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Adelaide People First

Newsletter No: 3, © December 2014

Welcome to Adelaide People First's December 2014 newsletter.

Contents

The keynote speech below is the opening speech I gave at our inaugural No to Institutions, Yes to Valued Lives we held on the 12th and 13th of November which was sponsored by JFA Purple Orange. At the end of my speech we have included references to our research which supports our advocacy position.

Silvana Gant

Keynote Speech - No to Institutions, Yes To Valued Lives

Public Forum 2014

Welcome to Adelaide People First's inaugural public forum – No to Institutions, Yes to Valued Lives. We decided to have this public forum because we are deeply concerned about the continuation and growth of institutions. Not just the physical buildings which look like institutions but the way organisations and community think about disability issues; what this means for the implementation of the National Disability Insurance Scheme and the National Disability Strategy.

We need a truthful conversation about institutionalised attitudes or thinking and behaviour or practices. We've never had a truthful conversation about institutionalised thinking and practices and their detrimental impacts in peoples' lives in South Australia and Australia more broadly. This public forum is our opportunity to do so with passion and heart and head knowledge.

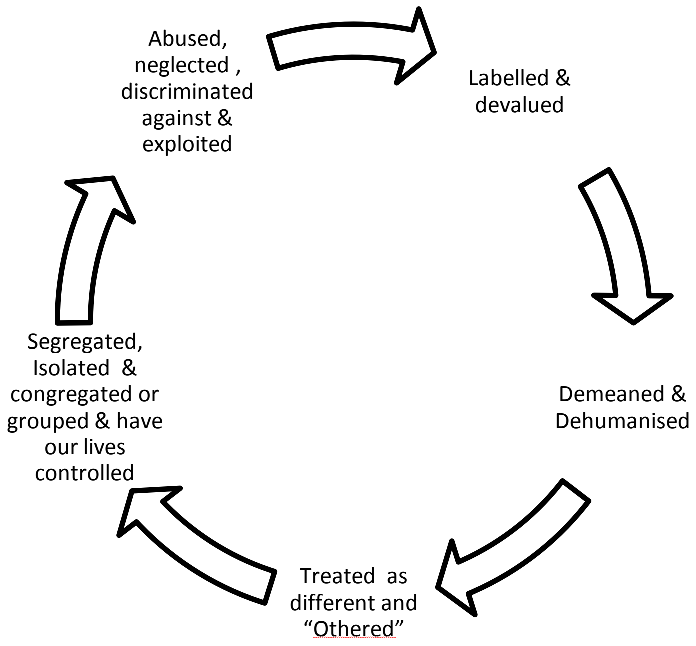
Our public forum also gives us the opportunity to imagine a different life than an institutionalised, controlled one. A life where we reach for the stars and have meaningful connection to family, friends and community. A valued life where we are valued for our contribution to society and have many and varied socially valued roles. A valued life in which our personhood and citizenhood is respected. We will explore the possibilities for individualised funding in respect to connecting a vision to a valued life.

We will explore the role for independent, values driven advocacy support in challenging institutionalised practice in the lives of people living with significant disabilities who are controlled by institutionalised human services; the leadership and accountability roles of independent, values driven advocacy support. We will also explore the leadership required to transform our society more broadly.

All of the information and ideas gathered from our public forum will inform the submission Adelaide People First submits to relevant individuals and organisations.

Before we start with where institutions came from, their purpose and their detrimental impacts in peoples' lives, 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 skill or talent and intelligence. The attributes or qualities our society values are superficial and have no substance. This demonstrates one aspect of how our society is broken.

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 been made powerless. The consequences have been we have historically and continue to be cast in socially devalued roles within society and community.



What happens when we are devalued?

The devalued roles we 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 powerless people living with significant disability need to be protected from society and/or society needs to be protected from powerless people living with significant disability. This need for "protection" has led to the practices of isolating and segregating us from family, friends and community and congregating or grouping us 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 Powerless People's Lives?

Disability being seen and treated through the lens of the medical model has meant people living with significant disability including, those of us 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 citizenhood.

