


Women With Disabilities Australia (WWDA)



NDIS GRASSROOTS



WA NDIS/My Way Peer Support

**ILC Codesign**

**ndia** National Disability Insurance Agency

**ILC/Tier 2 Codesign**

A collaboration between

- NDIS Grassroots Discussion
- WA NDIS/My Way Peer Support
- Women with Disabilities Australia

# NDIS ILC Codesign Online Forum Report



Report compiled by  
Women with Disabilities Australia

This report has been written to supplement the online survey for the NDIA's ILC Codesign process.

The report outlines the details of a forum held on Sunday November 1, 2015 by a number of women with disability and family members for Women with Disabilities Australia, the NDIS Grassroots Discussion group and the WA NDIS/My Way Peer Support Group. The group was facilitated by a member of Women with Disabilities Australia and supported by a number of volunteers, all women with disabilities and family members.

## About the groups

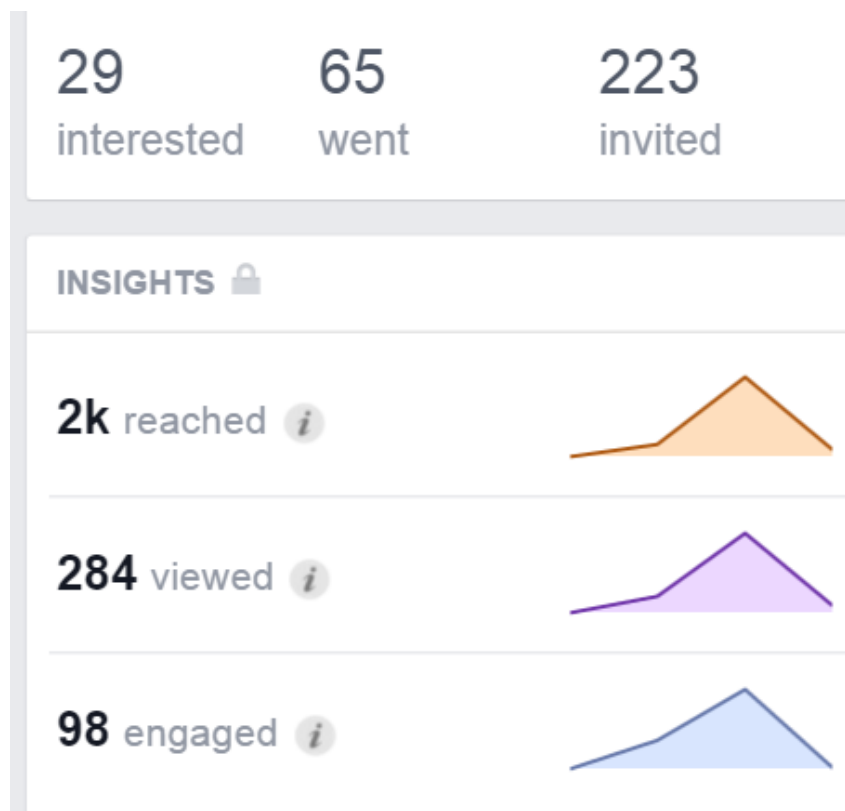
**Women With Disabilities Australia (WWDA)** is the peak organisation for women with all types of disabilities in Australia. WWDA is run by women with disabilities, for women with disabilities. It is the only organisation of its kind in Australia and one of only a very small number internationally. WWDA's work is grounded in a human rights based framework which links gender and disability issues to a full range of civil, political, economic, social and cultural rights. This rights based approach recognises that equal treatment, equal opportunity, and non-discrimination provide for inclusive opportunities for women and girls with disabilities in society. It also seeks to create greater awareness among governments and other relevant institutions of their obligations to fulfil, respect, protect and promote human rights and to support and empower women with disabilities, both individually and collectively, to claim their rights.

**NDIS Grassroots Discussion** is an online Facebook group which was created in June, 2012 in response to an identified need for a place for people with disability, the families and the service sector to enter into discussions about the scheme as it was developed, trialled and rolled out. In November, 2015, the group had over 8,500 members, and was equally comprised of people with disability, their families, frontline and government workers and members of the service sector. The group was originally administered by four Western Australian women with disability, but has more recently expanded to include a larger administration group of passionate and dedicated volunteers who include family members and service sector staff.

**WA NDIS/My Way** is a more recently created online discussion group and has almost 600 members since its inception in July, 2015. It was created to discuss the differences between the Federal Government's NDIS scheme and the WA Government's My Way scheme and to compare issues and share learnings. The group is run by a small group of people with disability and family members.



## Engagement



The event reached 2000 people and 284 people viewed the event. A total of 98 people engaged with the event, and their unedited comments are included below.

We held the event over a 12 hour period (7am – 7pm) on Sunday November 1. The decision to hold the event on a Sunday was driven primarily to weigh the balance of responses by private individuals rather than service or government organisations.

*Image description: A screenshot of the forum statistics as outlined above.*

The attendees included people from all states of Australia, and included a number of people who identified as Aboriginal or Torres Strait Islander and people from culturally and linguistically diverse backgrounds. A number of separate phone calls were made to women with disability to supplement the information received in this report.

# Questions and Individual Responses



## Did participants identify any services (existing or future) that are worthy of funding but don't seem to fit into any funding category?

*Text description – an image of an open filing cabinet. The file tabs are categorised alphabetically.*

Respondent's answers:

- Dont know where to put this post so sorry if this is not the place. I am wondering how ILC could work with PwDs that have severe and profound disabilities and do not have a family, support circle ect.. there are many PwD's who are living in a group home with the same people they went to school with, the same people they "access" the community with all run by the same DSO. How can we make their lives valued? When will they get choice and control? They dont get reasonable or necessary just the bare mininum to ensure the DSO doesnt get abuse and restrictive practices thrown at them. What can be done, can ILC help?. Maybe if an advocacy group came in and said "hey lets set up a microboard for this guy" maybe then they may get something other than token supports shared between five. But who would be on this microboard? Ah so the advocate finds out this persons story and discovers that over the years there has been stand out people in this persons life but for some reason or another they lost contact. Advocate contacts persons of

interest and discusses real possibilities, a real life for the person and then they come together, a microboard is set up and the PwD has reasonable and necessary and over time has even more maybe even a "good life". Is this possible?

- We need to develop the capability and capacity of people with disability and families around self direction. We need to promote knowledge of this choice, and skills in making that choice realised, we need to increase numbers of people who are self directing in Australia. We need to fund legal advice and clearinghouse in the area of becoming an employer.
- Paid community visitors as versus volunteers who only get petrol costs reimbursed in every state and territory to visit group homes on a monthly basis and ensure that residents are participating in a high quality life. They also could keep a very close eye on the paperwork generated by group homes where everything must be documented. Their prime purpose in visiting is to ensure that the residents receive the best possible care as can be given.
- Oh and give them teeth by ensuring everything goes to the Public Advocate in every state and territory. This could also apply to residential care homes.
- Julie that is such a great idea!!
- My problem is that the NDIA is proposing the following funding priority areas:  
Specialist or expert delivery - such as diagnosis-specific advice services  
Cohort focused delivery - such as awareness raising for services for particular cultural groups

Multi-regional supports - such as a national awareness raising campaign

Remote/rural solutions - such as development of specific online support

Delivery by people with disability for people with disability - such as a peer support group for people who want to self-manage their plans.

To me this looks like cherry picking some of the elements of the original ILC proposal and leaving out the really important focus such real individual and community capacity building. There is nothing wrong with these elements themselves but they lack a cohesive strategy or framework that draws them together. The idea of community development lying at the core of the ILC does this.



**A further question was asked to expand upon the first question and encourage brainstorming.**

**'Time for change.'**

**If there was one big change in your wishlist, and it couldn't be paid for out of 'normal NDIS funding', what would you want it to be?'**

***Image: A big green sign that reads 'Change'.***

- I want every Scout leader in Australia to have met a person with a disability at least once, to know where to get a support worker when they need to for Troop night or a camp, to know how to make reasonable adjustments - I want every Scout Hall to be accessible and every Scout troop to be inclusive and if they are not I want them to have a plan to make them so.
- I want innovative ideas around transport to be thought of. There are giant white vans and buses and vehicles sitting around that nobody is using on the weekend in garages and sheds and workshops. I want people to be able to derive income from those vehicles if they are able (if they are pwd or carers) by being Uber drivers or just renting out the vehicle if they want to and I want those unused day service vehicles to be utilised for real life things.
- I want day services and other things that are often traditionally crap to be audited somehow by people with disability and a series of 'good life benchmarks' to be developed

- I want there to be the same benchmarks that anyone else would expect from other services, not gluing raffia on bottles with 33 others in a disused church hall. I want us to not be penalised to go to events because the wheelchair bays are more expensive, or because we can't afford support at night.
- I would like to see a similar scheme they have in England whereby you can lease a wheelchair van for 4 years then have the option to buy it. If people in wheelchairs want to be able to regularly access the community then they need their own van and not have to rely on the maxi taxis all the time.
- I want EVERY 'special school' or segregated setting to cease to exist and for their vast resources to move with their students into the mainstream.
- I want EVERY teacher in the state to work one of one with at least one student with a disability in a regular school setting and to be supported to gain new and valuable skills. This would not only benefit the student with the disability but every other child the teacher teaches or is going to teach.
- I want all politicians to understand and take on board the right of every child no matter where he or she comes from to gain an effective education. One that values difference and can see the individual as a person.
- Its change in the school system that drives the future. In the 1800's several department took responsibility. The education department looked after regular children. The health department looked after the 'feeble minded' (Their definition, not mine) With full inclusion the future leaders will understand where people with disabilities are coming from. They may be there friends or just passing associates. They are tomorrows employers, politicians and community base and will have a fer better understanding of whats needed.
- Education is the main one that's at the top of my brainstorm list. This alone will drive change like never before.
- I want Dave Hingsburger to come out to regional West Australia and run workshops for PwD's on bullying and sexuality
- Can we replicate those ideas for employment?
- I totally agree with Les. Its in the school system where change needs to happen. When our future politicians businessmen teachers university students rub shoulders with children with disabilities. If you watch little children at play groups and kindy when tney are around children w.d. then you can see how they love to help them and befriend them. Wouldn't it be wonderful if this could continue throughout their schooling.
- I want every church to actively include and welcome families with a family member with disability. To celebrate and embrace diversity. To bend over backwards to make sure parents know their son or daughter makes is welcome regardless of if they make unusual sounds during prayer or use a ramp to access the Sunday school. That these aren't even battles the parent needs to fight. That the church finds a valued and integral role for each person in its community.
- No service can offer anything anymore that is segregated and congregated, unless people are gathering for self or collectively identified political/identity/peer support

