



## **Adelaide People First**

### **Newsletter No: 2, June 2014**

Welcome to Adelaide People First's June 2014 newsletter.

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#### **Is It Safer To Live in large Residential Institutions Rather Than Community?**

The main article in this newsletter explores the myth or untruth; are people living with significant disabilities safer living in large residential institutions rather than community? There is a real belief in community, the human service system and even the disability advocacy movement, people who live with significant disability are safer living in large institutions rather than in community.

#### **Where Did Institutions Come From, What Do They Look Like?**

In taking a deeper look at whether this myth is real, we need to first ask ourselves a number of questions. We start with what does our society value? Our society values youth, beauty, wealth, power, good health, physical prowess and intelligence. People who live with significant disability including people who live or, are labelled with intellectual disability are perceived as not possessing any of the attributes we value in society. This means people living with significant disability including people living or, labelled with intellectual disability have historically and continue to be cast in socially devalued roles within society and community.

The devalued roles people living with significant disability including, people living with intellectual disability have been cast include subhuman, a menace, objects of pity, burden of charity and innocent-childlike. These socially devalued roles have led to the assumptions that either vulnerable people living with significant disability need to be protected from society and/or society needs to be protected from vulnerable people living with significant disability. This need for “protection” has led to the practices of isolating and segregating vulnerable people living with significant disability from family, friends and community and congregating or grouping vulnerable people together in hospitals and large residential institutions far away from the rest of community. This is where the medical model and the “fix them” mentality we have, comes from.

### **What are the Consequences of Institutions in Vulnerable People’s Lives?**

Disability being seen and treated through the lens of the medical model has meant people living with significant disability including, people living or, labelled with intellectual disability were grouped together on the basis of disability and treated all the same. The assumption being everyone in the group had the same needs, likes, and dislikes which needed to be met in the same manner. This led to a loss of personhood and citizenship. The loss of personhood and citizenship has meant people living with significant disability were sexually and physically abused, being over medicated to keep people “quiet” secluded from other people in the same institution, restrained to control “inappropriate” behaviour, deprived of food and proper health care, having unnecessary medical procedures including forced sterilisations, financial exploitation and at worst made dead through deliberate neglect of basic life needs or murdered. All abuse, neglect, discrimination and exploitation occurred hidden from public view.

### **What is Living a Valued Life in Community?**

Now we look deeper into what we mean by living a valued life in community. As part of our research we have looked at our values statement and a definition of community living found in a research paper. This has assisted us in developing our definition of a valued life in community.

The definition of community living found as part of our research.

“Definition of community living:

The aim of community living arrangements is to enable people with intellectual disabilities to use the same range of accommodation, living arrangements and patterns of living that are available to the rest of the population, and to have a good quality of life, participating as full citizens in social, cultural and economic activities to the extent and in the ways the individual chooses.

Thus community living involves:

- Using accommodation located among the rest of the population, which is adequate, appropriate and accessible to the individual
- Using the range of accommodation options ordinarily available to the wider population
- Enabling people, to the greatest extent possible, to choose where, with whom and how they live
- Providing whatever help is required to enable people to participate successfully in the community “

While we found the definition of community living helpful, we are concerned about how the disability service system in Australia has corrupted or bastardised the term “community living” along with other terms such as “community participation”, “community inclusion” and “community integration” to describe what they do, when the evidence suggests human services disguise and hide behind pretty curtains in the windows, fresh paint on the walls, landscaped gardens, manicured lawns and slick marketing and continue to employ the same institutionalised models of service. As a result of the human service system’s corruption of the above terms, our definition of a valued life in community is:

***“A valued life in community is being a valued contributing citizen in the social, economic, academic, cultural, spiritual and political life of community, where everyone lives, in housing which is available to the general population and is adequate, appropriate, accessible and affordable. A valued life in community is choosing where, with whom and how a person lives. Living a valued life in community is having meaningful, healthy relationships with family, friends and community.” Adelaide People First June 2014***

This definition of a valued life in community speaks strongly to citizenship, valued status, and the richness of community life. Meaningful, healthy relationships with family, friends and meaningful, valued connectedness through socially valued roles are vital for living a valued, rich life.