The loss of personhood and citizenhood has meant people living with significant disability were sexually and physically abused, being over medicated to keep people “quiet” separated 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.

Adelaide People First in deciding what we mean by an institution has decided to take the lead from The Canadian Deinstitutionalisation Taskforce which consists of People First of Canada and the Canadian Association for Community Living. Our definition of an institution can be found in our values and vision statements. Both our values and vision statements direct all our decisions. Our definition of an institution is:

“An institution is any place in which people who have been labelled 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***

Our definition of an institution recognizes the thinking and practices at the foundation of human services, how this thinking affects what human services do in order to control powerless people’s lives. Our definition of an institution leads us to 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 what has happened since the introduction of the Disability Services Act in 1986. Disability service providers have learnt to adapt, change the language they use. The language of “deinstitutionalisation” “community living”, “community inclusion” “community integration” and now “community participation”, “choice and control” and disguise their grouped/ congregated or institutionalised models of service with a fresh coat of paint on the walls, landscaped gardens and freshly cut grass.

Human services have learnt to talk the talk without walking the walk. In grouping or congregating people together, services have done this is smaller groups. These smaller institutionalised models of service include group homes, cluster housing, boarding houses, recreation services, day options, respite services and social groups established by services. Over time this has meant powerless people living with significant disability have moved from large institutionalised services to small “community based” institutions.

These institutionalised models of service have been established for the convenience of human service systems; continue to employ the practices of segregation or separation and isolation from meaningful connection with family friends and community. The continuation of institutionalised practices continue to lead to a loss of control in life decisions, greater dependence of service systems for daily needs and loss of meaningful connection with family, friends and community. The Shut Out Report 2009 speaks very well to the system’s and society’s institutionalised practices and doing things in a way that suits both systems and society.

The consequences of these practices have meant people living with significant disability have been and continue to be made powerless and dependent upon human services for their daily needs. This powerlessness 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.

So what’s been happening since the publication of the Shut Out Report?

We have become aware over the past year of medium to large disability service providers buying small, individualised, personalised services and applying their institutionalised models of service to them. Also medium to large disability service providers have been preparing to provide more services across more aspects of life to the point where there is a trend of services setting up their own self advocacy programmes or committees and “independent advocates”. This means institutionalised disability service providers also aim to control the advocacy support people receive, whose lives they already control.

All of life services lead to a lack of choice. After all where, is the choice when the only choice available or services are prepared to support are institutions? Given there is no choice, where is the control?

We are also aware of disability service co-ordinators and support agencies bringing two or three people together to whom they provide services, in an unnatural way. The individuals involved would otherwise remain unaware of one another. The purpose of this unnatural coupling or grouping is to combine service hours of the individuals involved and provide a service to the individuals in a way which meets the needs of the service and is convenient to them. In bringing individuals together in this unnatural way the service providers have also decided the terms of the relationship between the individuals involved where only one person in the relationship benefits, while the other gives up certain human rights like privacy. This happens under the disguise of “friendship”.

As a result people living with significant disability including those of us 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 powerless people’s lives.

Part our research over the past year we looked at the continued existence of large residential institutions in South Australia. Despite the talk of “deinstitutionalization” since the introduction of the Disability Services Act 1986   large disability service providers, still run large residential institutions. These large residential institutions are Strathmont Centre, Highgate Park, Brighton Campus institution and Balyana.

There has been little to no meaningful, consistent, values driven   challenge to the continuation of these large residential institutions with vision and purpose. While both Strathmont Centre and Highgate Park are “supposedly” closing, the questions that need to be answered are where are people being moved to? What are people’s lives going to be like? How are people being supported to live valued lives in and have meaningful connection to family, friends and community?

Then there’s the fact the other two large residential institutions, Brighton Campus institution and Balyana are still operating as they always have, unchallenged so far.

