Thank you for accepting my submission to the National Disability Advocacy Program.

I am a person with disabilities, the wife of a man with disabilities and the mother of two young women who each have disabilities.

In many circumstances throughout my daughters’ lives I have needed to advocate for them on issues as varied as human rights abuse from a service provider to advocating in medical settings and educational settings. My efficacy as an advocate for them depends entirely on my own impairment at the time. This has been a less than ideal situation for them at times.

Seeking assistance from a local advocacy service for personal advocacy on behalf of my daughter who has complex disabilities including communication and cognitive impairments I was less than impressed to receive a response that I needed to attain guardianship of my daughter and I have a right to guardianship. This is not in keeping with my beliefs and position on social justice which is best described as Human Rights based.

It is only in recent years that I have found and become a member of both, People with Disabilities Australia, and Women with Disabilities Australia two excellent organisations. My daughter who has complex disabilities also became a member of these two organisations.

Through discussion, meetings and forums with these organisations I have been able to better advocate for myself and my daughters as needed. However, there is an ongoing need for them each to have use of advocacy services that will be beyond the limitations of my own abilities and also beyond the span of my own life so I have a great interest in the review and development of advocacy programs that will, hopefully, exist in perpetuity.

Having placed a great deal of importance on this submission I have tried my best to consider as many options to each question and question part in its turn, though there are some question parts I have left unanswered as I do not have sufficient knowledge or experience in those particular fields.

I would like to say that the first question felt somewhat confusing to me because it asks about ‘support’ and I have supposed it to mean ‘advocacy support’ and not personal care or community access support.

