

NDIS SURVEY 2016-7

RESULTS



DANA

**Disability Advocacy
Network Australia**

Q1. Which best describes your organisation? (Select all that apply)

47 responses



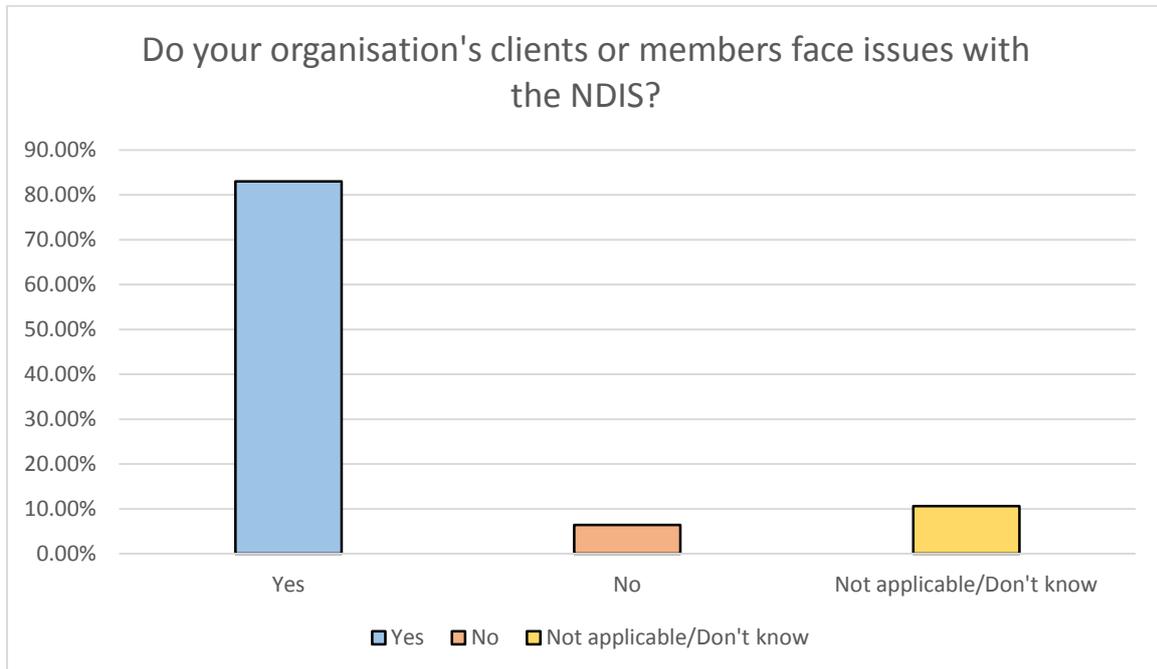
Q2. Where does your organisation provide advocacy? (Select all that apply)

47 responses



Q4. Do your organisation's clients or members face issues with the NDIS?

47 responses



Q5. What are the main problems that your organisation’s members or clients are facing, or will face, with the NDIS?

30 responses – 17 skipped

<i>“Rushed and inadequate planning process.”</i>	
<i>“Complexity of planning”</i>	
<i>“Inconsistencies in plans and funding allocations”</i>	
<i>“Necessary funded items are outside NDIS guidelines (e.g. access to a private vehicle due to behaviours of concern, replacement of broken furniture due to behaviours of concern)”</i>	
<i>“Planning consistency”</i>	
<i>“Reviewing and renegotiating their plans in a timely way.”</i>	
<i>“Very poor plans, a significant number are being reviewed”</i>	
<i>“Underfunded Plans”</i>	
<i>“Lack of flexibility around what the NDIS will provide”</i>	
<i>“Understanding the 12 monthly planning process; Goal setting; how much supports the participant may need if the person has never received supports before to include in the annual plan;”</i>	
<i>“Ability to contribute to the planning process”</i>	
<i>“Inconsistency”</i>	
<i>“More funding needed for quality support coordination in Plans”</i>	
<i>“People with cognitive disability being contacted by phone for brief planning session with no support”</i>	
<i>“Delays in formalising decisions and planning”</i>	
<i>“Planning”</i>	
<i>“Lack of understanding of self-management vs. agency management of funds; where to purchase supports from.”</i>	
<i>“Ending up with only segregated options on their plans”</i>	
<i>“Lack of understanding of self-management and plan management”</i>	
<i>“Plans developed by services”</i>	
<i>“Plans that do not make any sense (many of these); e.g. Funding for ADE's for a person who has been in open employment for 10 years”</i>	
<i>“Complex behavioural needs of some participants inadequately addressed in plan funding”</i>	
<i>“Inexperience of local area coordinators and planners resulting in very poor and inadequate plans with lots of errors”</i>	
<i>“No scrutiny of Service Agreements where the person does not have capacity to understand possible consequences”</i>	
<i>“Planners who do not know the NDIS Act or the NDIA operating guidelines and give people wrong information”</i>	
<i>“Pressure to sign Service Agreements”</i>	
<i>“No eligibility criteria for hearing impaired sector”</i>	
<i>“Hoping to be eligible even though they do not currently get package funds.”</i>	
<i>“Meeting eligibility criteria.”</i>	
<i>“Those aged over 65 being ineligible for the NDIS. This is having an impact on newly injured people over the age of 65 with significant disabilities whose only option is My Aged Care where funding is capped and is not designed to assist people with significant disabilities.”</i>	
<i>“Access and eligibility For new migrants who are not yet diagnosed or on waitlist for diagnosis;”</i>	
<i>“Poor communication from NDIS staff - phone planning meetings are not suitable for everyone and should not be "forced" on those that cannot communicate effectively this way”</i>	
<i>“Accessing information including clarity around items/services funded by NDIS vs State agency”</i>	
<i>“People wanting to know how to register and more information”</i>	
<i>“Language barriers for people from Non-English speaking backgrounds what NDIS might provide; how to access and why?”</i>	
<i>“Unsure about the process when it rolls out”</i>	
<i>“Ability to understand and be informed about NDIS”</i>	
<i>“Difficulties in forming communication links (call centre and generic email address for individual communication)”</i>	
<i>“Lack of accessible and clear information about the NDIS”</i>	
<i>“Lack of knowledge around NDIS”</i>	

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<i>"Information not readily available and easy to access."</i>	
<i>"Lack of correct and efficient simplified information"</i>	
<i>"Not being aware of choices available to meet their needs"</i>	
<i>"Very poor communication, 1800 number, dead email boxes and dead phone numbers"</i>	
<i>"NDIS application process unclear"</i>	
<i>"NDIS communication with participants - all communication forms"</i>	
<i>"Resort to NDIS webpage for service provider information instead of mailed-out brochure containing same information"</i>	
<i>"NDIS appeals process is unclear"</i>	
<i>"The NDIA is not very responsive to queries and participant feedback or clarification. It has been a difficult to seek clarification and answers to specific participant issues."</i>	
<i>"No clarity on who can access the MyGov Portal where the individual cannot do this themselves and do not have a legal guardian"</i>	
<i>"Unclear communication from DSC"</i>	
<i>"Information about the difference between NDIS grants and block funding"</i>	
<i>"Lack of knowledge of what NDIS funding can be used for."</i>	
<i>"Lack of information generally; goalposts keep shifting"</i>	
<i>"Lack of culturally appropriate information about the NDIS"</i>	
<i>"Information about the NDIS eligibility criteria is unclear"</i>	
<i>"Overwhelming number of calls with questions about the NDIS that do not have clear answers (e.g. will the NDIS fund replacement clothing for people who eat their clothing due to Pica?)"</i>	
<i>"Knowing that their Advocate needs to be listed as a Nominee with the NDIS"</i>	
<i>"No access to NDIS for people who are not already in services. NSW Government services unable to respond due to diminished staff and resources"</i>	
<i>"Access to interpreting and translating support"</i>	
<i>"Loss of service/supports"</i>	
<i>"People on the fringes not accessing NDIS due to no outreach"</i>	
<i>"Engaging a service provider"</i>	
<i>"Community access"</i>	
<i>"Lack of service providers in the region"</i>	
<i>"Access to appropriate and adequate supports"</i>	
<i>"Costs associated with remote service provision"</i>	
<i>"Lack of choice about all services due to living in rural areas"</i>	
<i>"Will not try and will just accept low or no service provision"</i>	
<i>"Older person with disability as primary carer of younger person with disability"</i>	
<i>"No informal support"</i>	
<i>"Not being able to verbalise their needs"</i>	
<i>"The process"</i>	
<i>"No assistance for people with cognitive disability to use complex process to apply for NDIS"</i>	
<i>"Young person with disability primary carer for parent with disability"</i>	
<i>"What do they do before the NDIS rolls out"</i>	
<i>"Decision-making"</i>	
<i>"Anxiety navigating NDIS from pre entry – implementation"</i>	
<i>"Lack of skills for families/carers in preparing plan"</i>	
<i>"Implementation complexity"</i>	
<i>"Ability to navigate the NDIS system"</i>	
<i>"Substitute or assisted decision making"</i>	
<i>"Lack of understanding of how to coordinate supports if the supports are being provided by more than one organisation."</i>	
<i>"Constantly changing processes/systems"</i>	
<i>"Not understanding management of own plans"</i>	