People, who live without disability and are respected as valued contributing citizens, often take for granted the socially valued roles and freely given interdependent relationships in their lives. The socially valued roles and freely given, interdependent relationships in people’s lives reduce the likelihood of abuse, neglect, discrimination and exploitation in people’s lives. Socially valued roles speak to one’s valued status within community and give opportunity to develop skills, knowledge and experience. This in turn adds to the perception the person is valuably contributing to community.

We need to understand what an institution is and what aspects of an institution if any, still exist in current services within our society, in order to determine whether vulnerable people living with significant disability, including people living or, labelled with intellectual disability are living institutionalised lives in disguise or really being supported to live valued lives in community.

### **The Continuation of Institutions in Disguise- Modern Day Institutions**

Adelaide People First has a definition of an institution, which we adopted from the Canadian Deinstitutionalisation Taskforce. This definition is found in our values and vision statements.

Our definition of an institution 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)**

Our definition of an institution recognizes the thinking at the foundation of and how this thinking affects what people and human services do in order to control vulnerable people’s lives. Our definition of an institution leads us asking a very important question. Are there services that meet the different aspects of the definition of an institution today?

In our research we looked at medium to large disability service providers, three of which, Disability SA, Minda Inc., and Bedford Group still run large residential institutions. These large residential institutions are Disability SA’s Strathmont Centre and Highgate Park, Minda Inc.’s Brighton Campus and Bedford Group’s Balyana.

Human services including institutionalised disability service providers have adapted to changes in expectations and policy by developing smaller grouped services like group homes, cluster housing, boarding houses recreation services and social groups and applied their institutionalised thinking and practices to them. Over time this has meant vulnerable people living with significant disability have moved from large institutionalised services to small “community based” institutions. These practices occur for the convenience of human services to provide services in a way which suits human service systems.

The consequences of these practices have meant people living with significant disability have been and continue to be made vulnerable and dependent on human services for their daily needs. This vulnerability and dependency in people’s lives has led to being subjected to, and at risk of, the same abuses neglect, discrimination and exploitation of the past.

This dependency encourages an organisational culture of violence which comes in the form of sexual and physical violence, being over medicated to keep people “quiet” secluded from other people in the same service, subjected to physical and medical restraints to control “inappropriate” behaviour and deprived of their daily needs. What needs to be understood is the large institutionalised disability service providers that run large institutions also run the smaller grouped institutionalised “community based” models of service.

As a result vulnerable people living with significant disability including people living or, labelled with intellectual disability have also been denied the opportunity and support to develop knowledge, skills and meaningful connection to family, friends and community, to live valued lives in community. The controlled institutionalised environment creates and encourages an organisational culture which prohibits these vital connections, skills and knowledge from developing, being maintained and strengthened in vulnerable people’s lives.

## **Conclusion**

Whether people living with significant disability including people living or, labelled with intellectual disability are living in large residential institutions or small institutions within “community settings” including group homes, cluster housing, boarding houses, human service run social groups, recreation services, respite services, day options programmes and sheltered workshops, there is an increased risk of abuse, neglect, discrimination and exploitation.

We know if vulnerable people living with significant disability including, people living or, labelled with intellectual disability were supported well through socially valued roles and meaningful connectedness to healthy relationships with family and friends, living a valued life in community would be safer than living in a large institution.

Through our research Adelaide People First has been unable to find evidence which supports the view, people living with significant disability including people living or, labelled with intellectual disability are supported well to live valued lives in community. This is not say that a small number of people living with significant disability, including, people living with intellectual disability aren’t living valued lives in community. However for the majority of people living with significant disability including, people living or, labelled with intellectual disability, a valued life in community remains unrealised and inconceivable in our institutionalised society.