Sincerely

Cheryl McDonnell

* 1. **How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?** 
     1. *If agencies are only funded to provide one or two models of support this holds little benefit for people with disabilities, their families and carers if there is a complexity of needs that fit into several layers of models of advocacy as they then have to tell the story of what has happened and what the problems are over and again to each advocacy service.*
     2. *It is better to provide advocacy for the person with disabilities according to what their personal needs, views, and situation are.*
     3. *It is possible that training for advocates in only one or two models is a cheaper system on the outset, though I daresay the interplay of unmet needs of people with disabilities that could possibly increase costs of support at a later time should be considered, as effective advocacy that meets the person at the point of their need and addresses the need of an individual person with disabilities in a timely manner can prevent expensive reparation later.*
     4. *The two exceptions to this would be systemic advocacy as there is a distinct need for Disabled Person Organisations working at systemic levels with government, business and organisations to advocate on a range of issues; and legal advocacy which requires a specific skillset for best possible outcomes.*
     5. *Organisations such as* ***Women with Disabilities Australia*** *and* ***People with Disabilities Australia*** *that seek to support, enable and encourage members to advocate for themselves and one another as individual self-advocates while* ***WWDA*** *&* ***PWDA*** *also work to address systemic issues through their work with government and business and their involvement with the* ***Australian Cross Disability Alliance (ACDA)*** *do not have the funding to employ advocates in other areas and time limited funding that requires annual or biennial requests for funding that takes time and attention away from the work they do systemically without sufficient funding to expand into other models of advocacy and the work it would take to set that up*
     6. *Organisations such as the* ***Penrith Disability Resource Centre*** *provide family, individual, and legal advocacy (and in our experience have a preference for family advocacy) can focus on issues that are relevant to the local area and people with disabilities in that locality.*
  2. **What are the drawbacks?** 
     1. *People with disabilities are individuals with unique and personal considerations and one or two models of advocacy are unlikely to meet the varying needs of all of the people with disabilities needing advocacy so if in one locality or another there is only one or two models of advocacy available then all of the other models remain unmet needs of the people with disabilities in that locality.*
     2. *Particularly in rural and remote areas there is a need for one-stop shops of advocacy that operate in all models of advocacy, though one service could not and should not meet all of the advocacy needs of the people in the area.*
     3. *The left hand does not know what the right hand is doing. If organisations that offer advocacy are not working together and aware of the works done by one another they could be reinventing the wheel especially on issues that overlap from one model to another thus wasting resources.*
     4. *Having to explain your story is difficult for many people, to have to do that over and again to more than one agency when your advocacy needs overlap the models can be stressful and can prevent people with disability from seeking advocacy to the full extent it is required.*
  3. **How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?**
     1. *We should be valuing and supporting people with disabilities not models of advocacy.*
     2. *Supporting and funding Organisations such as* ***Women with Disabilities Australia*** *and* ***People with Disabilities Australia,*** *to continue the work they do in the systemic model of advocacy on a national level along with the work of the* ***Australian Cross Disability Alliance*** *is valuable to and supportive of people with disability en masse and is imperative to ensuring the inclusion and participation of people with disabilities at all levels of life while ensuring government is informed of and up to date with the needs of people with disabilities.*
     3. *It would seem that* ***Legal Aid*** *needs to be funded in such a way that provides for them to be able to provide legal advocacy for people with disabilities. Legal advocacy is best handled by people with legal training and qualifications, anything less denies people with disability quality legal advocacy.*
     4. *While a one-stop shop may seem to be a good answer and it could be possible that a place of business for an advocacy service could offer an arrangement for legal advocates to work from in rural and remote areas it would be a waste of legal qualifications to have qualified lawyers working on advocacy in other models and an injustice to people with disabilities to not provide qualified legal advocacy when required. One-stop shops in rural and remote areas could also provide data (de-identified) to Disabled Persons Organisations and the* ***Australian Cross Disability Alliance*** *as well as to government to assist in the work of systemic advocacy.*
     5. *One-stop shops could conceivably be funded to:* 
        1. *provide training to citizen advocates*
        2. *train and support people with disabilities to self-advocate, individually and in groups*
        3. *work community wide in promoting the human rights and inclusion of people with disabilities while demonstrating in the community practical applications of inclusion.*
        4. *Host nationwide organisations that work in systemic advocacy and work with them to help identify the needs for systemic advocacy of people with disability in the area.*
        5. *Host legal advocacy services to people with disability. It is worth noting in towns, villages, and communities where there is only one law firm that law firm will no doubt have done business with the families, employers, landlords and or service providers of people with disabilities which may put them in a real or perceived legal conflict with advocacy for a person with disability. A visiting legal advocate who perhaps works on a circuit through rural and regional areas could be hosted by the local advocacy service.*
        6. *Advocate for individuals with disability*
        7. *Advocate for family supports.*
     6. *There needs to be caution around the idea of advocating for people with disabilities and their families as in some situations this could be particularly detrimental to people with disabilities and in conflict with their human rights because of the intricacies of familial relationships, the dynamics of particular families, and the financial interdependence of family members which causes a real or perceived conflict of interest.*

**2.1 How do we improve access for:**

• people with disability from Aboriginal and Torres Strait Islander communities and their families?

*Fund a national body that is a disabled persons’ organisation such as* ***First People Disability Network Australia*** *to develop and provide appropriate training in human rights, disability and advocacy to Aboriginal and Torres Strait Islander people so they can be employed as advocates by advocacy services and particularly in locations that have a higher Aboriginal & Torres Strait Islander population.*

• people with disability from culturally and linguistically diverse communities and their families?

*Fund a national body that is a disabled persons’ organisation such as* ***National Ethnic Disability Alliance*** *to provide appropriate training in human rights, disability and advocacy to culturally and linguistically diverse people so they can be employed as advocates by advocacy services and that culturally specific needs can be met in various locations according to the local needs.*

• people with disability in rural, regional and remote locations?

*Fund local advocacy services established by people with disabilities and fund training in human rights, advocacy and disabilities to equip local people to represent local people initially larger regional areas could be used to identify people suited to training in satellite areas and assist with the establishment of local advocacy services.*

*Where a local advocacy service does not exist in a regional area it will be necessary to fund a national organisation to develop and establish an advocacy service in the locality with appropriate training of advocates.*

• people who are very socially isolated including those with communication difficulties and those in institutional care?

