

CLAIMING FULL CITIZENSHIP – PERTH FORUM

16 November 2015

REPORT

by

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ENABLING CONTRIBUTIONS

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CLAIMING FULL CITIZENSHIP PERTH FORUM

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BACKGROUND

The Claiming Full Citizenship Perth Forum was a one-day event that built upon a 3-day 'Claiming Full Citizenship' International Conference in Vancouver in October 2015. Eighteen Western Australians attended the Vancouver Conference and many of them came together to create the Perth Forum event. 100 people attended the Perth Forum.

The **purpose of the Perth Forum** was to: share collective learning from the Vancouver Conference with other people in the WA disability sector; AND provide an opportunity for everyone attending to Perth Forum to explore the 'so what?' elements of how and why this learning is significant and useful in WA/Australia at the present time.

The intended **Outcomes of the Perth Forum** were that people who attended:

1. Are aware of the Vancouver Benchmarks¹ and their importance and relevance in the WA/Australian context;
2. Are aware of leading edge initiatives and innovations from other parts of the world that support people with disability (especially those with complex needs) to be full citizens;
3. Had an opportunity to discuss with one another the relevance and applicability to our context of leading edge thinking and practices from other parts of the world; and
4. Had an opportunity to consider how an NDIS might facilitate individual citizenship, and what supports might enable this to happen.

To address **Outcomes 1 and 2**, several Vancouver Conference attendees shared what they learnt in a way that stimulated small group explorations of what that might mean to or for people in WA. This information is VERY briefly summarised on the next page. The slides used by presenters have previously been shared with Perth Forum attendees and are available at: <http://www.sotica.com.au/archives/category/resources/citizenship> or by emailing Leighton Jay at Leighton@Sotica.com.au.

Outcomes 3 and 4 were addressed using some 'world café' style facilitated discussion process around some important themes and issues. Key elements of these discussions are summarised in subsequent sections of this document.

CITIZENSHIP IS BASED IN FUNDAMENTAL HUMAN RIGHTS

Underpinning the Perth Forum discussions was an acknowledgement that the meaning of 'citizenship' is contested in today's world AND is fundamentally grounded in the Universal Declaration of Human Rights which Australia signed in 1948 (and many other countries have also signed). Article 1 states: *All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.*

¹ Vancouver Benchmarks is the working title being given to a statement that the Conference organisers are hoping to generate by the end of the conference with meaningful input from Conference attendees. It is anticipated that this statement will be a guide for governments in terms of policy directions, investment and service design that facilitates people with disability being able to live 'full citizenship' lives. More will be said about this prior to the Conference and at the start of the conference.

The United Nations Convention on the Rights of Persons with Disability (UNCRPD – signed in 2007) is a derivative document that spells out the application of the Universal Declaration in relation to Persons with Disability. The United Nations website introduces the intent of the Convention with these words: *This Convention follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.*

*The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that **all persons with all types of disabilities must enjoy all human rights and fundamental freedoms**. It clarifies and qualifies how **all categories of rights apply to persons with disabilities** and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights; and areas where their rights have been violated, and where protection of rights must be reinforced.*

Similarly, Australia's National Disability Strategy is firmly grounded in fundamental human rights and aspires to achieve equal citizenship for people with a disability. Its vision is to create an *inclusive Australian society that enables people with disability to fulfill their potential as equal citizens*². It goes on to say that *people with disability must be afforded the same rights as all other Australians. Australia formally recognised this by ratifying the CRPD in 2008, and acceding to its Optional Protocol in 2009. People with disability are citizens with rights, not objects of charity* (p15).

SUMMARY OF PRESENTATIONS

This is a VERY brief summary of key points shared by the six presenters at the Perth Forum.

Allan Nash (Grandparent)

1. Inclusion Alberta is an exemplary organisation from which much can be learned. They successfully enable people with complex and high support needs to meaningfully participate in post-secondary education and mainstream supports without paid supports. They do this in part by working with education institutions and employers to build their capacity to provide such support. Their partnership approach means that they get significant funding from outside government sources.
2. It would be great to have similar organisations leading the way in WA/Australia.

Gilliann Frew (Area Manager Perth Hills Community Services – PHCS)

1. Service providers can often get in the way of people living great lives despite good intentions.
2. In guiding our organisations in the right direction (and governments as they establish the 'systems'), we will benefit people if we keep focused on Tom Nerney's four key indicators of citizenship (<https://www.youtube.com/watch?v=fBMzCCKEuss>) - a place to call home; active community participation and membership; genuine, long-term friendships; and being able to earn a private income) and/or Simon Duffy's Keys to Citizenship (purpose, love, life, home, freedom, help and money).

² Commonwealth of Australia. 2011. *2010-2020 National Disability Strategy*. Commonwealth of Australia p8.

Susan Stanford (Catalyst – Microboards Australia)

1. As citizens ourselves, we can all take the lead to create better citizenship outcomes for people with disability without having to wait for government.
2. We can spend time outside of our work roles befriending a person or people with disability and building a solid, reciprocal friendship with them. Through this we will be able to provide evidence to governments that citizenship for all matters, it is possible to achieve, it makes good sense AND it is good economics.