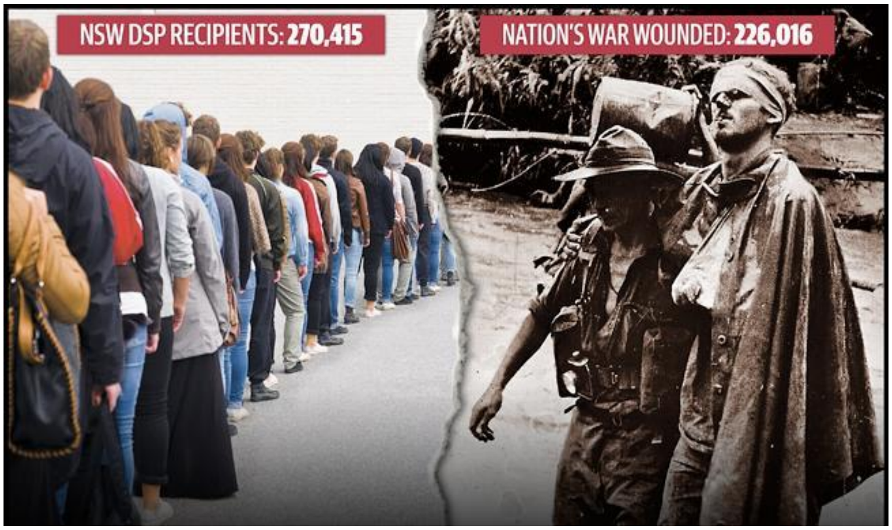
We understand from the relevant, institutionalised disability service provider's 2013 Annual Report, which runs Brighton campus institution, the institutionalised, disability service is planning a $200 million dollar redevelopment of their Brighton Campus institution over the next 10 years. It remains to seen and we at Adelaide People First remain to be convinced of any real significant change in the lives of people with lived experience of intellectual disability living at Brighton Campus institution.

Attitudes In Community, The Media and Political system.

Before looking at the implementation of the National Disability Insurance Scheme (NDIS) and the National Disability Strategy (NDS) we need to understand the social and political climate in which we live and institutionalised disability services operate.

We know from the Shut Out Report 2009 our lived experience is one of being shut out of community and society and Shut In institutions. Services put barriers in the way of our full and valued inclusion as contributing valued citizens.

More recently we have the continued attitudes of dehumanisation and demonization of people with lived experience of disability through the language of "Lifters" versus "Leaners" our political leaders and the media have been using to justify ill- informed social and economic policy. If this is untrue then, how does the language of "Lifters" versus "Leaners" and the derogatory newspaper headlines, images and stories being promoted challenge negative community attitudes about disability and provide for positive responses to disability the National Disability Strategy speaks to?



Source: "NSW Disability Support Pensioners now outnumber Australia's war wounded by 44,000", The Daily Telegraph, Friday 23 May 2014

This language or rhetoric and imagery is not only unhelpful, it results in institutionalised attitudes which lead to institutionalised behaviours or practices and adds to our lived experience of discrimination. How is this the case? Let's look at the different elements or aspects of our definition of an institution. 1 Labelling: Labelling us "leaners" implies we don't contribute or do any meaningful activity to make community a better place for all to live. We would vigorously challenge this assumption as human service systems rely on us for their jobs and many of us contribute to community and the economy through volunteer work, which contributes billions of dollars a year to the economy.

2: Congregated - Labelling us this way also groups or congregates all of us with lived experience of disability, treats us all the same, as one class.

Separating or segregating and isolating us from community and society, through the negative attitudes it is most likely meant to promote. Parts 3 & 4 of the definition of an institution, segregated and isolated.

The controlled message given seems to have the purpose of justifying ill-informed welfare and economic policies which once implemented control our lives. This is part 5 of the definition of an institution: Control over lives and day to day decisions.

Have you noticed there isn't a physical institution or place in sight? This demonstrates part 6 of the definition of an institution: An institution is not just a place, it's the way people think.

This is institutionalised thinking and practice at the heart of what is happening in our society. This institutionalised thinking leads to institutionalised practice which results in us being Shut Out of society and Shut In institutions. It makes it easier for institutionalised human services and broader society to justify their continued institutionalised models of service and practices in disguise.