*Identify people with the right qualifications solid track record of experience of working with people with complex disabilities, excellent interpersonal skills and solid awareness of disability issues and pay them what they are worth. (squillions)*

*Fund high grade training in disabilities; human rights; advocacy; awareness of gatekeeping and skills to deal with that; communication strategies for people with complex, cognitive and communication disabilities.*

*Legislate the right of persons with complex disabilities including cognitive and or communication disabilities to access to advocacy and give the advocates the power to act to meet with and assess for themselves; the needs met and unmet; the goals; views; safety; well-being; care; and support of the individual with disabilities. This may in some situations involve by-passing gatekeepers who may be hostile in word, deed or through manipulations of information.*

*The recent Senate Inquiry into Violence, Abuse and Neglect of People with Disabilities in Institutional settings is loaded with reasons to legislate the right of the person with disabilities to have unhindered access to advocacy and this includes people who cannot physically ask for advocacy, and people who may not have any experience of advocacy and people who have to date been denied access to advocacy through the use of policies, manipulation of data, failure of others to recognise and act on the need for advocacy.*

*It would make sense for people with severe, complex, and cognitive disabilities to be introduced to advocacy services during school years as a part of the curriculum and the advocacy service could maintain at least an annual contact with the person in the manner of a visit.*

*This level and complexity of advocacy is suited to a narrow range of individuals as the need to be able to negotiate access to people with disabilities increases with the complexity of disability. PAY them WELL! They deserve it.*

2.2 What are the strategies or models that have worked? What are the strategies that do not work?

*For me and my daughter when I attended an advocate service which was run by people with disabilities in our local area they encouraged me to attain guardianship for my daughter, I saw this as unhelpful as guardianship only works while I am alive and I need answers that last longer than I will. Also guardianship of one person over another is against the UNCRPD. The answer for long term advocacy and support for my daughter lays in government and society and not in me living longer than my daughter. What I think my daughter should have is not nearly as important as what my daughter wants and needs for herself.*

*Having access to organisations such as* ***PWDA*** *and* ***WWDA*** *have been successful in assisting my daughter to be central to all decisions and assisting me to understand the needs of a person with disabilities in regards to their human rights and social justice as well as the future planning for their life. A great deal of useful information is available on their websites and in their newsletters which discusses the various areas of advocacy and need.*

*A model of advocacy that allows and encourages individual advocates to spend sufficient time with individuals who have complex needs to gauge who that individual is and what their advocacy needs are is necessary and in particular where there is little or no family support or where the family support is inadequate to the needs and rights of the person with disabilities.*

3.1 What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?

*FIBRE to the Premises via the Broadband network. Information technology is paramount to getting information to where it needs to be in a timely and efficient manner.*

*Advocacy services and other organisations need to provide de-identified information to a database and this data needs to be openly available to organisations like* ***Women with Disabilities Australia*** *and* ***People with Disabilities Australia*** *who work in a systemic way to address needs of people with disabilities.*

*No data, no funding, but funding needs to include sufficient funds to employ data entry operators so that advocates time is not taken up with administrative tasks. The data is important to organisations so that they know what issues are the most pressing and which issues vary according to location as well as the patterns of advocacy sought and can identify gaps in advocacy support. This data can help disabled people’s organisation working systemically to know in a clearer way where the urgency of need is and understand patterns of need.*

*Give disabled people’s organisations access to the database. Perhaps the database could be managed by one of the universities or the national library if the Bureau of Statistics cannot or will not manage the database or a new organisation created to provide database management for people with disabilities and the relevant organisations.*

*Require all departments of government at local, state and federal levels to provide to the database data that can aid in producing useful statistics on issues relating to disability.*

*There is much data on people with disabilities that is not kept or is not kept universally across the states and territories such as data that would reveal:*

*The frequency of the interactions between state and federal police and people with disabilities, the nature of those interactions and the outcomes of the interaction that could aid in identifying the need for systemic advocacy.*

*The frequency of interactions between various welfare departments and people with disabilities, the nature of those interactions and the outcomes that could aid in identifying needs for people with disability and identify the need for systemic advocacy in particular areas. Ie. People with disabilities having children removed from their care.*

*The national census needs to include more questions regarding people with disabilities to provide data to government and organisations.*