Kate Fulton (Organisational Development – PHCS)

1. People with disability need access to the right assistance – assistance that they identify and choose themselves. In the current reform process, they (and family members) need a strategic and influential voice.
2. Similarly, it is unwise to treat Service Providers simply as supply of paid support labour. They can and should be strategic partners in reform.
3. We should also make sure that as the system evolves, new service choices and offerings are aligned to and enhance citizenship rights rather than reflect more traditionally provided services (which are often segregated and/or congregated).

Samantha Jenkinson (CEO – People with Disabilities WA)

1. We need to challenge and change “legally constructed zones of exclusion”. These include legally recognised substitute decision-making zones such as guardianship that don’t also provide a legally enshrined and supported zone for the exercise of ‘supported decision making’.
2. Systemically, governments tend towards wanting to control systems. It is difficult to see how an individualised and flexible system can be built and up-scaled if government continue to want to control it tightly.
3. And to ensure the success of Australia’s reforms, we need to measure REAL change and REAL social citizenship outcomes. Australia needs to collaborate with researchers from other countries to identify and share tools and methods for gathering and measuring reliable and valid evidence.

Marita Walker (NDIA Trial Site Manager – Perth Hills)

1. Individualised Funding is necessary but not sufficient on its own for individualised services that promote economic inclusion and citizenship. Communities are also critical to success.
2. Australia has some way to go in building capacity for self-determination and meaningful ways of measuring this.
3. The NDIS as a Scheme is continuing to evolve in responsive ways that enable more self-direction, choice and control in how resources are managed and used.

KEY POINTS FROM DISCUSSIONS ON ASPECTS OF CITIZENSHIP

1. Supported Decision Making (SDM)

- Supported Decision Making (SDM) needs to become more widespread in the everyday aspects of individuals' lives, especially those with complex and high support needs.
- Many family members assume that a person doesn't have capacity to make their own decisions. They need careful and skilful support to explore the ways in which this is limiting for the person.
- SDM needs to be legally recognised and enshrined in law as a valid means of assisting people to make their own decisions with the support they need. This can and should (at least) stand alongside substitute decision-making mechanisms such as Guardianship and Enduring Power of Attorney (e.g. Representation Agreements legislation in British Columbia (http://www.bclaws.ca/civix/document/id/complete/statreg/96405_01)). This is a State-based legislative issue throughout Australia.
- WA Individualised Services has produced some very good, free resources available for those who want to learn more: <http://waindividualisedservices.org.au/supported-decision-making-project-resources/>.
- Service Providers can do more to train their staff in relation to this: as a Human Rights issue, and assumptions they make about individuals' capacity to make decisions; and in terms of developing and using SDM practices.

2. Building and Sustaining Long Term Relationships and Friendships

- The role of paid support staff needs to include supporting people with disability (PWD) to build friendships (when required). This can be included in job role descriptions.
- Supporting someone with complex and high communication support needs can be difficult and requires skill, creativity and determination.
- Begin with the connections a person already has and build out from there to their friends and contacts.
- Identify a person's skills and interests and look for opportunities to build their connections with people who share their skills and interests.
- Ensure that organisational policies and procedures don't create barriers to relationship building (e.g. limited visiting hours; vetting processes).
- Parents/family members often have their own 'baggage' and fears around this issue. These need to be acknowledged but should not result in the person being told how to live their life. Family-to-family support has been effective in supporting families to take positive steps that increase the options for their family member.
- Microboards (and similar approaches) represent a way of 'creating community around a person' – as suggested by Sue Swenson from the USA.
- Systemically, segregated schooling continues to be a major impediment to the development of natural friendships AND the development of friendship-building skills.

3. Legal and/or Political Citizenship Issues/Rights for People with a Disability

- There seem to be several areas where 'zones of exclusion' have been created that violate Australia's commitments to upholding fundamental human rights and/or the Australian Constitution. These include the following.
- The Criminal Law (Mentally Impaired Accused) Act enables people with a cognitive/intellectual disability to be indefinitely detained in the Justice system without trial.
- The potential for SDM to safeguard the rights and interests of persons in decisions is underutilised in WA laws relating to people with disability.

- The WA Disability Services Act (1993) seems to be at odds with the Constitutional requirement that a body other than DSC independently review and arbitrate contentious decisions.

