical areas of need include Accommodation support services, the transition from the family home to independent living, Respite care, employment services and the ongoing support needed for ageing carers of people with a disability. This is particularly so for people with intellectual disabilities and their families whose plight is consistently overlooked or undervalued.

An ageing population places many parents of people with a disability in crisis because they will no longer be able to support their adult children with a disability in their family home. The reality in Australia today is that there is often no alternative. There needs to be recognition that parent carers of people with a disability are one of the backbones of Australia's community care system.

Last year the Senate reviewed the operation and funding of the Commonwealth State/Territory Disability Agreement (CSTDA). Many important recommendations were made that address the key concerns of people with disabilities and their families and, in the climate of an imminent Federal election, we urge the Government and Opposition to commit to these recommendations, to make a real difference to the lives of this often forgotten group in the community.

There is a profound shortage of funded Accommodation Support programs. While some small steps have been taken, the large majority of families of a person with an intellectual disability are left with challenges they cannot meet to provide a reasonable life for their adult child. Rather they are left to sweat it out until a crisis is reached for the parents, or for the child, when the parents die. Policy and programs need to be developed that address this substantial shortfall.

Programs are also urgently needed that assist family carers of people with a disability to prepare their adult children for moving from the family home to their own home. These programs must be tailored to individual needs in an environment and funding that enables people with a disability to move to, and successfully live in, their own home before this is forced by family breakdown or the age of the parents. Special priority for this support is needed where the parents are approaching, or over, 60

years of age when care often becomes increasingly difficult. Regular access to age appropriate, flexible, respite care on a permanent basis, provided by a single agency, is therefore critical.

Current Respite programs that do provide some valuable support are generally not targeted to provide the level of sustained respite care that many such families need for this transition to succeed. Many families are under daily pressure arising from the nature of the disability of their son or daughter – a disability which is highly unlikely to ever change. Restrictions on respite care of a few weeks a year, such as that available under the Mature Carers program, are wholly inadequate.



The current CSTDA places the administration of most disability service types (eg Community Access and Respite Care) in the hands of the States, and keeps disability Employment services with the Commonwealth. This split of responsibilities has not worked well for the families of people with an intellectual disability.

Employment services funded by the Commonwealth are particularly inflexible and do not meet the needs of the people with disabilities. The splitting of disability Employment services in 2005 from one Commonwealth department to two has made service access harder. Further, the Department of Employment and Workplace Relations imposes constraints from its vastly wider Job Network on its open disability Employment program that work to the disadvantage of people with an intellectual disability. These people are not in a position to rip off a government program by exaggerating their disability. We therefore urge a return to the administration of all Commonwealth-funded disability Employment services to the Department of Family and Community Services at an improved level of funding than existed at the time of the split.

Disability service administration is very fragmented. It involves multiple arms of both State and Commonwealth Governments. The next CSTDA should reduce this fragmentation. The Commonwealth and States should coordinate the services they administer so that clients can negotiate packages of the services they need from a single agency.

Any person with an intellectual disability deserves a level of support which reflects their dignity as members of the Australian community and which allows them to lead as satisfying and as independent a life as can reasonably be achieved in the context of their disability.

The Senate review of the CSTDA had, as its primary recommendation, that all governments commit to substantial additional funding to address identified unmet need for specialist disability services, particularly for accommodation services and support. Other key recommendations, on transitional arrangements, on supplemental aged care services, on long term planning, on a nationally consistent assessment process and many others are all recommendations that we call on both the Government and Opposition to implement.

John Thorn

President, Client Guardian Forum Inc

Representing People with an Intellectual Disability in the ACT

Individual Advocacy

Quality of Life

The concept of Quality of Life is used today to measure the effectiveness of services for people who have a disability (Schalock 2000). Quality of life is:

“a concept that reflects a person’s desired conditions of living related to eight core dimensions of one’s life: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self determination, social inclusion, and rights”. (Schalock 2000, p. 121).

When we talk about quality of life, we generally speak of a person’s sense of well-being, their involvement in community, and their opportunity to achieve their potential (Schalock 2002).

Quality of life is a very personal thing and so means different things to different people. The way you see quality of life may change as you grow older. Quality of life is about feeling good about yourself, about being able to make choices and decisions, and to have personal control over your life.

There are many ways we can support a person in their quest for a life of quality (Schalock 2000). We can help a person by ensuring there are plenty of opportunities for them to be actively involved in their community. We can help them by ensuring the person has appropriate supports and networks in place. We can help by supporting the person to make decisions. We can help by recognizing the importance of providing services and supports that are person-centred.

References:

Schalock, R.L. (2000). Three Decades of Quality of Life. *Focus on Autism and Other Developmental Disabilities*, 15 (2), 116-125.

