



Adelaide People First

2013 Federal Election Bulletin ©August 2013

Welcome to Adelaide People First's 2013 Federal Election Bulletin

In our 2013 Federal Election Bulletin we address the main issues which affect people with lived experience of or, labelled with intellectual disability most being:

- The voice of people who are the most vulnerable to institutionalised practice;
- The human rights and social issues and;
- Rigorous accountability and evaluation of services, which control vulnerable people's lives.

We also look at the challenges.

Before we look at the main issues we give some background into the lives of people living with significant disability, including people with lived experience of, or labelled with intellectual disability.

Background

There has been a long history of people living with disability being institutionalised through the practices of 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". People with lived experience of, or labelled with intellectual disability continue to 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 Issues

We start with the voices of people with lived experience of abuse, neglect, discrimination and oppression, through institutionalised practices of segregation and congregation, with the purpose of controlling vulnerable people's lives. The voices of our most vulnerable citizens living with disability, who have their lives controlled by institutionalised practices, have been amplified in the Shut Out report (2009) and in the National Disability Strategy (2011).

Unfortunately, the voices of our most vulnerable citizens living with significant disability, who have been oppressed and controlled by institutionalised services, is silent in the National Disability Insurance Scheme Act (2013). This is most obvious in the disconnect between the objects and principles in the National Disability Insurance Scheme Act (2013). While the objects of the Act state that regard be given to the National Disability Strategy (2011) in the implementation of the NDIS Act (2013), the principles of the NDIS Act, neglect to include under the role of advocacy; to safeguard and advance the human rights, wellbeing and interests of people with disability in decision making processes.

In failing to amplify the human rights imperative in the principles and throughout the body of the NDIS Act (2013) effectively, not only silences the voices of our most vulnerable citizens living with significant disability, it weakens capacity for the social and economic imperatives to be effectively addressed. This further demonstrates a disconnect in the amplified voices in both the Shut Out report (2009) and the National Disability Strategy (2011)

Further, the bureaucratic nature of the process, an individual must go through to be approved for and receive an "individualised funding package", as in the NDIS Act, is so complex, that this will add to the vulnerabilities and complexities in the lives of citizens living with significant disabilities, who have their lives controlled by institutionalised services.

This is particularly significant in South Australia, because of the dominance of large institutionalised services. Added to the complexities is, Disability SA is our state's version of the one stop shop model, as seemly outlined in the NDIS Act, which Disability Care Australia appears to be operating within.

Dave and I know from our own experience with Disability SA, that the system decides what services and supports are offered. If an institutionalised option is all there is and you are offered it, then that's all you get to "choose".

As we stated in our first newsletter, 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.

There needs to be greater understanding at the community, political and societal levels, of the interconnected nature of the human rights, social and economic issues which affect all of us. This is especially significant for people with lived experience of, or labelled with intellectual disability, and others living with significant disability, because of the deep detrimental impact in their lives, from having their lives controlled by institutionalised services.

People living with significant disability need to have their human rights addressed through relationship based, independent, values driven, individual advocacy, which takes the time to know the person well, builds knowledge of the person's life. When this is done effectively with the purpose of safeguarding and advancing the person's wellbeing and best interests, it increases the opportunities to build in socially valued roles and freely given relationships into the person's life. This addresses the social and economic issues which affect the person's life. This also makes it more possible for the person to live a valued life and makes it possible to build community capacity. It must be understood this takes time, and given the deep detrimental impact which comes from being institutionalised may take a life time.

The systemic advocacy issues which are addressed need to be informed by independent, values driven, and relationship focused individual advocacy. There must be an understanding of the patterns of how systems function and systemic issues within service systems and community, before developing and seeking social and political change.

Adelaide People First sees the potential of individualised funding to deliver services and supports for people living with significant disability, to live valued lives in community. However, given the grouped models of services which control vulnerable people's lives, we ask, how will individual funding packages be separated from the grouped models of service, to support the person well, to live a valued life in community? How will institutionalised services be held accountable for demonstrating that the money allocated to an individual is spent on the individual, it's allocated to? And, how is the person living a valued life in community?

For almost the past three decades the Disability Services Standards have been a tick this box exercise. The voices of the most vulnerable people living with significant disability have largely had their voices ignored by the human service system, political systems and community at large. Independent advocacy organisations, both individual and systemic, have valuable insight into the lives of vulnerable individuals living with significant disability, who have their lives controlled by institutionalised services. There needs to be strong, evidenced based practices and principles, rigorously applied in the assessment and evaluation processes of both government and non-government organisations, which control the lives of vulnerable people living with significant disability.

Silvana Gant

References

Adelaide People First Values statement

Adelaide People First Vision Statement

Adelaide People First About Us document

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