

NDIS Autism Consultation

Written Response May 2021

Introduction

Feedback provided via the online 'submission feedback form' on the NDIS [website](#).

The Benevolent Society is the NDIS Partner in the Community, delivering ECEI services in the following regions of South East Queensland: Logan City, Redland City, Brisbane City and Moreton Bay Regional Council areas. The Benevolent Society is also a registered service provider in New South Wales, South Australia and Parts of Victoria.

Internal contributors

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Executive Summary

The following response to the consultation questions welcomes the proposed holistic planning approach and greater support for children on the autism spectrum, and their families, to access mainstream and community supports and services.

Within such an approach, our response highlights the critical need for interventions that build the capacity of families, NDIS providers and the broader community to understand ASD and create positive environments for people on the autism spectrum. We focus on the need for plans, interventions and monitoring processes to reflect the experience of autism within natural settings and across the lifespan, with particular attention given to the impact of transitions and life changes for people on the autism spectrum and the proven lifelong outcomes of effective early intervention.

We note the need for families and professionals to have access to current and reliable evidence around autism interventions and welcome the introduction of principles and standards based on the Autism CRC's research. Critical to ensuring the successful application of these principles and standards will be additional capacity and availability of expertise across the sector and ultimately through the development of a clinical guideline to support professional practice. In particular, we note the opportunity to create ASD Champion roles through PiTC, and highlight the importance of ensuring that those undertaking Independent Assessments have extensive knowledge and expertise of ASD across the lifespan.

We appreciate the opportunity to contribute to this important consultation. We look forward to seeing this result in great plans, interventions and, most importantly, great outcomes for children on the autism spectrum, their families and the whole community.

Consultation questions

Promoting best practice

1. Which of these would you use to find information about choosing and accessing best practice interventions (or services) for children on the autism spectrum?

All of the following

- NDIS website
- NDIS Operational guidelines
- Participant decision making guides (not yet developed)
- My usual NDIS or NDIS partner contact
- Autism organisations or peak bodies

2. Where else would you like to find information about accessing best practice interventions (or services) for children on the autism spectrum?

For our practitioners, the key sources of information about best practice interventions includes: Raising Children Network; Autism CRC; Griffith University – Autism Centre of Excellence (ACE); Autism Hub and Reading Centre (Qld); Telethon Kids Institute; and relevant Allied Health and Health journals and publications. We also develop our understanding and practice through Autism specific support groups and play groups; and learning from innovative services such as CliniKids in Western Australia.

Our practitioners highlight the value of hearing from Autistic adults about their experiences. As noted in the consultation paper, Autism is lifelong. Autistic children do not ‘grow out of’ autism but, with the right support, can learn how to manage their challenges and embrace their differences. Engaging the autistic community in developing best practice will help build the capacity of children on the autism spectrum, as well as the capacity of those around them to meet their needs.

3. Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum. A description of “holistic planning” is included in [Section 7.4](#).

How can we help families to find and connect with other supports outside of NDIS?

Holistic planning and connection to the range of mainstream and community supports outside of the NDIS is critical for children on the autism spectrum and their families. Such an approach requires a system wide perspective, as well as resourcing to educate and equip families; linkage and partnership services; and community and mainstream services to work together to support children on the autism spectrum.

We note that this approach is aligned to the work of the Systems Leadership for Child and Youth Wellbeing Project, currently being led through a collaboration between Every Child (<https://www.everychild.co>) and the Australian and New Zealand School of Government (ANZOG). The project’s vision is for children, young people and families to have well-co-ordinated, early access to supports across the breadth of services they need throughout their lives. The It Takes 6 partnership between Every Child and ARACY Australia also highlights the need for integrated responses to 6 basic elements all children need to be safe, confident in themselves and developing

well. These 6 elements include: HEALTHY emotional, physical and mental; LEARNING from the early years on; HOUSING and basics of living; POSITIVE identity and culture; VALUED, loved and safe; PARTICIPATING and having a say. The Benevolent Society encourages the incorporation of these considerations into holistic planning approaches for children on the autism spectrum.