*Recommendation 25 from the Senate Inquiry into Violence, Abuse, and Neglect against people with disabilities needs to be adopted without delay.*

*“Recommendation 25 10.74 The committee recommends that the Australian Bureau of Statistics ensures all of its surveys are inclusive of people with disability. The committee further recommends that the Australian Government commits additional funding to ensure the triennial survey of Disability, Ageing and Carers and the Personal Safety Survey include the collection of data on the prevalence of violence, abuse and neglect against people with disability. This data should include the following information: • age; • gender; • type of disability; • place of residence; • cultural background; and • whether the violence, abuse and neglect has been reported to an authority.”*

3.2 How can we help disability advocacy organisations work with a wide range of other organisations with similar aims, such as:

*• disabled people’s organisations (DPOs)*

*The* ***Australian Cross Disability Alliance******(ACDA****) is a great example of organisations working together for the greater good on systemic advocacy. This is helpful to all people with disabilities as well as to government in being able to govern for the one-fifth of people in Australia who have a disability.*

*Using this alliance that covers a broad spectrum of people with disabilities and their joint and several issues as a contact point for small organisations, and single-disability focussed organisations, would work well.*

*Again, funding is an important issue for such an alliance to survive long-term, particularly funding for a full time employee of the alliance and at least a few part time employees to complete data collation, reception, and other administrative duties to maintain the alliance’s effectiveness and efficacy to best serve the needs of people with disability and the organisations that help them.*

*Provide the means for ACDA to hold conferences, forums, and meetings that include other organisations on relevant issues.*

*Disabled people’s organisations, by their very nature, create employment for people with disabilities and this improves the overall situation for people with disabilities.*

*Supporting and funding of the four organisations that make up the alliance is beneficial to all people with disabilities and contributes to the work that the organisations do and to the benefit of Australia as a nation and in keeping with national responsibilities in regard to the* ***UNCRPD****. Such support and funding enables these organisations to develop the means to extend the work they do to include input from the smaller organisations and the single-issue disability organisations.*

*Encourage people with disabilities to join organisations, and in particular the four organisations of the* ***ACDA*** *and provide funding for the development of advertising materials that are accessible to people with disabilities in regards to membership of these organisations.*

*Continue to fund disabled people to attend conferences, forums, and take part in activities organised by disabled person’s organisations. People with disabilities are the least able to afford such events and have extreme costs involved in travel which is blocks participation.*

*Funding which allowed my daughter and I to travel to Melbourne for the recent WWDA forum enabled us to meet other women with disabilities and make important contacts to further create our circles of support that keep us going. Being able to take part in person in events such as AGMs of these organisations and forums conferences and meetings enables us to each develop as women and as people with disabilities. Being able to take part in the strategic planning of the organisations and to meet with important government officials gives us the experience of being actively involved in planning our future and the futures of other women with disabilities.*

*• the Australian Human Rights Commission*

*Enable* ***AHRC*** *to host conferences and forums with disability organisations to focus on human rights issues for people with disabilities and in particular in respect to the* ***UNCRPD.***

*Maintain the position of Disability Rights Commissioner as a separate role. Remembering many people with disabilities are only just beginning to receive the support they need to access advocacy and seek justice. The Disability Rights Commissioner will become busier as the NDIS rolls out. The number of people with disabilities in Australia is in excess of 4 000 000 people. With advances in science and medicine all people are living longer than ever before and many people are living with disability longer than ever before.*

*• Ombudsman organisations*

*The state and commonwealth Ombudsman’s offices need full time disability officer to work within the various units in each office to improve access for, representation of, and as a contact for people with disabilities. A disability officer could then be given the role of liaising with disabled people’s organisations on systemic issues.*

*• aged care advocacy organisations*

*• state disability advocacy organisations*

*• peak bodies?*

*‘Peak body’ is a term used by nearly every organisation and corporation to describe themselves and has little meaning in the present day. A google search of this term returns over 8 000 000 hits.*

4.1 What steps or organisational structures should be put in place to ensure conflicts of interest do not arise, or are minimised?