We know there is a welfare plan to reduce the income of those of us on the DSP. Where's the jobs plan for people with lived experience of disability? Let's hope it's not working in a sheltered workshop for $1.00 an hour or a day options centre having one's life wasted with people we don't know and have nothing in common with other than disability, doing things we don't want to do, for the convenience of meeting some systemic obligations.

This institutionalised social and political environment is where the National Disability Insurance Scheme is being implemented. What about the National Disability Strategy I hear you ask? We are asking the same question? The NDS has barely rated a mention by anyone with influence since the 2013 Federal Election. No one in the broader community even knows of its existence or its purpose.

The National Disability Strategy is a whole of community, whole of systems, whole of government and whole of society approach to the necessary changes required within our society so all of us with lived experience of disability are well supported to live valued lives in community as valued, contributing citizens. The NDS sets out the values and the vision for the changes required to transform our society and is the foundation on which the NDIS is built.

This means everyone has responsibility for challenging myths and stereotypes associated with disability and promoting positive attitudes towards and acceptance of, people with lived experience of disability as valued contributing citizens within community and Australian society.

Given the institutionalised social and political environment in which we live and the National Disability Insurance Scheme is being implemented we have grave concerns we will end up with more of the same crappy institutionalised services we have always had using individualised funding, especially given this seems to be the direction the disability service system is continuing to head towards.

Leadership Required For long lasting Change

Strong values driven leadership with vision and purpose which shines the light of truth and challenges derogatory attitudes and practices in the lives of people living with significant disability, within community is needed for long lasting, meaningful change.

Those of us in community with shared values and vision of valued lives in community for people with lived experience of disability must unite and speak out against institutionalised attitudes and behaviour in community, at the community, systemic, political and societal levels.

We must also speak to and act to implement alternatives to institutions. Alternatives to sheltered workshops and day options like the Micro Enterprise Project which will be discussed in greater detail tomorrow. We must aim for the stars and challenge low expectations and ill-informed social and economic policies.

We must advocate for individualised funding which delivers individualised, personalised, quality supports that lead to valued lives in community, a strengthening of socially valued roles, healthy, meaningful connection and belonging in family, friends and community; valued lives which respect our personhood and citizenhood within Australian society.

Silvana Gant
President & Convenor
Adelaide People First

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Adelaide People First

President and Convener's Report

December 2014

In The Lead Up To Our Public Forum

- This report will focus on our inaugural public forum- No to Institutions; Yes to Valued Lives we held on the 12th and 13th of November. Our inaugural public forum was sponsored by JFA Purple Orange. JFA Purple Orange provided the venue, catering, advertising, registration, design of flyer, program, feedback sheet and printing for our public forum. We are very grateful to JFA Purple Orange for their sponsorship and support for our public forum and as one of our allies, who share our values and vision.

- In the lead up to our public forum we decided who our speakers were going to be. Part of the process of organising the public forum was meeting with representatives from Julia Farr Youth, Community Living Project's Micro Enterprise Project and Independent Advocacy SA Inc. The purpose of meeting with these organisations/groups was to increase our network of individuals and organisations who share our values and vision.

- In preparation for our public forum we continued our research into what is happening in South Australia in regards to the Disability Service System's preparation for the full implementation of the National Disability Insurance Scheme. For those of you reading this who are from interstate or overseas, South Australia is the trial NDIS site for children living with disability up to the age of five years who currently receive no services by either the state or the commonwealth governments. The NDIS is not expected to be fully implemented until July 2018. What our research shows is medium to large disability service providers are getting larger and getting ready to provide more grouped /shared models of service, which control more aspects of people's lives.

- Another aspect of our research has identified an increase in the number of super special schools for students living with disability opening in South Australia. We understand that due to education being a state government responsibility this means no NDIS funds should be spent on supporting students living with disability to attend special school. Even if this is true, we at Adelaide People First are concerned about the real risk of reduced choice for students living with disability and what this means for students living with disability accessing mainstream society into the future. We know from experience special school usually leads to an institutionalised life from where you live, work and if and how you connect meaningfully to family, friends and community.