Foundational to helping families connect to external supports is helping them to understand and come to terms with a diagnosis of ASD. In our experience, access to specialist counselling and support, from professionals with knowledge of ASD and its implications for families, is a significant gap in the service system. While support is available through Chronic Disease Management Plans, some parents struggling with a diagnosis have had difficulties accessing any financial assistance for suitable counselling sessions. Ultimately, this limits their ability to fully engage in the process of finding and connecting to the range of early intervention and supports for their child, within or outside of the NDIS.

In addition to counselling and emotional support, families need help to understand ASD; how it might impact their child across their lifespan; how to help their child learn and manage transitions; how to modify environments; how to readjust their reactions and responses as parents; and how to advocate for their child. Without training and knowledge about ASD, and how it uniquely impacts their child, families can struggle to make informed decisions in relation to interventions. We highlight that transition through adolescence can be particularly challenging for families as they navigate the usual teenage behaviours within the context of ASD. These challenges are further impacted by a lack of funding for parent education, training and support after their child is seven. Extended and tailored support is needed to assist families to managed challenges throughout the lifespan.

While education programs (such as Early Days) exist to fill this need, access to these programs could be improved. Currently, the number of families accessing these programs is significantly lower than the number of families requesting our support to apply for the NDIS. Stronger collaboration among services delivering parent education and information will ensure greater awareness of these programs, smoother referral pathways, and consistency and quality of content. Additionally, barriers to accessing education programs, such as literacy, language and technology skills, also need to be considered to ensure all families have access. Cultural background may also impact the willingness of families to engage in existing training modules, and the application of the content to their own cultural beliefs and contexts. Greater cultural representation and alignment of content would support inclusion of all families in education programs. Peer learning models and connection to ASD specific playgroups, such as PlayConnect in Queensland, would also improve parent education.

In addition to education, families also benefit from the guidance of professional 'system navigators', who can discuss options with them and help them find and negotiate the best supports to meet the unique needs of their child. Services funded under the Partners in the Community (PiTC) program have a key role to play in helping families navigate supports within and outside of the NDIS. This important role would benefit from a comprehensive and consistently updated resource register, identifying the range of available ASD interventions and supports for families, as well as information on how to access them. The establishment of 'ASD Champions' within PiTC services would facilitate access to current, comprehensive and consistent knowledge of ASD for their professional peers. This role would also provide the opportunity to run support groups and information sessions for all parents of children on the autism spectrum registering with PiTC.

The role of PiTC and ASD Champions should include working alongside NDIS funded supports and existing mainstream and community services, with an aim of improving service responses and greater inclusion of children on the autism spectrum in the community. Over time, the service system has become more siloed and it is becoming more difficult to integrate and wrap supports around families. Feedback from our families is that it increasingly feels like they have to tell their

stories multiple times to multiple people, despite the expectation that the NDIS would reduce this. PiTC are well placed to take local level responsibility for driving a clear strategic and system wide plan that aligns a National and State focus for bringing mainstream and community services together with those offered through NDIS.

The broader community and mainstream service system also needs an understanding of and access to education about the needs of people on the autism spectrum. In particular, research recognises that transitions are particularly difficult for children on the autism spectrum. Specific work and coordination within community and mainstream settings is needed to foster supported transitions between different settings, such as Home to Early Childhood Education and Care Setting; Early Childhood Education and Care to School; School to working life; and includes transitions to extra curricula and community activities across the lifespan. Smooth, coordinated transitions not only support children on the autism spectrum but set all children up for success, and should be seen as best practice across community and mainstream settings. Coordination of those involved in each of these transitions will require informed leadership and resourcing to ensure that barriers to working together are removed and there is a whole of community approach to creating inclusive communities across Australia.

For First Nations families and communities, TBS supports the recommendations from the Macquarie University report, *“We Look After Our Own Mob: Aboriginal and Torres Strait Islander Experiences of Autism.”* Recommendations include a “road map” of post-diagnostic support services available for Aboriginal and Torres Strait Islander families, Aboriginal and Torres Strait Islander parent and carer support groups, and education, training, and research in autism founded on culturally safe principles and practices.