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<i>"The changeover from their current ISP's to NDIS may not be the same"</i>	
<i>"Health access"</i>	
<i>"Transport funding support is a particular issue around the country. Some states and territories are removing eligibility for taxi subsidy schemes once they enter the NDIS. This is being inconsistently applied around the country i.e. Tasmania is removing eligibility whilst NSW is maintaining eligibility under taxi subsidy schemes."</i>	
<i>"Equipment-Aids – Who's responsible - NDIS or Health"</i>	
<i>"Lack of interaction between NDIS and child protection"</i>	
<i>"Transport assistance"</i>	
<i>"Transport funding inadequate to cover many Participant's needs"</i>	
<i>"Issue around being in both aged care and disability"</i>	
<i>"Cuts made to other services - health/transport/community services which need to remain and NDIS funds should be adding to/complimenting rather than replacing"</i>	
<i>"Poor performance of Support Coordinators (e.g. difficult to contact, will not represent needs to NDIS)"</i>	
<i>"Lack of expertise in LACs"</i>	
<i>"Competent support workers"</i>	
<i>"Organisations are becoming business models and focused on making money rather than providing quality supports."</i>	
<i>"Lack of independent advocates (i.e. advocates not employed by service providers)"</i>	
<i>"Advocacy not eligible under NDIS"</i>	
<i>"Highly vulnerable people with no advocates at all."</i>	
<i>"Access to advocacy"</i>	
<i>"Reviews have been poorly undertaken"</i>	
<i>"Situations when older parent/carer needs to enter aged care home temporarily or permanently"</i>	
<i>"NDIS unable to respond to crises e.g. need for review of plan to enable person with disability to get bail leading to denial of bail and long period in gaol on remand"</i>	
<i>"Reviews are difficult to obtain and clients reporting that their money has run out."</i>	
<i>"Lack of clarity in review of decision processes"</i>	
<i>"No independent avenue for complaints about quality of NDIS funded services"</i>	
<i>"Inadequate service provision choice or being pressured to stay with service providers they currently have."</i>	
<i>"Lack of due process for people in group homes; the NDIS intake process treating the residents as a group rather than individuals"</i>	
<i>"Forced congregate living"</i>	
<i>"The promise of choice is not delivered through the processes used in NSW"</i>	
<i>"Services being or threatened to be dropped before Plan is in place"</i>	
<i>"Inconsistent funding approaches between states"</i>	
<i>"Self-management is not actually functional, lack of advance payments"</i>	
<i>"Roll out is too slow."</i>	
<i>"Time delays for decisions to be made"</i>	
<i>"Lack of understanding around cultural safety"</i>	
<i>"The [MyGov] portal!"</i>	
<i>"Unrealistic expectations of improvement."</i>	
<i>"Micromanagement, particularly with aids and equipment, and insistence on using OTs"</i>	
<i>"NDIA leadership out of touch with what is happening on the ground"</i>	

Q6. What specific issues in your region, State or Territory are arising from the interaction of the NDIS with the following systems?

34 responses – 13 skipped

System	Responses	Response rate (all participants)	Response rate (Q6 participants)
Aged care	17	36.17%	50.00%
Child protection	13	27.66%	38.24%
Education	11	23.40%	32.35%
Guardianship & administration	11	23.40%	32.35%
Health	17	36.17%	50.00%
Housing/accommodation	19	40.43%	55.88%
Justice	9	19.15%	26.47%
Mental health	12	25.53%	35.29%
Transport	14	29.79%	41.18%
Other (please specify)	11	23.40%	32.35%

Response
AGED CARE:
<i>"Finding information for clients between ages 50 and 65."</i>
<i>"No information being passed onto eligible people under 65."</i>
<i>"Most people in aged care facilities are not entitled to NDIS."</i>
<i>"Clients nearing 65 – will they fall under aged care services, not disability?"</i>
<i>"As stated above, there are many people now locked out of the NDIS due to the eligibility cut-off for those aged 65 and over. Funding allocations under aged care are very limited (Home Care Level IV Package maximum being \$47,000 per annum). Considering many people with significant disabilities will be reliance on this system it will not meet their needs without significant intervention or will entry into aged care facilities."</i>
<i>"Confusion if people can receive both aged care & disability support. DHHS confused and not able to provide adequate guidance."</i>
<i>"More people with disabilities fear that they may end up in the aged care system as a result of the age group roll out in Tasmania. There are a number of people with disabilities who are in their early to mid-60s and want to "age in place" but if they are not NDIS eligible in 2019 what happens to them then?"</i>
<i>"Lack of services."</i>
<i>"Some oldish adults with severe disability only offered aged care."</i>
<i>"Not understanding they have a choice if under 65."</i>
<i>"HACC Meals program was available to younger people with disability but they are no longer eligible under the CHSP."</i>
<i>"People aged 65 having missed the cut off. YPINH."</i>
<i>"Lack of real information."</i>
CHILD PROTECTION:
<i>"Difficulty getting disability services for parents with disability who are not already service users."</i>
<i>"There is potential that the person centred-approach will not always be effectively applied when the child is subject to the NDIS process."</i>
<i>"Uncertainty about interface with disability services."</i>
<i>"Lack of interaction, child removal hasn't reduced, restoration isn't being supported."</i>
<i>"Overload of workers – therefore not enough time is spent on caseloads and mistakes are made."</i>
<i>"Demarcation."</i>
<i>"Are the child's family acting in their best interest or making decisions to suit themselves?"</i>
<i>"It is very difficult (but not impossible) to form working partnerships with Child Safety staff when matching vulnerable children to advocates."</i>
<i>"Parents not getting parenting supports in their plans."</i>
EDUCATION:
<i>"Lack of real information."</i>
<i>"Many schools not informed about NDIS, benefits, guidelines or options, or clarity of who pays for what between health,</i>

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education and NDIA.”
“Standards and policies relating to accessible education.”
“NDIS not being applicable for school supports.”
“Incompatibility of service methods with the education system.”
“Lack of understanding by the participants as to whether the education system or the NDIS would meet the cost of assistive technology; extra supports in the classrooms.”
“Department using funds other than for individual outcomes.”
“Child with disability does not fit with mainstream, too hard for schools to be flexible.”
“Therapists not always having access to schools.”
“What is funded under education and what is now covered under the NDIS?”
“Unclear boundaries between NDIS/education.”
“Lack of real information.”
“GT [Guardianship Tribunal?] having to intervene when NDIS rules do not cover decision-making.”
“Guardianship role and functions in relation to the NDIS.”
“Possible inappropriate referrals to SAT to solve decision issues.”
“The State Trustees are refusing to get involved with the administration of NDIS funding, leaving participants with no access to NDIS funding.”
“Many PwD still haven't heard of the NDIS, so someone else is running their lives for them.”
“3rd parties insisting that they may need a guardian - this is not coming from the OPG (Office of the Public Guardian) in Qld but rather from another Qld Government organisation.”
“Citizen advocates are receiving letters from the Office of the Public Guardian which assume that they are fully briefed and confident to advocate effectively for their protégés as they become participants in the NDIS.”
“Feeling they have to get guardianship to communicate with NDIA on behalf of person.”
“Lack of real information.”
HEALTH:
“ADHC transfer to NGO sector – concurrently with NDIS implementation is massive, with services being cut (see CID position statement).”
“Health V disability interface - and PwD are left without assistance in the middle of it.”
“Unclear what is covered by NDIS and what is [covered by] health.”
“There is an overlap in the service provision between.”
“Hearing health (specifically with CaLD).”
“We've had difficulty getting participants with permanent health conditions like severe arthritis accepted into the NDIS, but then again, we have two different trials of NDIS in WA.”
“People with severe dietary restrictions are denied support for nutritional supplements under the scheme despite having this funding with DHHS.”
“Using NDIS supports in hospitals, we've done some ground-breaking protocol work here.”
“Still having difficulties with access.”
“Waiting lists [are] too long in rural areas.”
“Will health remain a free service or does a person with NDIS plan need to use their funds?”
“The unknown of service delivery, if unexpected hospital stays occur, and the transition back home”
“Interface. Ruling out things they consider health responsibilities.”
“Lack of real information.”
HOUSING/ACCOMODATION:
“Housing shortage - though not NDIS's fault.”
“Huge wait times on home modifications.”
“Different jurisdictional responsibilities between NDIS vs. state agency in out-of-home care funding.”
“Consumers experiencing language or other barriers.”
“Lacking of understanding about the provision of house modifications and [the] confusion that NDIS doesn't provide accessible houses.”
“Is housing covered in NDIS package or separate?”
“Despite the release of Specialised Disability Accommodation guidelines, of themselves the funding and guidelines will not meet the need. There is a significant shortfall in suitable transitional and long-term accommodation options for people with disability. Broad change is needed beyond the group-housing model. Integrated housing models should be looked at and finding ways to fund these projects.”
“There are no viable alternatives yet available for people to leave Shared Supported Accommodation to live in their own

