



## **Adelaide People First**

### **2014 South Australian State Election Bulletin © February 2014**

#### **Welcome to Adelaide People First's South Australian State Election Bulletin**

In our 2014 South Australian State Election Bulletin we address the main issues which affect people with lived experience of or, labelled with intellectual disability most in this election.

Before we look at the main issues we give some insight into our research process in preparing to write our state election bulletin and give some background into the lives of people living with significant disability, including people with lived experience of, or labelled with intellectual disability.

#### **Our Research Process**

We gave the state Labor government, SA Liberals, SA Greens and Dignity for Disability the opportunity to answer the same questions in researching our bulletin. We did this so each political party would have the opportunity to address the issues of most concern to us as a People First group.

We also gave Disability SA, Minda Inc., Orana and Bedford Group the opportunity to address the issues of most concern to us. We took these four organisations as a sample of what is happening in the disability service system in South Australia.

We looked at organisations websites, annual reports values, vision, service information and publications. We also read relevant reports and legislation. We have also compared all information gathered with our group's values and vision statements to decide our advocacy position on the issues of deinstitutionalisation and valued lives in community for people living or, labelled with intellectual disability. You will find all these in the references section of our bulletin.

At time of publication we received no responses to our questions from the political parties we asked. Minda Inc., was the only institutionalised disability service provider who responded to our questions, whom we approached. We hope to update you of further developments in our April newsletter.

## Background

There has been a long history of people living with disability being institutionalised through the practices of isolation, segregation and congregation. This has resulted in people living with significant disability being abused, neglected, exploited, discriminated and oppressed. 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.

The Disability Services Act of 1986 opened up new opportunities for a different approach to providing services and supports for people who live with disability. This resulted in funding of advocacy support and a few small individualised focused services and supports, which support people living with disability to live in community.

Unfortunately, large institutionalised service providers have adapted and learnt to disguise their institutionalised models of service as “community participation”.

## The Continued Institutionalisation of People Living With Disabilities Under The NDIS

Since the introduction of the NDIS (National Disability Insurance Scheme) as an idea, the disability service system in South Australia has been moving towards preparing itself to be a one stop shop for any and every service and support a person living with disability and their family may need.

This means that already large institutionalised disability service providers are becoming even larger and more institutionalised in their approach.

Adelaide People First has a clear definition of an institution. Our definition is:

***“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](http://www.institutionwatch.ca)

Institutionalised disability service providers continuing down the path of becoming “all of life” disability services, therefore one stop shops in preparation for the full implementation of the NDIS is happening unchallenged and accepted by the political parties we approached.

This approach by our political leaders is most obvious when we look at the closure of Strathmont Centre and the “integration” into community of people living with intellectual disability who live there. The South Australian government is proclaiming this supposed “community integration” as a success.

When we take a deeper look into the situation however, we find people are being moved into smaller institutions or group homes. It is unclear if Disability SA is both landlord and support service. This is a major concern Adelaide People First has of all the four large disability institutionalised service providers we approached. Being both landlord and support service is a clear conflict of interest.

This conflict of interest increases the vulnerability of the people receiving and dependent on grouped models of service to abuse, neglect, discrimination and exploitation, especially when a problem arises with the support service or landlord.

Adelaide People First's advocacy position is simply segregating one service type from another within the larger organisation does not adequately address the conflict of interest issues which arise. Nor does it safeguard vulnerable people dependent on services for their life needs from abuse, neglect, discrimination and exploitation.

Large institutionalised disability service providers continuing on the path of being an "all of life" service providers is strong proof of the continuation of the institutionalisation of people living with significant disability including, people living or, labelled with intellectual disability.

On close inspection of the NDIS Act 2013, the National Disability Insurance Agency responsible for managing the NDIS is the national institutionalised disability service provider. The process of becoming eligible for and obtaining an individualised funding package is long and complicated. The NDIA makes the final decision.

Adelaide People First is concerned that institutionalised models of service will continue to thrive and grow. This will lead to vulnerable people living with disability receiving poor quality services which increase abuse, neglect, discrimination and exploitation. Our concerns are shared by Simon Duffy, from the Centre for Welfare reform, the SA Office of the Public Advocate and the SA Health and Community Services Complaints Commissioner.

### **Services Setting Up "Self Advocacy" Programmes**

Adelaide People First is extremely concerned about institutionalised disability services setting up "self advocacy" programmes/ groups within the services they provide. Minda Inc. has established a self advocacy training programme as part of the services they offer. The NDIS also appears to be implementing a service driven, institutionalised "train them into independence model of self advocacy

Adelaide People First has experience in being a service driven, institutionalised self advocacy group. In 1986 Intellectually Disabled Services Council (IDSC), the main service provider for people living with intellectual disabilities sponsored the establishment of a funded self advocacy group, SAID Inc. (Self-Advocacy for Intellectually Disadvantage People SA Inc.), through the Disability Services Act..

SAID became the structure used by the disability service system to give credibility to their tokenistic consumer representation processes.

Added to the tokenism with which we were treated, was the increased abuse, neglect, discrimination, and exploitation members who were dependent on institutionalised services, were subjected to.

The simplistic “train them into independence” model of self advocacy places all the responsibility for achieving change on the shoulders of the person advocating for themselves.

This resulted in the strengthening of the power of institutionalised disability service providers in the lives of the people living with intellectual disabilities, whose lives they controlled. The disability service system absolved itself of any responsibility for achieving real change or accountability in the lives of the vulnerable individuals, to whom they provided services

Adelaide People First believes Minda Inc., and the NDIS have established consumer representative structures, where the people involved are only allowed to make limited decisions. Meaningfully involving people in decision making processes, which affect them, is a valuable aspect of what any ethical organisation providing services to vulnerable individuals does. However, this is not self-advocacy.