*Accept that breaches of confidentiality happen everywhere, urban, suburban, rural and remote. Do not expect it to not happen just because there is a policy about that. People with disabilities are particularly subject to breaches of confidentiality because of the widespread levels and many forms of dehumanisation that happen to them. Breaches of confidentiality has deleterious effects on people with disabilities within their community, framing the individual and their disability in particular ways that increases social isolation, loneliness, and disempowerment. So advocacy that is completely internalised in a single community may not be as effective as advocacy that comes from outside a particular community which make satellite services that visit locations around a central location more helpful in some situations and in particular in rural, regional and remote areas.*

*Do not expect one organisation to be able to carry out all kinds of advocacy. Legal and systemic advocacy are very specialised fields and require specific skillsets. It is important to deconstruct the skillsets required for each model of advocacy and understand the level of expertise required for each model.*

*Ie systemic advocacy requires a higher level of tact and diplomacy when advocating to government, departments or corporate bodies.*

*Legal advocacy requires an intimate and professional training in legislation, human rights law, discrimination and criminal law.*

*While knowledge and understanding of these issues is needed for all advocates an individual advocate would not require the same depth of training and knowledge. Many people could work as an advocate quite efficiently in one circumstance but not have the depth of training, knowledge and skills equal to that required in systemic or legal advocacy, so to require every service to provide every kind of advocacy would mean the pool of people from which to draw staff from for the service would be smaller and advocacy positions would remain unfilled. By deconstructing the skillsets of advocates for each field it is possible to see where overlaps can happen while maintaining a larger pool of prospective advocates from which to draw staff.*

*Do not fund or support Service Providers to undertake advocacy work. Service provision and advocacy need to be kept separate to avoid conflicts of interest that can disadvantage people with disability. Service Providers could perceivably use information gained in an advocacy situation to further their own company/corporate needs including unwritten agreements to promote back and forth the need for one another’s service. If an organisation provides, support, accommodation, or other forms of assistance to people with disabilities they cannot and should not be funded for advocacy work because of the obvious conflict of interest.*

4.2 How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?

*Provide more advocacy services with funding to meet the increased need that the NDIS has created.*

*The key to avoiding gaps is to hire highly skilled pre-planners and planners for all people with complex disabilities. Pay these pre-planners a higher rate of pay than other pre-planners to keep them in the position long term and to acknowledge the higher skillset which they must possess.*

*It takes many hours of work to discuss all of the life, aspects and issues for a person with complex disabilities to enable a plan to be worked out. Our pre-planning sessions for my daughter with complex needs are up to the sixth one today and each has been in excess of an hour and some in excess of two hours and I have completed a great deal of background work for the pre-planner and provided them with dozens of pages of information about my daughter, her life, her needs, goals and aspirations.*

*Not all people with complex disabilities have someone in their life willing and able to put in this workload so there needs to be funding for filling this gap with highly skilled pre-planners. This also includes many hours of me talking with my daughter, explaining everything. Having to phrase questions in a yes/no manner to enable her to have her say and to make alterations on her communication app to enable her to make responses that are not yes/no and to explore broader concepts and ideas.*

*To ensure fairness for people with complex disabilities an advocate is needed to work with the pre-planner to achieve the right supports that meet the human rights of the individual with complex disabilities.*

*All up with research about the NDIS and what can and can’t be achieved through it and providing information to pre-planner and meeting with the pre-planner this process has already exceeded 120 hours for me plus the many hours of work the pre-planner has dedicated to the process for one person in preparation for the transition to NDIS.*

*Without me being the driving force behind all of this, my daughter would probably not have had preplanning, her plan would not suit who she is as a person and the NDIS will have achieved next to nothing for her. This highlights the fact that people with complex disabilities will experience huge areas of unmet need via the NDIS without suitable individual advocacy and experienced pre-planning for them, leaving the people with the most need for support and least able to ask for it in situations that make them vulnerable in many ways and amounts to neglect of them and their human rights.*