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home.”
“What role does the NDIS play in supporting people to access housing?”
“Forced congregate living.”
“Still having difficulties with access.”
“More ‘institutional’ type care accommodation type settings may prop up as a way for organisations to keep afloat (a good money spinner for them... not so good for the clients!).”
“Not enough affordable housing; waiting lists are too long”
“People in congregated settings forced to remain there”
“The high demand for, and lack of, critical disability housing/accommodation for those under aged-care-facility age”
“Not enough available housing. NDIS forcing people into group living by not giving enough support funds.”
“Lack of real information.”
JUSTICE:
“Justice [is] not informed regarding the NDIS, benefits, guidelines or options.”
“NDIS time frames are too slow to meet the need to satisfy the court that services are available to enable court to make a diversionary order. Much more difficult to get evidence of disability to support a diversionary order. No workable system in place for transition of people from gaol to community. NDIS unable to respond to this. General problem is inability of NDIS to respond to crises.”
“There is no clear provision for assistance in legal.”
“New benefits may flow from NDIS to people engaged with justice.”
“Lack of interaction between NDIS and justice systems, including prison exits.”
“Not enough is explained to people about decisions that have been made.”
“Services and NDIS access for those currently in correctional facilities and what happens to those that may enter. Transitioning out concerns also.”
“Lack of real information.”
MENTAL HEALTH:
“Lack of clarity on demarcation.”
“Providing evidence to enable access to Scheme is often fraught - psychiatrists who will not provide evidence of disability needed, health organisations not releasing documents needed.”
“Unclear eligibility to the NDIS relating to different.”
“Mental health consumers may be drawn into a system based in choice and control.”
“Reluctance by the potential participant to apply for eligibility for the fear of being rejected.”
“NDIS Planners are unclear about how past abuse and neglect creates mental health problems that require considerable funding to manage.”
“Demand of advocacy with few if any organisations available.”
“Lots of unknowns around whether or not some people with mental health condition will be eligible because of the episodic nature of the illness.”
“Not enough services and far too long waiting lists to get case management.”
“Same as under Health but with the added uncertainty on classification and service delivery.”
“Lack of real information.”
TRANSPORT:
“People losing mobility allowances.”
“Organisations previously block-funded used to absorb cost of transport/require nominal fee - now charging 78c/km on top of the support worker/assistance hours.”
“It seems that people will have less access to transport with loss of [the] mobility allowance and [the] taxi subsidy scheme.”
“Mobility allowance is cut from Centrelink.”
“Most participants are happy with the transport allowance but when it's fully rolled out in the regional WA, where there is no public transport available, we expect that lots of issues may come up.”
“...Mobility Allowance changes come in from 2017, tightening the eligibility and aligning it with NDIS eligibility; locking out those with less significant disabilities and also those aged over 65.”
“People with behaviours of concern that have had a private vehicle funded under DHHS are no longer able to put funding towards the cost of running the vehicle despite being unable to travel in a workers car (e.g. is known to smash windows and tear upholstery) or needs specific modifications in the vehicle that make the vehicle their only means of transport (e.g. spit guards, driver protection, seatbelt locks)”

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<i>"Lots of concerns that people will lose their mobility allowance and that there is not enough funds to pay for transport within their package."</i>
<i>"Not enough in rural areas."</i>
<i>"Limited or non-existent."</i>
<i>"Regional, rural, remote and extremely remote funding. Lack of adequate (if any) transport services."</i>
<i>"School transport; mobility allowance; levels of funding."</i>
<i>"Lack of real information."</i>
OTHER (PLEASE SPECIFY):
<i>"Many PwD are concerned that they can't access NDIS until 1 July 2018 and they report that they are told there is no state funding available when they register."</i>
<i>"Will cease providing funding to state advocacy orgs in 2019."</i>
<i>"The simple ability to speak to or contact someone to ask questions."</i>
<i>"Other organisations still haven't got their systems in place, so using someone's funds without consent, not delivering their plan, the CAP debacle!"</i>
<i>"[There] seems to be a lot of 'employment agencies' doing things that aren't within scope such as group outings to cafés, budgeting, etc."</i>
<i>"NDIS not rolled out within this region. Date for rollout set October 2017."</i>
<i>"ATSI peoples and CaLD communities – difficulties within accessing the system are compounded even more."</i>
<i>"Approvals of equipment - the quote process."</i>
<i>"Not rolled out in the Northern Territory."</i>
<i>"Lack of real information."</i>

Q7. What impact are these problems having on your organisation’s members or clients?

Responses:
<i>“Confusion, stress and low expectations of scheme and possibilities.”</i>
<i>“People are very stressed and anxious - particularly with WA trialling two schemes and WA government choosing to roll out a WANDIS with what seems like very little consultation with the PwDs themselves. Families have lost quality supports whilst waiting on reviews of Plans / funding to be allocated from NDIS.”</i>
<i>“Delays in decision-making, frustration and anxiety.”</i>
<i>“Many people are confused about the various NDIS messages, their eligibility and concerned that they may not have their needs met.”</i>
<i>“Consumers are confused, concerned about the future, concerned about their capacity to speak out if planning occurs over the phone.”</i>
<i>“In two words, confusing and stressful.”</i>
<i>“People are uncertain about what will happen in the future. The meals program helps people with disability to stay living on country, which is very important to Aboriginal people in this region.”</i>
<i>“There is an increased need for advocacy support in the pre-planning, application, plan-implementation and appeal stages. NESB consumers will more than likely miss out. NDIS info creates uncertainty as well as confusion as info keeps changing and most of our cohorts are not technically adept and also have language barriers.”</i>
<i>“Confusion around eligibility and what resources can be obtained and what services.”</i>
<i>“Uncertainty Challenges with negotiating with multiple providers.”</i>
<i>“Our clients are expected to have some general knowledge of the disability supports and services in Australia. Most people, who didn't get any supports and services prior to the NDIS, don't know how to access/approach it and are very reluctant. However those that are included as participants are mainly happy with the supports they get.”</i>
<i>“We get a lot of calls and concerns on the above issues. It is still early days in the scheme but no doubt will have a big impact.”</i>
<i>“People give up, they don't want to live and they want to take their own lives. People just accept that no one cares People say it's too hard to fight. People are given different messages about the NDIS, that they are meant to be better off with the scheme but often are not, they see huge reductions in services/supports compared to what they did have in the past. The NDIS makes things almost go backwards for people with disabilities.”</i>
<i>“No impact at this moment – it's not rolled out yet. Concerns are that families are not getting the detailed information they are requesting, and all the forums and 'information' sessions are just attempting to sell them on how wonderful it will be; people can see through this and are leaving more confused as ever.”</i>
<i>“Frustration and poor access.”</i>
<i>“Anger, frustration and a very clear desire to return to State/Territory administered funding.”</i>
<i>“More people are being denied bail and spending longer in gaol on remand. Less diversionary orders because of difficulty of accessing NDIS in reasonable timeframe Some clients disillusioned re NDIS because their experience has not been in line with the rhetoric about NDIS and choice Confusion and anxiety. This is compounded by process for transfer of NSW government services to non-government sector happening at the same time as NDIS roll out.”</i>
<i>“We have around 10 families who have a family member with severe behaviours of concern who have had essential items ruled out by the NDIS (e.g. replacement of a modified vehicle) and are now being forced to take the issues to a formal review. These families are already burned out from ongoing issues with funding, and are extremely distressed about losing funding under the NDIS that makes life bearable for the person with behaviours of concern.”</i>
<i>“Not receiving eligible supports.”</i>
<i>“Disruption, prison, child removal, lack of control and choice, forced congregate living, unwanted guardianship, lack of school supports, exclusion.”</i>
<i>“They are left without support. There is limited service providers in remote areas. The service providers struggle to find support workers and there is a high turnover of support workers.”</i>
<i>“Many of our older clients will not be eligible for the NDIS by the time it rolls out in full. This has been extremely worrying for them as there is a lot of uncertainty about who will pay for their supports into the future, when they are currently funded under disability block funding etc. and have lived in their "group home" for most of their life and wish to remain there.”</i>
<i>“Worry; less holistic service.”</i>
<i>“The difference in response to persons living in family home from those living in congregated (group home) settings. No effort to assist people to move out of congregated settings in their own home even when person or family want this. No acknowledgement of need for transport for people to access ordinary life opportunities - without transport people are left isolated or reliant upon congregated and segregated programs that are life wasting and death-making.”</i>
<i>“It is putting pressure on them to become informed and confident, without them necessarily wanting to do this.”</i>
<i>“Stress; anxiety; not getting needs met.”</i>

Q8. What solution(s) does your organisation see in resolving any of these problems?

Responses:
<i>"WANDIS needs to fund support coordination adequately in plans. WANDIS needs to provide external mechanisms for appealing NDIS decisions. The 1800 call centre personnel need to be upskilled - enabling them to answer basic queries, provide access forms to potential participants etc. Planners who consistently have feedback re their poor communication / people skills need to be either put on training or on probation."</i>
<i>"block funding be made available to organisations to assist participants/carers in transitioning to NDIS"</i>
<i>"In the short term, there is no simple solution. Some of the issues could be teething problems of a new scheme – such as inconsistent funding allocations. However, some issues are protracted – housing – and this will require multidimensional input across government agencies and NGOs."</i>
<i>"Advocacy must be funded as an option for people with NDIS packages."</i>
<i>"Increased access and resourcing to independent advocacy support Clarity around aged care and disability interface Increased access to people to speak to in NDIS / NDIA."</i>
<i>"More flexible limits to planning and funding. Acknowledgement of higher costing. More open view of support models."</i>
<i>"The NDIS and the Aged care funding system need to have a combined bucket of funding for people with disabilities who wish to age in place and are not ready, it is not or willing, or it is not appropriate for them to enter the Aged care system."</i>
<i>"Flexibility from the NDIS about subsidising meals/food (also clothing and swags are items that our clients want) if that is what a client requires to stay living in country."</i>
<i>"More decision support being available; Better information from the NDIA; More capacity building for people; Strategies to upskill mainstream service providers and workers."</i>
<i>"NDIS to slow down the transfer of bulk people from NSW government services to NDIS at the expense of choice and an individualised planning process. NDIS to work collaboratively with justice and advocacy on implementing strategy for arranging access to NDIS before people are ready to leave gaol NDIS to develop urgent response capability and prioritising for people who are in crisis."</i>
<i>"Continue to communicate with NDIS decision-makers at a personalised level."</i>
<i>"Collaboration/partnerships."</i>
<i>"1. Increased funding for independent advocacy 2. Training, on-going information sessions and capacity building."</i>
<i>"Sharing skills in negotiation Offering advocacy when needed Standing beside people in negotiations to witness and support Monitoring trends for systemic reform activities."</i>
<i>"We have been focussing on assisting those most vulnerable and holding discussions with Office of the Adult Guardians regarding the role of advocacy for people with impaired capacity. We are also trying to estimate the number of people this may have an impact to ensure we have sufficient resources to meet the need."</i>
<i>"Success with ongoing negotiations."</i>
<i>"We are working as closely as we can with our regional NDIS Quality and Community Engagement teams to identify and rectify issues before they escalate. This open communication is allowing us to clarify issues and information being passed around our communities and sorting out fact from fiction. Also working with providers and sharing information and lessons learned from our clients and members. Providing any organisation or government department with workshops, in-house training or talks with their staff and clients."</i>
<i>"Some of it requires changes to NDIA practices, some requires changes to communication, some requires a re-set of people's expectations, all require better engagement between NDIA and PWD/advocacy."</i>
<i>"The CaLD strategic plan needs to be completed and implemented."</i>
<i>"The NDIS needs an alternate pathway or guidelines for items that can be funded for people with severe behaviours of concern, rather than asking for each family to justify basic and common sense needs."</i>
<i>"Advance payments would be a start; Child protection getting into the 21st century would be dandy; Governments caring about disability justice issues would be a distinct thing!"</i>
<i>"Better planning and better understanding of the areas people live and what they require; Follow the Disability Act 2006; Ensure people are not worse off under this scheme especially in remote or rural areas."</i>
<i>"A radical change of management which cascades the real purpose of the NDIS throughout the organization and demonstrates a commitment to people with disability. At the moment the main 'feeling' is one of total disrespect!"</i>
<i>"Planning and funding must do what the rhetoric says - give people choice and control in their lives and provide the necessary support to live a full and meaningful life - relevant and appropriate support to live in home of choice, relevant and appropriate transport and support to experience the ordinary and extraordinary fullness of life"</i>
<i>"Reaching all aged car facilities and identifying those with a disability; providing advocacy to register for the NDIS."</i>
<i>"By linking the person with a disability with a citizen advocate we are helping safeguard the person."</i>
<i>"Our citizen advocacy program is now appointing people who will voluntarily provide professional support to our advocates regarding the NDIS. (Advocate Associates)."</i>