Schalock, R.L., Brown, I., and Brown, R., Cummins, R.A., Felce, D., Matikka, L., Keith, K.D., and Parmenter, T. (2002). Conceptualisation, Measurement, and Application of Quality of Life for Persons with Intellectual Disabilities: Report of an International Panel of Experts. *Mental Retardation*, 40 (6), 457- 470.

Introducing our new advocate – **Ian Goodacre**

Background information:

Ian is a mature age student at the University of Canberra where he is halfway through a Bachelor of Community Education, majoring in counselling. Prior to entering university Ian spent many years in various service industries, such as international freight forwarding and customs clearance, real estate marketing and public transport, where he most enjoyed dealing with people’s issues on a personal level in face-to-face situations. His hobbies include off-road touring and camping, industrial archaeology, viewing rural architecture, and almost anything to do with old steam railways. He also bicycle toured in UK, USA, Europe and New Zealand when he was younger and much fitter.

Ian will be working as an individual advocate alongside our popular, capable and experienced individual advocate, Sheryl Woolnough.

Advisory Forum - Update!

The Advisory Forum is a group of people who have an intellectual disability, who get together regularly to share stories, look at issues that impact on everyday life, and discuss topics that are related to the experiences of people who have an intellectual disability in the community.

During the past year, members of the Advisory Forum have been discussing employment, and the issues relating to applying for, and maintaining employment for people who have an intellectual disability. Speaking from their own experiences Advisory Forum members began to develop a list of the key issues that were common among the participants, which reflected the ongoing and unresolved problems that are facing people who have an intellectual disability seeking meaningful employment.

With the support of the Project Officer, members of the Advisory Forum sent Minister of Employment and Workplace Relations Joe Hockey, a letter about who the Advisory Forum are and an attachment of the list of key issues that was developed by the Forum in regards to employment. The letter is not only an example of the contribution each member of the Advisory Forum brings to the group, but also the contribution the Advisory Forum has in informing the community and other governing bodies about the realistic problems facing people who have an intellectual disability. With the permission of the group, below is a short list of some of the key issues that was discussed among Advisory Forum members, and resonated most strongly with participants.

Advisory Forum Meeting Key Issues from discussion on Employment

- Advisory Forum members want to feel like they are a welcome part of the organisation. Members of the Advisory Forum feel that people who have an intellectual disability should expect to be able to come into work and experience the satisfaction of working, and being part of a team, just like their work colleagues who do not have an intellectual disability.
- Members of the Advisory Forum feel that employers and their fellow employees do not know how to communicate with people who have an intellectual disability. This in turn makes it difficult for people who have an intellectual disability to take the initiative to approach their supervisors or foster meaningful working relationships at their place of employment.
- Members feel that Employment agencies lift their expectations about finding employment. Advisory Forum members are concerned that they are told by the employment agency that they are ready to go out into the workforce and employable, but become disappointed when they can not find work- despite doing everything that the employment agency has directed members to do, in order to find employment.

The Advisory Forum invites people who have an intellectual disability to participate in meetings, with the next meeting on **Saturday 27 of October**. If you are interested in attending or would like more information, please call the Project Officer, **Stephanie Soriano** the Advocacy for Inclusion Office on **6286 9422**.

Something to think about...

The Mouse Trap

One day a mouse looked through the crack in the wall to see the farmer and his wife open a package. The mouse wondered - "What food might this contain?" He was devastated to discover it was a mousetrap.

Retreating to the farmyard, the mouse proclaimed the warning: "There is a mousetrap in the house! There is a mousetrap in the house!"

The chicken clucked and scratched, raised her head and said, "Mr Mouse, I can tell this is a grave concern to you, but it is of no consequence to me. I cannot be bothered by it."

The mouse turned to the pig and told him "There is a mousetrap in the house! There is a mousetrap in the house!"

The pig sympathised, but said "I am so very sorry, Mr Mouse, but there is nothing I can do about it but pray. Be assured you are in my prayers."

The mouse turned to the cow and said "There is a mousetrap in the house! There is a mousetrap in the house!"

The cow said "Wow, Mr Mouse. I'm sorry for you, but it's no skin off my nose."

So the mouse returned to the house, head down and dejected, to face the farmer's mousetrap alone.

That very night a sound was heard throughout the house - like the sound of a mousetrap catching its prey.

The farmer's wife rushed to see what was caught. In the darkness, she did not see that it was a venomous snake whose tail the trap had caught. The snake bit the farmer's wife. The farmer rushed her to the hospital, and she returned home with a fever.



Everyone knows you treat a fever with fresh chicken soup, so the farmer took his hatchet to the farmyard for the soup's main ingredient.

But his wife's sickness continued, so friends and neighbours came to sit with her around the clock. To feed them, the farmer butchered the pig.

The farmer's wife did not get well; she died.

So many people came to her funeral, the farmer had the cow slaughtered to provide enough meat for all of them.

The mouse looked upon it all from his crack in the wall with great sadness.

So, the next time you hear someone is facing a problem and think it doesn't concern you, remember - when one of us is threatened, we are all at risk.