Submissions
The National Disability Insurance Agency (NDIA)

22 February 2021

Re: - Supporting young children and families early, to reach their full potential.

To whom it may concern,

Thank you for the opportunity to respond to how the NDIS works with young children and families early, to reach their full potential submission. I am responding on behalf of the Genetic, Undagnosedand Rare Disease (GUARD) Collaborative Australia.

About GUARD
The GUARD Collaborative Australia is a coalition of peak body organisations; Genetic Support Network of Victoria, Genetic Alliance Australia (NSW), Syndromes Without A Name (SWAN) Australia and Genetic and Rare Disease Network (WA). We stand together to represent the voice of people living with genetic, undiagnosed and rare disease and those who support them. We strive for a fair, equitable and collaborative approach to disability, health and wellbeing for all our population members.

Our submission is in the context of the National Strategic Action Plan for Rare Disease, a focussed plan outlining the priorities and areas of action required to improve the lives of people living with rare disease.

We have addressed the consultation questions on the following pages along with our key issues and recommendations.

We would be would be happy to provide further information about our submission if required.

Kind regards

Heather Renton
Chief Executive Officer
Syndromes Without A Name (SWAN) Australia
On behalf of the GUARD Collaborative

About Undiagnosed and Rare Diseases

According to the Australian Government - Department of Health, it is estimated 8% of Australians are living with a rare disease, of which 80% have a genetic origin. It is estimated by geneticists that at least 80% of rare diseases have a disability component that impacts them.

There are over 6000 rare diseases, 75% of them affecting children. Many rare diseases are life-threatening or have a chronic illness associated with them. Unfortunately, 30% of affected children will not see their fifth birthday.[1] Obtaining a diagnosis and/or treatment can be a long and difficult journey. About half of children with learning disabilities and approximately 60% of children with multiple congenital problems do not have a definitive diagnosis to explain the cause of their condition. [2]

We live in the rapid genomics era where we are discovering new rare diseases every week. Some of these gene changes are complex and we are only just learning about the relationship between some genes and the environment. Discovery can bring hope and possibility; understanding and knowledge, fear and despair. Lack of diagnosis can bring frustration and isolation and with limited access to both medical, disability, social and mainstream and community supports.

People living with genetic, undiagnosed and rare disease are amongst the most vulnerable groups in society. Their diseases are highly complex, often chronic, and severely disabling conditions, which generate specific care needs. They are difficult to understand for clinicians and researchers, let alone by the lay person.

For our vulnerable rare disease population, who also present with disability, it is imperative that additional measures such as the NDIS can support them in either maintaining or improving their functional capacity in a fair, equitable and timely manner.

[1] https://www.mcri.edu.au/content/rare-disease

[2] https://www.undiagnosed.org.uk/support_information/what-does-swan-or-being-undiagnosed-mean/

KEY ISSUES AND RECOMMENDATIONS

ECEI participants to increase to 0-9	GUARD supports extending the age range for ECEI participants from 0-7 to 0-9 to allow for more support to be given to families.
Transition phase	GUARD supports a longer and smoother transition for ECEI families exiting the NDIS, which needs to be funded in participants plans.
Best practice	GUARD supports the best practice model of ECEI. The best practice model needs to be clearly explained to participants.
Registered NDIS providers	GUARD does not support the introduction of ECEI participants into only using registered NDIS providers as it undermines choice and control, which are principles of the NDIS.
Independent Assessments	GUARD does not support the use of independent assessments. Reports provided to the NDIS written by clinicians and allied health professionals working with and supporting families should be read and understood as reports from "experts" in their fields and used to develop appropriate supportive NDIS Plans. Independent assessment should not determine plan budgets.
Resources	The NDIA should not replicate existing resources such as peer support groups but should utilise existing resources such as GUARD to support participants.

CONSULTATION QUESTIONS

General questions

- **Do you have any specific feedback in relation to:**
  - **the increased focus on STEI outside of access to the Scheme**

    GUARD agrees with Recommendation 12: *Increase Early Childhood partner capacity to provide Short Term Early Intervention (STEI) support to eligible young children and families for longer.*

    Our concerns are that once the STEI supports are removed, education settings and other mainstream and community supports may not have the capacity or resources to support the transition process. Children may regress and families might well feel unsupported.