- There is also the question of the South Australian government's commitment to implementing the National Disability Strategy through the Strong Voices Report, http://www.decd.sa.gov.au/speced2/files/pages/Better%20Pathways/Strategic%20links/Strong_Voices__Social_Incl.pdf, under the Council of Australian Governments Agreement. https://www.dss.gov.au/sites/default/files/documents/01_2013/nds_first_year_final_-_20_12_12_2.pdf . We ask how is building more special schools consistent with the South Australian Government's commitment to implementing the National Disability Strategy?

- We also looked at who the registered approved service providers under the NDIS are, as part of our research. We discovered there used to be a state by state list however; the NDIS no longer has the list available in that format. Now if you need to find a service provider, you need to tick the box next to the service type and type in your postcode. This new way of finding out the service providers registered under the NDIS is harder and a longer process, especially if you need more than one service. Also the assumption that everyone has access to the internet and telephone is a false assumption.

Our Public Forum

- Our public forum was very successful. Our purpose was to hold a public forum where we would have a truthful conversation about institutionalised thinking and practice and the detrimental impact in people's lives. We also wanted to have a deeper discussion about the quality supports which are required to live valued lives in community.

- Our public forum explored issues of what we mean by institutionalised thinking and practice, where we find such thinking and practice in community, services, systems, the media and broader society. We explored the myth of deinstitutionalisation and how we know it isn't happening; how disability and human services world keeps getting bigger and community keeps getting smaller. We explored the impact of the NDIS being implemented in an institutionalised social and political environment. We explored the importance of a vision for a valued life in community and how it connects to the National Disability Strategy. We explored and challenged the barriers to living a valued life in community. In challenging barriers to living valued lives in community we looked at alternatives to sheltered workshops and day options, through the Micro Enterprise Project. We explored the likely consequences of the proposed welfare changes and the downgrading of the Disability Discrimination Commissioner's position. We explored the safeguarding and accountability roles of independent, values-driven advocacy support.

- Some of the issues that came out of our public forum are:
    - Disability service providers still providing services that suit them in ways that suit them. We will get more institutions.
    - The need to educate community, media, service providers, families and governments about institutionalised thinking and practice.
    - Downgrading of Disability Discrimination Commissioner's position meaning that disability discrimination complaints won't be dealt with appropriately and we will be further disempowered and silenced.
    - The need to educate community, the media and people living with disability about the NDS and the NDIS.
    - Proposed welfare reforms leading to less control over our own lives and less economic security.
    - The perception that the needs of people living with disability are of little to no priority for the government. The perception the NDIS won't be fully implemented.
    - The need for real, independent, values-driven, individual and systemic advocacy support, especially given the implementation of the NDIS.
    - The need to live valued lives in community, to have healthy relationships with family, and friends, within and outside of family.

- We take this opportunity to thank the following individual for speaking at our public forum:
    - Lorna Hallahan
    - Jarad McLoughlin from Julia Farr Youth
    - Robbi Williams from JFA Purple Orange
    - David Oakey from Micro Enterprise Project
    - Rosey Olbrycht from Citizen Advocacy SA Inc.
    - Fiona Campbell from Independent SA Inc.

  All our speakers made it possible to have a public forum which allowed all of us to have a truthful, in-depth conversation about the issues that matter most in our lives.

Since Our Public Forum

- Adelaide People First was invited to, and on our behalf, I attended the National Disability Insurance Agency (NDIA) Invitational Roundtable regarding the design of the NDIS. The Roundtable was held by the NDIS independent Advisory Council. The Roundtable was held at Balyana Conference Centre. The conference centre is situated on the grounds of Balyana residential institution. It is very peculiar indeed, to be at a meeting discussing the design of the NDIS, which is meant to support people living with disability to live good lives in community, on the grounds of one of South Australia's largest residential institutions for people living with disability. What was the NDIA thinking? What message is the NDIA sending people living with disability about where they think those of us who live with disability belong?

- I don't know if being on the grounds of one of our state's largest institutions was why the discussion which followed sounded superficial and untruthful, however unfortunately that is exactly what the discussion was. There seemed premature praise on hand with some suggestions on how to: ”tweak” the NDIS so as to improve it.