Q10. What systemic advocacy for NDIS issues is your organisation involved in?

At a regional level:
<i>"Assisting local governments with developing social and inclusion planning."</i>
<i>"Assisting participants by running workshop, increasing capacity of participants."</i>
<i>"Peer support initiatives to influence the 'demand' side of the NDIS equation."</i>
<i>"Yes."</i>
<i>"NPYWC Reports to the NDIS regarding the needs of our clients and families."</i>
<i>"spreading the word about NDIS Appeals."</i>
At a state level:
<i>"Yes."</i>
<i>"we feedback all NDIS related concerns to PWD WA."</i>
<i>"State level - raising the problems in accessing NDIS for people who have no support. Collecting case examples to raise about the impact we are seeing for people in the justice system."</i>
<i>"provide feedback to state disability plan."</i>
<i>"Liaising with NDIS about concerns of participants and their families."</i>
<i>"Drawing attention to issues manifesting from advocacy and consultations."</i>
<i>"EDAC is part of the WA CaLD strategy reference and provides self-advocacy workshops and living a good life information sessions."</i>
<i>"Taxi subsidies and transport issues around eligibility for such schemes and inconsistencies being applied."</i>
<i>"violence, article 12, parenting, justice, gender equality, article 19 (accommodation), NDIS."</i>
<i>"ACT."</i>
<i>"When asked to contribute."</i>
<i>"regular engagement with NDIA local office."</i>
At a national level:
<i>"Yes."</i>
<i>"Submissions to government on hearing health, joint committee for NDIS, Minister for Health/Education etc."</i>
<i>"Through DANA."</i>
<i>"EDAC is part of the National CaLD reference group."</i>
<i>"As above. Funding allocations for core supports and assistive technology (capital) and how those allocations are being meted out."</i>
<i>"Violence, gender equality, article 12, NDIS (even though I'd rather not)."</i>
<i>"Self-Management, Plan Management, Employment, Transport, etc, etc."</i>
<i>"When asked to contribute."</i>
<i>"We have made a submission to the NDAP review with regards to the future of disability advocacy in the NDIS era."</i>
<i>"We have been on various committees facilitated by the NDIS such as the NDIA Rural, Remote and ATSI Reference Group."</i>
<i>"Current civil society action; trying to resolve secure email/portal/MyGov issues."</i>

Q12. Do you have any example(s) that you can share to help illustrate advocacy making a difference to the outcome for an NDIS participant?

Responses:
<i>"With one of my clients, she felt my advocacy ensured a quicker formulation of planning and approval in order to ensure her son's specialist interventions were funded as soon as reasonably possible after becoming lost in the maze of initially registering her son with the NDIS and identifying which jurisdiction would continue to fund one particular service and how, NDIA contact being lost after that/huge delays in formalising her son's NDIS Funding Plan."</i>
<i>"A young lady with Autism requires a support person so she is able to participate in education and in meetings. We supported her in preparing her plan and she has now been granted her package."</i>
<i>"Attending critical meetings with planners and service providers in order that people are not alone in these dealings. One young woman with complex issues benefitted from support in a planning meeting due to the survey-style model of information gathering that requires concentration and interpretation of questions to provide the best responses. Independent support worked to slow the process down and ensure quality answers, including deferring completion until a later meeting."</i>
<i>"Indigenous person with impaired capacity received excellent package. We provided two advocates to attend the planning meeting one legally trained and one of our ATSI advocates. No doubt package value would not have been achieved without this."</i>
<i>"A family with two children with the same disability, close in age having one plan cut and pasted into the other child's. Expecting to share hours and providers whether both children want to or even like the same workers - grossly inadequate hours i.e., OT assessment for over 80 hrs with a package delivery under 20hrs each. Plan total less than \$25,000 each. 2 x Internal Reviews later and only 3 days off sending in the NDIS Appeal, both plans amended and increased to \$80,000 and \$58,000. Of course there are many relating to participants and their families having no idea how to go about making a plan let alone setting goals. Feeling pressured by current services to stick with them even if someone else could provide a much better service. Having no idea on what a planning meeting is and completely unable to express themselves and being just too overwhelmed to go through changes let alone speak out if the plan is inadequate in any way."</i>
<i>"Working with PwD and their families to test their eligibility for NDIS supports, through the Planning process and ensuring the supports proposed in the Plan are appropriate. Supporting PwD in appealing funding as needed resulting in the support they require. Working with PwD in understanding their Plan and in connecting to a support coordination agency that suits their needs to ensure that they access their funds as soon as possible. Working with NDIS to ensure communication lines remain open and the Participant and their needs are heard."</i>
<i>"We have assisted a number of people to apply for eligibility to NDIS, strongly advocated for a person from trial area to get a review of their NDIS plan to facilitate him getting released from gaol on bail. Managed to get the wait time halved but still there was a 6 week wait."</i>
<i>"Through EDAC's systemic advocacy work, the NDIA at the Perth Hills has agreed to assign an agency staff member and an interpreter to assist a participant from CaLD background to apply for eligibility / access to NDIS."</i>
<i>"Advocate triggered External Merit Review."</i>
<i>"Many of our Advocates are beginning to learn about the NDIS in order to support their client to navigate the system. Without an advocate ensuring and questioning why things are done in certain ways they may potentially end up with a package of care and a plan that has been influenced by others rather than the person in receipt of the supports. Many have also already asked for reviews as the plans are simply not adequate or appropriate."</i>
<i>"Support with internal review so that the person was found eligible for the scheme; support with appeals processes; support with information and advice so the person feels more prepared for the process; providing information on rights, processes etc.; Circumventing the communication barriers and speaking with planners; support at planning meetings to ensure that everything is included reassurance, confidence building."</i>
<i>"Setting up the ID Ref Group - broad impact not individual. Info service would have also helped people."</i>
<i>"The inconsistency in taxi transport subsidies being applied across the country. I.e. some states and territories removing eligibility for new NDIS participants. We wrote directly to the NDIA CEO David Bowen who responded positively to our concerns and raised this issue with the DSS as the coordinating body rolling out the scheme. As to the ultimate effect, who can say? I would have thought the pertinent body to raise this issue would have been the Disability Reform Council at a COAG level."</i>
<i>"NPYWC sought out appropriate Allied Health professionals in the region to provide services for children with disability in the APY Lands as our families were unable to do this for themselves we also supported those Allied Health professionals to ensure they work in a culturally appropriate manner."</i>

Q13. Do you have any further comments about disability advocacy and the NDIS?