- I want every workplace to develop an action plan for inclusive employment mirroring it's reconciliation action plan and to be held accountable if it doesn't take action!!
- I think this idea has been mentioned elsewhere around vehicles - Imagine if current, large providers with assets, space, homes, bricks and mortar, cars, people with expertise in particular areas, access to technology, funding, fundraising capability .... could view themselves as a RESOURCE. A way that people could get their innovative ideas off the ground (and perhaps pay, partner, auspice etc for the privelege). A sort of incubation. Leverage the 'assets' as the wank-parlance would have it.
- I would like government (of all levels), businesses and others in the community to understand and commit to creating, maintaining and supporting accessible venues and services.
- I would like all organisations who work with people with intellectual disability to use video as a tool for ongoing self improvement in their work.
- I want the government to put teeth in the tiger of the disability discrimination act! Start now and implement the laws that exist!! Prosecute businesses and organisations that do not comply.
- OK, so to be clear, I don't like the group home model, but... while we still have this model in the mix, I'd like to see an active community development focus for each house. With specific people dedicated to supporting it. So, like L was saying, each house is an asset to a neighbourhood - a focal point for community asset mapping, or perhaps helping to organise street parties or perhaps garden working bees or ukulele singalongs or any other type of community development stuff.
- That it be mandatory every TAFE and university student be made to participate in a disability set of units during their time at school so they emerge with more understanding that disability does not mean DISABLED. Also work places also have mandatory training sessions to understand how valuable PwD can be in the workplace.
- I write that due to the fact that even though we explained how our son on the spectrum operates to his employer he still received 2 written warnings. As his parents we rapidly swooped in and went to the workplace to not only re-explain autism and rearrange his work environment to be more autism friendly. He thrived in it and went onto become one of their most valued employees. He is now fully qualified and still in fulltime work.
- I want the NDIA to mandate that there will be no new group homes or congregate day services funded unless the need for such a service has been independently audited and all other possible options have been explored and discounted.
- I want to see user led disabled person;s organisations located, funded and supported in each local government jurisdiction.
- I want the same thing to happen for parents of young women who see no other option than suppressed menstruation or sterilisation and who have these things carried out in the absence of a diagnosed gynaecological



condition and usually in the absence of good support for women to have their reproductive rights observed.

- I want to see community development practitioners located in all local government jurisdictions with an emphasis on real inclusion of people with disabilities in that community.
- Imagine if they were in libraries, councils .....
- Who should carry out that role? Community development officers?
- I want to see a nationally accredited program that sees people with disabilities trained as teachers who will train and mentor support workers and services.
- Some have Disability Access Officers.
- I want to see an independent group of auditors comprised exclusively of people with disability who are authorized to conduct random audits of support services, including Serco and Bupa.
- I want to see a course in disability rights delivered by people with disabilities as a mandated part of the training for Med, Physio, OT, Speech and Psych students.
- P Gregory I need to think about what to call these people but they would be people whose role it is to focus on capacity building at the individual and community level.
- I want to see the day we have no "special" anything....
- One thought that popped into my head during the recent ndis conference was to have drop-in tech-help. So often the things people were asking for on the "digital dreams" panels were things that already existed, but needed bringing together or hacking or tweaking to make it work

## Should there be a sixth/seventh/eighth funding priority? If so, what should it be? Why?

- One of the things that got pretty much lost from the productivity commission report (PC) and implementation of NDIS is the role of disability support organisations (DSOs). These were envisaged as new types of organisations that would assist people to build their capacity to exercise choice and control over support. Some of the tasks that PC identified for DSOs fall within the tier 2 (or ILC), and aligned though separate from the LAC role. Other tasks envisaged by PC were acting as intermediary between NDIS participants and services.

Click the following and scroll to p414-421 for details

<http://www.pc.gov.au/.../report/disability-support-volume1.pdf>

The gaps i see in the roll out here in Newcastle are where the small local DSOs would have been.

- Advocacy.
- Community awareness unless we have that we have nothing.



**Did participants have any concerns about these funding areas? Do they overlap? What risks do they foresee?**

- We have already identified one risk, that 'awareness' campaigns if run by untrained people may not spread the right messages.
- I am worried that people who will be developing strategies might not be the people for whom strategies will be effective. For example, one of the suggestions for the regional and remote area is that we have an online group to connect siblings. 'A good example might be an online support group for siblings of people with disability, which allows siblings from rural and remote areas to communicate/share experiences.' That strikes me as a particularly bad example - there are few people with internet connections, let alone computers, in Tennant Creek. It might not be the way that people communicate and share experiences, either. I think people who are in regional and remote communities have a bunch of ways they communicate already, and they should be the ones who come up with those ideas. It is no good for white metrocentric types to come up with solutions for others.
- it's far to easy for untrained people to put their own take on a situation. It needs to be far broader and effective training is key. We ran up to three

training sessions yearly as we developed our training videos. The videos themselves did much of the talking and it was the discussion booklets included with them that assisted process and the right info to be given and accepted.

- also that the LAC role might too big for anyone to do. It might need to be divided into sections with specific people having specific roles.
- So, really, it was C (a young man with a severe and profound disability) who was doing the training, via the videos. Is there a way we could train others to use resources like the ones C has created with support? Or a way to identify really good resources that are based on human rights principles?
- Accessibility of information. Whether it be in alternative accessible formats or in appropriate accessible language - non jargon non buzz words.
- can I ask your opinion on the specialist supports area and how it important it is from the perspective of a member of the blind community? Or do you rate the 'expert' status of blind folk themselves as more important than the specialist skills?
- I see a few risks, 1 - that private organisations contracted to run ILC (as per Victoria's current contract tender) profiteer and manipulate the scope of services. 2 - funds are allocated to "charitable" bodies or "PBI's" or Local Government bodies for provision of services that they already claim, but fail, to deliver. Proven poor performance should not be rewarded.
- We have been banging on with the NDIA top decision makers since day one and every day about the need for Specialists Supports and Experts in Sensory Impairments, rather than LAC's Googling in front of participants about sensory impairments. Both the Australian Blindness Forum which is an organisation of blind consumer groups and blind service providers has been advocating for blindness specific specialist services such as Orientation & Mobility training (dog guides /White cane) specialist adaptive technology like screen readers - navigation aids - magnification software are just a few examples.

Some people who are blind or vision impaired will be experts in this field and would dip in and out of such speciality advice others such as those who go blind in later life would probably need this specialist advice before developing a NDIS or WA My Way NDIS plan. Some people will know whether they are their own Expert, while others will prefer to know what they know but with the support of someone who probably had more access to relevant and timely information. I vote for A and E !

- One of my other concerns is in a federated system of NDIS, is the rigidity of a standard Government system (one size fits all) that works well in Canberra or Melbourne or Sydney or those 3, being the answer to the rest of Australia, like outer suburban Darwin, Kunnunurra or Wommerá
- I am worried that 2 of my children's current plans that allows them to interact with the community will be slashed to pieces on the basis the activities they choose to participate in are not approved under NDIS.
- Feedback from other spots -. I can't get there but I have been thinking more since the conversation we had on Thursday and the concern I have is about



people who don't have packages not getting the support from ILC either because the LACs will be so focussed on people with packages. Particularly given the tenders now out in Victoria which have the LACs doing the NDIS plans with people and submitting these to the NDIS. That model didn't work when the NDIA employed 'plan support coordinators' within the ACT trial and yet they are setting up the same thing in the LACs within an NGO. The thing that got lost was anything that wasn't doing plans themselves - so no support linkages information..... I fear that the LAC function for people without packages will be lost and the scheme won't support the many many folk who have disability but won't get a package. I didn't include that in our feedback yesterday but hope you can include it in yours after tomorrow.

- I have absolutely no idea what any of this stuff means. No idea what stage this or that or what level/tier one or two is about. When I saw ILC, my first thought was the Independent Living Centre because that's where I got the grant for my air-conditioner.
- DSS & the NDIA de-funded the Autism Advisors in SA and ACT that were part of the Helping Children with Autism package (not sure whether a similar thing happened to Better Start). The Autism Advisors helped people who didn't (don't yet) have an NDIS package ... they help people before they get into the NDIS, and some people with disability who won't ever be eligible for Tier 3. Transitioning this service was an initial (albeit small) test for the ILC ... and already it failed completely. The ILC not off to a good start.
- I am worried about, people who are not currently in "Launch or Trial Sites" and are likely to be ILC participants rather than NDIS Plan participants being turned away by Disability Specific Service Providers because they haven't a NDIS Plan. Or the other worry that if they are likely to be ILC participants rather than NDIS Plan participants that the Fee For Services, will be a barrier (because they can't afford the product, program or service).
- Currently NDIS and WA My Way NDIS participants are waiting and waiting to hear back from the NDIS or My Way about how they are progressing, some people are already waiting up to and sometimes more than 12 months. Is this normal?
- I am worried that the LAC role will focus more on connecting people to disability services than connection to the community.
- I am also worried the ILC work will sit with big organisations with out space (or Funding) for local grassroots organisations
- in Better Start, they gave the funded recruiting and advisory role to Carers Australia, rather than the disability groups being served by the program. I kid you not. Then Carers Aus got their state Carers org to do it and guess who they came to to find out about the disabilities and how to contact our families? Jan.
- DSS also funded a generic parenting org to produce Down syndrome resources and put them on their website. Unbelievably, the video they made for parents of new babies with DS was mainly about prenatal testing. It was shameful.

- So, yes, it must be peer led/produced/delivered information and support. Like the blind groups, Down syndrome has been advocating strongly re ILC for some time re the importance of peer support orgs.
- I am worried that all the funding is going to just be dolled-out to the existing peaks, advocacy and other known organisations. A second concern is around funding to general community organisations - we don't just want all of them starting to create segregated programs as a way of responding to so-called community need. So we need people in community who can help shape the direction these organisations might want to go in or thinking down - is this an LAC role? Perhaps it's a process like "Are you interested in this funding? Do you provide services in your community pwd could benefit from? Do you see unmet needs in your community? well here's some information to read and also, you need to be in contact with this person to discuss your ideas..." Perhaps this will be far too resource intensive. I don't know I'm just thinking of it now. Or that funding criteria is developed that dissuades people from putting up segregated solutions.
- I am worried that 5000 LACs are 5000 people sitting in traditional NGOs that have varying values, skills, beliefs about the potential of people, community development experience ..... I saw another post that listed out the amazing qualities and expertise to be found in such people. In the end, these roles are only as good as the people in them, and the organisation they have around them. How the hell are you going to ensure quality? I see the varying outcomes depending on which organisation has been funded in the NSW Ability Links program. These programs can SO SO quickly become shrivelled and reduced. I really love P's thoughts about community development work and the conversations I have had with him about the roles that are needed.
- I think a risk is that there is segregation which is demanded by different cohorts of pwd/carers. I shudder when I hear about the movement demanding only asd schools and education etc where would this lead us? There does need to be some overarching(and yes I am saying this struggling each day with our mainstream school) principles.

## Results of funding priority vote

In the future, funding to organisations may fall into multiple Initiatives that fit into more than one funding area could be a priority.

However, it will be a challenge to compare services that fit in funding areas.

The NDIA needs to know which area is more important to you

The funding areas are outlined in the first comment below.



Image description: The funding areas from A to E are prioritised in order.

E – 9

B – 7

C – 3

A – 2

D – 2

Please note that Facebook does not allow for weighting of votes – twenty three participants answered the online question with their top priorities nominated.