4. Citizen Rights to a Private Income (Participate In the Workforce)

- Planning for post-school life that includes employment can begin MUCH earlier for students who have a disability.
- Expectations and aspirations about the type, level and quality of contributions that PWD can make when employed can significantly be raised significantly across the whole of society.
- Disability Support organisations can do more than they currently do to employ PWD.
- Look to organisations like Inclusion Alberta for evidence of approaches that succeed. They have established long-term success with mainstream employers as key partners and low levels of paid support staff involved. This represents true citizenship in this area.
- The current system for supporting PWD to gain employment is confusing and often unhelpful in providing the right incentives to achieve successful outcomes. Reform is needed.
- People can tend to get 'trapped' in Australian Disability Enterprises (ADEs) and Disability Employment Services (DES) once they enter this system. (Interestingly, just last week the Ontario Ministry of Community and Social Services decided to progressively close all of Ontario's sheltered workshops in a move that has taken advocates by surprise. The Ministry spokesperson involved is Barbara Simmons whom many of us met in Vancouver:
<http://www.thestar.com/news/canada/2015/11/29/ontarios-sheltered-workshops-to-close-forever.html>).
- PWD can and should be supported as needed to be Board members and decision makers on a range of influential committees in service provider organisations.
- Approach industry bodies to include meaningful employment of people with a disability as an award or recognition item alongside their other awards and recognition.

5. A Place to call 'Home' (where I control the front door)

- Family members' beliefs and expectations often have a limiting effect on the choices given to PWD as to their living arrangements. While these are understandable, a 'citizenship rights' view of this issue suggests that these views should not overrule or limit what a PWD might be able to choose themselves.
- Family-to-family support can be of great assistance in helping family members process their fears and reservations about a person living independently.
- Some PWD who have high/complex support needs may need a concrete experience of living in a 'mainstream' situation before they can realistically indicate their preference.
- Building a circle of supportive friends around a person creates a great safeguard.
- Recognise that learning frequently involves some pain so allow for mistakes to be made.

6. Shaping Organisational Systems in ways that Support Citizenship

- Changing organisational systems happens from the top. Therefore, PWD can and should be supported (as needed) to be Board members and decision makers on a range of influential committees in service provider organisations.

- It can be challenging to change organisational systems in ways that accommodate individualised approaches.
- There aren't clear and established measures for individual wellbeing and social citizenship outcomes.
- Employ more PWD in service provider organisations.
- Involve PWD and family members in staff induction and training.
- Do more at a systemic level to support and enable self-advocacy.

RECOMMENDATIONS AND SUGGESTED ACTIONS

1. Support PWD to become Board members and decision makers in key organisational committees (service providers, DSC, National Disability Services).
2. Employ more PWD including people with intellectual and cognitive disabilities (service providers, mainstream employers).
3. Involve PWD and family members in staff induction and training (service providers).
4. Training for support workers and coordinators (at least) to include SDM training and ways to support friendship building (service providers).
5. Review policies and procedures to ensure that these don't unnecessarily create barriers to citizenship rights such as developing and maintaining friendships (DSC service providers).
6. Ensure that funding is available to enable family-to-family support where that can assist family members to better support someone to exercise their citizenship rights (NDIS Information Linkages and Capacity building policy development, DSC).
7. Industry bodies to recognise the meaningful employment of people with a disability with an award or recognition item alongside other awards and recognition (Employer groups, Industry bodies, DSC, Count Me In Ambassadors).
8. Better support school aged children to have fully inclusive schooling (All of us).
9. Develop SDM as a legally recognised decision making alternative to substitute decision-making options (Office of the Public Advocate).
10. Review the Disability Services Act (1993) to align it with Constitutional requirements to have an external party arbitrate contested decisions involving PWD and their services (DSC, Office of Attorney general – WA).
11. Review the Criminal Law (Mentally Impaired Accused) Act to ensure that it upholds Australia's citizenship and human rights obligations and commitments. This Law seems out of step with the National Disability Strategy (Rights Protection; Policy Direction 5) (Office of Attorney General – WA).
12. Review Police and criminal justice responses to ensure that they are appropriate to the specific needs of people with disabilities for procedural fairness and rehabilitation outcomes (Police, Justice, DSC).
13. Produce an update report on any recent progress made (or actions planned) to address recommendations 10, 11 and 12 (relevant government Agencies).
14. Ensure that PWD and families have an influential voice in shaping the current disability sector reform processes and outcomes (NDIS Information Linkages and Capacity building policy development, DSC, service providers).
15. Ensure that emerging service choices and options reflect and enhance individuals' citizenship rights rather than traditional services (NDIS Information Linkages and Capacity building policy development, DSC).
16. Begin, build and maintain a friendship with someone (or more than one) who has disability-related challenges in ways that support them to live as fully included citizens (All of us).

APPENDIX 1: SUMMARY OF GROUP DISCUSSIONS OF CITIZENSHIP ISSUES

1. Supported Decision Making (SDM)

1a. *What gets in the way of good SDM practice?*

- i. Assumptions **WE** make such as: the individual is unable to make a decision; or unable to realise what they want; or in other ways not believing and understanding that the individual is more capable than we think.
- ii. Restraints in where funding is allocated and how it can be used.
- iii. Perceptions of liability and duty of care vs self-determination.
- iv. Not offering individuals a broad spectrum of what is possible.
- v. Culture needs to change.
 - i. Getting people with disability to contribute to Boards (solution).
- vi. Supporters of people, paid and unpaid, may not be aware of how to support someone with their decision-making.
- vii. Patronising attitudes **WE** hold.