Reasonable and necessary

4. Building from the Autism CRC research, the consultation paper outlines specific principles that the NDIS considers as early intervention best practice for young children on the autism spectrum (Section 6.1.) Is there anything you would like to add?

Transparency around the application of the principles by service providers will support families and those supporting children on the autism spectrum to make informed decisions. Such transparency could take the form of a public facing statement from service providers against each of the principles and how they apply them in practice.

In response to each of the principles, The Benevolent Society would like to add the following:

1. The intervention is based on a good understanding of autism

It is essential that parents and carers have easy access to current, consistent and reliable information about the characteristics of ASD and common interventions and that this information considers learning style, literacy levels and cultural nuances in the way in which it is presented.

PiTC should be resourced to ensure they can consistently update staff knowledge about ASD, ASD interventions and information about what services are offering. ASD Champions in the PiTC workforce (mentioned in the previous section) should deliver nationally consistent information, advice and support sessions on best practice approaches to all families who have a child with ASD.

2. The people who deliver the intervention know the person well and respect their feelings and views

All NDIS funded services should provide family and child centred approaches that support diversity and inclusion. This should include the capability to support children and families from a variety of cultures and differing family structures. Such approaches require that interventions be individualised and, wherever possible, occur in natural settings. This will ensure that those delivering services understand the child and the family, as well as their context and situation.

Families will require support from the PiTC (as per point 1) to understand what child and family centred best practice looks like so that they can make informed choices and self-advocate where necessary.

3. The intervention is adapted to the needs of the person receiving it.

As with the response above, individualised approaches that respond to the unique needs of the child and their family benefit from connection to the natural setting and experiences of the child.

Consideration needs to be given to how such individualised approaches could be monitored, however, the involvement of families and PiTC will be key.

As per the research it is also important to note that this individualisation may, at times, include brief periods of intensive intervention throughout the lifespan to build specific skills that can then be applied and generalised across many settings.

4. The intervention is based on theoretical principles that are logical and scientifically plausible

Families will need support to understand terms such as *evidence based*, *evidence informed*, and *practice informed*, and have the knowledge and skills to judge the quality of information they are relying on to assess and select interventions. Such support to families will need to consider all levels of literacy, cultural differences, and points on their emotional journey that may impact their capacity to understand and evaluate information.

Similarly PiTC's will need to ensure the same level of understanding and knowledge in their staff, in addition to ensuring that staff know how to explain these concepts to the wide variety of parent/carers they are in contact with.

Similar to the recommendation in point 1, this will benefit from a nationally consistent information and support package, rolled out by PiTC ASD Champions.

5. The intervention works in the real world, not just in a research laboratory

It is well understood that children on the autism spectrum find it difficult to generalize techniques that they have learned in one environment to additional settings that they find stressful. As mentioned above, intervention plans should include at least some work in real environments that are part of the child's everyday life. Parents should also be coached to use strategies and tools across the range of environments that are relevant to them and their family.

Funding should reflect the need for services to be delivered across environments, and such delivery should be monitored as part of the requirements for funding relevant interventions.

Importantly it is also key to recognise that the 'real world' is different for each child and often changes as the key stakeholders in their life grow and adjust to the news of diagnosis.

Interventions need to work in a real world that is shaped most often by a young child's parents or carers. Understanding parental capacity to take on advice and strategies is key to intervention that works. While it is understood that parents and carers will play a key role in their child's development across the life span, coaching and capacity building will need to match parental capacity and sometimes wait while complex grief and trauma is processed and supported. In a real world, it is during this time that parents and carers need additional supports, above and beyond their usual support networks to adjust and become familiar with the diagnosis and the strategies they can employ to support their child.

The support of schools as a key real world environment for children also requires strategic attention. In our experience, schools are becoming increasingly reluctant to allow access by therapists to the school, either by refusing entry or creating barriers, such as charging a fee for use of a room. The environments in which interventions occur should be driven by the needs and choices of the clients or parents.