## What were the reasons why participants prioritised/de-prioritised each funding area during voting?

- Funding area E is incomplete. What happened to Delivery by people with disability for people without disability. We have a shitload to share with the ablebods and they can learn amazing stuff. Why is it that we are seen to not be able to assist non-disabled people? Is it ablebod arrogance rearing its ugly head as usual?
- Whilst I value on-line support for people with disabilities and have benefited greatly from engaging with my peers in this practice. There is a whole other population out there who aren't on-line and possibly will never go down this road. Support for people who fall into this category is around meeting and doing things together in spaces where they feel safe and understood. This may run counter to some current ideas of mainstreaming however what are we mainstreaming people into if they don't feel welcome or understood
- I like the idea of localised knowledge, but the coordinators need to be linked to ensure ideas from other areas are available.
- Additionally, there needs to be a minimum level of expectation of information/contact. We are already seeing some orgs with interactive FB pages, while some are lucky to have a regional telephone number. PWD, and/or those that act for them already have enough hoops to jump through. Ease of contact, and reliability of contact would be good.
- Funding Level E also contains all the other possible conditions of the other funding areas. A pwd is not naturally an expert in every area of disability or support, just by virtue of having a disability. Who said this would be easy?
- And disconnected pwd would not know about inclusion if they are routinely discriminated against. But by connecting people with disability who have experience in other areas, maybe that sharing of learning is an excellent start to build capacity of people with disability themselves. Question is how to do it - not everyone has internet.
- Someone to actually answer the phone, or return phone calls would be good. People often wait for a crisis before they call, and they then cannot wait for a waiting list, or for someone to pass the message through the chain. They need the information now, or soon. They also need to now upfront if the service will not be suitable/accessible (for whatever reason), as otherwise it's a waste of valuable time.
- All of these are important for peer support organisations.
- Sometimes circumstances can rapidly escalate and you need an organisation to be able to respond quickly if things get out of hand and you need support as in yesterday.



## Further discussion on Funding area E

- By working with advocacy groups in the community to assist people to access and contribute to such forums. Simple English versions for example. We definitely need to try harder in that area. Also, we could look at "beginners" support for those with difficulty accessing huge amounts of written information and new to the subject area. Have volunteers provide 1:1 explanations privately so that people can get up to speed in their own way.
- I honestly think advocacy groups are the way to go also. It's a matter of getting the word out to everyday people with disabilities that these groups do exist.
- Just being a parent and not involved with any disability services other than as a client, I'm struggling with the wordiness of it all a bit.



Seven times as many people voted for funding area 'E' (Delivery for people with a disability by people with a disability) over 'A' (Specialist and expert delivery).

Is this because people think we are the experts in our own lives? Why do you think we are better placed to deliver ILC programs and services? And which kinds of organisations or groups should be doing that work?

*Text description: A cartoon of a man with the caption 'not an expert' and the same man standing slightly differently with the caption 'an expert' - the last caption reads 'can you spot the difference'?*

- What denotes "an expert"? This is fundamentally the question.
- I think first hand, lived experience is more valuable than experience separated by even one degree, such as a parent or support worker.
- Understandable, although debatable. My son (the pwd) has only limited experience of all that has happened around and for him, because he is unable to understand all that (so am I at times). If we only took his lived experience into account, he would get nowhere fast....unless by lived experience you mean he lives without assistance, in order to truly understand his level of disability. That ain't gonna happen - the experience, or the realisation. I'm not arguing, just trying to understand the direction smile emoticon Mind you, we certainly kow what he doesn't want, and do our best to ensure that doesn't happen.
- but a person who uses a wheelchair is only really an expert on using a wheelchair as a person who is blind is only an expert on blindness. We have to remember that when we say "we are the experts" we only have \*our\* lived experience. the experience of our lives which people in similar situations can relate to. That said, I still think 'by pwd, for pwd' is by far the best way to do it.
- I think 'specialist skills' means knowledge around one particular area, like a diagnostic type. For me, your son has lived experience, but he needs support to articulate it. That might include a person who has been alongside him to recount his experiences or record it in a way others can understand it. Whether he can communicate it or not is less of an issue if he is supported to communicate it. At the NDIS conference, Alison and Suzy Proctor talked about the idea of a 'wheelchair cam' to assist people who were not always

around to understand what Suzy's life looked like. That kind of idea is a brilliant one, I think, because it could capture what inclusion looked like, as well as what other things look like from Suzy's perspective. Your son might not understand how to employ support workers, but he has the lived experience of being the employer of those workers and others around him have the experience of how to employ people or interview them or deal with them - that, I think, is what we need to know.

- wheelchair cam is a great idea. disappointed i missed the presentation.
- Disability does not always equal intellectual disability. Those whose lived experience can be and should be the primary participants and contributors to any service developed for those with a disability.
- a person with an intellectual disability still has expertise in intellectual disability and while they may need support to articulate that experience it still stands that they are the expert. Also people with ID are often able to articulate their expertise if only the world stops and listens.
- Similarly, disability does not always equal physical disability. If I have to explain one more time my son does not need wheelchair access, but it's wonderful to have the access for those that do require it. Wheelchair accessibility should not be the only understanding of disability. Disability is THIS.....
- Autism is a silent disability and if I hear one more person say but he doesn't look autistic I might commit a crime. Intellectual disability is much more difficult because it requires input from others to get assistance.
- Or..."but he doesn't look VERY Downs". Always gets me sharpening my knives.
- The look of someone is just that. Remember the old saying. Never judge a book by its cover.
- I think the user led model is very useful when thinking about ILC. I think the user led model springs from the UK and is founded on promotion of the rights of PWD. While experience may differ due to each individual's experience of their disability, the themes of exclusion are pretty much the same. The peer support which is just one funding area should be the touchstone of all ILC work.
- If we take a community development approach (rather than a service development approach) to this question we assume that the people know and understand their situation well (The question of how people with an intellectual disability express that insight into their circumstances is another matter.) those same people may also want to change those circumstances. In order to do this they may need advice from someone who has a technical skills to assist them to work through the issue. I am avoiding the term 'expert' here as I think it is misleading. Where there are complex issues the community of people may draw on the expertise of a number of people. The people who provide technical support do not have to be from the disability sector because the issue to be addressed may not be about disability (At the NDIS Conference Christopher Hills said that he got his advice about an iPhone initiated door opener from the tech nerd community.). A good community

development worker knows how to guide this process without disempowering the community and building their capacity to manage their own circumstances. For example, during a recent conversation with the Brotherhood of the Wordless (They use facilitated communication to write poetry, plays, deliver workshops etc) we shifted a key question from "How do we attract more trained facilitators into our support teams and networks?" to "What do we need to build our individual and collective capacity to train our own facilitators?" The first question assumes the facilitators will magically appear. The second question assumes that the FC users will manage the training of their support team and other people in their network. (This is most succinctly demonstrated by Marlena Katene who has photographs of her showing the Pope, Russell Brand and many others how to facilitate.)

- BTW... What I just wrote describes a role that is not the LAC as I understand it. I think the LAC role is being devolved away from community development and into something like a community case manager or a social worker/case manager/social facilitator hybrid. The result will be the achievement of nothing particularly innovative or creative.
- Finding it hard to find the right place to comment LOL - but I think it would be fabulous if there were ideas coming out of the DSO-funded groups that could be supported to further develop through ILC funding. So they actually targetted these groups. I don't mean to continue the funding of these groups (which should also happen if they are making a difference) but ideas that are emerging in these groups that could really grow and be something if they were resourced.
- I think CDAH should be funded to be the lead agency in helping others start their own user-led organisation!!!! LOL
- I think that is a brilliant idea. At present, there is a very long and painful evaluation tool that has been developed for DSO groups to engage with. But the groups are discovering their own outcomes which don't look anything much like the outcomes from the evaluation tool - collecting that information would be incredible.
- I put a post re all this in another thread - peer to peer is where I see funding should go.. As a respectful Ally I see my role as helping spread the word etc but this needs no \$ just a commitment to the principles of the UNCRPD
- [www.cdah.org.au](http://www.cdah.org.au)
- as a parent of a child with ASD, there are times that I am overwhelmed and cannot see the forest for the trees (Or is it the other way around?) Sometimes during this time a 'technical expert' can provide that clarity and assist with developing a pathway. I would hope that ILC/LAC doesn't mean a choice between one or the other....



## What Individual-level outcomes and/or indicators did participants identify for the ILC? What community-level outcomes and/or indicators did participants identify for the ILC?

- Attendance is a tangible outcome. The implementation or action of implementing information shared is an outcome. Where participants have no need to attend a peer support group and have moved on to bigger better things.
- How would you distinguish between that, and when someone has moved on because it was crap or they were living in poverty and unable to get there? +
- How can they evaluate without doing cumbersome evaluations? What should NDIA do and not do?
- it's important to allow people to design their own outcomes, because they differ for each person. The traditional kpis or measures developed by government 'do you feel like you are more able to get a job than before' 'are you more confident' are generally crap. More able to find out where to get help might be an example of that outcomes based shift for people with disability which demonstrates community capacity, or more able to do something yourself (like self managing or knowing where to find out about how to get insurance or how to join a community group).
- I would like to see peer support groups in regional areas, way out. That way already established supports can come and deliver workshops to PwD's in areas such as People First, advocacy, self confidence, bullying and planning and the importance of it. I do not see LAC's doing this job even though they should. Then the only funding required is the established person travelling to deliver the workshops to the people that matter
- The outcomes would show by PwD's in their community, by seeing them with more resolve, standing up for themselves, not requiring pity to survive, accessing community facilities cos they know they can without support and being valued when the community SEE that they can do these things. We dont need alot of money just let PwD come into their own
- Key Performance Indicators are often general and easily faked and do not necessarily indicate the performance of an organisation. I would consider an organisation that is receiving funding to increase inclusion in the community would be able to demonstrate that function by actually having PWD involved in lots of different activities at lots of different locations with lots of choice available. ie if half of the participants are at ten pin bowling every tuesday it is pretty darn obvious not a lot of inclusiveness work went into that and the outcomes are not anywhere near optimal.
- R I have witnessed support staff all smiley faced and encouraging assisting S How do we measure outcomes (both individual and community) then Rose? And what kind of outcomes should they be measuring?
- I am thinking of that report last night where four pwd were stuck in a van outside a shopping centre for an hour in the heat. And how when we wrote that up, it would have looked like 'community outing to be included and learn valuable life skills through community participation'

- measuring the success of a program has to be done in a way that is relevant to the individuals that the program is meant to support. Measurements would have to be more specifically worded than anything I have ever seen to date. ie. "Are you happy with the service provided?" is far too general and a positive answer far too easily persuaded. and questions like "How many new people have you met in the last two weeks?" is far too general, ie some would count all the people at the train station that said 'hello' and this kind of generalisation would seriously skew results. What are the names of two new people who are not support workers you met this week? is far more specific and implies spending at least some time with the people. So questions I can think of are: "What are the names of two people who are not support workers you have met for the first time in the last month?" "What new activities have you done in the last month? "name a place you visited for the first time in the last month?" Though in writing this I can see how Service Providers would then be in the frame of mind of constantly providing 'new' and 'first time' experiences rather than supporting people in doing what they want.
- R, do we underrate things like 'chilling on the couch with my dog watching Project Runway' as an 'activity'? Are people frantically engaged in community tourism and is it a risk that this will increase that, or as you say constantly provide new or first time experiences?
- I think who measures it is hugely important. thing is, if pwd are measuring it is there a risk that they then are in a cycle of constantly completing surveys (or whatever) about the services they receive? will they be compensated for it? and how do you know, as R mentioned, that service providers are not assisting people to complete them and skewing the results.
- I think pwd should be the ones that decide what it is that indicates success. As mentioned KPI's are awful. Counting how many people you have made contact with does not in any way show that you are good at what you.
- Yes, I know I stunned a Service Provider by saying that part of my daughter's community participation is staying home and chilling out, they argued funding was for participating in the community, I argued my daughter's home is a part of the community...
- Good on you R, I know of two PwD's now into their 50's and have worked for next to nothing for a good 30 yrs of their life with everyone saying how wonderful it is that they are working blah, now they have retired and its all about how lazy they are. Community's and igwigs need to recognise that PwD's have life stages too
- The point of the NDIS at all levels MUST be to enable PWD to do as they choose and this will include staying at home, and it will include visiting a friend or neighbour for a cup of tea/coffee/scotch/whisky/beer/wine and it will include any other activity that any other person may want to do...
- I have seen situations where someone is applauded for exceeding the KPI's but it makes me wonder how well you have performed if you have had that many "clients" in a short time frame. for me that is a warning that something is wrong not an indication that something great is happening.