1b. *What each of us can do to enhance good practices*

- i. Behaviours of support workers (SWs), family, and friends.
 - i. Give people the opportunity to take risks.
 - ii. Assume the person has capability.
 - iii. Know the individual and understand their preferences.
 - iv. Identify and provide the right support as needed.
 - v. Listening to what is important to the individual in their multiple ways of communicating including their behaviours.
 - a. Supporting individuals' choice and control.
 - b. Enables individuals to understand consequences.
 - vi. Exploring all of the options.
 - vii. Always try to actively involve individuals in decision-making.
 - viii. Involving the right support people to help make the decision.
 - ix. Focusing on one decision at a time.
 - x. Make a wish list of what individual wants.
 - xi. Ask other people with disabilities for advice.
- ii. Organizational practices and implications.
 - a. Getting people with disabilities to contribute to boards, committees, staff induction and training etc.
 - b. Have more people involved in shaping services.
 - c. Increasing training and awareness about people's rights and ability to make their own decisions.
 - d. Train support workers in SDM.
- iii. Implications for guardianship and power of attorney legislation.
 - i. A person's rights under the UNCRPD has legal implications.
 - ii. Determining range of capacity to make decisions in different areas and situations.
 - iii. How are decision makers appointed / who are the best persons for this role?
 - iv. Supporting people in exercising their human rights vs what is legal/permitted (e.g. Representation Agreements in BC).

1c. Implications for service providers – changes they can make to enhance SDM practices

- i. 'Duty of care' (to clients and staff) policies and rules may need to be revised to enhance SDM practice.
- ii. Engage with DSC's "Code of Practice for the Elimination of Restrictive Practices" to reduce and eliminate practices that restrict a person's rights to decide.
- iii. Providers feel a sense of liability if things go wrong. They need to know they will be properly supported by the system if a person uses SDM to take increased risks.
 - a. This may require some review of legislative constraints.
- iv. Less people "upstairs" more people giving direct support.

1d. What can DSC, NDIS, and "government" do to enhance good practice?

- i. (Although group discussion ran out at this point, Leighton Jay noted that he is a member of the NDIA's Intellectual Disability Reference Group and is involved in drafting guidelines for the NDIA with respect to SDM being practised and supported in the NDIA and beyond).

2. Building and Sustaining Long Term Relationships and Friendships

(including a look at Microboards since they were a key theme in Vancouver)

2a. What gets in the way of people with disability having genuine long-term friendships and relationships?

- i. Role Clarity: e.g. SWs are there to help make connections or find activities and opportunities that facilitate these connections.
- ii. Policies/Procedures/Rules: e.g. People requiring checks and balances; e.g. being vetted to visit.
- iii. Skills mastery: e.g. someone may have the skills to say hello but are challenged when it comes to developing a meaningful conversation; or may not know how to take a friendship further.
- iv. As family, finding the balance to support friendship building but not overstep to start telling someone how to live their life.
- v. Lack of spontaneity: Difficult to just get out and meet up with people. Need to plan things out. Feel awkward phoning on someone else's behalf.
- vi. Privacy (and logistics): e.g. catching up with someone often involves a third party (a different third party sometimes). In shared accommodation, hard to find private space to develop conversations and friendships.
- vii. Safety concerns: fine line between safeguarding and being overly protective.
- viii. Logistics of online world and added risks where this is new to people (there is sometimes a need to develop one's own skills).
- ix. History of excluding people with disability from mainstream – e.g. school.
- x. Lack of understanding/inclusive readiness in the general community.
- xi. Differing expectations: e.g. school insisting on academic 'success' meant someone changed schools and lost key friends.
- xii. Cultural/Generational issues: e.g. discomfort with discussing intimacy; or religious/ values mismatch.
- xiii. Parents being reluctant to trust others and to 'get out of the way'.
- xiv. Opportunities: may be more limited, so less time to practice and learn.

2b. Ideas/Things that work

- i. Volunteer mentors – shared interest enables friendship to develop. Focus on interests; facilitate community engagement; build shared relationships.
- ii. Education/support systems that start in integration in pre & primary school.
- iii. Build on friends and contacts already in the individual's world.
- iv. Challenge the rules (government, Service Providers).
- v. Get to know neighbours and local area.
- vi. Understand the interests and expertise of support staff to put people in contact). e.g. some are musical; artistic; good cooks etc. (instead of traditional approach that may just look at gender or age).

2c. How might a microboard approach (or similar) effectively support a person to build and sustain long-term relationships and friendships?

- i. Concept of mastering – how can we tap the potential within a person? Art Partners Bunbury is good example of this (<http://artpartnersbunbury.com>).
- ii. Build on something that's already there e.g. developing a wider circle.
- iii. Change SW role expectations – allocate time & training to this not just to daily needs and logistics; skills development for these particular skills!
- iv. Knowing the people who are already friends; and who are friends of friends.
- v. Establish a safe, online way of staying engaged (training as needed).
- vi. Developing interests that create communities around people.
- vii. Working on role clarity; might start with paid support but can be expanded.
- viii. Check neighbours, check places/people where friendships can begin.
- ix. Focus on shared interests. Look at personality. Mentor other people to understand about people with complex support needs.
- x. Microboard – Example shared of overseas travel - expanded thinking about what might be possible; oversight to look at risks, contingency plans etc.
- xi. Microboard – a broader range of people bring different perspectives e.g. what is okay for a 19 year old (input from other 19 year olds; or siblings; friends) i.e. a parent perspective might not always be in sync.
- xii. Microboard – as people share experiences with others, it widens the circle.