6. Research evidence shows the intervention can work for people on the autism spectrum

Parents and service providers require support to understand and assess the quality of evidence surrounding interventions. In particular, parents and service providers would benefit from education around the CRC's evidence based findings regarding the intensity and frequency of interventions, and the value of parental involvement in the intervention.

Further, The Benevolent Society supports the recommendation of the Autism CRC that the review of evidence-based interventions in autism is the first step towards best practice outcomes for children on the autism spectrum. The second step is to engage in broad consultation with the autism community and professionals to understand what works in the practice context. The third step is to develop a clinical guideline for working with children with autism to achieve the best possible outcomes for children, families, and communities.

7. The intervention supports mainstream and community participation

In order to support mainstream and community participation for children and adults on the autism spectrum, interventions need to target the people and environments with which children interact. Interventions should include an educative approach where the community is informed on what autism is, with the goal of normalising interactions with people on the autism spectrum. True inclusion and participation requires modification of the environment and upskilling those within it, including same aged peers, mentors, other families, and staff.

Currently, many interventions (particularly intensive, centre-based, clinical interventions) aim to 'eliminate' behaviours that are characteristics of autism and likely to be lifelong. Misinterpreting characteristics as deficits can have long term, detrimental impacts for a person on the autism spectrum. Upskilling those in the community and the child's natural settings (including staff, peers, other parents) on the characteristics of ASD, including an understanding of sensory differences, can promote inclusion and sustain long-term relationships. Such supports should be expected to develop communities in which diversity is valued and difference is minimised.

Funded intervention plans should include identified ways that the plan will actively promote inclusion of the child and family in mainstream and community activities of interest to them. These elements of the plans should also be measured as outcomes. Funding PiTC to provide support and training to community groups, and to work alongside and collaborate with community groups and mainstream agencies, is essential to developing community understanding and acceptance of diversity. Change within the community and in mainstream agencies, like health and education, takes time and a consistency of messaging.

In addition to supports for children autism spectrum, inclusive interventions that support mainstream and community participation of the whole family, in line with the advice above, is also essential. As sense of inclusion and acceptance is fundamental to the mental well-being of all family members.

5. Building from the Autism CRC research the consultation paper outlines specific standards that the NDIS considers as early intervention best practice for children on the autism spectrum (Section 6.2.)

Is there anything you would like to add?

Transparency around the achievement of agreed standards by service providers will support families and others supporting children on the autism spectrum to make informed decisions. Such transparency could take the form of a consistently presented, public facing statement from service providers against each of the standards, and/or a star rating system against each of the standards that is informed by families and centrally monitored and moderated.

In response to each of the standards, The Benevolent Society would like to add the following:

1. The intervention is delivered by, or supported by, appropriately qualified and experienced professionals

The Benevolent Society agrees that both minimum qualifications and ASD experience are necessary to deliver the high standard of support and interventions that children on the autism spectrum and their families deserve.

Attracting and retaining qualified staff, particularly in allied health, will require significant, system wide efforts around workforce attraction and conditions. Growing the experience of existing professionals to work with people on the autism spectrum will require additional capacity to enable mentoring and coaching by senior and more experienced staff. This is another potential role for ASD Champions within PiTC services. Further, ensuring that the workforce has capacity to upskill and adapt their practice in response to new research will help to improve client outcomes and minimise the effect of the 'research to practice' gap.

Funding and resourcing of service provision through the NDIS should also more effectively reflect and accommodate the training and skilling needs of the workforce.

2. The people delivering the intervention follow established guidance

It will be essential to ensure that established guidance is available, accessible and remains current.

3. The intervention provides significant and lasting benefits

It is important to note that 'lasting benefits' can be difficult to measure consistently, as regression is a typical characteristic for children on the autism spectrum. This is particularly evident when they transition across settings, environments, and relationships as skills learnt in one setting are often not well-generalised to others. Skills will re-emerge, however, the impact of transitions will need to be considered when progress and outcomes are being measured.

Interventions that involve parents should also be measured to highlight the value and lasting benefits of family-centred capacity building.

4. The intervention is carefully monitored and reviewed on a regular basis

As noted above, monitoring and review points should consider the impact of transition periods for children on the autism spectrum.