- I have known parents who insisted the PWD offspring had to go out for the day every day because the parents were at work... and yet in many of these cases there was no reason the PWD could not stay home other than that they would need assistance with daily tasks like lunch, toilet use etc. so in fact th offspring could stay home if there was the support to do so.
- Someone at the conference raised the issue of when pwd are allowed to retire. G, has anyone you know had discussions around this? Because other sixty year olds are sometimes doing their gardening or working part time or not working at all and enjoying the fruits of their labors, without being dragged off to endless activities. 'Age appropriate' is raised for us when we are younger but not older.
- 1. Build sustainable networks and relationships around people and their family (if relevant) 2. Moved people's expectations of and for themselves 3. Show some concrete examples of number 2 in terms of changes in people's lives 4. less dominance in people's lives by service, less service-filled lives
- Not that I have heard. The only one that I have heard that relates is that it seems that we are going to be cured when we reach 65. We are not eligible for NDIS after 65 so I guess it's true.



**What advice did your participants have for the NDIA relating to measuring outcomes?**

**'If you could give any advice to the NDIA in moving forward with these funding areas, what advice would you give? What should the NDIA make sure of?'**

*Image description: Lucy (the character from Peanuts) sits in a stall labelled 'Advice'. A sign reads 'The Blogger is IN'.*

- Don't forget the people with no family and those that are stuck forever in servicerland, those that have no voice because no one bothers to listen.
- Accessible formats. Accessible language.
- Don't spend all the money on setting it up and maintaining the government machine.
- Please listen to People With Disability
- Good disability-specific peer support encompasses all the funding streams, so they need to ensure orgs are funded to do them all; it's essential for the holistic approach people want.
- They need to get a lot better at Plain English.
- We as people with Disabilities are not ALL generic.
- Websites are not the be all and end all. People want real support from real people.
- Make the programs work for the end users, rather than the end users working to prop up the program by endless paperwork, reports, red-tape and justifications

- Make sure that you clearly identify vested interests, because we are the ones who have the important ones, not the people who just want to make a dollar.
- The NDIA must not enhance segregation by making inclusion another service. It should however strengthen "natural supports". This can be done by connecting unpaid community members with isolated people requiring support with choices and bursting the service bubble, through volunteer programs and networks. Peer support groups do not suit everyone. Thousands of people can not use Internet, they are unaware of their rights. Conversations, one to one need to be promoted in various formats.
- Whilst the overarching guidelines may need to be indulged in bureaucratic parlance, the day-to-day working documents and procedures must be basic and real-world practical. The scheme cannot and will not succeed if it is buried in bureaucratic nonsense.
- What do people think of call centres manned by volunteers to answer queries from all sectors of societies with the motto that if they don't know the answer to a question they will hunt it down and get back with a reply as soon as they find the right information?
- These call centres could be based at local council offices.
- The NDIA needs to understand that high quality capacity building and community development work takes a great deal of time and energy but the investment is worthwhile. We need to change an entire culture built on perceptions of welfare, pity and exclusion. Deliberate and intentional focus on changing this culture may not bear fruit for a generation but embedding this work into the structure is vitally important. That embedding will, by necessity, be very local, tailored to the characteristics of the community and will draw on solid community development practice. The structure will vary from the corporate and elitist structures that are now in place where offices, practices and position descriptions limit opportunities and predispose to maintaining what already exists. The purpose of this new way of implementing grassroots change will be to rupture and challenge the old paradigms by replacing them with genuinely community based and collective activity that is driven by the people themselves not by faux rhetoric of inclusion that is still controlled by the marketplace as the only way of viewing the world. The purpose of this work will be to challenge the very idea that people with disabilities are a commodity to be marketed and that the marketplace is the only lens through which the NDIS can be understood.... that building social capital is also a worthwhile aim. Given that social capital cannot be owned by one entity and traded in the marketplace this will stand as a challenge to the dominance of the market rhetoric that so consumes the disability sector at the moment.
- I have "thunk" so hard my brain hurts in between coping with domestic disasters off screen. One thing that does stand out for me is that PwD in the intellectual field can be extremely low functioning and I have to use every muscle I have to understand what they are telling me. The thing that saddens me the most as a community visitor is how many only have us as their advocate as their family has disavowed any knowledge or even the slightest bit of interest in them. We become their voice and we need to listen very hard

to them to understand how life is going for them. I would love to visit more often rather than 4 times a year. A lot can happen in the time in between which scares the crap out of me. I know group homes are not the best choice but some of the resident have nobody advocating in their life but us. On that note I bid the group good night.

- Social capital lives in community.....



# The Important Stuff

## Respondents' Comments and Questions

1. *After reading Ss's unpacked Part 1. learning About ILC.*

*It seems that LAC's are either Super-Human or there are different types of LAC's.*

*LAC's that work on your plan, those that tell you are not eligible but show you how to use the ILC, those that Advocate for inclusion, those that facilitate forums, those that market inclusion and/people with disabilities, those that head-hunt businesses, those that initiate opportunities, those that innovate, those that know about specialist services, those that use the medical model, those that use the social model, those that understand the potential capacity of people with disabilities, those that understand how the government wants things.....*

*Clearly I could go on.*

*How do I get a LAC to do all this and how do you (if you are the employer of LAC's) pay the same rate of pay for all those skills and knowledge?*

- I am wondering too, what the difference is between LAC's and the Support Connection, Coordination of Support and Specialist Coordination of Support role is. Our business, (we are people living with disability by the way) is registered with the NDIA to provide those last three items of service. But how do they differentiate to the LAC model as outlined in the ILC Policy discussion paper?
- there is some information on R's site that sorts this out nicely - and I agree about the super human LAC role. Check out the job description and then the tender document. This is what they have in mind for LAC.NDIA releases tender for \$60m of Victorian LAC services - Disability...
- this is what LAC is supposed to do - What will Local Area Coordination do? The purpose of the LAC service is to both help people with disability to engage with the NDIA and their funded supports to make the most of the NDIS as well as improve inclusion of people with disability across the community. This NDIA's tender bases the roles for LACs on the Productivity Commission's report as well as the more recently released ILC Policy Framework. The role of LACs in the tender is broader than many expected – they key change to the role of LACs is that they will be developing plans with cohorts of participants and submitting these to the NDIA for approval. To date, the NDIA has employed its own planners to work with participants and has not outsourced its plan development functions (except for some participants in Large Residential Centers). The tender identifies the specific tasks for LACs as: Assisting all people with disability and their carers to exercise choice and engage with the NDIS Assisting NDIS participants engage with the Scheme



Building community awareness of the needs of people with disability and promoting inclusion Encourage greater options for social and economic participation for people with disability in local community Assist people not eligible for the NDIS: Deliver capacity building activities (for non-eligible people with disability and their families and carers) Provide information, linkages and support services (for non-eligible people with disability and their families and carers) Assist participants engage with the NDIS: Assist in explaining and communicating the Scheme Create plans for participants that are submitted to the NDIA for approval Help participants move from getting supported by the NDIA in their planning (Stream 2) to become self-planning (Stream 1) Provide support to people to implement their plan including choosing a provider for their NDIS funded supports and linking with community and mainstream service Engage with the broader community Provide information about the NDIS, including what the NDIS is not responsible for funding Create more options for people with disability to participate socially and economically Build understanding of the needs of people with disability Document how options for participation have changed over time

- But, you know, I am not terribly sure the 'non essential' parts like advocating for inclusion is going to happen when Sam is swallowing razor blades and Tim is homeless and Robert needs a new wheelchair because he just had a stroke. Are they being realistic? Or are some of these tasks better placed with people with disability and families who have been doing this stuff forever?
- The sentiment is great. but it should be competitive and being a huge program i feel there is a risk that large organisations like Serco, Bupa etc are in the running to manage the LAC role. I could be wrong. But bigger is not necessarily best.
- We have found the power in people living with disability and their families/carers are best place to do the LAC role.
- I think its better placed with pwd and family because like you said, we have been doing it forever and because it creates employment. imagine a section of NDIS where the roles are only for pwd and family?
- I'd like to see NDIA commit to real jobs for pwd within its structure.
- That is absolutely a concern given that it is going to non disability orgs who can demonstrate that they can deliver this.
- the other part to your question - How do I get a LAC to do all this and how do you (if you are the employer of LAC's) pay the same rate of pay for all those skills and knowledge? - is who the LACs would need to partner with to do that job?
- The current WA LACs are struggling and making that known so how on earth would they begin to tackle all this? If your LAC is also handling funding of any type and a family or PwD gets knocked back they may not be too keen to engage with that LAC again on a different level. Is the future of LACs going to be like a one stop shop. In regional areas you may only have two LAC's covering a big area. HmMMM

- what does your LAC do and what's the difference between the scenario advertised and what WA LACs actually do?
- In my area (Wheatbelt) the LAC covers a case load of 79 clients over a very large geographical area. Historically, you would get a cup of tea and a lamington if you went in - might never get a call or an email - if you were 'high support' you would get a response if you hassled them
- our LAC's do plans with PwD, they have also taken over some types of funding like CLI, FLI ect.. and most of their time is doing a little bit of planning say 30mins per person and the rest is submitting and doing paperwork, going to meetings with their managers and going to training. Only way you can get them is to email and they may get back to you. Oh and they only work 2 - 3 days and have a massive area say approx 350km
- Oh and we do not get a lamington not even a bickie
- My fairly disjointed thoughts (given singing Old McDonald over and over on repeat) - I'm also from regional WA, and I have found too many LAC's that "preach" the right words, but the practice comes down to the old paternalistic model of I am here to do to you, I am here to do for you, rather than WITH you. Whilst acknowledging LAC's may be constrained in their role by the requirements placed upon them through the organisation they work for, I feel as though there is a shitload of a way to go, before those much bandied words like "choice and control", "reasonable and necessary" really have some genuine meaning. I hate intensely that the NDIS is under the dss portfolio, it casts a "charity" shadow over the Scheme, rather than it being recognised as an entitlement - ie pwd etc have every right to access an insurance scheme, because they matter, rather than a "poor people", lets feel sorry for them and give them a hand, because wouldn't ti be terrible to have a disability. I think too much of the cash is being absorbed into service providers and other agencies - the percentage of funds which actually reach directly into the lives of PWD, and help make that difference in attitude and perception that we ahve all fought so hard for, is being lost. If fucking Serco, Bupa or those huge multinationals are engaged, I might shoot myself. It bothers me that in the regions, pwd are not more conscious of the fact that they are the employers, its their funding, they own it - its their choices that really matters - not some vaguely qualified person, who's range of experience may not be terribly wide. Sorry for the ramblings, I'm too tired to be coherent.
- The DSWA experience re LAC is an interesting one. DSC won't fund DSWA because "LACs support families" (yeah right). But guess who ring unfunded peer support org DSWA asking for info and support for people with DS and their families? Yep, the LACs.
- I had basically the same experience in Vic. Funded case managers etc calling me as contact for a peer support/self-advocacy group. I eventually had to change the group's answering machine message to say "we are run part-time by volunteers with a disability", coz paid workers in funded orgs didn't realize!