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## **President & Convener's Report**

### **Setting and working on our goals**

Adelaide People First has decided what our goals are from June 2013 till the end of 2014. Our goals are:

- Publish 2 newsletters and two bulletins highlighting the issues of institutionalised practice and valued lives in community for people living or, labelled with intellectual disability, in the Adelaide metropolitan area. The Bulletin is to focus mainly on political and advocacy issues affecting people living with intellectual disabilities.
- Hold a public forum focusing on institutionalised practice and quality supports needed to live a valued life in community. Use material from public forum as basis for submission to be sent to relevant government departments, disability and community organisations.
- Develop an online presence through a website or Facebook.

### **Our newsletter and bulletin**

We have published two newsletters and three bulletins. Our newsletter and bulletin are our main advocacy tool. They outline our advocacy position on the issues we are passionate about most, challenging institutionalised practice and advocating for people living with intellectual disability to be well supported to live valued lives in community.

People First of Canada posted our August 2013 Newsletter on the Institution Watch website in the resource section. Brain Injury Network of South Australia posted our South Australian State Election Bulletin on their website. This tells us we are on the right track with how we are using our newsletter and bulletin to advocate our advocacy position on the issues we are passionate about the most. We thank both People First of Canada and Brain Injury Network of SA for promoting our advocacy work and giving us an internet presence. This is vital as we have been unable to develop an internet presence of our own so far.

I was interviewed by Marnie Round from SACOSS on Radio Adelaide about institutionalised practice and our people first group. The interview went very well. Adelaide People First hopes to explore the possibility of an alliance with SACOSS in the near future.

### **Work on our public forum**

We are in the process of developing and finalising our plan for our public forum. We have also been searching for a sponsor who shares values and vision with us, to cover costs of a venue and catering. We hope to hold the public forum by the end of the first quarter of the new financial year. We will keep you updated on progress.



## **Building positive relationships with Allies**

Adelaide People First has been looking to develop alliances in the community. We have been looking at and meeting with potential allies with whom we share values, vision and understanding of grass-roots, independent, values driven advocacy, to assist us in achieving our goals.

We have met with Sandy Edwards from the Health & Community Services Complaints Commissioner Office. This meeting was requested by Sandy Edwards as a result of our Post Federal Election Bulletin. This meeting was to discuss safety and quality of SA government and non-government services. This was a very fruitful meeting. We were able to give Sandy Edwards information about how our people first group works and the issues we are concerned about most. We were given useful information about how the Health and Community Services Complaints Commissioner's office works and useful resources and research material. These resources and research have been very useful for our newsletter and bulletin.

We became members of the Disability Advocacy Network of Australia (DANA) earlier this year.

We have met with Robbie Williams from Purple Orange to explore shared values and vision and learn about how each other work. It has been a positive experience for us. We look forward to exploring the possibilities of working together to challenge institutionalised practices in the lives of people living with significant disabilities, including people living or, labelled with intellectual disability and quality supports for people to live valued lives in community .

We continue to develop and strengthen our relationship with Reinforce Victoria. Reinforce Victoria is the oldest self advocacy group in Australia. They have a long history advocating closing institutions and advocating for people living with intellectual disability to live valued lives in community.

## **Contribution to consultation processes and community forums**

Adelaide People First was invited to participate in Salisbury Council's Inclusion forum. We are pleased we were able to attend and influence such an important forum. Our contribution included getting the issues of social inclusion and institutionalised practice on the agenda. We hope our contribution will lead to a deeper conversation and appropriate action at community and council levels about recognizing and addressing institutionalised practice at the individual, systemic, community and societal levels. We look forward to receiving the report from the inclusion forum and working with the Salisbury Council on ensuring people living with significant disability are valued, contributing citizens in the life of community.

We contributed to DANA's submission to the NDAP Better Collaboration and systemic advocacy issues consultation process. . We were unable to contribute to this important consultation process in our own right, as we are a non NDAP advocacy group. We greatly appreciate DANA giving us the opportunity to have our group's voice listened to and respected.

Better collaboration and systems issues affect everyone in the community. Adelaide People First is a systems advocacy people first group advocating against institutionalised practices and for valued lives in community for people living or, labelled with intellectual disability. If we were given the opportunity to contribute to the consultation process in our own right, we would have given valuable insight into the institutionalised social and political environment within which we conduct our advocacy and the impact in the lives of people who through their lived experience of significant disability, continue to be institutionalised in “community” settings.