*A good plan will minimise the need for advocacy for each individual as a good plan will include their needs, goals, aspirations, and will enable them to take part in the broader community and as more and more of that happens across the board in all communities there will be increased awareness of people with disabilities, their needs and how to include and engage with people with disabilities and people with the most complex disabilities will enjoy a safety net of community contacts, increase of relationships with others who would develop concern for them as individuals making them less prone to the vulnerabilities that come with isolation while also giving them opportunities to access advocacy as and when they need it.*

*Fund the National Disability Strategy (NDS) to continue the work of identifying and bridging the gaps.*

4.3 What policies and strategies do we need to protect the rights of people with disability?

*UNCRPD… Every word of it enacted in our laws! Laws being upheld.*

*Training of all public service personnel in disability rights. Training that is developed and delivered by people with disabilities.*

*Training of all public service personnel in the intersections of social justice for people with disability, meeting the need for education of people with disabilities who are from the LGBQTI community, women with disabilities, Aboriginal and Torres Strait islander people with disabilities, CALD people with disabilities and understanding the junctions where these sub-groups of people with disability overlap. Ie an Aboriginal gay man with disabilities, or CALD women with disabilities etc.*

*UNCRPD… No organisational policies that will detract from the rights of people with disabilities to live a full and included life engaged with their families, communities, health and educational facilities and society in general.*

*Advocates to have unhindered access to people with cognitive and communication disabilities even if it is inconvenient for the people who work with them or live with them.*

*Identify gatekeeping strategies that are used and make policies and legislation that will prevent gatekeeping.*

*Stop educating disabled children in segregated facilities. It is not necessary and has lifelong negative effects that cannot be undone. Attending the local school with the local kids is essential in developing relationships with others in your own community and in learning about friendship in your own neighbourhood.*

*While children with disabilities are educated outside their own community and separated in childhood from their sibling, neighbour, and community peers the separateness creates damage that cannot be undone by the process of reaching adulthood.*

*The damage is two-fold. It means that the community you live in hardly knows you exist and does not learn how to include you, engage with you, and has no experience of you as a person of worth and value and thus leaving you to live in isolation from your own neighbours. So you develop no skills in engaging with your community and your community develops no skills in engaging with you.*

*Children with disabilities who are transported out of their local community for schooling are deprived of important recreational and play time because of the length of time spent in transit.*

*Children with disabilities are no more ‘special’ than their age peers without disability and their needs are not ‘special’. This ‘magical’ terminology does serious harms to how children with disabilities see themselves and does harm to them because of how it makes other children view them.*

*The need for education, friendship, appropriate support and equipment is a need all human beings share, there is nothing special about that.*

*All schools should cater to all of the needs of all of the children in their catchment area. This will require some restructuring, it will require more in-depth training to all Department of Education staff and it will require society as a whole to review and learn different ways of thinking about people with disabilities.*

*A child who does not have disabilities that grows up within an education system that includes children who do have disabilities is socially and emotionally better experienced to be an inclusive and engaged adult. Diversity makes us all better people.*

*The loneliness and isolation for people with disabilities who were educated outside of their own community is sometimes never overcome leaving them with a lifetime of loneliness and isolation.*

*The right of a child to education is not met by attending a school that offers ‘special education’ which has become a code for ‘nothing academic’. Education is education and the disabled child’s right is no different to any other child’s right to an education.*

*Many children labelled intellectually disabled are not offered academic instruction at all and thus the label becomes a self-fulfilling prophecy. Some of these children later attain a means of communication that works for them and express a high level of intelligence that was sadly ignored throughout their school years because a label was placed on them in infancy. Give all kids an equal opportunity of learning.*

*There is no such thing as a static person, we all learn throughout our lifetimes and our capacity to learn varies depending on many variables. There is no harm in teaching a child that 2+2=4 if the child cannot understand it but there is a great deal of harm not teaching a child if the child does in fact understand but cannot communicate that understanding. The ability to complete a test is not the purpose of education.*

*You cannot protect the human rights of people who are forced into segregation from childhood. Segregation, not disability makes people vulnerable.*