2. *I have a great concern regarding linkages and capacity building. Having been excluded from much of society by design (the way our community is planned, designed and built for a few but inaccessible to many) Can the government be serious about linking PWD into their communities when the government does not enforce the laws created to enable accessibility?*

*No amount of wishing, wanting, hoping, planning to be a part of the community will ever change the very inaccessible features in our built environment. A lot of money, planning and remodelling of buildings has to happen. There can be no pretence of otherwise.*

*A simple task such as PWD wanting to go away for the weekend (or longer) can not be done on the spur of the moment, because accessibility needs to be ascertained and support needs to be arranged and often a simple weekend away becomes a mammoth logistical challenge.*

*Can funding be provided to improve and increase accessibility in all publicly accessible buildings. Cafes, Hotels, Motels, museums, galleries, shops.*

*Social links can not happen where there is no accessibility. Capacity is minimal and often non-existent when accessibility does not exist. There is no possibility to build, extend, or create capacity where there is no accessibility.*

*While the ideals of ILC seem to be a great leap ahead, the reality of implementation to me seems more like wishful thinking.*

- Consider too the schools, colleges, universities around the country. How accessible are they?
- That fits for me inside this funding area, Rose - Funding area C: Multi-regional supports The role of LACs and other ILC supports are to actively work in their local community. They should connect people to their local community and look for ways to support things that will make the local community more accessible and inclusive. But some activities make more sense if they are run across areas of the whole country because they impact large groups of people with disability. It might also be that the issue is shared across communities and does not require a local solution. The ILC could fund some of these activities. A good example might be a national, public campaign run by people with disability to promote social inclusion.
- Could that not be a funded activity run for and by people with disability to promote accessibility as a way towards social inclusion? It could also educate people with disability about how they can lodge a DDA complaint or educate business owners about their responsibilities under the Act (\*which I agree is a toothless tiger). What do you think?
- I do think that a program planned, run, and managed by PWD to educate communities, (am thinking via educating local Rotary Clubs, Chambers of Commerce, Lions Clubs, Council meetings, Women with Altitude, Business organisations, Industry organisations etc start the education at the top of the social ladder in town and work down) that shows the need for accessibility

and what accessibility looks and feels like. This could certainly be a funded project that would involve providing employment for PWD while educating the decision makers in the community.

- Follow that up by giving the tiger some teeth and implimenting the laws that exist and then strengthening those laws. Would love to see town planners, architects and builders held accountable for the inaccesibleness of their creations, things would soon change.
- i was thinking something similar. do you think something like a grant program to contribute the cost of ramps etc? maybe for half the cost or something? or some other kind of incentive?
- Wouldn't it be wonderful if we had regular planning meetings amongst creative, visioning pwd and families who could come up with ideas like this? I'm just reading about the Ministry of Awesome from Christchurch. <http://www.ministryofawesome.com/inspiration> Imagine all of us imagining how this could look MINISTRYOFAWESOME.COM
- strengthen the DDA and where people show real financial hardship they can get some assistance?
- When I think of accessibility I think of vision accessiblity, auditory accessibility, intellectual accessibility as well as physical accessibility, so yes grants to provide ramps/grabrails/ accessible bathrooms woul db good, but progams that hire PWD to consult with businesses, organisations, etc about how to increase accessibility for all would be essential..
- What if every cafe in your town had every menu in photos with a braille description. and instead of ordering a chicken parmegiana with garden salad you could order "A" and instead of ordering a skinny double decaf mochacinno you could order "2".
- The local councils need to make concerted efforts to make their whole council area inclusive. How many of the netball, football, or tennis courts in your community have any accessible bathrooms let alone sufficient for a team of PWD to access? We need to think in the big picture and the little details all at once.
- I also think there needs to be people whose job it is to prepare, educate, support the wider community to be inclusive. To have those possibly confronting conversations before anyone show ups with a pwd who wants to participate or a pwd knocks on the door and experiences the rejection most of us are familiar with (getting people to speak openly about their fear, or what ever it is, is another conversation) .
- its not fun trying to do things and a hitting wall because, in my opinion, the wider community still largely has that 'there are special places for people like that' attitude.
- I feel like so much of this sits with the community to become more accessible both physically and attitudinally. How do we make that happen?
- that menu example. i use it often tiny thing that cafes etc could do and would make huge difference to many people. I had a conversation with a chef friend about it once, there was concern about cost and the frequency of menu change and whether that is sustainable for smaller businesses.

- In WA, Inclusion WA does just that. <http://www.inclusionwa.org.au/> INCLUSIONWA.ORG.AU
- Would love to see Inclusion WA model across the nation.
- Yes, the experts on disability are those with lived experience and they have much to offer the rest of the community. PWD also have a great deal to offer the community that has nothing to do with educating the community about disability.
- Great ideas, I can only add that if you want to enact change from the "top of the social ladder" then you have to start at the real top - the HR Nichols society, the Melbourne Club, the Savage Club etc. without them on board we will never get true acceptance.
- Exactly they need to put their money where their mouth is and enforce better.

3. *I'm sorry I was in here this morning, but have had a day where I can only come back in now.*

*I've tried to find where this post might fit, but I'm having difficulty. I saw a post earlier about funding categories. I also posted earlier about this idea of 'asking up' instead of 'telling down'. In my mind this is about trying to find innovation (which you could outline/define) in a number of key areas (which you could also define). Especially VERY TRICKY AREAS where ideas and practices are very stale. I was thinking of it like an innovation fund. It's a search for whether there are ideas out there that can demonstrate they could crack open a very dusty old area, and be replicable etc. Or anything really - like "we want to have X% of people self managing. Do you have a solution to help us achieve this?"*

*Take the Digital Dreams process during the conference. What if that group of people around Estella Jones got funded to work with any one or a number of those tech firms to come up with some solutions to the problems they were facing. They were so clear on what the problems were. They were already tweaking and inventing technology ..... why not give them a boost? A solution that could potentially benefit many many people in rural and remote communities. They would need to demonstrate that their solution is scalable.*

*Check-out how The Funding Network works -*

<https://www.thefundingnetwork.com.au/about/what-we-do/what-is-the-funding-network/>

*Basically they filter/choose (much like the Pitch contest at the conference dinner) 4 innovative ideas and organisations and create a live crowd-funding event to provide start-up \$. It needed be a replica of this, but it uses these ideas in the search for innovation. They also choose themes - eg if you have an idea that will benefit women and girls .... etc*

*You could set criteria so that you seek ideas that specify that people must partner with business, mainstream organisations, expertise in particular areas*

*you are interested in - so you reward collaboration outside of the disability world.*

*Perhaps this crosses over too much into their "Market and Workforce development strategy" but i thought I would put it here. I believe these could also be the search for capacity building ideas and solutions.*

4. *I am really looking forward to sharing ideas, dreams and possibilities about what an ideal ILC program would look like under the NDIS, managed by the NDIA. Lets continue with an accent on the positive.*
- An ideal ILC would ensure there is an ongoing funding stream to assist with implement project ideas and strategies targeting community capacity building for people living with disability and their communities.
  - As a private company (yes, we live with disability), I am rather biased when I say, that applying for funding should not just be limited to non-government organisations. We believe that the current projects we have running are based on principles of innovation, fairness and bloody good value for money!!
  - I would like to hear more about this. What do you mean by community capacity building? Can you give some examples to make it more concrete?
  - I also agree with your second point but you are faster than me! I would like to see a discretionary pool or innovation fund that 'asks up' rather than 'tells down'.
  - Community Capacity: identifying the needs and gaps and working with communities to resolve the issues. Building resilience and new ideas. Sharing networks, changing the mindset...looking at what is possible.
  - I would love to hear an example.
  - we are currently doing a project in Dorset municipality called Rural Links. We had anecdotal evidence of families with disability having to send their loved ones away to larger regional centres to access disability services. Why can't the local region provide those services? We are looking at what is the human and social capital and what needs to happen in that community so that local communities respond better to disability. In a nutshell!
  - I'm not sure if this is the type of thing we are talking about here, but my family needs reliable, unbiased information on setting up wills and special disability trust funds. It's so confusing and so important.
  - It was very interesting the criteria for the 'pitch competition' at the NDIS conf: been operating for less than 3 years, annual income under \$500k, using technology to benefit people with disability..... It's pretty easier to free up your criteria a bit in order to 'ask up'. I thought they discovered some pretty cool ideas.
  - Yes! How would you see that working where you live?
  - It could be an online, easy to access and understand App or it could be a series of networking and information forums held in B's local area.

- To add to that idea B and J , I am connected with a fab organisation called The Groundswell Project. They are really innovative and run a workshop called 10 things to know before you go. We have been talking about doing something together. Because they are experts in death LOL. So also I would like to see COLLABORATION outside Disability sought and rewarded. .  
<http://www.thegroundswellproject.com/10-things-workshops/>
- Yes, forums would work well.
- Online info would be cheaper, but there are so many variations to people's needs, it would be difficult to include enough relevant information
- Can you ever beat good opportunities to dialogue together with others to learn together collectively - whether it be via a workshop like the above or a more ongoing participatory process?
- How can people who are really isolated and disconnected do that, Neil? I'm thinking of those who are regional and remote or people living in institutionalised settings, especially those older folk with disability and those who have no family. Who could be the people connecting those folk to learn collectively - and what would that place of learning look like? A self advocacy peer support group? Something else?
- I thinking peer led discussion groups that focus on a range of aspects of concern. These would include: Self advocacy, society and discrimination, exploring choices, decision making, people experiences of the system they have now or have had in the past, and where they would like to go in the future. Other topics could be on choice, control, power, what has worked well in the past, what people know works for them, what makes them feel valued, listened to, respected.
- Discussions about experts, providers, being told what to do. Let's face it people have a real expertise about what does or doesn't work , its just in the past funded services haven't wanted to listen
- At the NDIS conference, I was talking to a lady who is running a project called 'the Plumtree Project' which is for parents to use gaming and a multimedia platform to vision and work through stuff for their small children. They have invested in a repository of 250 stories (I think they are for sale, sadly, on iTunes). Would a video repository of people's stories be something that we would engage with? Made for us, by us? For me, I get bored with videos and avoid them at all costs if I can do so. I get inspired by being in the company of awesome others who drive peer led discussion.
- Funding area E is incomplete. What happened to Delivery by people with disability for people without disability. We have a shitload to share with the ablebods and they can learn amazing stuff. Why is it that we are seen to not be able to assist non-disabled people? Is it ablebod arrogance rearing its ugly head as usual?
- I get inspired by how people have addressed barriers, issues, or adversity. Its in those actions which we harness and adapt and apply to either our own situations or with our community.
- A Bank of Ideas of how others have implemented strategies or applied practice to empower, enable and become resilient.