Clear guidance on monitoring and review process, including review processes (how the review should be conducted), schedules (when they should be conducted) and responsibilities (who should conduct them), will be needed to ensure reliability.

5. The intervention does not cause significant physical or emotional harm

Clear definitions of physical and emotional harm, and guidance on how indicators of harm might present for children on the autism spectrum, will help parents and service providers identify and assess actual or potential harm caused by interventions.

6. The benefits outweigh any costs (including risks)

Similar to the above, clear guidance on potential risks and costs will support decision making.

7. The intervention is good value for money and time invested

Determinations of good value should take a holistic view to include the compounding benefits offered by building the capacity of parents, families and the community. The transferability of skills learned by the child and family across environments and time should also be considered.

Determination of investment (or costs) should include the time directly invested by families through involvement in interventions, but also consider the impact of that involvement on the child or family's ability to be involved in other activities (i.e. time away from work, education or social commitments). This investment should also include ensuring families are well-supported across the lifespan to take on this caring role, including opportunities for them to seek help above and beyond their usual support networks, especially at periods of high stress and during life transitions. The investment in ensuring strong family and carer network must be considered good value for money.

6. “Reasonable and necessary” is a term from our legislation. Appendix one of the consultation paper includes case studies which might be used to explain reasonable and necessary.

Do these case studies help you to understand what we mean by “reasonable and necessary”?

Reasonable and necessary can be difficult to understand across unique cases. Practical, real world examples of how decisions are considered are an effective tool to support understanding and explanations of R&N that are meaningful for families and staff.

Further examples illustrating R&N considerations for intensive level ASD supports, in-home supports and respite for families with children on the autism spectrum would be helpful. Families will often seek support for in-home assistance, which is an important element to promoting family wellbeing and working on interactions in a natural setting. Unfortunately, these supports are always a challenge to quantify and evaluate and would benefit from specific case study examples.

More examples in a similar vein to the first case study on building community inclusion for Jenny, would also be useful as this example clearly demonstrates R&N considerations within community and mainstream settings. Further examples should clearly illustrate and identify the purpose of ‘in-home’ assistance - for example, assistance to develop social skills with siblings or social groups;

assistance to generalize and reinforce the learning of specific skills (such as toileting) – and address the reality that the timing and workers involved in these different types of support will vary.

The case studies for Jenny and Aron help illustrate what are “reasonable and necessary” supports for the NDIS to fund.

The final case study - for Jackie - is less clear with regards to the reasonable and necessary criteria. This case study could be clearer on who is providing each of the supports and why.

Based on the earlier tables, Jackie would receive an indicative level of funding of \$8,001 - \$12,000 (level 2), which, at the mid-range and based on the current Price Guide, would enable approximately 1 hour of therapy per week (inclusive of travel, reporting, and consultation with the early childhood team). This is captured in the implementation table on page 44, which identifies 1 hour per week of funded supports. However, the table includes both funded and non-funded supports, totalling 22.5 hours per week.

Although a mix of funded and non-funded supports reflects best practice, the example may be confusing to families, particularly given that Jackie’s family is concerned she is unable to access 20 hours of intervention for at least one year. By presenting the funded and non-funded supports in this way, the case example does not clearly explain what is “reasonable and necessary” under the NDIS.

Whilst this example presents a best case scenario, drawn from best practice, it does not reflect the actual reality for most parents, and most LDCs would say that there is insufficient capacity in their staffing rosters to provide this level of support to individual interventions.

It would be useful to more explicitly and realistically step out how each support is funded or not funded under the NDIS and why, with links to practice standards or R&N considerations, as per case study 1. This would help families see how decisions are made using the practice standards, paired with the R&N criteria more consistently.

7. Do you have any other feedback about how we explain “reasonable and necessary?”

The explanations are clear and our staff are skilled at discussing “reasonable and necessary” with participants.