Response
<i>"A more coordinated systemic advocacy might be beneficial given the shemozzle NDIA is in. Also, need to be strategic in approach to NDIA as they don't seem to talk to each other!"</i>
<i>"It is crucial - particularly with the extra degree of uncertainty in WA - that DA continues to be funded - and that external appeals are funded under the WANDIS."</i>
<i>"Due to the increased difficulty of accessing services and NDIS, we are needing to divert resources from advocacy into assisting isolated clients to apply for eligibility to NDIS."</i>
<i>"Advocacy is a productive and measurable benefit for those parents who seek clarity and a more time-efficient process of being provided with a Funding Plan following NDIS registration; having decisions clarified and overturned; and ensuring they exercise their rights on behalf of the child as registrant, to accessing the Scheme in a more efficient and less stressful (and exhausting) manner."</i>
<i>"In WA, the conversion of LAC roles to NDIS planners has removed a quasi advocate from the equation and left families and individuals alone in the planning process. Independent third parties in meeting processes are critical and serve an array of purposes, including witnessing the conduct of the planners and providers, recording critical information, reducing the stress of meetings, providing a means for advocates to see interactions first hand in order to use this information for reform activities. This new resource distribution system is cumbersome and wasteful in many respects, not certain to deliver resources down at the human and family level. Disability advocacy over the next 5-10 years will be critical to agitation for poor processes to be improved and individual voices to be heard. The amalgamation of smaller services into bigger corporate systems risks becoming a drain on the limited NDIS reserves without delivering substantial improvements or greater coverage of the new system to more individuals and families. Robust, independent systemic advocacy is an accountability check on poor policy and processes that ultimately benefits the entire community through ensuring best value for money for consumers and the public purse."</i>
<i>"Individual advocacy alone doesn't help recurring issues that impact on large number of participants. Systemic advocacy work needs to be better resourced to overcome systemic issues."</i>
<i>"We would like to have regular national links to other advocacy agencies to ensure the NDAP funded agencies are providing consistent models or support and feedback to DSS & NDIA."</i>
<i>"Only that as more people enter the NDIS – new and existing clients from state funded services – the need for advocacy will certainly increase and also it would be helpful if the NDIA were a little more responsive to feedback and concerns. It's not necessarily about money or funding but an understanding of individual need."</i>
<i>"We need to keep having open dialogue and finding collective measures to support advocacy to play a key role in NDIS."</i>
<i>"They just don't get it. We also struggle with the lack of consistency by the Agency."</i>
<i>"This is absolutely essential."</i>
<i>"DSC it is hard to find eligibility and policy details on the DSC website. There should be an area where all support and advocacy workers can access more details around eligibility, application and appeal process."</i>
<i>"When the NDIS first rolled out there was much hope and excitement for people with disabilities that they would finally receive the support that they needed, and initially many people who had their plan completed appeared to have received great quality packages that were person centred etc. Without advocacy involvement it appears we may be fighting again for people's basic rights to receive adequate supports as the NDIS makes further and further cut backs. You have to wonder whether or not it is creating more gaps than filling them..."</i>
<i>"Disability Advocacy is needed to navigate and support those people who have not been heard and their services or supports have been reduced."</i>
<i>"The NDIS appears to have created some confusion among our clients. Information is provided however the full impact the NDIS will have on our community will not be realised until the roll out date of the scheme in October 2017"</i>
<i>"Our organisation advocates for people who do not currently have any supports or services and are not on any lists so are therefore not in any head count for the rollouts. we respond to complexity and vulnerability and all of the people we advocate for are likely to be eligible</i>
<i>"We have just learned that if a participant has an advocate and they want them kept apprised on what is happening in relation to planning, Advocates need to be listed as a Nominee, much link with Centrelink. And it is up to the Participant and/or Guardian to notify the advocate of any planning meetings. A fact we found out the hard way when two clients had their planning meetings held without us."</i>
<i>"The NDIA is not interested at all in promoting the role of independent advocates or individual advocacy in safeguarding NDIS participants."</i>
<i>"Advocacy on other issues is at risk of being pushed aside because demand for NDIS advocacy is so high."</i>

The following comments were made in response to a survey about the “unmet need for advocacy”. We have selected the responses related to the NDIS and presented them here.

“For people with intellectual disability who are living independently and who are about to seek NDIS funding it is essential for local knowledge and specific understanding of how to assist people with intellectual disability in a ‘Way which makes most sense to them’”

“The outcome for people with disability and their families/carers depends on what models of advocacy is funded and available in their local area. Unfortunately, both states and Federal Government funds specific organisation for a specific advocacy model. specialist, independent advocacy services in each state and territory are not appropriately resourced to provide self-advocacy support, individual advocacy, legal advocacy and systemic advocacy to people with disability and information on the importance and value in participating in the NDIS to get continuous supports and services to meet each individual’s and their families/carers specific needs. This is evident in the current NDAP funding model, because no single NDAP agency is funded for all models of advocacy. This is a concern for CaLD people with disability who may present multiple unmet advocacy needs –subsequently with multiple challenges and poor advocacy outcome.”

“Our organisation find ourselves doing a lot of advocacy with families around inclusive education and problems entering the NDIS”

“The introduction of the NDIS has seen a significant increase to the demand on services already in the first 5 months of the roll out in Queensland.”

“We have an extensive data base on calls and where they rank. Services were not mentioned and they rank very highly with an extra layer of the NDIS. We are starting to see a peak in calls that relate to services and the NDIS.”

- ➔ Education – 1
- ➔ Discrimination/rights – 2
- ➔ Housing/accommodation – 3

The following comments are in response to the question “who are you most worried about?”

“People with intellectual disability who have profound, severe and multiple disability and are unable to indicate what their needs are. Particularly those people who live in congregation arrangements and are to be “moved across” to NDIS funded arrangements. It is essential that they are offered the opportunity to have individual advocacy by local disability specific orgs who know them well or which can assist their family, friends or those who know them well to get the best result for them from the NDIS.”

“People who are unable to articulate their needs and people with intellectual disability or cognitive disability needing further support to understand complex systems like NDIS.”

“I recently attended a forum on violence, abuse and neglect against people with disability, staged by the NSW Ombudsman. This all day event had many speakers but apart from IDRS, none from the disability advocacy organisations (PWD, WWDA, etc.). The NSW Ombudsman is experienced at excluding disability advocacy organisations. It also excels at putting out chest beating comms but therein lies the problem - the huge disconnect between rhetoric and reality. So much of what is said in the disability field nowadays speaks to the principles of the CPRD, CAT, etc. but the practice remains that people with disability and especially those whose support needs are the highest and most complex, remain at grave risk of harm. This can only get worse as the NDIA takes the lead role in overseeing the 'safeguarding' regime.”

“Those in “State Care” today because all indicators are they will be our most needy in the years to come. Also the ATSI population with the roll out of the NDIS as they aren't culturally represented, won't be heard by the agencies & therefore will be thought to be “not complaining” & will simply go away to live poorly & die even earlier.”

“Those clients that are not eligible for NDIS.”

“I know this might sound clichéd but the amount of trauma we have witnessed from people who have already transitioned to the NDIS is staggering and to the point of hopelessness and despair. We are very concerned about all issues of course but our work at the moment in this area is quite confronting.”

“Families that do not understand their rights and get squashed by 'professionals' and 'experts' in the education, employment and NDIS systems.”

The following comments are in response to the question “do you have any examples or stories that you can share to help illustrate the unmet need for advocacy?”

“We are receiving calls daily with requests for assistance to prepare for the NDIS, to attend their planning meeting, to sign Service Agreements where the person cannot consent, and to support people through a formal review process. We cannot provide individual advocacy for every request because we have not been provided with additional individual advocacy funding to manage the influx of calls. I believe this will only get worse as the roll out continues across Victoria.”

“Recently the local NDIA office advised support coordinators that they are not to advocate on behalf of their clients back to the NDIA if there is a problem with the plan. That they should leave this to advocacy services. However we know that if we were to do all this work we would have no time to advocate on any other topic.”

The following comments are in response to the question “do you have any further comments about unmet need for advocacy, or gaps in the provision of advocacy?”

“I think we are at a really critical point in the lack of resourcing to advocacy in the sector and especially with NDIS being rolled out.”

“Service providers will become default advocates for many people with disabilities seeking to be participants in the NDIS. These organisations are clearly not independent, as they have a vested interest in retaining their clients.”

APPENDIX.

1.1 QUESTION 5 – CATEGORISED BY THEMES

Issue(s) with planning

Response	
<i>"Rushed and inadequate planning process."</i>	
<i>"Complexity of planning"</i>	
<i>"Inconsistencies in plans and funding allocations"</i>	
<i>"Necessary funded items are outside NDIS guidelines (e.g. access to a private vehicle due to behaviours of concern, replacement of broken furniture due to behaviours of concern)"</i>	
<i>"Planning consistency"</i>	
<i>"Reviewing and renegotiating their plans in a timely way."</i>	
<i>"Very poor plans, a significant number are being reviewed"</i>	
<i>"Underfunded Plans"</i>	
<i>"Lack of flexibility around what the NDIS will provide"</i>	
<i>"Understanding the 12 monthly planning process; Goal setting; how much supports the participant may need if the person has never received supports before to include in the annual plan;"</i>	
<i>"Ability to contribute to the planning process"</i>	
<i>"Inconsistency"</i>	
<i>"More funding needed for quality support coordination in Plans"</i>	
<i>"People with cognitive disability being contacted by phone for brief planning session with no support"</i>	
<i>"Delays in formalising decisions and planning"</i>	
<i>"Planning"</i>	
<i>"Lack of understanding of self-management vs. agency management of funds; where to purchase supports from."</i>	
<i>"Ending up with only segregated options on their plans"</i>	
<i>"Lack of understanding of self-management and plan management"</i>	
<i>"Plans developed by services"</i>	
<i>"Plans that do not make any sense (many of these); e.g. Funding for ADE's for a person who has been in open employment for 10 years"</i>	
<i>"Complex behavioural needs of some participants inadequately addressed in plan funding"</i>	
<i>"Inexperience of local area coordinators and planners resulting in very poor and inadequate plans with lots of errors"</i>	
<i>"No scrutiny of Service Agreements where the person does not have capacity to understand possible consequences"</i>	
<i>"Planners who do not know the NDIS Act or the NDIA operating guidelines and give people wrong information"</i>	
<i>"Pressure to sign Service Agreements"</i>	

Issue(s) with eligibility

Response	
<i>"No eligibility criteria for hearing impaired sector"</i>	
<i>"Hoping to be eligible even though they do not currently get package funds."</i>	
<i>"Meeting eligibility criteria."</i>	
<i>"Those aged over 65 being ineligible for the NDIS. This is having an impact on newly injured people over the age of 65 with significant disabilities whose only option is My Aged Care where funding is capped and is not designed to assist people with significant disabilities."</i>	
<i>"Access and eligibility For new migrants who are not yet diagnosed or on waitlist for diagnosis;"</i>	

Access to information (inc. NDIA communication issues)