    There needs to be allocated transitions funding in participants NDIS plans to support them exiting the scheme.

  - **the proposed increase in age range for the EC Approach from under 7 to under 9 years of age,**

    GUARD agrees with Recommendation 14: *Increase the age limit for children supported under the Early Childhood Approach from 'under 7' to 'under 9' years of age to help children and families receive family centred support throughout the transition to primary school.*

    Increasing the age limit of ECEI from under 7 to under 9 will ensure a smoother transition to the community and mainstream services. The families GUARD represent have reported that once an ECEI service no longer assists their family, they feel lost as they struggle to find and utilise mainstream supports and services.

    This has been evident when supports fall away from an educational environment, where previously a key support worker has supported a child's integration into school. Families have reported feeling lost when there has been nobody to ensure that additional supports, e.g. continence supports have been provided or suitable individual learning plans established. A key support worker can ensure that therapists communicate with one another and the school. They can advocate on behalf of families and assist them with NDIS portal concerns.

    ECEI key workers assist with ensuring there is a smooth transition into community and mainstream supports. Many families focus on their child settling into school over the first few years rather than have them undergo extra curriculum activities. Extending the cut off for ECEI supports from 7-9 will allow children to be supported and integrated more smoothly into community and mainstream supports.

    Many of the families GUARD represent utilise individual therapists or therapists who act as individual contractors as part of a therapy centre or are self employed. For some of them, it has created issue as there has not been effective communication between their support team. From our understanding, the families that use the ECEI best practise model of support, receive a much more coordinated team approach to support.

The need for coordinated care and good communication that the ECEI best practice model provides is even more critical for the members we represent who need supports, particularly for those with multiple disability and complex conditions. Key support workers can work as part of transdisciplinary team and provide practical support and strategies to families where necessary.

- **the desire to see more successful transitions from the Scheme to the next state of life.**

  Very few of our GUARD families have transitioned out of the NDIS due to the complexities of their rare genetic condition and disability. People do not grow out of genetic or rare conditions and treatments are available for less than 5%/[3] Many are also degenerative and become mor chronic with co-morbities over time.

  Of the few that have transitioned out of the scheme, they have reported feeling like they were left to their own devices with little support. They felt they lacked the confidence to seek out mainstream and local community supports on their own and request appropriate adjustments to their programs to accommodate their needs. Some also reported feeling lost and unsupported in the school environment, which should never be the case.

  We feel that transition out of the NDIS maybe even more difficult as there is little understanding of undiagnosed and rare genetic condition into the broader community. There is still not a lot know about so many rare genetic conditions, particularly those which have been recently discovered. We don't know whether they will be progressive, episodic or regressive.

  Genetic and genomic testing takes time and still have low diagnostic yields. The average time to receive a diagnosis for a genetic condition is five years. Even with genomic testing expanding, the diagnostic yield is only between 40-%-60% [4].

  With the current lack of support for transition, we are particularly concerned for our vulnerable communities from CALD backgrounds or a low socio-economic backgrounds and their parents/carers who have an intellectual disability. GUARD would like to see a smoother and supported transition phase that would wean NDIS participants away from the scheme. This would involve funding transition capacity building supports in plans. This could assist with the transition away from the NDIS, so families could establish their own support networks and connections within mainstream communities.

- **How can we help families and carers better understand some of the terms the NDIA, and Early Childhood partners use such as:**

  The NDIS needs to provide families with good examples and short casestudies which illustrate the following terms:

  - **best practice** - family centred, inclusive, collaborative and evidence and outcomes-based. It involves a transdisciplary support worker who can meet a lot of the child's needs. The model can be extended to include additional allied health professions to best support the child's needs at the level they require for them to meet their goals. It is a more flexible approach than the medical model.

[3] *Orphanet Journal of Rare Diseases Nov 2018*
[4] *https://www.nature.com/articles/s41431-018-0099-1*

- **capacity building –** supports that aim to improve a person's functional capacity
- **natural settings, and/or –** usual or familiar environment
- **evidence –** researched and credible

Support with achieving goals

- **What is the best way for us to check in with families and carers on how their child is tracking to meet the goals for their child?**

  Communication will be the key to checking in with families. Have a conversation with a family to ascertain which means of communication will work best for them and in what frequency they would like someone to get in touch with them.