There will, however, be varying perceptions of reasonable and necessary based on the commonly used explanation that the NDIS funds necessary services and supports that are over and above what a family would typically provide for a child without additional needs. This is due to the fact that families are unique and what one family would typically provide, another might not. This interpretation may also vary for a family over time in response to unanticipated stressors, such as sudden unemployment; changes to relationships; housing needs; or exclusion from childcare or early schooling. Interpretations should also recognise the multiple and additional barriers often faced by families with a child who has a disability and what this might mean for ‘reasonable and necessary’. This is especially true for those families where there are multiple disabilities, and the intersection between disability, poverty, and family breakdown. The potential for varied interpretation of a typical family may also impact those deciding on support approvals.

As stated above, provision of more mainstream service/community facing examples of R&N considerations in action (such as case study 1) would be welcomed.

8. Table 2 (0-6 years) and Table 3 (7-12 years) are an example of how we might explain Indicative level of funded support for children on the autism spectrum (Section 7.5.)

Do these table/s clearly explain the indicative levels of funded supports?

Whilst the tables do explain the levels, the indicative levels of funding (i.e Level 1 funding) are similar to the descriptive terms commonly used to designate severity of ASD symptoms (i.e. ASD Level 1). This may cause confusion for parents who automatically link the level of the child's ASD diagnosis to the same indicative level of funding. Renaming the levels of funding would avoid confusion. Further case studies on the application of funding levels in practice, similar to those used for the R&N guidelines, would be useful. As the levels apply to capacity building funds only, consideration into understanding the additional support needs across settings will be important. Consistency in how this is communicated across the nation to a variety of stakeholders will also need to be planned.

Table 2 does not clarify what happens when a child has several low/medium needs in the absence of what is deemed a 'high need.' The paper notes that, "where one area of need may be impacting on another areas...this is also taken into account" but does not provide guidance on how this would impact the indicative level of funding or available supports.

It is also unclear from Table 2 as to what constitutes an "area of need." For example, under Level 2, the example states, "A high area of need related to sensory behaviours, such as avoidance of smells and sensations and only wear certain fabrics. This impacts on their self-care skills and daily life such as meal times, dressing, bath time, not yet toilet trained." This is counted as one area of need, but arguably could be considered to be three areas of need (e.g. sensory needs, grooming/self-care, and mealtimes).

In our experience, young children who receive a diagnoses of ASD are likely to have displayed 'apparent and persistent deficits' in each of three areas of social communication and interaction, plus at least two of four types of restricted, repetitive behaviours. It is important to note that this is likely to result in more children being identified for Level 3 and 4 of funding. Level 1 diagnoses are often not achieved until school entry and beyond.

Table 3 suggests a move to a more consultative model of service delivery than in the 0-6 age group, with 24 – 36 hours of professional support available for children with indicative funding at Levels 1 and 2. This is in keeping with a peripatetic model of support delivery; however, may become problematic if short bursts of direct intervention are needed. For example, short-term, targeted interventions to support transition between school years; introduce a new extra-curricular activity; or respond to changes during puberty.

Further to the above feedback, in our experience, current practice support is determined in hours, rather than value. Against the indicative levels outlined in Table 2, this equates to:

Level 1 \$4,000 - 8,000 Equates to current practice of 24 hours \$4655 to 27 hours \$5237 with addition of 3 hours for the high domain (state by state)

Level 2 \$8,001 - \$12,000 Equates to current practice of 44 hours \$8535 to 49 hours \$9473 with addition of 5 hours for the high domain (state by state)

Level 3 \$12,001 - \$30,000 Equates to current practice of 56 hours \$10863 to 62 hours \$12027 with addition of 6 hours for the high domain (state by state)

Level 4 \$30,001 – \$35,000 Equates to current practice of 68 hours \$13191 to 75 hours \$14548 with addition of 7 hours for the high domain (state by state)

We note that the table does not provide information on indicative levels for 4 or more priority areas, which is currently 81 hours + 9 hours for the high domain \$15713 + \$1745 = \$17458

This analysis raises the following questions:

- Where is the capacity for *intensive* hours of support currently approved for up to 20 hours per week, equalling plans ranging from \$65,000 to \$100,000?
- Will the Intensive Guide to Capacity Building still be applied?
- Will Options A and B (Part 1 and Part 2) still be applied? Currently most requests/assessments and recommendations for this level of Intensive funding are provided by the service provider delivering the intervention. How can this be scrutinised?