2d. Who needs to take what actions to enable people with disability to have long-term friendships and relationships more successfully than is typically the case now?

- i. Role clarification and agreeing expectations (i.e. dedicated resources who can help create opportunities – e.g. Art Partners Bunbury).
- ii. Be explicit about paid support role re- friendship (facilitate not substitute).
- iii. Identify interests and build on these and pre-existing relationships.
- iv. Find balance between policies/rules etc. and what people want – e.g. better manage 'vetting' that occurs in supportive/shared accommodation; adjust 'visiting' hours.
- v. Addressing logistics; understanding challenges of transport etc. and getting to know local community and local options better.
- vi. Finding the balance between safeguarding and creating more opportunities for people to practice and learn; understanding dignity of risk.
- vii. More information needed; and better ways to share that information.

3. Legal and/or Political Citizenship Issues/Rights for People with a Disability

- i. Criminal Law (Mentally Impaired Accused) Act (CL(MIA)): people detained under legislation as unfit to stand trial – mental health/cognitive issues – This removes basic rights from the individual.
 - a. Attorney General reluctant to move on it.
 - b. small number of people with tricky stories, therefore no need to act.
 - c. need to build awareness within the disability sector.
 - d. people need to (and have) come together in sophisticated ways.
- ii. Because the Justice system in WA does not deal with disability sector in general, it has no way of identifying those with challenges (e.g. police can't do anything different when someone is identified with a cognitive disability such as Acquired Brain Injury (ABI)) – so they end up in the Justice system.
- iii. Police and criminal justice responses need to be able to respond to the specific needs of people with disabilities for procedural fairness and rehabilitation outcomes.
- iv. Inertia rules – because there are a number of (complex and legal) issues.
- v. State and Commonwealth laws and practices often clash. Where there is a clash, Commonwealth Law prevails (under Constitution). In disability, Commonwealth laws have processes to address conflict between person and service provider/system (with an objective body making final decision). Under state system, DSC has all the power (no separate party to rule).
- vi. Attorney general makes all decisions.
- vii. Constitutionally the language of “constriction”.
- viii. Legally constructed zones of exclusion where people are excluded from their rights by virtue of a label (e.g. “cognitive foreigner” used in Vancouver).
 - a. Vancouver e.g. was of application of euthanasia laws; we need to be vigilant about the subtle ways groups can be excluded under law. Supported decision making ensures people can be heard.
 - b. At conference – was wary of giving legal description...what does that mean in terms of supported decision making? – therefore how do we ensure people are supported / have claims?
- ix. Guardianship and Administration laws differ in every state – Vic has supported decision-making built into their system – not mandated that we do that in WA.
- x. Confusion within NDIS re- guardianship and administration – how do you support someone in the decision making? - at what point do we accept the level of risk?
- xi. being able to change your decision...change your mind?
- xii. Finance decision making currently the clearest area – however financial admin covers ALL aspects of decision-making (including small ones). How do we enable people to make decisions that are within their capability?
- xiii. Regional issues – endemic WA problem with many general implications.
- xiv. Voting – cognitive exclusion – have we provided frameworks to assist people to think through what it means to vote? (focus more on day to day things...). Need to find the right language to create opportunities.
- xv. DSC promotes flexibility – but holds all executive powers – needs power to be distributed back to the individual.

- xvi. Peter Shergold (former head of PMs office – WA Economic Audit Committee Report member; former Chair of Centre for Social Impact) was referenced – “it’s not your money; it’s the people’s money!” (power belongs to the people).
 - a. Stories of people achieving successful outcomes when given the opportunity to use government-provided money as they wished.
- xvii. Justice centres for PWD – legislation allows for declared places (alternative places of custody). Traditionally was hospital/prison (no other options).
 - b. This Government created enabling piece of legislation – create another institution – can declare any place (currently at Caversham – houses 10 people) – created to be developmental in nature, written to operate like a disability service.
 - c. There are four people from corrective services overseeing the service.
 - d. Evidence against you doesn’t get tested – not designed to be a long term residence, rather transitional.
- xviii. Political representation – PWD not adequately represented (as with women / ethnic minorities).
- xix. Current system may not even allow decision makers to make decisions (e.g. re- service agreements (e.g. told to sign documents or no service)).
- xx. PWD have no power – need assistance before they break the law. Some supports are currently in place (if they want to engage in that programme).
- xxi. Regional areas offer little in support for teenagers (with ABI) transitioning out of PMH support.

