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Adelaide People First

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The President's and Convener's Desk

Welcome to Adelaide People First's 1st Newsletter. Adelaide People First is a small grass roots, independent, values driven, systems advocacy, voluntary, People First group. We formed our group in June 2010. We have been working on and have developed our values and vision statements which form the firm foundation for our systems advocacy action. You can find out more about our People First group in the About Us section of this edition of our newsletter.

Our newsletter is our main advocacy tool for stating our advocacy position on the issues of deinstitutionalisation and valued lives in community for people with lived experience of, or labelled with intellectual disability in the Adelaide metropolitan area.

We hope you enjoy reading our newsletter and that we increase your understanding about the issues we are passionate about most. We welcome your feedback by email on adelaidepeoplefirst@adam.com.au

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Silvana Gant

Choice and Control - The Myth of "Choice"

David Gant OAM and Silvana Gant

There has been a lot of talk over recent times, about how people with disability and their families will have greater choice and control over services and supports we receive, through the National Disability Insurance Scheme or Disability Care Australia.

Well, if this is true, where's the evidence? Where's the move towards a new way of thinking and delivering disability services and supports for people with significant disabilities in South Australia?

The reason is this, since David came home from the rehabilitation centre, we have been unable to receive anything which remotely resembles a support or service; which would strengthen David's relationships and valued roles in the life of community.

We have asked. The response we received from disability services was the offer of a day options centre. When we asked about the day options centre, it turned out David would be segregated from community, congregated with other people with disability whom he doesn't know, and only has disability in common with, and isolated from family, friends and community who he's familiar with, doing things he's not interested in, therefore, an institution.

Our concern is disability services are waiting for a crisis, before they respond in their usual crisis driven manner, with yet another institutionalised option. Given our over twenty five years' experience in the advocacy movement, we know our experience of being offered institutionalised options only, is not isolated to David or our family.

I am the loving and devoted husband of Silvana and father of three young adult children. I am our family's historian, genealogist and wordsmith. I am a home owner, rate and tax payer. I am a social activist, a competent, compassionate treasurer and committee member of an advocacy group. I am an avid reader. I am a deep thinker, insightful and passionate about the issues which matter most to me. Family matters most, contributing to community matters most. Fairness, justice, equality and equity for all matters most. My speech may have diminished, but my voice in my and the lives of those who love and care for me most, and whom I love and care for in return, is crystal clear, valued and respected.

Silvana and I have been active, passionate social activists in the self advocacy, disability advocacy and now People First movements in Australia. We are passionate about a strong, independent, values driven, People First movement which advocates for deinstitutionalisation and valued lives in community for people with lived experience of or labelled with intellectual disabilities, with vision and purpose. We have consistently advocated for valued lives in community for people with intellectual disabilities and for institutions to close, for most of our adult lives. I received an Order of Australia Medal in 1989, for my activism for people with intellectual disabilities.

What does it say; when you're unable to obtain for yourself and the one's you love most, what you've been advocating for others, most of your adult life? It says the system has been playing at "inclusion"; the system is unshakable in institutionalised practice; unwilling and/or unable to make the necessary changes required to ensure vulnerable people living with disability receive appropriate and adequate support to live valued lives in community.

Given the disability service system's expertise in disguising their institutionalised options as "inclusion", where's their incentive to provide supports which meet the needs for a valued life in community for people with lived experience of or labelled with intellectual disabilities? I, Silvana, heard recently, that if people with disability and their families demand different options then, market forces will be the incentive for services and systems to change.

This is a very familiar argument. This is what was supposed to happen when the Disability Services Act was introduced in 1986. What's happened since is, services have changed their language to make it appear that they've changed and continued to adopt the same models of segregated and congregated options in every aspect of life, which isolates people with disability and their families, from each other and community.

The "Shut Out" report, 2009, states among other things that the current disability services system is: "broken; the money in the system is not spent well; the way the system works only suits the system; It doesn't suit people with disabilities; the system needs to change completely, not just given a quick fix." This vital report strongly articulates that the disability service system's institutionalised approach doesn't work.

The thinking in disability services seems to be, that if they segregate and congregate people with disabilities in smaller numbers, say five, and put a fresh coat of paint on the walls and pretty curtains in the windows, then what they provide won't look like an institution.

What do we, Adelaide People First say about institutions?

"An institution is any place in which people who have been labeled as having an intellectual disability, are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise, control over their lives and their day to day decisions. An institution is not defined merely by its size. An institution is not just a place; it's the way people think."

www.institutionwatch.ca

This definition speaks strongly to the thinking and practices of institutionalisation. Through our advocacy action we will strive to break down the walls of such thinking and practices. We do not accept any form of an institution, not even in disguise.