Response	

Disability Advocacy Network Australia – NDIS Survey 2016-7 – Results

"Poor communication from NDIS staff - phone planning meetings are not suitable for everyone and should not be "forced" on those that cannot communicate effectively this way"	
"Accessing information including clarity around items/services funded by NDIS vs State agency"	
"People wanting to know how to register and more information"	
"Language barriers for people from Non-English speaking backgrounds what NDIS might provide; how to access and why?"	
"Unsure about the process when it rolls out"	
"Ability to understand and be informed about NDIS"	
"Difficulties in forming communication links (call centre and generic email address for individual communication)"	
"Lack of accessible and clear information about the NDIS"	
"Lack of knowledge around NDIS"	
"Information not readily available and easy to access."	
"Lack of correct and efficient simplified information"	
"Not being aware of choices available to meet their needs"	
"Very poor communication, 1800 number, dead email boxes and dead phone numbers"	
"NDIS application process is unclear"	
"NDIS communication with participants - all communication forms"	
"Resort to NDIS webpage for service provider information instead of mailed-out brochure containing same information"	
"NDIS appeals process is unclear"	
"The NDIA is not very responsive to queries and participant feedback or clarification. It has been a difficult to seek clarification and answers to specific participant issues."	
"No clarity on who can access the MyGov Portal where the individual cannot do this themselves and do not have a legal guardian"	
"Unclear communication from DSC"	WA
"Information about the difference between NDIS grants and block funding"	
"Lack of knowledge of what NDIS funding can be used for."	
"Lack of information generally; goalposts keep shifting"	
"Lack of culturally appropriate information about the NDIS"	
"Information about the NDIS eligibility criteria is unclear"	
"Overwhelming number of calls with questions about the NDIS that do not have clear answers (e.g. will the NDIS fund replacement clothing for people who eat their clothing due to Pica?)"	
"Knowing that their Advocate needs to be listed as a Nominee with the NDIS"	

Access to services and community (service availability)

Response	
"No access to NDIS for people who are not already in services. NSW Government services unable to respond due to diminished staff and resources"	
"Access to interpreting and translating support"	
"Loss of service/supports"	
"People on the fringes not accessing NDIS due to no outreach"	
"Engaging a service provider"	
"Community access"	
"Lack of service providers in the region"	
"Access to appropriate and adequate supports"	
"Costs associated with remote service provision"	
"Lack of choice about all services due to living in rural areas"	
"Will not try and will just accept low or no service provision"	

Help to understand and navigate the system

Response	
<i>"Older person with disability as primary carer of younger person with disability"</i>	
<i>"No informal support"</i>	
<i>"Not being able to verbalise their needs"</i>	
<i>"The process"</i>	
<i>"No assistance for people with cognitive disability to use complex process to apply for NDIS"</i>	
<i>"Young person with disability primary carer for parent with disability"</i>	
<i>"What do they do before the NDIS rolls out"</i>	
<i>"Decision-making"</i>	
<i>"Anxiety navigating NDIS from pre entry – implementation"</i>	
<i>"Lack of skills for families/carers in preparing plan"</i>	
<i>"Implementation complexity"</i>	
<i>"Ability to navigate the NDIS system"</i>	
<i>"Substitute or assisted decision making"</i>	
<i>"Lack of understanding of how to coordinate supports if the supports are being provided by more than one organisation."</i>	
<i>"Constantly changing processes/systems"</i>	
<i>"Not understanding management of own plans"</i>	
<i>"The changeover from their current ISP's to NDIS may not be the same"</i>	

Boundaries between NDIS and other systems (e.g. education, health, transport)

Response	
<i>"Health access"</i>	
<i>"Transport funding support is a particular issue around the country. Some states and territories are removing eligibility for taxi subsidy schemes once they enter the NDIS. This is being inconsistently applied around the country i.e. Tasmania is removing eligibility whilst NSW is maintaining eligibility under taxi subsidy schemes."</i>	
<i>"Equipment-Aids – Who's responsible - NDIS or Health"</i>	
<i>"Lack of interaction between NDIS and child protection"</i>	
<i>"Transport assistance"</i>	
<i>"Transport funding inadequate to cover many Participant's needs"</i>	
<i>"Issue around being in both aged care and disability"</i>	
<i>"Cuts made to other services - health/transport/community services which need to remain and NDIS funds should be adding to/complimenting rather than replacing"</i>	

Issue(s) with NDIS-funded services

Response	
<i>"Poor performance of Support Coordinators (e.g. difficult to contact, will not represent needs to NDIS)"</i>	
<i>"Lack of expertise in LACs"</i>	
<i>"Competent support workers"</i>	
<i>"Organisations are becoming business models and focused on making money rather than providing quality supports."</i>	

Advocacy and NDIS

Response	
<i>"Lack of independent advocates (i.e. advocates not employed by service providers)"</i>	
<i>"Advocacy not eligible under NDIS"</i>	
<i>"Highly vulnerable people with no advocates at all."</i>	
<i>"Access to advocacy"</i>	

Reviews and appeals (crises response)

Response	
<i>"Reviews have been poorly undertaken"</i>	
<i>"Situations when older parent/carer needs to enter aged care home temporarily or permanently"</i>	
<i>"NDIS unable to respond to crises e.g. need for review of plan to enable person with disability to get bail leading to denial of bail and long period in gaol on remand"</i>	
<i>"Reviews are difficult to obtain and clients reporting that their money has run out."</i>	
<i>"Lack of clarity in review of decision processes"</i>	
<i>"No independent avenue for complaints about quality of NDIS funded services"</i>	

Choice and control

Response	
<i>"Inadequate service provision choice or being pressured to stay with service providers they currently have."</i>	
<i>"Lack of due process for people in group homes; the NDIS intake process treating the residents as a group rather than individuals"</i>	
<i>"Forced congregate living"</i>	
<i>"The promise of choice is not delivered through the processes used in NSW"</i>	

State disability systems

Response	
<i>"Services being or threatened to be dropped before Plan is in place"</i>	
<i>"Inconsistent funding approaches between states"</i>	

Issues with NDIA/S's system(s)

Response	
<i>"Self-management is not actually functional, lack of advance payments"</i>	
<i>"Roll out is too slow."</i>	
<i>"Time delays for decisions to be made"</i>	
<i>"Lack of understanding around cultural safety"</i>	
<i>"The [MyGov] portal!"</i>	
<i>"Unrealistic expectations of improvement."</i>	
<i>"Micromanagement, particularly with aids and equipment, and insistence on using OTs"</i>	
<i>"NDIA leadership out of touch with what is happening on the ground"</i>	

2.1 QUESTION 7 – CATEGORISED BY THEMES

Q7. What impact are these problems having on your organisation’s members or clients?

Anxiety/stress/worry

Response	
<i>"Confusion, stress and low expectations of scheme and possibilities."</i>	
<i>"People are very stressed and anxious - particularly with WA trialling two schemes and WA government choosing to roll out a WANDIS with what seems like very little consultation with the PwDs themselves. Families have lost quality supports whilst waiting on reviews of Plans / funding to be allocated from NDIS."</i>	
<i>"More people are being denied bail and spending longer in gaol on remand. Less diversionary orders because of difficulty of accessing NDIS in reasonable timeframe Some clients disillusioned re NDIS because their experience has not been in line with the rhetoric about NDIS and choice Confusion and anxiety. This is compounded by process for transfer of NSW government services to non-government sector happening at the same time as NDIS roll out."</i>	
<i>"Delays in decision-making, frustration and anxiety."</i>	
<i>"Many people are confused about the various NDIS messages, their eligibility and concerned that they may not have their needs met."</i>	
<i>"We have around 10 families who have a family member with severe behaviours of concern who have had essential items ruled out by the NDIS (e.g. replacement of a modified vehicle) and are now being forced to take the issues to a formal review. These families are already burned out from ongoing issues with funding, and are extremely distressed about losing funding under the NDIS that makes life bearable for the person with behaviours of concern."</i>	
<i>"Consumers are confused, concerned about the future, concerned about their capacity to speak out if planning occurs over the phone."</i>	
<i>"Many of our older clients will not be eligible for the NDIS by the time it rolls out in full. This has been extremely worrying for them as there is a lot of uncertainty about who will pay for their supports into the future, when they are currently funded under disability block funding etc. and have lived in their "group home" for most of their life and wish to remain there."</i>	
<i>"Worry; less holistic service."</i>	
<i>"In two words, confusing and stressful."</i>	
<i>"It is putting pressure on them to become informed and confident, without them necessarily wanting to do this."</i>	
<i>"People are uncertain about what will happen in the future. The meals program helps people with disability to stay living on country, which is very important to Aboriginal people in this region."</i>	
<i>"Stress; anxiety; not getting needs met."</i>	

Confusion/uncertainty

Response	
<i>"Confusion, stress and low expectations of scheme and possibilities."</i>	
<i>"More people are being denied bail and spending longer in gaol on remand. Less diversionary orders because of difficulty of accessing NDIS in reasonable timeframe Some clients disillusioned re NDIS because their experience has not been in line with the rhetoric about NDIS and choice Confusion and anxiety. This is compounded by process for transfer of NSW government services to non-government sector happening at the same time as NDIS roll out."</i>	
<i>"There is an increased need for advocacy support in the pre-planning, application, plan-implementation and appeal stages. NESB consumers will more than likely miss out. NDIS info creates uncertainty as well as confusion as info keeps changing and most of our cohorts are not technically adept and also have language barriers."</i>	
<i>"Confusion around eligibility and what resources can be obtained and what services."</i>	
<i>"Uncertainty Challenges with negotiating with multiple providers."</i>	
<i>"Our clients are expected to have some general knowledge of the disability supports and services in Australia. Most people, who didn't get any supports and services prior to the NDIS, don't know how to access/approach it and are very reluctant. However those that are included as participants are mainly happy with the supports they get."</i>	
<i>"Many people are confused about the various NDIS messages, their eligibility and concerned that they may not have their needs met."</i>	
<i>"We get a lot of calls and concerns on the above issues. It is still early days in the scheme but no doubt will have a big impact."</i>	
<i>"We have around 10 families who have a family member with severe behaviours of concern who have had essential items ruled out by the NDIS (e.g. replacement of a modified vehicle) and are now being forced to take the issues to a formal review. These families are already burned out from ongoing issues with funding, and are extremely distressed about losing funding under the NDIS that makes life bearable for the person with behaviours of concern."</i>	