Suggested actions

- i. Amend the WA Disability Services Act to comply with Federal and Constitutional requirements for an external arbiter when required.
- ii. Dissolve DSC and join the NDIS.
- iii. Commitment to independent advocacy to enable people to find supports – committing an offence is an opportunity to make contact with those people.
- iv. Need independent third person (not a lawyer) – an observer – for those with less obvious disabilities (get stuck in interview situations) who may not have skills to navigate that interview without support.
- v. Create automatic flagging for a person who may have functioning issues – keep an eye on them when they move into the legal system, with guidelines in place for referral to independent advocacy.
- vi. Mandate service provision within a certain time frame (interface between justice and community system). Court – ideal place to do it. Need to work with people on parole.
- vii. SDM under custody order - what does that look like to ensure supports are in place?

4. Citizen Rights to a Private Income (Participate In The Workforce)

4a. What barriers prevent people with a disability in WA/Australia from gaining meaningful employment in mainstream organisations?

Schooling:

- i. Career/future aspirations discussed too late for planning and development, or not discussed at all.
- ii. Limited understanding of who a student is as a person – their dreams, skills, knowledge and abilities.
- iii. Low expectations that students will go on to meaningful, valued jobs so streamed into Australian Disability Enterprises (ADEs) or Alternatives to Employment (ATE).
- iv. Work experience, if offered, is in ADE environments. Lack of knowledge of how to place teens with extra challenges in meaningful work experience.
- v. Family / advocates are generally not good at promoting a student's job ready skills as it is not how they think of their son/daughter.

ADE's / Disability Employment Service (DES)

- i. Hard to leave once you are enlisted and 'in the system'. Seen as secure.
- i. Lack of consistency – positive and negative experiences depending on which placement coordinator you get.
- ii. Not clear about ALL the options for employment. Tend to favour easy options as long as 8 hours a week is achieved.
- iii. Assessments, if completed, do not measure job readiness in a meaningful way that is accessible to the majority of people with a disability.
- iv. Reduced focus on job ready training and development. Tendency to work with 'what they have'.
- v. Disability Support Organisations (DSO) plan for the segments of a person's life they are funded to support.

Government Policy

- i. Families misinformed / misunderstand how employment and pension effect each other.
- ii. Limitation in accessing different kinds of funding.
- iii. Confusion with supports currently available (traditional DSC/NDIS/MyWay).
- iv. Government rules & wage subsidy encourage employers to take on people with a disability - tokenistic rewards that result in 6-month contracts.
- v. If working within ADE generally, are not able to job seek or access open DES due to time and eligibility constraints.

Mainstream Employers

- i. Concerns, fear and misunderstanding about insurance, risk management and legal issues.
- ii. Intensive paperwork for wage subsidy; low incentives for taking on people with a disability.
- iii. Unaware of the support available to employers to embrace employee opportunities and address challenges in short, medium and long term.
- iv. Little culture within DSO's and mainstream employers to employ people with a disability in meaningful roles that recognise and develop skills.

General

- i. People with a disability in general are rarely:
 - a. asked what they would like to do,
 - b. given opportunities to try different things,
 - c. supported to consider tertiary education,
 - d. considered to have careers or expected to change jobs regularly,
 - e. offered promotions or professional development / upskilling.
- ii. Employment (ADE's) seen as respite so is often meaningless to the person.
- iii. Older people with a disability and lived experience of unemployment, unsuitable roles etc. lack confidence, fear failing and may have lost belief in their knowledge, skills and abilities.

4b. What can be tried or done differently to create some positive movement around this issue at this time?

- i. Better planning for study, support, further education, work experience and careers; commence in primary school and increase in focus through high school (support everyone to develop more aspirational expectations).
- ii. Support people with a disability to create a CV/Resume and focus on the skills, experience and development required to achieve their goals.
- iii. Regularly and meaningfully review employees to capture career aspirations and assist them to develop a career path.
- iv. Schools programs where past students/families visit as role models and supports to embrace mainstream employment and overcome challenges.
- v. Natural supports, networks and friends need to be at the forefront of mainstream employment opportunities and support, not funding bodies / DSO's as 'the solution to everything'.
- vi. Staff in the workplace support people instead of a support worker.
- vii. Change the language; talk about people having careers, taking risks, having a gap year, finding their dream job, managing their own business.
- viii. Support and explore microbusiness opportunities. Identify developmental support required in all schools, ADE's, DES, DSO's and Funding Offices.
- ix. Develop and publicise a one-page profile and support 'passport' template (e.g. Autism Assoc. WA) so that support mainstream employers know and support a person well and have less fear/concerns.
- x. Disability sector organisations employ more people with a disability in meaningful roles, role-modelling this for others (e.g. NDIA).
- xi. Systemic reform is needed (funding, planning, pension/income, incentives & assessment) to increase employment outcomes for people with disability.

4c. Who can do what as a useful next step or steps towards addressing this issue and/or stimulating some movement for change? What can you or I do?