9. Do you have any other feedback about how we explain the indicative levels of funded supports?

The tables show how the indicative levels of funded supports relate to functional impact; however, the information on page 25 does not clearly explain how the indicative levels of funding will be determined, other than to reference the Independent Assessment Framework. There needs to be consistent, well-documented and publicly available decision making guidelines established in relation to using the tables to determine level of need. Currently there is a lot of variation in the way in which needs are decided upon, and this is likely to increase with the breadth of presentations of the characteristics of ASD.

We also need clarity on the tools that will measure severity, and how this will be communicated to families. The consultation document does not detail how areas of need will be quantified, who will be responsible for deciding this, and what expertise or qualifications they will have to make these decisions. PiTCs and organisations delivering the IAs responsible for determining these levels will need to have experience and qualifications relevant to this field, just as in the NDIA practice standards. The NDIA should not expect these practice standards to be applied externally by service providers without holding the same expectations for those delivering the IA and making funding decisions. The NDIA could invest in development of a national minimum standard of delivery for IAs for people on the autism spectrum, and create a specialist team in this across the different portfolios.

The indicative levels of funded support are illustrated through the case studies provided in Appendix 1 of the Consultation paper, however there are gaps in these examples. The first case study, Jenny, provides an example where identifying the child's needs through individualised and contextualised assessment has not been well described.

The example describes how Jenny and those around her respond to her experience of the swimming class: Jenny is agitated and emotionally and behaviourally distressed; the other children in the class are disrupted; and Jenny's parents are upset.

Later in the case study, it is noted that, "As Jenny's confidence around water increases she is able to participate fully in the group swimming lessons" and "The swim school may make a decision to offer a 'quiet time' program." From this, we conclude that Jenny's experience of emotion and behavioural distress is triggered by lack of confidence in the water and the noisy pool environment. The process of determining these factors, however, is excluded from the case study.

Understanding the child's needs is an important and necessary step in the support planning process; otherwise, we run the risk of using the tables as a 'broad brush' approach to responding to children on the autism spectrum that will not meet their individual support needs.

10. There may be situations where families or carers need extra NDIS supports such as during first plans, or where plans reduce in value due to the impact of mainstream services.

What do we need to consider in those situations?

Assessment and recommendations around extra supports must be from qualified and independent sources. There needs to be greater clarity on how additional supports will be measured in terms of outcomes, and clear guidance on how R&N applies to these.

An example of additional support that may be needed in a child's first plan relates to family wellbeing. Families are often experience diagnosis-related grief when they are on their first plan and would benefit from additional whole-of-family supports to prevent family breakdown. Consideration and guidance needs to be given to how information related to family wellbeing and stress is collected, how this translates into additional supports, and what evidence will be needed to ensure access to these supports. A case study using an example like this would be helpful.

Research tells us that, for a whole range of reasons, families of children with a disability are more likely to breakdown than those with children that are typically developing. We also know that strong family and carer networks, above and beyond usual support networks, are an indicator for success of interventions and life-long outcomes. Therefore investment in families and the provision of additional family supports such and programs like [Volunteer Family Connect](#), should be considered good value for money. This will be especially important in a child's first plan and also at high-stress times including life transitions.

Supporting parents and carers to exercise choice and control

11. We want to support children and parents with implementing plans using the Autism CRC research and best practice. In [Section 8.2](#) there is a suggested list of questions for parents and carers. These can be used to understand the best intervention for a child and their family and how a provider is delivering an intervention.

Are these questions helpful for parents and carers when selecting providers?

The questions proposed in the paper are helpful to ensure the family has clear expectations around the aims, evidence, and commitment required for the specific intervention.

We suggest the addition of the following questions:

- What supports will you provide to help my child transition into and have positive experiences of mainstream settings, such as school/childcare?
- How will you provide information on ASD to those in mainstream settings – i.e. staff, other families, and other children in the setting – and work with them to ensure positive transition and experiences for my child?