- At the Roundtable I brought up two of the major issues which came out of our public forum; the need for the National Disability Strategy to be implemented and promoted broadly to community, systems and society; the real concerns that we would end up with more of the same institutionalised services which control our lives.

- Also at the Roundtable meeting, I highlighted that 6 new special schools have been opened by the South Australian state government since 2011. I asked whether NDIS funding would be used to support families to send students living with disability to special school. The NDIA representatives assured me that given that education is a state government responsibility, no NDIS funding would be go towards supporting students living with disability to attend special schools.

- Thankfully there were people present who expressed shared concerns of vulnerability about people living with disability in group homes and supported residential facilities who have no families. There were also concerns expressed about the need to understand the significance of a low number of complaints about abuse in institutional services. It needs to be understood the low number of complaints of abuse in institutional human services is a sign of an organisational, institutional culture where abuse is hidden and ignored.

- Four Corners/ Fairfax shocking report into abuse of people living with disability in the oldest, largest institutional disability service provider in Victoria aired on the ABC on Monday the 24th of November 2014. http://www.abc.net.au/4corners/stories/2014/11/24/4132812.htm

- The Assistant Minister for Social Services has come out stating it is not the Federal Government's responsibility to conduct an inquiry into abuse of people living with disability in institutions because the Federal government doesn't have responsibility for disability services and won't do so until the full implementation of the NDIS in 2019. http://www.probonoaustralia.com.au/news/2014/11/govt-rejects-disability-abuse-inquiry

- In the Four Corners/Fairfax investigation it was reported the relevant institutional disability service provider receives $85 million dollars in combined Federal, state government funding and public donations. This means Assistant Minister Fifield is wrong in his statement of the federal government's need not to conduct a national inquiry into abuse of people living with disability in all institutions.

- We know the federal government funds sheltered workshops or Australian Disability Enterprises (ADE''s) as they are disguised as. Sheltered workshops are institutions. The Federal government is also responsible for administering and ensuring all disability service providers comply with the National Standards for Disability Services.

- Given all these circumstances, how is the Federal Government free of any responsibility for conducting an independent, national inquiry into abuse of people living with disability in all institutions? What message is the Federal Government sending those of us living with disability about how seriously it takes its responsibilities to investigate violence, abuse, neglect, discrimination and exploitation in all disability services it is responsible for funding and monitoring?

- We have set up our Facebook page. We will be posting our newsletter, bulletin, media releases and updates on our advocacy work including public forums we will be holding. Check us out on Facebook on the following link: www.facebook.com/adelaidepeoplefirst

- Meeting with Glenda Lee from JFA Purple Orange, User Led Initiative. It was a productive meeting. We shared how we set up Adelaide People First, what our purpose is and our advocacy work so far. Glenda Lee shared what the User Led initiative is and how it can offer support to groups like ours to increase our capacity to do our work. We were encouraged to find out that there are groups like ours being set up by people living with disability, families and communities all over the world. We asked Glenda Lee to inform us of groups like ours she knows, with whom we share values, we could network with.

- I met with Robbi Williams from JFA Purple Orange, our public forum's sponsor and ally to update him about how our inaugural public forum went and our group's activities. We discussed the possibility of JFA Purple Orange sponsoring, so Adelaide People First could hold another public forum in early 2015 on the same topics as our first public forum. I am very pleased to report that with JFA Purple Orange's sponsorship, Adelaide People First will be holding another public forum in the autumn of 2015.

- We will restructure the public forum and hold it over three, half days over 2 weeks. We hope with other improvements this will enable more people living with disability, families, advocates and allies to attend our public forum.

- I informed Robbi Williams about our media release calling for an independent, national inquiry into abuse of people living with disability in all institutions, as a result of Four Corners program, " In Our Care."

- On Thursday the 11th December Adelaide People First published a media release calling for an independent, national inquiry into the abuse of people living with disability in all institutions. You can find our media release on our Facebook Page, www.facebook.com/adelaidepeoplefirst

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