- i. Career and employment to be included in all planning by everyone in a person's life (not just the bit you are funded to provide) to change the conversation and promote choice, change and original thinking.
- ii. Talk to students and people looking for a job about ALL the options available to them (ADE/DES/mainstream/microbusiness).
- iii. Providers / schools in a person's life lead by example and refer or promote using their networks and connections to assist relationships to develop and possibilities to be explored.

- iv. Support schools to have meaningful conversations, planning and job search/ work experience achievements.
- v. Lead by example and raise our expectations that people with a disability will have meaningful careers. Employ people in meaningful roles, develop accessible skills assessments and job readiness training.
- vi. Have your HR department help another company's HR department overcome their fears.
- vii. Create better incentives for mainstream employers, better support and increased expectations of success through collaborative approaches. Show them that by expecting more, providing development opportunities and recognising good performance a person with a disability will grow just like other employees.
- viii. Widely and enthusiastically promote progress, success, outcomes and appreciation outside the disability sector.
- ix. Make people with a disability visible through engaging with peak industry groups; find ways to promote through their markets the success which will get others to invest.
- x. Approach industry bodies to include meaningful employment of people with a disability as an award or recognition item alongside their other awards and recognition.

5. A Place to call 'Home' (where I control the front door)

5a. Barriers to a person having control over their housing choices:

- i. Availability of affordable and accessible housing in WA/Australia.
- ii. Parents/family often create barriers based on their needs, rather than the person's needs.
 - a. Parents' need for assurance that the person will always be safe; not feeling able to trust other people.
 - b. Assumptions such as the person is non-verbal so unable to communicate and has no preferences.
 - c. Is incapable of living in mainstream community with regular housemates.
 - d. Seeing limits of the person rather than possibilities.
 - e. Parents with general issues of moving and clearing out – life has been stable and predictable in a certain way for so long.
- iii. The person needs a concrete experience of living out of home or on his or her own before being able to indicate or show a preference.
- iv. Lack of access to suitable housing. Lack of personal assets to create a solution without government support (e.g. Department of Housing).
- v. Uncertainty about the stability and dependability of an arrangement (e.g. in one case, parents asked two housemates to move out due to their actions, taking over the house). Can create trust issues for the person (which is in fact a normal thing for anyone with housemates). Can become a barrier if the person isn't able to decide or tell people to move out.
- vi. Family and (lack of) money are biggest barriers.
- vii. Helping the person realise that they CAN make decisions, they have the ability to say yes or no to things, and have that decision making ability. Sometimes

service providers want to coach/support a person to have their own place, and find the family resistant to allowing the person to decide.

- viii. We put our own limitations on everybody.
- ix. Housemates not respecting the person or the house.
- x. Usually need to ask people in to make these arrangements work.

5b. What are the positive changes happening with this issue at this time?

- i. More of a partnership approach – services and families have to work together, and this appears to be happening more and more.
- ii. Individualised living arrangements are being requested in Plans more frequently now. Decreasing requests for people to move into group homes.
- iii. Sharing experiences –those who have made this shift are sharing their experiences and supporting people and families beginning the journey.

5c. How are current disability reforms affecting this issue?

- i. Increased recognition that many people with disability will now outlive their parents.
- ii. Increased recognition that people have a right to choice and control.
- iii. The NDIS will support individualised living arrangements. However, the NDIS has no control over the supply of appropriate housing so is unable to ensure that suitable housing is available even if that is what a person clearly wants in their plan.

5d. Who can do what as the next steps?

- i. Family-to-family support – Parents (especially) need support in the process of letting go and allowing “risk” to occur (as it does for young adult children who don’t have disability issues).
- ii. Realise learning occurs with a bit of pain – make room to allow mistakes to be made.
- iii. Find and create a balance between normal house-share and safe environment – difficult but not impossible to create and maintain.
- iv. Finding housemates – if friendship circle is limited, where do you find housemates?
- v. The person needs to have ongoing and growing social connections (many participants expressed negative views of segregated and “special education” schools which separate people and limit friendships and connection with the wider community).
- vi. Have a goal – e.g. son will move out on or soon after his 20th birthday. Parents to create an expectation that their son/daughter will move out. This is assumed for the general population – why shouldn’t it be for people with disabilities?
- vii. Create the environment – invite neighbours over for drinks/food. Include them in the broader support circle around the person. Often people will say yes if you ask but won’t offer, so don’t be afraid to ask!
- viii. Educate us ‘normal’ people – we need to stop differentiating, educate the public.
- ix. Allow and enable the person themselves to make the choices they want – e.g. who they want to live with.

- x. Get input as to how to facilitate this choosing (see SDM discussion): create and maintain a culture of choice (if people aren't taught how to choose they won't exercise choice).