- Like this? <http://bankofideas.com.au/>
- One of my ideas for Tasmanian's living with disability and community here is to run a community builders program here and leadership, then I dream of hosting a conference to motivate, inspire, share ideas and mentor change agents. Can that be funded in a ILC?
- It's one of the ideas raised here - why not?
- the issue of wills etc is one that Down Syndrome WA has helped people with in a few ways - when people find a good advisor, they let us know and we pass on their details to others who ask about them, we also have had information forums
- Community capacity building is something DSWA also do in lots of ways including PD for teachers, health, childcare, disability support staff. We link with community arts organisations to help plan and run events - the organisations and the people with DS benefit. We have lots of ideas but haven't been funded, though the DSO funding is helping at present.
- Part of the DSO local support group aim is about connecting to the community. DSWA is developing some skills stuff for the groups to do local community mapping, to identify links, gaps, asserts and where development/capacity building is needed. But the DSO funding ends late next year...
- I am jumping back in here to try and pick up on N's comments. I think we could think about all different ways to access different kinds of information. If you think that an app will deliver the same kinds of information or outcome as face-to-face, I think this is where you might run into trouble. Apps - what DO we use them for? Many of them provide us a really great entry point, an answer to a question or set of questions, a way to integrate an idea into our lives (ie I want to meditate in the morning but i don't want to leave home to go to a class) etc. Apps can 'nudge' or shape our behaviour. Face-to-face - what does this give us? You can do the same kind of thinking ....



5. *Let's talk about the famed 'Disability One Stop Shop'.*

*A participant below says that she wanted a phone help line which could help her to connect to services and navigate the system for her son, who is Autistic.*

*We often talk about having a 'one stop shop' - but how effective are they?*

*People need specialist expertise in autism or Down syndrome or diagnostic areas like blindness or hearing, but what's the best way to get that information?*

*Tell us what you think.*

*Funding area A:*

*Specialist or Expert Delivery*

*The NDIA recognises that Local Area Coordinators should not be expected to be specialists in every kind of disability nor understand the impact a particular diagnosis may have on a person's life.*

*That kind of expertise should be available too and would complement the general information LACs would be able to provide.*

*A good example might be a website which provides information about a particular disability or condition such as Down syndrome, or autism, or vision impairment.*

*Image description - a picture of a stop sign with the words 'one stop shop'.*

- Funding for developing a website about a particular condition is an AWFUL example. There are billions out there already and if you have a condition so obscure there's not one already, websites are basically free to assemble, that's not something I'd want to see funded!
- I was thinking the same thing.

- How do people connect to information? I agree, by the way - but if you are a person who has had brain surgery and woken up blind, how do you connect to information? This is actually a hilariously good example because your website access depends now on you being able to a) access and b) use JAWS or another type of screen reader software. If you have had an accident, you get information via a hospital and sometimes via peer support. You take it in a little at a time. If you have a child with a disability, you get the information from your peers, via the Google machine, via your doctor. If you are a person with a disability, you get the information - where? If you are disconnected from other people with disability, how do you get good info? For me, my diagnostic group is sometimes helpful with cool tips to help out with things, like how to lean your elbows on something whilst brushing your hair. Or finding out about a particular medical problem and what it means. I find out these things from peers rather than medical professionals - ditto equipment. Not from a one stop shop on the internet.
- Departments and agencies need to cooperate and let others into their silos.
- In my general experience any website which purports to be a "one-stop shop" is both incomplete and almost always out of date and has a ton of useless information. The Victorian "Better Health Channel" is a great example of a government "one-stop-shop" that's completely useless for almost anything I've ever looked for there. <https://www.betterhealth.vic.gov.au>
- Also if your problem is that you need a screen reader or that you don't know where to go for information, funding new websites isn't going to help you anyway, so I'm not sure the relevance of those things?
- There are plenty of websites etc with plenty of information but the skill of being able to navigate the internet and also to discern between good ie. useful information and bad ie useless information is a limiting effect. Also many people can not access the internet at all and find it a huge barrier if all of the information is there. However I think a phone line in your local community/region that you can call to speak to a person who has good general informaton and the skill and ability to findout specific information would be good. Ring up and talk to an actual person and they either give you the answer or phone you back wth the answer.
- In fact the idea of a phone/text/teletext contact in your own region is yet anoher opportunity for employment for PWD a service that can be by PWD for PWD...
- Increasingly I am taken with the idea of a website that incorporates a search engine that is able to draw down from the web all the information about a particular area of information you're looking for. There is a ton of information out there but it is quite overwhelming to do a straight search on Google and then filter it. This site would learn about the type of information you usually require and filter that for you.
- I know this sounds like what google does already but I am thinking more of a refinement of the search algorithm so that it is able to focus on quite discrete communities of interest. An example would be the one given by Christopher Hills at the NDIS Conference. He wanted to open his door via his iPhone. The

manufacturer of electric door openers couldn't help him without great expense but a member of the community of tech nerds was able to provide him with a cheap and easily built fix.

- There is no such thing as a one stop shop. For anything. We should stop even contemplating that as a goal.
- Diagnosis specific is also really not helpful. People with very different diagnoses can benefit from similar solutions.
- For me it's about building better networks of people - online and in the community. The "does anybody know?" question gets answered more effectively that way, so long as it is collaborative and people feel confident to suggest the way to find the answer, rather than necessarily having to provide the answer itself.
- People react far more positively when they see real life examples. Some of this could be picked up through the community video and material resources that might be developed. My other post on Attitudes are Everything mentions this. How about videos that target positive outcomes and shows good outcomes and examples. Some that cover Downes Syndrome. Some that cover Autism. Some that cover blindness. Etc. the list could go forever. But how powerful would these be in creating awareness and changing attitudes to the better.
- What could a clearinghouse for videos look like, L? A place where you could search 'moving out for the first time' or 'leaving a group home' or 'getting a new provider' or 'self managing' and finding an awesome video? Who would fund them, who would upload and maintain them, who would find past material?
- its possibly not about diagnosis but more about info needed or problems that need solving. the elbows on the sink to brush your hair could be a solution for people other than those diagnosed with MD. Do we need to get away from this grouping people by diagnosis stuff?
- I think it is in there because some of the groups say there are issues specific to the diagnosis. Nobody knows about cochlear implants unless they have a connection with the Deaf community, for example. But I do agree - that is assistive technology, just like captions are about information, just like Auslan is about language. And that is common to a whole bunch of other people - I am pretty sure it has been argued into the ILC because of the recognition of the need for 'specialist skills' in those areas.
- I was appalled by the 'website about Down syndrome' being touted as a good idea in the ILC reading materials, and told them so in the DSWA submission. A website is important, that's why each state DSA and the national association have them, but people need a lot more than that.
- In the Down syndrome community, we really value having an organisation with expertise and experience re Down syndrome. It's very different to getting your info from a generic disability source and you can talk any time with another parent. The connections become life long...parents and people with DS. We do see ourselves as a community too. The stuff that ILC talks about is what we have been doing for decades, all of it, even the LAC part. In WA

LACs have always come to us for help re DS...so I guess in a sense we are a one stop shop. But the WA govt attempt at one of those, Disability First Stop was it? Was pretty hopeless.

- So a website that all PWD and carers could use to upload tips ideas, and even videos could be a great idea however there is the risk of "superMums/Dads" seeking their 12 minutes of fame by filming their PWD offspring doing tasks activiti that would and should be kept private ie toileting, so rules regarding the privacy of anyone being videoed would be needed and would have to be enforced.
- Would this one stop shop also include mental disorders? I have a son on the spectrum with co-morbid mental disorders.
- A website that separated information into categories such as 'sensory stimulation' or 'vision impairment' which applies to many different diagnoses could be useful
- I really liked the idea that was presented earlier by P about a search algorithm that would find \*anything\* you wanted to know. That's a bit of a different twist than the 'category' idea.
- how do people with DS themselves engage with supports and services offered to them? And what else \*could\* there be?
- The trouble with that is that search algorithms that automatically do what you mean, not what you tell them to, don't exist.
- This is true.
- Another reason for categorising information is that a person might not know what it is they don't know until they see it. So you might not know you need to know about how to steady your arm while brushing your hair until you see it written somewhere and have an 'Aha!' moment.
- it is not hard to imagie a website that ctegorises information and also has an algorithm for finding specific information/ideas/tips
- other than a website what are some other options?
- I find out things by seeing them.
- Depends on the person and their circumstances. Part of what we are doing with DSO is building capacity for people with DS to do more themselves.
- A lot of what there could be is tied up in the community being more welcoming, there being better personal support to really engage, get and keep jobs etc
- So for example most of the wheelchair users at the conference scoped out other people with tech or gear or watched them doing things. A woman near us learned that K carries an Allen key set in her bag (lol) and another person learned that you can steal a conference chair when your crappy hotel room doesn't have an accessible shower chair. Or hire one from a conference organiser. Some able bodied people learned that yes, it is totes okay for one power chair to tow a manual chair with a piece of nylon webbing and you can even drink a cup of coffee whilst you're being towed. I learned about bluetooth powerboards from Chris Hills and about where Estella lived in Tennant Creek and how there was no power (\*because of a video). Rhonda spent a bunch of time asking me about a Smart Drive that she couldn't get to work and I could

tell her about the new one because other people had told me, and there was even a cool life hack from an inspirational paralympian about getting a new Smart Drive.

- This involved people who are generally isolated and segregated getting together to observe stuff. All those things we learned did not come from the conference, but from being in the same space. Perhaps that creating of spaces to learn and share is one idea - has there ever been a conference for and by people with disability outside of diagnostic groups? Why not?
- an actual disability conference or yearly event. by and for disabled people.
- Other options I can think of are call/information centre and also information being disseminated through a variety of organisations that already exist such as schools, colleges, local libraries and various service providers. So for each region information regarding disability can be provided and disseminated through a range of means.
- I love the idea of a big disability festival (festival is a much better word for it) for all the reasons you just said. add in learning stuff about self advocacy and human rights and i reckon it would be hugely successful.
- I agree there are plenty of websites out there. I've found even though my daughter has a rare syndrome, accessing information has not been a problem. The problem is turning information into action. With rare syndromes, in Western Australia anyway, you often walk into appointments more informed than the 'expert' you've come to see.
- And then they google your condition with two fingers whilst you watch the clock and count the dollars
- It's even the case with more common syndromes!