- What if my child doesn't achieve his/her goals through the interventions you offer?

Parents will need guidance on the 'best' responses to look for against each of these questions. They will need support to probe and to understand what they can and should ask and who they can ask this of. Not all families are able to be equal advocates for their child – education levels and literacy, language and cultural differences, confidence and personality type need to be considered in approaches to supporting them to assess and select the best intervention options for them. Parent training and ongoing access to a parent coaches will be essential to support parents to question and evaluate information based on their needs, goals and values.

Parents will also need to be empowered to change services or enquire further if the initial responses to these questions are not being delivered along the way. They may also need reassurance that, in the current climate of significant wait lists for most private services, simple availability of a provider or intervention does not make it the best option for their child.

In addition to questions to be asked of potential providers, families and carers should also be encouraged to ask *themselves*:

- How does the proposed intervention align with the child and family goals?
- How does the intervention align with the findings of individualised, contextualised assessment?
- How does the intervention consider the child's environment and other people in that environment?

For example, if we return to the case study example of Jenny, the goal is to participate in swimming lessons with her peers.

First, the intervention must target Jenny's participation at swimming (or steps towards participation).

Second, the proposed intervention must reflect the findings of Jenny's assessment within the swimming context. A proposed intervention could be to use a visual schedule to help Jenny understand the expectations of her swimming class and the sequence of activities within the class. While this is a valid intervention, and one which may work well within a suite of approaches, if Jenny's underlying issue includes sensitivities to water and noise, the visual schedule alone will not be the most effective approach.

Third, the intervention should consider the environment in which the activity takes place. In this example, we know that the swimming pool is wet and noisy. We also know that the other children are disrupted and Jenny's parents are upset. Best practice would consider the effect of their responses on Jenny and work with the people in Jenny's environment to enable them to respond to her in more positive ways.

12. What other guidance or tools do families need to feel confident to implement plans in line with the Autism CRC research and best practice?

In addition to clear recommendations in the IAs, parents will benefit from tailored and responsive guidance from key workers and coaches. The support offered to families should meet their unique needs and situations, and should consider key factors that may impact their confidence to implement plans, such as literacy levels, or cultural background. Aboriginal and Torres Strait Islander families and families from CALD backgrounds should have access to culturally skilled and responsive supports.

Guidance and tools for families should promote a strengths based focus and highlight the application of best practice *across the lifespan* of a person on the autism spectrum. They should also reflect the emotional impact of autism on families over time and acknowledge the grief and stress parents commonly experience at each life transition point.

In addition to supports, access to information and education for parents on recent research developments and best practice interventions is fundamental to developing their confidence to lead the implementation of their child's plans.

By way of example, the paper refers specifically to the 'refrigerator mother' theory, which has been debunked for several decades and does not reflect new approaches in autism support. A more recent research development, which would support parents and communities in their approach to children on the autism spectrum, is the Double Empathy Problem. The DEP explains how interactions involving autistic and non-autistic people are susceptible to frequent misunderstandings. It is a "double problem" as both people experience it, and so it is not a singular problem located in any one person." By applying the DEP to our interventions with children on the autism spectrum, we also build the capacity of families and other people in the child's environment to adapt their communication and behaviour in ways which promote success and align with best practice. Exposure to theories like DEP would equip parents to enquire and assess intervention approaches proposed by providers.

Conflicts of interest

13. This question relates to [Section 8.3](#) of this paper: "Addressing conflicts of interest." How can we support families and carers to feel confident to make decisions about what is in the best interest of the child and family?

Parents need more support at all stages of their journey with autism and through each transition point in their child's life. As the paper notes, access to impartial and good quality advice and support is particularly important in the early stages of the diagnosis. The support of specialised and skilled advisors, such as family coaches or ASD Champions in PiTCs is essential at this point. A dedicated hotline or central contact point would help parents get easy access to clinical or subject matter expertise and guidance on questions they have. This would be of particular benefit to families in rural and remote locations, or locations where limited opportunity exists to get impartial advice.

Another element of addressing conflict of interest is to ensure a greater mix of providers across the system and address the emerging culture of 'we can provide it all'.