6. Shaping Organisational Systems in ways that Support Citizenship

6a. *What are some things that restrict organisational systems from being supportive of full citizenship for people with disability?*

- i. There are multiple Standards that organisations have to meet. This sometimes limits the focus on individual outcomes.
- ii. Service Providers are constantly being evaluated, meaning more staff spending more time behind the desk, and not enough time out with individuals.
- iii. Auditing happens regularly and has impacts on service providers.
- iv. DSC has a different perspective to service providers.
- v. Housing options/accommodation is a barrier. Accessing a suitable house/home is difficult. Current systems make it difficult.
- vi. Lack of a system, not encouraging advocacy/having a voice.
- vii. If someone wants to stay in his or her home, system can be a barrier to that happening.
- viii. Not listening to people about where they want to live.
- ix. Access to transport requires a welcoming community. Sometimes this happens naturally but it can need to be consciously encouraged. Supporters need to know how to do that well.
- x. No flexibility – the system is assessment orientated, and not individually oriented. This is a total barrier.
- xi. Community itself is not flexible enough for transport.
- xii. Regional communities have limited transport systems, where there is limited freedom and choice, so this can be very restrictive.
- xiii. When transport is limited, turn to people in their community. Takes strategic thinking and planning.
- xiv. State and local governments don't work well enough together to create inclusive communities. This can include transport accessibility. Local gov't needs to step up, with support of state.
- xv. Relying on others for transport removes a measure of independence.
- xvi. Difficult for local government, with the scope and demand for this. Umbrella focus, not reliant on one person/position.
- xvii. Transport is one element/challenge. The number of parties involved can make it challenging.
- xviii. Communities often don't have a great perception of building and facilitating better access and inclusion.
- xix. It's not just disability, it's a whole community issue. How can everyone be involved in this?
- xx. People not working effectively together.
- xxi. Getting community to see the bigger picture requires supporting others and helping everyone to see that it could easily be them with a

disability. It is about everybody's access to, and inclusion in, community.

6b. In what ways are current reforms in the disability sector (and/or aged care and mental health) likely to inhibit or enhance progress in this direction?

- i. It's not just about the money. That's not understanding what this is really about.
- ii. Focusing on the individual in the context of a bigger picture that includes community perception and inclusion.
- iii. Not being sure where I fit in.
- iv. Current reforms aim to give greater choice and control to individuals.
- v. Do we give enough attention to these individuals? Don't think we do
- vi. There isn't yet enough education at young age about inclusion, and what it means to be a good citizen, including thinking about the challenges others face.
- vii. Attempting to create a 'natural response' that is inclusive rather than a 'charity' response.
- viii. The Government has set a good framework. Providers are the barriers – they need to engage and be the enablers. Help people work towards self-management if they wish. Providers are not working towards people managing their own funding and selecting their own supports etc.
- ix. There seems to be a fear among some Providers that they might do themselves out of business by encouraging people to manage their own funds. This needs to be discussed with individuals and communities. Providers need to be open and transparent.
- x. Families want leaders who are well trained.
- xi. Reform changes work toward individual funding differences - positive progress in right direction. Consumer directed care, better direction.
- xii. Tension between what's 'reasonable and necessary', and 'choice and control'. How is the funding spent for someone's well-being is creating new tensions that need consideration in a responsible way.
- xiii. There is a tension between trusting people to purchase what they need and accountability for taxpayer money.
- xiv. Moved toward generalized assessment, did you get your hours of support or is the outcome wholly satisfactory for individual. It is hard to measure lives and wellbeing.
- xv. Find some kind of in-between, not deciding in terms disability. Individual situation.
- xvi. Mental health is moving away from a medical model.
- xvii. Conventional type of arrangement doesn't work, trying to make it work. Promoting wellness can limit the episodic issues happening.
- xviii. Moving towards enabling, rather than inhibiting.

6c. Who needs to do what to help shift organisational systems in a direction that positively enhances citizenship?

- i. Change in organisational systems need to happen from the top. Individuals with disability need to be supported and given opportunities to be involved in many ways from Board down. This filters through the organisation to the services they provide. It brings different experience and access to different skill sets. Having a range of board members opens up differing views on risk.
- ii. Buddy-mentoring role, training process to be on a board. Support people with a disability to become a board member, be mentored by a buddy through process.
- iii. All workers being thoughtful about their work, not just following policy.
- iv. Don't require people to have to sacrifice their freedoms to get the support they need. Know there a standards and accountability to be met; seeing the person at the centre is the right path.
- v. Many service providers still don't see the person; they haven't adopted progressive views/approach.
- vi. Simple understanding, its about the people we support.
- vii. Support people in a way they can understand, especially when they have high needs in this area.
- viii. Service providers could have advisory panels/reference groups made up with people with disabilities (and perhaps family members) who can be asked "what would you do?". Decisions are currently being made for historical and financial reasons.
- ix. This group can also advise about policies and processes and engage end users for broader input.
- x. Employ people with disability and lived experience.
- xi. Some of the people we support can be working for our organisations. Can give them opportunities and benefit the organisation.
- xii. People with lived experience of disability can deliver the message as a co-facilitator better than some employees; and people will listen to them more positively at times as sharing from experience.
- xiii. Taking away some funded structures within the community through the individualised funding system and not the block funding, that individuals can slip in and out of as they prefer.
- xiv. Community development, self-advocacy and system advocacy happens here. Communities support things that have value to them.
- xv. Have a life coach for school graduates rather than disability enterprise employment.