6. *There is a lot of positive information coming from here re access, process and supports etc. I have several friends who would qualify for ILC support when it arrives. However these guys are the unseen ones that find it difficult to find and keep employment. Not in a wheelchair, fit in readily in the community yet have difficulties in some cognition areas or in processing instructions quickly. Currently the 'system' tries to get them work. They go with the lowest common denominator. Unskilled work that runs out after a month or so or is so badly paid they are taken full advantage of.*

*One young man had a great job and kept it for years. At that stage he did not not have a 'disability'. After having an epileptic seizure he was diagnosed with Asbergers. He used to drive a truck delivering and assembling goods around the state, but that's ceased due to the seizure.*

*Some of the points made to date may be useful and provide answers. We can make the work community and general community aware but whats the best way to shift the thinking in the current system for people on the borderline.*

7. *Attitudes are Everything. Put into the mix expectations and watch the dominoes fall. .*

*I visited the coordinator at a community house several years ago to suss out what activities were available in the community. This was to prepare and plan ahead for my son who was moving.*

*The first thing the coordinator said was "we don't have activities for people with disabilities in our community".*

*"That's okay" I said. "Just tell me what activities you have for everyone else" Beautiful, she got it.*

*Effective capacity building for me is not building more facilities that exclude people. It's about using and building on what we have now in every community. Clubs, interest groups, libraries, schools, galleries, creative outlets etc. How do we ensure this type of thinking is embedded in the ILC. Discuss?*

- is this a missing funding priority? Changing attitudes?
- I don't have an answer but think this stuff is key. there is no point sending people off into the world with a bucket of funding if the world is not yet fully accepting. I think there is still a large belief in the wider community that there are "special places" for pwd and that is where we should go. Those attitudes need to be turned around.
- This is slow long work, the people doing it probably won't get warm fuzzies at seeing the work they are doing because it will be so slow. A lot of people like the warm fuzzies they get from working with pwd so thought will have to put into who is best to do this work.
- And what would it look like? Funding area F: Attitudinal change and community capacity building The ILC Framework recognises the importance of activities that change attitudes and build existing capacity in the community to welcome people with disability into mainstream spaces. A good example might be...
- the disability sector is almost built on networking. maybe we "network" the hell out of mainstream. maybe thats pwd (in a paid capacity) continuously showing up at the clubs, groups, libraries etc and talking about access and inclusion and what ever else. maybe its a non-disabled person doing that because maybe people can be more honest about what their concerns, issues, fears about including pwd are if there isn't a crip in front of them?
- Don't inspirational Paralympians do this already?
- yep to the training. there is a real issue with pwd speaking on behalf of pwd but only from their own experiences. it is hugely dangerous. Anyone doing that work or any kind of public speaking where they purport to represent us should have a good understanding of the social model and human rights.
- What about finding people who are already in those mainstream areas to talk to other groups? For example, some schools and workplaces and Scout



- troops and karate clubs are more inclusive than others. Could the twist on the 'story' (this is me and I am an inspiration) could maybe be around inclusion?
- Or using kitchen table style conversations around inclusion. L's question was 'It's about using and building on what we have now in every community. Clubs, interest groups, libraries, schools, galleries, creative outlets etc. How do we ensure this type of thinking is embedded in the ILC. Discuss?'
  - Could part of the work of ILC be around developing training for those places to understand how to include people, paying people with disability as speakers as per the above, doing community assets audits about accessible and inclusive places and promoting them to the community as part of a program? Maybe something like Neighbourhood Houses, where you know that place is 'safe' (but in this case, inclusive?)
  - I see the people best placed to assist this process are those whose life's experiences have not been colored negatively through prejudice or negative expectations. There are many professionals who do get it and understand how to change attitudes. Ideally this needs to change at school level with inclusion being available for all children. This in itself changes the attitudes of tomorrows keepers. These are our future decision makers and what they learn will stay with them.
  - Currently, just rocking up to a club or interest group works for my son who can only do this with a support worker. He does not have physical needs that require access solutions as he is mobile. ( I do understand access for others is a major barrier) It's having the desire and belief in yourself to approach others that's the key. This could be a major part the LAC provides support with. Yes, funding would be a positive and useful way to provide education and supports to assist in changing attitudes. It should be available not only to disability groups but community and other groups as well. It could be done in so many ways. i.e.
    - Talking to key community groups. Lions and other social support clubs and networks for example who have for years been supportive but retained the 'special' approach to support. Talks are far more effective when given directly by people with disabilities and or their advocates.
    - Producing videos along with training booklets to assist people who do the talking with skills and processes that work.
    - Networking and sharing good resources and ideas effectively. There are many disability groups and sometimes I think they work against each other. Specialist for this group and not that one etc. Exclusion occurs within some groups at times. The collective we were part of actually did work together. Using a set of principles that were clear and put everyone the same page was crucial.
    - Written texts along and social media is pretty powerful.
  - they also need to explore what other disabilities look like and how things affect them as a result. As a wheelchair user i have no experience of having no spoken language, or being blind or deaf etc etc. As someone who is developing opinions and contributing the forums such as this it is my responsibility to try and have some understanding of what that might be like

so i dont cause disadvantage to those people. I do this by reading blogs and listening to the people who have those experience when ever the opportunity arises. I think its very important that we do that when we start forming and voicing our opinions

- I've though about the video idea before. what if your really awesome Scout group made a video of the things they do to be inclusive and made that available to other Scout groups and to the people doing the work around community capacity building and inclusion? people might need some ideas on what adjustments they can make or consider that Jonny in the wheelchair could man the Lions club bbq or cash register. They have probably just never had to think about it before so if we start demanding they do, it would be good to kick start them with some ideas.
- Maybe that's done via a grant project, clubs etc that think they do really well can apply for a small grant to produce a video.
- One of the best examples of this floating around at the moment is Emma Lynam's video on ABC Open. Emma lives in Townsville and runs her own paper shredding business. She has a mile ling list of impairments that would traditionally be used to justify to going to a time wasting congregate day service. There are some great moments in the video. One of the business owners who contracts her services talking about the significance of Emma's work in their office. Emma talking to some office workers about her new shredder using an app on her iPad.
- 'Attitudes are everything'. This is an example from a series of videos we put together as part pf the collective years ago. Its this type of resource that we used when changing school community attitudes. This is an approach that worked absolutely then. Similar resources based on the now could be developed, They would not only be valuable for the community but I suspect LAC also. How many of these could be put together along with supportive material to make a difference. <https://vimeo.com/26257094> Attitudes are Everything (Part 2)
- just caught up on the questions and comments here, this is all moving very quickly.. and there is a lot of ideas, issues, thoughts to cover. There is a possibility of a person with a particular diagnosis misrepresenting themselves as 'all PWD' however there is a need to understand that this misrepresentation would need to be addressed from the outset and a lot of training provided for anyone taking on a role of liaising in the community so why not provide that training to PWD.
- Is it confronting to have a person with total vision impairment and their guide dog turn up at your place of business, group, or organisation to talk about inclusiveness. Yes, it is, and that is a good thing this kind of confrontation opens the conversation in ways that ablebods just cant. Likewise if a person using a wheelchair appeared at the Lions club to discuss accessibility and inclusion at ther meeting would it be confronting to some members, yes, would that be a bad thing? No. Experieincing people with disabilities taking roles of leadership, education, and information would be a great first step in opening the conversations that are needed to achieve inclusiveness. PWD in

key roles will do much more for inclusiveness than any ablebod. And really do we want/need/care to hear the objections, reasons etc that inclusiveness is not possible. Ablebods objections are actually irrelevant and only increase exclusiveness.

- Maybe encouraging something similar to the Reconciliation Action Plan (RAP) system for organisations. Many organisations and government departments are rolling them out now as a way of promoting reconciliation with Aboriginal Australia. Something similar but with Inclusion of PWD as the goal may be an idea.
- That's an awesome idea, T - there has been so much good work done under some of the plans like Closing the Gap and people don't ever think of mirroring that work for the disability sector.
- Agree that T's idea is a winner.
- I think a version of Cultural Awareness Training could easily be developed and delivered too, before something like a RAP was implemented. With the same level of protocol and consultation that we currently have with Aboriginal Cultural Awareness training. The most important being that it must be delivered and developed by PWD
- I have a son with disabilities interested in art. Painting to be specific. I researched around and found a local community house offering a course in his area of interest. They were not phased by him joining the group and even asked if he needed to take a support worker with him. He does not need that type of assistance. We drive him there and pick him up as he gets sensory overload with public transport. It has been a total success with him now enrolled for the second time in the course that has seniors among their members of the class attending. My worry is will NDIS fund this type of activity as it gives him much needed inclusion in the mainstream community in an area where he has strengths in a group that does not "people" him out. Would this be classified as an activity that is much needed in his life and could we get funding to not only pay for the course but a carer to drive him there and pick him up and drive him home after?
- If it is a non 'special' activity like the gym or pool or a mainstream class, the answer is probably no if it is about his actual fees for the course. Re the carer and transport, yes, they would be covered by NDIS. It would be great to connect to others who are progressing their art career, too, Julie - Josie is off exhibiting in New York <https://www.facebook.com/worksbyjosie/?fref=ts> and Tim Sharp is promoting the new book about him, written by his mum Judy. Lots of successful artists with disability. What did you do to research around? Because that would be an ILC function, under this proposed new model. How could someone else replicate what you did to make it easier?
- I would like some practical ideas on how a person could participate in their local library for eg.
- I just sat and thought where would be an environment that would suit my son. I knew from experience that a TAFE or university course even online would crash and burn from bitter experience. It then hit me that maybe a community house would be more suitable as it would be far more welcoming and have

smaller more casual style classes. After that I goggled around the area we live in for community houses offering a painting course. It took me about 5 hours and lots of phone calls but I finally found one in a suburb near us. I contacted them and explained the situation along with his disorders. Then it blossomed from there. This is his first successful time of inclusion in the mainstream community. While it could be classified as a hobby for him it is a lifeline that is allowing him to mix with non disabled people on a regular basis. He is now in his second term of participation and it is a stunning success. We have tried so many other things with him that have crashed and burned within 3 weeks of him starting them. His disability is so severe it even impacts on him going to the movies as this "peoples" him out. He even missed a day at his class as he just couldn't cope being around people too soon.

- how did you know about the community houses in the first place?
- I would love him to other people like himself regarding art. That would be to me something beneficial to be able to share his experiences with others that understand the challenges he faces. The hard bit would be getting him to join in. An online art community discussion group would be a great help and make life a little easier for him. He really is extremely autistic which is why I am so pleased his art group sessions have been such a success
- I read about them in our local community guide they send us once a month. Plus I was attending one for a mental health program for myself. I have physical and mental disorders so my case manager arranged for me to attend some sessions at our local community house run by her organisation.
- I would love it if our library held some suitable groups so I could mix in the mainstream as well. Currently all I do is use the library to borrow books.
- Like you, J, we looked for something that our son would be interested in, rather than something that caters to people with special needs. Our son, is now a valued volunteer at a local heritage steam train museum. He has a support worker to help him as necessary, and he shovels gravel, coal, clears the public areas of natures little obstacles (branches, slabs of bark) and places them in piles to be later burnt. he is one of the guys. That's what he wants, and that's what he is. He also does it alongside enormous steam trains, which he sometimes gets to ride, while looking disdainfully at general members of the public, who don't also work there. I say work, because he works bloody hard, as do all the volunteers. They are all volunteers - no discrimination there. Ability Links made the initial contact, and then myself, my husband, and the support worker were there, finding things our son could do. Our son was also there, demonstrating on the first day how hard he could work. <http://www.richmondvalerailwaymuseum.org/>
- I have been trying to get my son involved in community for a long time. But the reality is thst there is nothing much in his area where he lives. He visits the librsry and knows everybody there. He goes to the two local cafes and thsts about it. If he was capable of speaking to people or even bei g able to use his hand for various things then maybe he may have a chance of doing some voluntary stuff But being so physically disabled I honestly doubt that there is anything in his local community he could get involved in.