Adelaide People First wrote a strongly worded letter to the National Disability Insurance Agency about the timing of the consultation of their strategic plan. The consultation process took place during the Christmas/New Year holiday period. We expressed our concerns that few submissions would be received and that this would result in the deep and broad issues which affect people living with disability most in need being ignored. We feel vindicated in our concerns as we were made aware by the NDIA that they received 53 submissions in total nationwide.

On behalf of Adelaide People First, I participated in the NDIS self advocacy and meet the governors webinars, which was hosted by the NDIA. I was disappointed to report to my fellow people first members, I found both webinars disappointing and frustrating as they either failed to cover the deeper issues or did so inadequately. In the self advocacy webinar our main concerns are the service driven, “train them into independence” model of self advocacy was heavily promoted. While the internationally recognised systemic advocacy people first group model was ignored. This vital people first model focuses on the collective and united voices of people with lived experience of intellectual disability speaking up to close institutions and for vulnerable people living with significant disability to be supported well, to live valued lives in community.

In the meet the governors webinar we are concerned the issues of challenging the institutionalised practices within human services and creating quality individualised supports so people living with significant disability would be well supported to live as valued, contributing citizens in community, were largely forgotten in the conversation. It was encouraging to hear Dr Rhonda Galbally state the importance of not ending up with more of the same broken service “options” we have always had. This says someone at board level understands the important issues.

### **Increasing our systems advocacy capacity**

I attended a strengthening advocacy workshop hosted by Citizen Advocacy SA Inc. The workshop was very informative in increasing my understanding of how society works, its impact in the lives of people living with intellectual disability and what is needed for ethical advocacy practice in vulnerable people’s lives. Our plan is to develop material to increase our group’s understanding and advocacy capacity.

## **Service driven, institutionalised advocacy being established**

Adelaide People First remains concerned at the continued lack of understanding by the institutionalised disability service system, of the importance of the independence of advocacy from human service provision and minimized conflict of interest in advocacy practice.

Adelaide People First has become increasingly concerned about institutionalised disability services establishing service driven “train them into independence” self advocacy groups and/or “independent advocates” as part of the services they offer people living with significant disability.

Our main concerns with the “train them into independence” model of self advocacy is it fails to address the power imbalance between the person living with intellectual disability and the service provider they are dependent upon for their daily needs. It makes the person with the least power in the situation take all the responsibility for achieving the change required, while strengthening the power of the service provider, by maintaining their decision making power in vulnerable people’s lives whom they control. The power imbalance in the situation means people living with significant disability including people living or, labelled with intellectual disability are at increased risk of abuse, neglect, discrimination and exploitation. Another concern is the institutionalised disability service system is driving this model of self advocacy.

The most worrying concern about institutionalised disability service providers establishing “independent advocates” is institutionalised disability services which control vulnerable people’s lives are denying vulnerable people access to real independent advocacy support. This denial of access to real independent advocacy support increases the risk of further abuse, neglect, discrimination and exploitation, in the lives of vulnerable people dependent on services for their daily needs.

This renewed move to be “all of life” services by the disability services system, to include advocacy as part of the group of services it offers vulnerable people living with significant disability, whose lives it controls, is even more concerning when one realizes the full implementation of the NDIS is only a few years away.

## **Individualised funding, the NDS and the NDIS**

Adelaide People First fully supports individualised funding however; we remain to be convinced the NDIS will deliver individualised supports and services, to people living with significant disability to live valued lives in community. Our main concern with the NDIS is, we will end up with more of the same institutionalised models of service, which we know, don't work and expose people living with significant disability to abuse, neglect, discrimination and exploitation. The NDS sets out the values, vision and the six key priority areas for a whole of community, systems, government and society approach to transform Australian society in disability policy. It is also and the foundation on which the NDIS is built, which has been largely ignored. We are deeply concerned this will negatively impact the implementation of NDIS and the broader societal disability reform required to transform our society.

Silvana Gant  
President & Convener