If both Minda Inc. and the NDIS haven't established a service driven, institutionalised, tokenistic, “train them into independence” model of self advocacy, then what model of self advocacy is being implemented?

Minda Inc. has also established an “Independent Advocate” as part of the services they offer. Adelaide People First understands the “independent Advocate” is an employee of Minda Inc. and directly responsible to the CEO of Minda Inc. Minda Inc. employing their “independent advocate” is a clear conflict of interest. How can the “Independent Advocate” advocate to themselves on behalf of the people living with intellectual disabilities, to which they provide services?

### **Access to Real Independent Values- Driven Advocacy Support**

Adelaide People First is extremely concerned that people living with intellectual disability being controlled by institutions currently cannot have access to independent, values driven individual or systemic advocacy support, unless there is a referral made.

Institutionalised service providers have been using the “referral” process, consent and privacy and confidentiality as methods of preventing advocates gaining access to the individuals, during crucial decision making processes. This has increased the abuse, neglect, discrimination and exploitation many people living with intellectual disability experience in human service systems.

Independent advocacy support has a vital safeguarding and accountability role in the lives of people living with intellectual disability, whose lives are controlled by human services.

This vital safeguarding and accountability role of advocacy has been weakened over time. This weakness is best demonstrated in the Disability Services Act 1986 and the NDIS Act 2013. Both these pieces of legislation use weak language to describe the role of advocacy. Policies and procedures being misused by human services, meant to protect vulnerable individuals and ensure their best interests and human rights are addressed through advocacy, have compounded the accessibility of advocacy to people living with disability most in need of advocacy support.

There needs to be a clear understanding as to what is meant by independent advocacy. Advocacy is a social justice movement, ***not*** a service. For this reason Adelaide People First understands the critical need for advocacy to be and remain independent from service provision. Our definition of independent advocacy is:

**“To establish independence, an organisation or group needs to have advocacy as its core activity and not to be a provider of any services, especially the following: employment, accommodation support, personal care support, independent living support, respite, vocational training, brokerage, mediation, case management.**

**Advocacy for people with disabilities must be conducted by organisations or groups which are able to demonstrate independence from all actual, potential or perceived conflicting interests. Independence cannot be indicated by the separation of services from advocacy within an organisation or group.”**

Values provide focus, purpose and direction in deciding the advocacy position taken. It is also vital to be clear about the principles which strengthen the advocacy action taken.

Independent Advocacy must address the welfare, basic needs; seek justice for and is loyal to the least powerful person/group in the advocacy action taken. Advocacy must be strong, powerful and be there for as long as it takes. Advocacy must be mindful of third parties who are even more vulnerable than the person, group being advocated for. Advocacy must be prepared to share in the lived experience of the person/group being advocated for. Advocacy must have integrity.

### **Transparency and Accountability in Disability Policy Decision Making**

There has also been a lack of transparency by the Labor state government on consultation with people living with disability, their families, advocates and relevant others in the disability sector.

Since Minister Piccolo took over the disability portfolio, it has been difficult to find out whether the Ministerial Disability Advisory Council (MDAC) still exists and whether it is affectively utilised. What we know is the website link to MDAC can no longer be found. It has also been difficult to find information on what the structure for consulting with people who will be affected by disability policy decisions.

It remains unclear who Minister Piccolo is talking to and what he is talking to them about on disability policy issues. However we can make an educated guess as to who Minister Piccolo has the voices of. There are a number of media releases over the past year and a half where Minister Piccolo and the government has enthusiastically supported institutionalised models of service and institutionalised service providers.

This strongly suggests Minister Piccolo is talking to institutionalised service providers and individuals who support institutionalised models of service like group homes, special schools, nursing homes, cluster units, supported residential facilities and centre based respite services, to name a few.

The SA Liberals, SA Greens and Dignity 4 Disability have been silent on the lack of transparency in regards to consultation with, and accountability to, people who are affected the most by disability policy decisions.

Compounding the lack of transparency on disability policy decision making processes, is since the federal election, there is also a lack of transparency and accountability on disability policy decisions at the federal government level. The National People with disability and Carer Council has been abolished. There is yet no replacement so, how is the federal government accountable for its disability policy decisions?

### **The National Disability Strategy- What Happened?**

Strong Voices, the South Australian government's disability plan was publicly released in late 2011. This is part of the South Australian government's commitment to the implementation of the NDS. There has been silence from the South Australian government on progress made in its implementation. There has also been silence on this matter from the SA Liberals, SA Greens and Dignity4 Disability.

Since winning the federal election, the Coalition government has also been silent on the implementation of the National Disability Strategy. The NDS is a whole of community, system, government and society approach to the changes necessary in the national disability policy reform agenda. This adds to the perception that commitments made at all levels of government under the Council of Australian Governments, have been wiped clean.

### **What about the State Election Outcome?**

All these events demonstrate we live in a socially and politically institutionalised environment in South Australia, where powerful institutionalised services thrive and grow unquestioned.

Regardless of who wins the South Australian state election on March the 15<sup>th</sup>, People who live with significant disability, including people who live or, are labelled with intellectual disability will continue to have their lives controlled by powerful institutionalised service systems.

## **Leadership Required**

Adelaide People First believes strong, visionary, values based, consistent leadership is required to challenge the increased power and control, institutionalised human services have in the lives of vulnerable people living with intellectual disability, who depend on services and supports for their daily needs.

This vital leadership is absent from our political leaders. This means the leadership must come from us, the community. Adelaide People First stands ready to work alongside our allies with whom we share values and vision. Together we will challenge institutionalised practice in the lives of our most vulnerable citizens who live with significant disability, including citizens living or, labelled with intellectual disability.

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