- Exactly. You really have to think outside the box when they are very disabled by mainstream standards and be prepared to put in the hard yakka of looking for creative solutions to ensure they get included by society.
- My son is involved in a community radio station where he "speaks out" the sports news on his iPad. But that is a long way from his home and his support put all the info in on his iPad for him. He just has to press the iPad to speak.
- We are lucky as our location is 10 minutes from the bush but also 10 minutes from the suburbs.
- Thanks J for your thoughts on accessing community. Not dissimilar to my son's journey in using community houses for activities. So, community houses are in most communities here in Victoria. They may have different names or not exist as such in other states. Whether it's a community house or the local sport club it's using facilities that everyone else does that's the key. These are the places and organisations that need information and can readily adapt to include rather than exclude. Perhaps when the NDIS arrives in full we should be saying okay, that's the end of the charity model. It's now up to you guys to shape up and work with us.

Here are several things our lad is involved in through community houses.

- Attending a local writing group where they share stories and set writing tasks each week.
- Going to film sessions and seeing some of the classics with friends.
- Going to community lunches.
- Attending a trivia night and wowing everyone with his knowledge. Although not always right.
- Going to the op shop in the house with his workers and buying items that he needs for himself or his home.
- Writing articles for the community House.

Oh yes and he does paint as well to accompany his poetry work but this is done at his house where it's all set up for him. Just waiting for some painting sessions to start up at the community house.

- Sounds great L. I only wish my son was capable emotionally to do more things. I would love for an online group where they can discuss and share their painting ideas to be formed for PWD to join in. That is what I would be asking a LAC about.
- I can see that you have worked hard to get him involved in various community things. I think our local suburbs are pretty boring compared to yours. Maybe that's the drawback of living in a Brisbane suburb.
- His painting and community components J fits readily into several of the key components of the NDIS. Health and Wellbeing, (emotional state) Relationships (friends) Lifelong learning (classes and education) and Social and Community Participation. Except I am unsure if ILC uses the same criteria. One would think they should as without support their needs may increase to dare I say it tier 3.
- Yes that idea just crossed my mind too. I will run it by my son and get his feedback. I would love for him to have a group at Facebook to share ideas and art discussions with.

8. *It would be good if more money was directed toward advocacy for employment for PWD, and advocacy around discussions re flexibility. Many of us can work in some fashion or other, and if we choose to (in my experience), the unreliable nature of some conditions creates barriers because 'the way things are done' can be so rigid. We need a concerted effort to start discussions with employers from an NDIS perspective, being able to show that being flexible isn't detrimental to their business, and just how the NDIS can help bridge that gap with a bit of inventive thinking from both sides. I guess I'm talking about increasing openness to these ideas through an advocacy push of some kind - opening conversations up.*
9. *My preference is that funding is put into community development type stuff. I've been watching different programs designed (i thought) to create inclusion with interest, Ability Links is a great example (sorry Linkers, hubby included lol).*

*When i first read up on what Ability Links was about I was pretty excited. I interpreted it to be about changing attitudes and going out to community and talking about what inclusion looks like and educating where necessary (education not awareness raising). Providing support to places that maybe aren't sure how to include pwd because of what ever reasons. Some of this might be uncomfortable and confronting because real and raw conversations need to happen about what it is about pwd that makes other people reluctant to include or welcome them.*

*I imagined it would be a role in which the work is slow and you wouldn't always see the outcomes but it would be preparing community to also be ready for NDIS so that when people got the funding to enable them to live the life they wanted the work had already been done to remove the attitudinal barriers we often face.*

*I'm not sure how much that has happened. We have had bucket loads of conversations amongst each other about what might need to happen and we all no doubt have examples and ideas of what inclusion looks like but who is sharing that with the wider community? Preparing for NDIS is not something that just disabled people and their families need to do, if this is going to work then the whole country needs to be involved. This is where i see the bulk of the work for these programs. I am not saying people in these roles should not be working with pwd but I wonder how many people have had to compromise on what they really wanted because they kept hitting walls and are now doing something other than the original goal (or nothing at all). We all should just be able to go out and do the things we want and be included in the same way everybody else is but that is often not the case. We need to work towards making that a reality, however that looks.*

- You are absolutely right... There is a real need for genuine community development work alongside building the capacity of NDIS participants to direct their own support and unhook from specialist disability services. As you've also said this is slow work where changes occur over time.
- There is almost a continuum that operates here:
  - (1). Individuals begin to see their future beyond serviceland and service programs. They have the tools and strategies to direct their own lives and support from peers who have been down that road before them.
  - (2). There is conscious effort put in to connecting people with mainstream opportunities. This has the dual effect of seeing people with disabilities as making their contribution to the world around them and for community members to understand and embrace inclusion as something that is real, possible and necessary.
  - (3). Community development work that sees ALL citizens coming together to find ways of addressing shared issues within their community. I'm not that convinced that awareness raising campaigns do that. I think they tend to reinforce the same old stereotypes, but when people share the same space and work on shared issues their emerges a shared understanding and shared commitment.

Some interesting reflections of my own as I have explored these ideas:

  - (1). Funders don't regard this as real work. It doesn't fit within the neat funding boxes and therefore are blind to its necessity and importance.
  - (2). Service providers are challenged by this work because it deliberately encourages people to look outside the disability support system for solutions to their day to day support. On more than one occasion I have heard a service provider say I have no right to encourage people to explore more mainstream and inclusive lifestyles. The paradox of course is that all service providers profess a deep commitment to person centred and inclusive support... But of course it is usually on their terms not that of the individual or their community. The most vulnerable here are those who are most deeply embedded in the system and who have others speaking for them. These are are people for whom low expectations and non inclusive lifestyles dominate.
  - (3). This work can only happen if you are a part of the community as well. Where you operate out of a nice shiny office with keycard access and corporate reception you cannot do this work. If you want to do community you have to be in the community.
- Can I also say, My husband is actually an Ability Linker, most of his work colleagues are in my friends list, as is his manager. They will possibly all see the post i just made using them as an example. I thought about that before i wrote it, will i upset people? will they be offended by my post? etc etc and I came to the conclusion that i needed to say what i was thinking anyway because we are only going to get one chance at building this whole system. If we get it wrong because we were worried about upsetting someone or being victimised by agencies. if we never said what we actually wanted it all to look like then we will have missed the biggest opportunity we have ever had.



So that is my message, say what you think and want and say it now because once its all done it will not matter much what you wish had happened. It will be too late.

10. *I'm looking at the people commenting here and can see its mostly the same, almost predictable bunch of us. It is awesome that we are all spending our Sunday doing this and that there is a mixture of disability types. I am wondering though, how do we get other people to take an interest and recognise that this new system that is being built is also their responsibility.*

*I think what i am mostly saying is, how do we get people to recognise their power? Lots of talk about inclusion and needing to get community ready but do we also need to get pwd empowered? this all has to work together, there is no point giving funding to access community if community rejects you. there is no point getting community to be inclusive if pwd are so dis-empowered and disengaged that they won't/can't/whatever engage.*

*Besides funding and and a welcoming community what else do pwd need, if anything, to achieve the 'good life' that is so often talked about and how does that fit into the ILC (if it does at all)*

- How can we make it known that advocacy exists? The nfp and orgs that provide these services need advertising, they need funding to tell people help is available. That advocacy and support doesn't have to come from a provider or dsc. It can come from a non judgemental org that isn't in it for the money they are in it to actually help people. Getting funding to get advocacy groups out in communities into events going along to support groups to tell people what they can do for them and what PWD rights really are.
- lets get the advocacy groups that are great and really fund them, imagine what they could do!! They could come out to regional areas and give advice, let PwDs know their rights ect.. this could work. Say you had say PWDWA get funded properly and they could make things happen all across the state.
- I also think there needs to be an understanding that not every pwd travels through predetermined roads, in oder to get to a certain place, and meet up with everything they need to know along the way. People constantly fall through the gaps, because gaps exist. If we can't close the gaps, can we not set up orange booths at regular intervals? GP surgeries would be a good place to start.
- You are correct, thre are a lot of famiiar names, but some us are just watching and reading and liking ideas too. Its too hard sometimes to come up with better ideas than you guys, but dont discount the rest of us participating
- Yes, re regional contact. DSWA gets out to regions when we get a specific funding grant e.g. to do PD for teachers, and we then use the chance to meet

up with families too. But otherwise, we can't afford to. We do have local contact parents in many areas though.

- I'd like to contribute but I really don't understand what's happening here despite reading all the posts... Something about suggestions for activities to be included should you be part of the NDIS rollout? Quite lost really. I think perhaps practical folk like me sight the word 'policy' and just sigh, seeing another word fest that achieves not much. That is, we make suggestions so that the govt Inclusion/Consultation obligation gets a big tick but nothing actually happens. Do forgive my cynicism or even just general cluelessness cos I'm not sure what we're supposed to be doing. I'm used to govt not giving a flying fuck what I actually would like to achieve with whatever funding I get and I can't get my head around this process being an exception to that. The likeliest thing tho is that I just don't grasp the purpose. Sorry.
- I know I keep bringing up the Aboriginal initiatives, but that's what I'm most familiar with and I see a lot of similar issues around reaching out and engaging harder to reach people. Maybe we need a universally recognised symbol that can be attached to logos and signs (like the blue wheelchair symbol I guess :-/), more funding for advocates to be out in the community in a truly flexible and proactive way, the commitment from funders that this type of engagement is all about relationship building and won't look like it does at the commonwealth bank (for example), having community engagement workers whose job it is to build relationships with organisations and community groups and community members so that everyone can participate in whatever is happening in their community. And I think those positions need a classification equivalent to the 50d (ATSI specific positions).
- we need to properly fund advocacy orgs so that they can come out on a regular basis, that what ILC should be used for.
- As a respected Ally, I also see my role to let those people I know what the NDIS is, what the Act and the UNCRPD expects from all Australians and also the importance of ILC.. This role needs no \$\$ just my commitment to spread the word whenever, however ie constantly ( ha never thought of myself as an evangelist lol)
- So I'm meaning all those Australians who do not know anyone with a disability and have never considered the importance of community in people's' lives
- If every person ( worker, NGO staff, the local butcher, advocates) made the commitment to always spread the word then the funding can go to self advocates and peer to peer groups so that the details/shared stories can be given by those with lived experience
- What revolutionary idea. My son and his support workers are doing their bit - educated a woman, who then educated her three young charges in how pwd can enrich the community.
- i agree with you, it is probably less about money and more about talking and talking and talking. Some people should get oaid to do that in a professional capacity though (those people should be pwd). Im wondering a campaign where people pledge to so something. Become accessible, inclusive or what ever. Bad idea that wouldn't work or have an undesired effect?