The issue of "choice" is used to justify the continuation of the institutionalisation of people with lived experience of, or labeled with intellectual disability. The statement one often hears is "But it's the person's right to "choose" to live in an institution." People with lived experience of, or labelled with intellectual disability have their lives controlled by services; have only ever known an institutionalised life and/or have been poorly supported or abandoned to live in community. If this is all a person knows and they are poorly supported, then of course they will "choose" to live in an institution.

Added to services disguising their institutionalised options as "inclusion" and abandoning people with little to no support to community, is that large institutions are buying small services with an individualised focus;"gobbling them up" and applying their institutionalised models. This activity is further reducing the options which vulnerable people with intellectual disabilities have.

Adelaide People First supports the introduction of the National Disability Insurance Scheme. We see its potential to deliver individualised supports so Australians living with significant disabilities, are well supported to live valued lives in community. However, in observing the thinking and practice of disability services, given the power and control of the institutionalised models they employ in the lives of vulnerable Australians living with disability, we question whether Disability Care will live up to its potential.

Added to our concerns about whether Disability Care will achieve its potential of supporting vulnerable people with disability well, to live valued lives in community, is the simplistic view apparently held by Disability Care Australia and others in the sector, that people with disability just need to be supported to develop self advocacy skills. The goal of increasing peoples' knowledge and skills in understanding and standing up for their rights and responsibilities is admirable however, Adelaide People First members have experienced this simplistic thinking within a service driven self advocacy group- SAID (Self Advocacy for Intellectually Disadvantaged People SA Inc.)

SAID operated under the same "train them into independence" model of self advocacy, with devastating consequences for the vulnerable individuals living with intellectual disabilities; 99.9 percent of whom came from institutionalised services. The devastating consequences demonstrated themselves in the form of increased abuse, neglect, discrimination, exploitation and victimisation, in peoples' lives.

The reason is, the "train them into independence" model of self advocacy fails to address the power imbalance between the person living with intellectual disability and the service provider whom they're dependent upon. This is especially significant in South Australia, given the dominance of institutionalised services and supports.

It is now time for independent advocacy groups to increase our vigilance, strength and power of advocacy in holding society, community and service systems accountable for whether and how, vulnerable people living with significant disabilities are supported to live valued lives in community. Adelaide People First looks forward to working in solidarity with people and groups who share our values and vision, in advocating for valued lives in community for people living with significant disability.

What about choice and control; real or myth? Indications are "Choice" and "Control" over services and supports for vulnerable people living with intellectual disabilities are likely to continue to be institutionalised ones, in South Australia. A choice is really only a choice if, it exists and a person is well supported to take up that choice. Without real choice there is no control.

Our challenge to the disability services system. Prove the services and supports you provide support vulnerable people well to live valued lives in community.

References

Adelaide People First – Vision Statement

Adelaide People First – Values Statement

Adelaide People First – About Us document

National People with Disabilities and Carers Council, (2009) Shut Out Report The Experience of People with Disabilities and their Families – The National Disability Strategy Consultation Report- Easy English version; pg 16

Sonia Bernardi, (1995), Personal Vulnerability, Citizen Advocacy News

Housing and support for people with disability; Shut In Position Statement

<http://www.disabilitycareaustralia.gov.au/community/advocacy>

https://www.bedfordgroup.com.au/my_future/housing/balyana_accommodation

https://www.bedfordgroup.com.au/my_future/housing/homes_for_100

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A Tribute to A valued Founding Member of Adelaide People First

Veronica Button - 1947 - 2013

Adelaide People First takes this opportunity to remember Veronica Button, one of our founding members, who passed away from a serious illness in March this year.

We remember with great appreciation and fondness Veronica's thirst for a heart understanding for the lived experience of other people with lived experience of, or labelled with intellectual disability, who continue to live institutionalised lives in South Australia; for her growing understanding of advocacy and the need for strong, independent values driven advocacy in the lives of people who remain institutionalised.

Veronica was instrumental in deciding our People First group's values and vision statements. We will miss her gentle, kind and giving spirit. Our thoughts and prayers go to her husband Peter and their family.



About Us

Why we decided to form a People First group:

A small group of individuals with lived experience of or labelled with intellectual disability, became concerned that the system advocacy issues of deinstitutionalisation and valued lives for vulnerable people with intellectual disabilities were not being addressed from a values driven perspective with a clearly stated vision and purpose, systemically, in South Australia.