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<i>"Consumers are confused, concerned about the future, concerned about their capacity to speak out if planning occurs over the phone."</i>	
<i>"Many of our older clients will not be eligible for the NDIS by the time it rolls out in full. This has been extremely worrying for them as there is a lot of uncertainty about who will pay for their supports into the future, when they are currently funded under disability block funding etc. and have lived in their "group home" for most of their life and wish to remain there."</i>	
<i>"People give up, they don't want to live and they want to take their own lives. People just accept that no one cares. People say it's too hard to fight. People are given different messages about the NDIS, that they are meant to be better off with the scheme but often are not, they see huge reductions in services/supports compared to what they did have in the past. The NDIS makes things almost go backwards for people with disabilities."</i>	
<i>"In two words, confusing and stressful."</i>	
<i>"No impact at this moment – it's not rolled out yet. Concerns are that families are not getting the detailed information they are requesting, and all the forums and 'information' sessions are just attempting to sell them on how wonderful it will be; people can see through this and are leaving more confused as ever."</i>	

Frustration/anger

Response	
<i>"Delays in decision-making, frustration and anxiety."</i>	
<i>"Frustration and poor access."</i>	
<i>"People give up, they don't want to live and they want to take their own lives. People just accept that no one cares. People say it's too hard to fight. People are given different messages about the NDIS, that they are meant to be better off with the scheme but often are not, they see huge reductions in services/supports compared to what they did have in the past. The NDIS makes things almost go backwards for people with disabilities."</i>	
<i>"Anger, frustration and a very clear desire to return to State/Territory administered funding."</i>	

Longer wait times

Response	
<i>"People are very stressed and anxious - particularly with WA trialling two schemes and WA government choosing to roll out a WANDIS with what seems like very little consultation with the PwDs themselves. Families have lost quality supports whilst waiting on reviews of Plans / funding to be allocated from NDIS."</i>	
<i>"More people are being denied bail and spending longer in gaol on remand. Less diversionary orders because of difficulty of accessing NDIS in reasonable timeframe. Some clients disillusioned re NDIS because their experience has not been in line with the rhetoric about NDIS and choice. Confusion and anxiety. This is compounded by process for transfer of NSW government services to non-government sector happening at the same time as NDIS roll out."</i>	
<i>"Delays in decision-making, frustration and anxiety."</i>	
<i>"We have around 10 families who have a family member with severe behaviours of concern who have had essential items ruled out by the NDIS (e.g. replacement of a modified vehicle) and are now being forced to take the issues to a formal review. These families are already burned out from ongoing issues with funding, and are extremely distressed about losing funding under the NDIS that makes life bearable for the person with behaviours of concern."</i>	

Loss of/lack of support(s)

Response	
<i>"People are very stressed and anxious - particularly with WA trialling two schemes and WA government choosing to roll out a WANDIS with what seems like very little consultation with the PwDs themselves. Families have lost quality supports whilst waiting on reviews of Plans / funding to be allocated from NDIS."</i>	
<i>"Not receiving eligible supports."</i>	
<i>"There is an increased need for advocacy support in the pre-planning, application, plan-implementation and appeal stages. NESB consumers will more than likely miss out. NDIS info creates uncertainty as well as confusion as info keeps changing and most of our cohorts are not technically adept and also have language barriers."</i>	
<i>"Our clients are expected to have some general knowledge of the disability supports and services in Australia. Most people, who didn't get any supports and services prior to the NDIS, don't know how to access/approach it and are very reluctant. However those that are included as participants are mainly happy with the supports they get."</i>	
<i>"We have around 10 families who have a family member with severe behaviours of concern who have had essential items ruled out by the NDIS (e.g. replacement of a modified vehicle) and are now being forced to take the issues to a formal review. These families are already burned out from ongoing issues with funding, and are extremely distressed"</i>	

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<i>about losing funding under the NDIS that makes life bearable for the person with behaviours of concern."</i>	
<i>"Disruption, prison, child removal, lack of control and choice, forced congregate living, unwanted guardianship, lack of school supports, exclusion."</i>	
<i>"Frustration and poor access."</i>	
<i>"They are left without support. There is limited service providers in remote areas. The service providers struggle to find support workers and there is a high turnover of support workers."</i>	
<i>"Many of our older clients will not be eligible for the NDIS by the time it rolls out in full. This has been extremely worrying for them as there is a lot of uncertainty about who will pay for their supports into the future, when they are currently funded under disability block funding etc. and have lived in their "group home" for most of their life and wish to remain there."</i>	
<i>"People give up, they don't want to live and they want to take their own lives. People just accept that no one cares. People say it's too hard to fight. People are given different messages about the NDIS, that they are meant to be better off with the scheme but often are not, they see huge reductions in services/supports compared to what they did have in the past. The NDIS makes things almost go backwards for people with disabilities."</i>	
<i>"Worry; less holistic service."</i>	
<i>"The difference in response to persons living in family home from those living in congregated (group home) settings. No effort to assist people to move out of congregated settings in their own home even when person or family want this. No acknowledgement of need for transport for people to access ordinary life opportunities - without transport people are left isolated or reliant upon congregated and segregated programs that are life wasting and death-making."</i>	
<i>"It is putting pressure on them to become informed and confident, without them necessarily wanting to do this."</i>	
<i>"Stress; anxiety; not getting needs met."</i>	

3.1 QUESTION 8 – CATEGORISED BY THEMES

Q8. What solution(s) does your organisation see in resolving any of these problems?

Funding

Response	
<i>"WANDIS needs to fund support coordination adequately in plans. WANDIS needs to provide external mechanisms for appealing NDIS decisions. The 1800 call centre personnel need to be upskilled - enabling them to answer basic queries, provide access forms to potential participants etc. Planners who consistently have feedback re their poor communication / people skills need to be either put on training or on probation."</i>	
<i>"block funding be made available to organisations to assist participants/carers in transitioning to NDIS"</i>	
<i>"In the short term, there is no simple solution. Some of the issues could be teething problems of a new scheme – such as inconsistent funding allocations. However, some issues are protracted – housing – and this will require multidimensional input across government agencies and NGOs."</i>	
<i>"Advocacy must be funded as an option for people with NDIS packages."</i>	
<i>"Increased access and resourcing to independent advocacy support Clarity around aged care and disability interface Increased access to people to speak to in NDIS / NDIA."</i>	
<i>"More flexible limits to planning and funding. Acknowledgement of higher costing. More open view of support models."</i>	
<i>"The NDIS and the Aged care funding system need to have a combined bucket of funding for people with disabilities who wish to age in place and are not ready, it is not or willing, or it is not appropriate for them to enter the Aged care system."</i>	
<i>"Flexibility from the NDIS about subsidising meals/food (also clothing and swags are items that our clients want) if that is what a client requires to stay living in country."</i>	

Increased collaboration/communication

Response	
<i>"More decision support being available; Better information from the NDIA; More capacity building for people; Strategies to upskill mainstream service providers and workers."</i>	
<i>"WANDIS needs to fund support coordination adequately in plans. WANDIS needs to provide external mechanisms for appealing NDIS decisions. The 1800 call centre personnel need to be upskilled - enabling them to answer basic queries, provide access forms to potential participants etc. Planners who consistently have feedback re their poor communication / people skills need to be either put on training or on probation."</i>	
<i>"NDIS to slow down the transfer of bulk people from NSW government services to NDIS at the expense of choice and an individualised planning process. NDIS to work collaboratively with justice and advocacy on implementing strategy for arranging access to NDIS before people are ready to leave gaol NDIS to develop urgent response capability and prioritising for people who are in crisis."</i>	
<i>"Continue to communicate with NDIS decision-makers at a personalised level."</i>	
<i>"Collaboration/partnerships."</i>	
<i>"1. Increased funding for independent advocacy 2. Training, on-going information sessions and capacity building."</i>	
<i>"Sharing skills in negotiation Offering advocacy when needed Standing beside people in negotiations to witness and support Monitoring trends for systemic reform activities."</i>	
<i>"We have been focussing on assisting those most vulnerable and holding discussions with Office of the Adult Guardians regarding the role of advocacy for people with impaired capacity. We are also trying to estimate the number of people this may have an impact to ensure we have sufficient resources to meet the need."</i>	
<i>"In the short term, there is no simple solution. Some of the issues could be teething problems of a new scheme – such as inconsistent funding allocations. However, some issues are protracted – housing – and this will require multidimensional input across government agencies and NGOs."</i>	
<i>"Success with ongoing negotiations."</i>	
<i>"We are working as closely as we can with our regional NDIS Quality and Community Engagement teams to identify and rectify issues before they escalate. This open communication is allowing us to clarify issues and information being passed around our communities and sorting out fact from fiction. Also working with providers and sharing information and lessons learned from our clients and members. Providing any organisation or government department with workshops, in-house training or talks with their staff and clients."</i>	
<i>"Some of it requires changes to NDIA practices, some requires changes to communication, some requires a re-set of people's expectations, all require better engagement between NDIA and PWD/advocacy."</i>	