5.1 What forms of legal review and representation do people with disability need most?

*Guardianship orders made for a lifetime in the past all need to be reviewed, no matter who was appointed as guardian, what was true ten or twenty years ago may no longer be true and the review of such guardianship orders needs to employ the services of individual guardians. No person’s skills, abilities and understandings remain static, we all grow and develop throughout life and this true of people with disabilities including those with complex, and cognitive disability. Ie some people may have been placed in a group home or in the employment in an ADE by a parent who had guardianship of them because at the time that was the most helpful, least restrictive option open but today there are many more options available and these decisions may no longer suit the individual. In keeping with the INCRPD and the Operational Guidelines of the NDIS which place people with disabilities at the centre of their own lives and enable and support them to have choice and control in their own lives the, use of individual guardians becomes a barrier to the individual accessing their right to autonomy.*

*Guardianship of one person over another is not in keeping with the UNCRPD. Each person should have full autonomy.*

*Advocacy in every area.*

*Official visitors to follow up after any legal decision has been reached to support the person with disabilities in understanding the process and the decision and to ensure such decisions are being enacted appropriately.*

*Tenancy and housing issues including but not limited to a need for accessible housing, an issue which could be addressed by legislation requiring all builders to adopt Universal Design principles to the housing that is built and requiring a percentage of residential premises to be built with basic accessible requirements.*

*Homelessness. While the majority of people with a disability are not homeless, it is my experience, from volunteering with two local homelessness services,* ***Mama Lana’s Community Foundation (MLCF)****, Penrith NSW &* ***Hawkesbury Helping Hands (HHH)****, Windsor NSW (which between them cover the Blue Mountains, Penrith and Hawkesbury city areas which is a considerable percentage of the population of NSW) that the majority of homeless people have a disability. For more detailed information from people who are working on the front line with homeless people please contact Lana Borg of MLCF and Linda Strickland of HHH*

5.2 What barriers prevent people with disability from accessing justice?

*Fear of being misunderstood or misrepresented.*

*Fear of authority.*

*Fear of unknown effects of outcomes and not knowing the possible outcomes.*

*Lack of accessible information about justice issues and how to seek reparation of injustices.*

*Communication difficulties that may affect how others judge them and their responses, ie. Maintaining eye contact; becoming nervous or anxious around figures of authority; inability to communicate.*

*Insufficient training of justice officials in the needs of individuals with disability that is delivered by disabled persons’ organisations.*

*Insufficient support to access justice, know about their rights, and enact their rights.*

*People with disability experience barriers in justice when their testimony is disbelieved based on the fact they have a disability, this often occurs because of societal mythology, anecdotal evidence about people with disability and especially people with cognitive and communication disabilities. Ie. “They can’t be trusted”; “They don’t know any better”, “they are a danger” etc.*

*Gatekeeping by either family/carers or service providers which prevents or oversees in a manipulative or censoring way, access to advocacy, legal and other services by the person with disabilities is a barrier to justice.*

*People with disability experience barriers from accessing justice when testimony delivered on their behalf by people who can communicate for them is treated as hearsay, rather than first hand evidence, when in fact the person delivering the communication is carrying out the service of interpretation equal to that of a person who does speak English needing an interpreter to translate from another language into English for a court or other justice system.*

5.3 What models of legal advocacy are most effective?

*I would support a human rights based approach. The Human Rights Commission report “Equal before the Law” (February 2014) discusses all of these legal issues and I would suggest implementing all of the recommendations made in that report in regard to all of the ‘legal’ questions posed.*

Addendum 1,

Cheryl McDonnell

Submission to National Advocacy Program Review.

The purpose of this addendum is to demonstrate the need for advocacy and the lengthy process involved when advocating for a person with complex disabilities. I use these when I advocate for my daughter to ensure she is included in the processes in her life.

Some measures to ensure you are including a person with complex disabilities in the process of advocating for them during NDIS planning are:

1.) Assume competence.

2.) Be aware of gate-keeping. If others come between you and the person you are advocating for and or limit your access to the person you will need to explore ways to minimise gate-keeping behaviours and perhaps set some clear boundaries for the gate-keepers.

3.) Have the person present during meetings and discussions about their life, activities, and future path. Nothing about me without me.