Who is Adelaide People First?

Adelaide People First is an independent, voluntary, small, grass-roots, values driven, People First group which once fully established, will advocate on the systems advocacy issues of deinstitutionalisation and valued lives in community, for people with lived experience of, or labelled with intellectual disabilities in the Adelaide Metropolitan area. We work within a Social Advocacy Framework. We have developed our values and vision statements, which form the firm foundation for our advocacy action.

Adelaide People First has taken the lead from the international People First movement and adopted the strengths of this vital social justice movement; its systems advocacy capacity to advocate on the issues of deinstitutionalisation and valued lives in community, for people with lived experience of or labelled with intellectual disability; with the purpose of seeking social and political change.

Adelaide People First strives to be a leader in the world wide People First and social justice movements. We work with our allies in solidarity, in the People First, Disability advocacy and other social justice groups with whom we share values and vision, with the purpose of advocating for valued lives in community, for vulnerable people living or labelled with intellectual disability.

As a People First group which works within a Social Advocacy Framework from a values driven perspective with vision and purpose, Adelaide People First strongly believes it is vital to be clear about what our People First group's purpose is and what our People First group does not do and the reasons for this.

What Adelaide People First Means by Peer Support

We give each other peer support through sharing of knowledge, experience, emotional, social and practical assistance. This strengthens our group's capacity and skills to advocate on the issues of deinstitutionalisation and valued lives in community, for people living or labelled with intellectual disabilities in the Adelaide metropolitan area.

Our People First motto is:

We Are Stronger Together.

What We've Learnt from Our Lived Experience:

Adelaide People First values its independence from the human service system. The founding members of Adelaide People First have learnt from our experience in a service driven self advocacy group – (SAID - Self Advocacy for Intellectually Disadvantaged People SA Inc.), the harm caused through the “train them into independence” model of self advocacy. We know firsthand, how the simplistic model of providing information and training, to people whose lives are controlled by institutionalised services increases the risk of abuse, neglect, discrimination, exploitation and victimisation.

For this reason the “Train them into independence” model of self advocacy fails to address the power imbalance, between the person living with intellectual disability, dependent on services he/she is advocating to on their own behalf and the service who has the power in their lives. Our lived experience of the “Train Them into Independence” model of self advocacy is why Adelaide People First has decided it is

NOT:

- A service, eg: Independent living support
- A Self Advocacy group
- A training organisation
- A Paid Individual Advocacy organisation
- A Citizen Advocacy organisation
- A representative group
- A peak body

How Often and Where Adelaide People First Meets:

Adelaide People First meets monthly.

Our meeting place is: 99 Frome Street

Adelaide SA 5000

Our Email address is: adelaidepeoplefirst@adam.com.au

Our email address is the best way to contact us.

President & Convener: Silvana Gant

Issues Of Concern For Our Group Include:

- SA is an institutionalised state in the way services think and in their practice of delivering services.
- Holding services accountable systemically, from a values driven perspective, with vision and purpose, for only providing institutionalised services and supports disguised as “community living”, while the NDIS (National Disability Insurance Scheme) is being implemented and beyond.
- How to ensure vulnerable people living with intellectual disability, who are institutionalised have access to independent, values driven advocacy support, now the National Disability Insurance Scheme has been introduced.
- Services establishing: “self advocacy” groups within their service delivery and the impact on the vulnerable individuals living with intellectual disabilities within these services, given the “train them into independence” approach to “self advocacy”.

Values and Vision statements available upon request by email only

Personhood

Personhood is having dignity, honour and respect in my humanness.

Personhood is having hopes and dreams and reaching for the stars.

Personhood is being in two way relationships where I'm valued for who I am and what I bring to the relationships.

Personhood is being with family and friends and knowing I'm loved and am free to love others in return.

Personhood is experiencing, love, joy peace, sadness, disappointment, heartbreak, grief and all the feelings in between.

Personhood is having a home of my own and making it mine.

Personhood is being passionate about what's happening in the world and seeking to make it a better place for everyone.

Personhood is expressing creativity in ways which nurture my heart, soul, spirit and mind.

Personhood is knowing within my spirit, there is a being or entity greater than self.

Personhood is making mistakes, learning from them and given the opportunity to make amends.

Personhood is learning about the world and life, my whole life long.

Personhood is being challenged and challenging others to give human endeavours our all.

Personhood is being defined by my strength of character, not my human characteristics.

Personhood is, knowing there is no-one else in the world like me and being content in being me.

Silvana Gant