Systemic change

Response	S
<i>"More decision support being available; Better information from the NDIA; More capacity building for people; Strategies to upskill mainstream service providers and workers."</i>	
<i>"NDIS to slow down the transfer of bulk people from NSW government services to NDIS at the expense of choice and an individualised planning process. NDIS to work collaboratively with justice and advocacy on implementing strategy for arranging access to NDIS before people are ready to leave gaol NDIS to develop urgent response capability and prioritising for people who are in crisis."</i>	
<i>"Sharing skills in negotiation Offering advocacy when needed Standing beside people in negotiations to witness and support Monitoring trends for systemic reform activities."</i>	
<i>"The CaLD strategic plan needs to be completed and implemented."</i>	
<i>"We have been focussing on assisting those most vulnerable and holding discussions with Office of the Adult Guardians regarding the role of advocacy for people with impaired capacity. We are also trying to estimate the number of people this may have an impact to ensure we have sufficient resources to meet the need."</i>	
<i>"In the short term, there is no simple solution. Some of the issues could be teething problems of a new scheme – such as inconsistent funding allocations. However, some issues are protracted – housing – and this will require multidimensional input across government agencies and NGOs."</i>	
<i>"The NDIS needs an alternate pathway or guidelines for items that can be funded for people with severe behaviours of concern, rather than asking for each family to justify basic and common sense needs."</i>	
<i>"Increased access and resourcing to independent advocacy support Clarity around aged care and disability interface Increased access to people to speak to in NDIS / NDIA."</i>	
<i>"Advance payments would be a start. Child protection getting into the 21st century would be dandy. governments caring about disability justice issues would be a distinct thing!"</i>	
<i>"More flexible limits to planning and funding. Acknowledgement of higher costing. More open view of support models."</i>	
<i>"The NDIS and the Aged care funding system need to have a combined bucket of funding for people with disabilities who wish to age in place and are not ready, it is not or willing, or it is not appropriate for them to enter the Aged care system."</i>	
<i>"Better planning and better understanding of the areas people live and what they require. Follow the Disability Act 2006. Ensure people are not worse off under this scheme especially in remote or rural areas."</i>	
<i>"A radical change of management which cascades the real purpose of the NDIS throughout the organization and demonstrates a commitment to people with disability. At the moment the main 'feeling' is one of total disrespect!"</i>	
<i>"planning and funding must do what the rhetoric says - give people choice and control in their lives and provide the necessary support to live a full and meaningful life - relevant and appropriate support to live in home of choice, relevant and appropriate transport and support to experience the ordinary and extraordinary fullness of life"</i>	
<i>"Flexibility from the NDIS about subsidising meals/food (also clothing and swags are items that our clients want) if that is what a client requires to stay living in country."</i>	
<i>"Some of it requires changes to NDIA practices, some requires changes to communication, some requires a re-set of people's expectations, all require better engagement between NDIA and PWD/advocacy."</i>	

Increased advocacy

Response	
<i>"Reaching all aged car facilities and identifying those with a disability; providing advocacy to register for the NDIS."</i>	
<i>"Sharing skills in negotiation Offering advocacy when needed Standing beside people in negotiations to witness and support Monitoring trends for systemic reform activities."</i>	
<i>"Advocacy must be funded as an option for people with NDIS packages."</i>	
<i>"Increased access and resourcing to independent advocacy support Clarity around aged care and disability interface Increased access to people to speak to in NDIS / NDIA."</i>	

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<i>"By linking the person with a disability with a citizen advocate we are helping safeguard the person."</i>	
<i>"Our citizen advocacy program is now appointing people who will voluntarily provide professional support to our advocates regarding the NDIS. (Advocate Associates)."</i>	

4.1 QUESTION 12 – CATEGORISED BY THEMES

Planning

Response	
<i>"With one of my clients, she felt my advocacy ensured a quicker formulation of planning and approval in order to ensure her son's specialist interventions were funded as soon as reasonably possible after becoming lost in the maze of initially registering her son with the NDIS and identifying which jurisdiction would continue to fund one particular service and how, NDIA contact being lost after that/huge delays in formalising her son's NDIS Funding Plan."</i>	
<i>"A young lady with Autism requires a support person so she is able to participate in education and in meetings. We supported her in preparing her plan and she has now been granted her package."</i>	
<i>"Attending critical meetings with planners and service providers in order that people are not alone in these dealings. One young woman with complex issues benefitted from support in a planning meeting due to the survey-style model of information gathering that requires concentration and interpretation of questions to provide the best responses. Independent support worked to slow the process down and ensure quality answers, including deferring completion until a later meeting."</i>	
<i>"Indigenous person with impaired capacity received excellent package. We provided two advocates to attend the planning meeting one legally trained and one of our ATSI advocates. No doubt package value would not have been achieved without this."</i>	
<i>"A family with two children with the same disability, close in age having one plan cut and pasted into the other child's. Expecting to share hours and providers whether both children want to or even like the same workers - grossly inadequate hours i.e., OT assessment for over 80 hrs with a package delivery under 20hrs each. Plan total less than \$25,000 each. 2 x Internal Reviews later and only 3 days off sending in the NDIS Appeal, both plans amended and increased to \$80,000 and \$58,000. Of course there are many relating to participants and their families having no idea how to go about making a plan let alone setting goals. Feeling pressured by current services to stick with them even if someone else could provide a much better service. Having no idea on what a planning meeting is and completely unable to express themselves and being just too overwhelmed to go through changes let alone speak out if the plan is inadequate in any way."</i>	

Eligibility

Response	
<i>"Working with PwD and their families to test their eligibility for NDIS supports, through the Planning process and ensuring the supports proposed in the Plan are appropriate. Supporting PwD in appealing funding as needed resulting in the support they require. Working with PwD in understanding their Plan and in connecting to a support coordination agency that suits their needs to ensure that they access their funds as soon as possible. Working with NDIS to ensure communication lines remain open and the Participant and their needs are heard."</i>	
<i>"We have assisted a number of people to apply for eligibility to NDIS, strongly advocated for a person from trial area to get a review of their NDIS plan to facilitate him getting released from gaol on bail. Managed to get the wait time halved but still there was a 6 week wait."</i>	
<i>"Through EDAC's systemic advocacy work, the NDIA at the Perth Hills has agreed to assign an agency staff member and an interpreter to assist a participant from CaLD background to apply for eligibility / access to NDIS."</i>	
<i>"A family with two children with the same disability, close in age having one plan cut and pasted into the other child's. Expecting to share hours and providers whether both children want to or even like the same workers - grossly inadequate hours i.e., OT assessment for over 80 hrs with a package delivery under 20hrs each. Plan total less than \$25,000 each. 2 x Internal Reviews later and only 3 days off sending in the NDIS Appeal, both plans amended and increased to \$80,000 and \$58,000. Of course there are many relating to participants and their families having no idea how to go about making a plan let alone setting goals. Feeling pressured by current services to stick with them even if someone else could provide a much better service. Having no idea on what a planning meeting is and completely unable to express themselves and being just too overwhelmed to go through changes let alone speak out if the plan is inadequate in any way."</i>	

Reviews

Response	
<i>"Advocate triggered External Merit Review."</i>	
<i>"We have assisted a number of people to apply for eligibility to NDIS, strongly advocated for a person from trial area to get a review of their NDIS plan to facilitate him getting released from gaol on bail. Managed to get the wait time</i>	

<i>halved but still there was a 6 week wait."</i>	
<i>"Many of our Advocates are beginning to learn about the NDIS in order to support their client to navigate the system. Without an advocate ensuring and questioning why things are done in certain ways they may potentially end up with a package of care and a plan that has been influenced by others rather than the person in receipt of the supports. Many have also already asked for reviews as the plans are simply not adequate or appropriate."</i>	
<i>"Support with internal review so that the person was found eligible for the scheme support with appeals processes support with information and advice so the person feels more prepared for the process providing information on rights, processes etc Circumventing the communication barriers and speaking with planners support at planning meetings to ensure that everything is included reassurance, confidence building."</i>	

Navigating the system

Response	
<i>"Advocate triggered External Merit Review."</i>	
<i>"We have assisted a number of people to apply for eligibility to NDIS, strongly advocated for a person from trial area to get a review of their NDIS plan to facilitate him getting released from gaol on bail. Managed to get the wait time halved but still there was a 6 week wait."</i>	
<i>"Many of our Advocates are beginning to learn about the NDIS in order to support their client to navigate the system. Without an advocate ensuring and questioning why things are done in certain ways they may potentially end up with a package of care and a plan that has been influenced by others rather than the person in receipt of the supports. Many have also already asked for reviews as the plans are simply not adequate or appropriate."</i>	
<i>"Support with internal review so that the person was found eligible for the scheme support with appeals processes support with information and advice so the person feels more prepared for the process providing information on rights, processes etc Circumventing the communication barriers and speaking with planners support at planning meetings to ensure that everything is included reassurance, confidence building."</i>	

Systemic change

Response	
<i>"Setting up the ID Ref Group - broad impact not individual. Info service would have also helped people."</i>	
<i>"Working with PwD and their families to test their eligibility for NDIS supports, through the Planning process and ensuring the supports proposed in the Plan are appropriate. Supporting PwD in appealing funding as needed resulting in the support they require. Working with PwD in understanding their Plan and in connecting to a support coordination agency that suits their needs to ensure that they access their funds as soon as possible. Working with NDIS to ensure communication lines remain open and the Participant and their needs are heard."</i>	
<i>"Through EDAC's systemic advocacy work, the NDIA at the Perth Hills has agreed to assign an agency staff member and an interpreter to assist a participant from CaLD background to apply for eligibility / access to NDIS."</i>	
<i>"The inconsistency in taxi transport subsidies being applied across the country. I.e. some states and territories removing eligibility for new NDIS participants. We wrote directly to the NDIA CEO David Bowen who responded positively to our concerns and raised this issue with the DSS as the coordinating body rolling out the scheme. As to the ultimate effect, who can say? I would have thought the pertinent body to raise this issue would have been the Disability Reform Council at a COAG level."</i>	
<i>"NPYWC sought out appropriate Allied Health professionals in the region to provide services for children with disability in the APY Lands as our families were unable to do this for themselves we also supported those Allied Health professionals to ensure they work in a culturally appropriate manner."</i>	