4.) Have an agenda for the meeting and stick to it so that you or other persons can discuss issues ahead of the set day and time to allow for the person to consider their choices. Wherever possible have several meetings to allow time for information processing.

5.) Observe facial expressions, body language, and sounds that are made by the person. Assume all are valid forms of communication and these should be accepted as such.

6.) Refer all questions about the person, to the person themselves and allow a space in time for the person to respond in whichever manner they can before offering other means of communication.

7.) Explore various tools that can be helpful in assisting communication:

a. An Ipad with a yes/no App;

b. a set of answer cards from which to choose;

c. An Ipad with the Tap Speak Sequence App for more comprehensive choices;

d. a series of picture cards that show some of the possibilities of answers (Google images print and laminate); (consider adding a textural cue on each card to help give extra means of identifying one card from another.)

8.) Consider and respect all responses as valid answers. Check responses with another question if the initial response is unclear, however be sure not to be forever clarifying any one point that will only confuse you and the person you are supporting. Let it go and move along.

9.) Give the person opportunities prior to the meeting to experience different options that might be discussed during the meeting. If meeting is broken up into several meetings, some activities can be arranged to explore options and give some experience of other options between meetings. It is hard to communicate what you want when you do not know what options exist or you have no experience of the options.

10.) Give choices to the person that are easy to respond to and that can be built on. Choose between 2 or 3 options at a time. Ie. If working out a weekly routine give two or three options for each different day of the week.

11.) Avoid giving only yes/no options. It is advisable to consider making four answers available, yes, no, not sure, something else.

12.) Make it clear to the person that they are allowed to choose things that are different to what they do now. Discuss how some people like to explore new things and try things they have not done before. Explore the idea that decisions about them need to be made by them.

13.) Make it clear to the person that they can try some new things before deciding. It may need to be arranged for new avenues to be explored prior to the start of meetings. If you suspect these avenues have not been explored, you may need to arrange meetings with possible gate-keepers to find out why it has not been done and how that can be rectified. If you suspect other avenues have not been explored with the person it is unfair on them to continue the meeting until that has been rectified.

14.) Ask for all written materials to be in Easy English and show these to the person as you read the contents to them. Assume understanding. Read in a way that gives space and time for information to be processed.

15.) Collate a list of things the person has been observed not enjoying and have this list at the meetings and discussions.

16.) Collate a list of things the person has been observed enjoying. Have this list in the meetings and discussions.

17.) Identify the skills a person has and collate a list. Skills no matter how incremental are useful to build pathways and will assist in developing other areas. Ie. The ability to grasp a railing may develop into the ability to grasp a paint brush, pen, or baseball bat.

18.) If the person can draw, paint, dance, make music, either with actual materials/instruments or via the use of a device allow them to do this and consider what they create as a contribution to the conversation. Art, Dance and Music are expressions of communication. Accepting communication in all of it forms as valid communication reinforces the sense of having a voice and that voice being important and heard.

19.) Use video as a means of collecting information about the person and also as a part of their own statement for the planner. Video can provide a more relatable means of demonstrating some of the likes, dislikes, and abilities of the person.

20.) Accept you may make some mistakes in understanding the person's communication. Do the best you can anyway.

21.) Ask other people who know the person what their experience of the person is and write that down and have it at the meeting. It is important to include comments and ideas that are different to your own so a variety of information and ideas can be brought to the table.

22.) Do NOT fall into the trap of treating a person as a baby or someone who does not understand. or is younger in intellect than his/her peers. This is harmful and does not allow meaningful same aged peer related programs to be developed for current and future growth. No person remains static. A person with an intellectual disability, communication disability and or complex disabilities has years of life experience. These years of experience count, just as the years of anyone’s life count. It is wrong to think of people as having the mind of a three-year-old unless they are in fact a three-year-old. A person of adult age should always be spoken to as an adult.

23.) Ask other people of the same age/gender what they are doing with their lives and what is important to them. This can be used as a guide and as a means of suggestions to propose.

It will take time and effort to ensure the human rights of people with complex disabilities are respected, supported and implemented but it is our responsibility to do so and to engage people in the lives of people with disabilities who also respect, support and implement their rights.