- **Would a mandatory early childhood provider report developed between families and their provider be useful for tracking against their goals?**

  Mandatory reporting may be useful but it is not without concerns. There are privacy concerns as families don't always want their information shared with other people that support them. It might highlight a lack of cohesion between service providers, and goals may be different and supports duplicated. There may be an inconsistent approach to the amount and frequency that information is reported. Before any implementation of a mandatory report, it would be necessary to ensure that this did not place additional burden on service providers at a cost of service delivery. Providers should have already established a system to track goals and communicate with families without a mandated format or style.

- **How can we better support families to connect with services that are either funded or available to everyone in the community?**

  ECEI key support workers or support coordinator should understand what community supports are appropriate and would be suitable for families to be connected with. There may be cultural and other factors to consider when thinking about which mainstreams supports would be best for the family to utilise.

- **How can we make the process of transitioning out of the NDIS something to celebrate?**

  Enure the transition phase is smooth and that participants are well supported. Transition needs to be adequately funded in participants plans for this to occur.

Targeted support

- **If you live in a remote or very remote part of Australia, what are some ideas you have on how we can get early childhood supports to work in your community or communities like yours?**

  Offer incentives to attract early childhood supports to remote areas as well as offering allied health student placements. More support around could be provided around digitally interactive telehealth appointments with allied health professionals. This may required further funding, training and internet access for those involved.

- **How can our Early Childhood partners and mainstream services best support peer-to-peer connections?**

  GUARD specialises in supporting genetic peer support group leaders, yet we rarely receive phone calls or emails from ECEI coordinators looking for a genetic support group for a family. Community groups such as MyTime, mothers group and playgroups also offer peer to peer support and connections. The NDIS could support ECEI coordinators to build their understanding of the resources available for peer support connections and actively promote them.

- **Are you interested in helping us co-design an approach that would make peer-to-peer networks easier to find and join for people?**

  The GUARD recommends the NDIA do a landscape analysis of the existing groups that already support participants with peer to peer support prior to replicating or duplicating their supports. More referrals could be made to existing support groups. GUARD would be prepared to be adctively involved in co-designing an approach that utilises this landscape analysis, identifies gaps and is committed to resolving them.

- **How can we better reach and get support to young children and families who experience vulnerability and remove barriers so they can receive outcomes in line with other children and families?**

  We need to ensure vulnerable families are provided with NDIS funding in their child's plan for an ECEI key support worker and a support coordinator. That way, they will receive guidance to access the supports to assist their child.

  This may involve training and education for ECEI key support workers so they can be better advocates for what a child/family requires. It is also critical to listen to the family and the expert knowledge they have ensuring they can access about what the current and future needs of their child are. Timely access and processing is also critical to create a more level playing field. It is also possible to fund genetic and rare disease networks to establish information guides on disease groups to assist understanding within the disability sector.

  It is important that the different needs and values of culturally diverse families are better understood by those who support them.

<u>Tailored Independent Assessments (IAs) approach</u>

- **Do you have any feedback on this recommendation and/or any suggestions on how this proposed approach would work best for young children and their families/carers?**

  GUARD does not agree with tailored independent assessments to assess eligibility and plan budgets. With the proposal of utilising ECEI partners to conduct these assessments, you will be taking allied health professionals away from what is already a thin market, particularly in rural areas. This will create even longer allied health waiting lists for families and they will not be able to use the capacity building supports in their plans. Many families struggle to utilise their first choice allied health professional because of their lack of availability, e.g. for appointments at the times that are convenient for them.

Life is difficult enough when you have a child with a rare genetic condition. Many of them already undergo extensive testing in the health system, they do not want to undergo further testing that may be unnecessary. Many children have difficulty concentrating and focusing for extended periods and will be unable to participate actively in assessments, and will score – "non-compliant". Families do not want to feel bad when their child cannot complete a task.

These assessments will most likely be delivered by strangers who can cause huge anxiety for families. Our families have enough anxiety living with the unknown, and they don't need anything more to add to their worries. There is already too much unknown for rare disease families. A one size fits all approach will not work for the community we represent, particularly with our cohort of families where progressive and episodic symptoms can occur.

Families should be confident to lead their child's engagement with the NDIS including developing their goals and services and supports that help them achieve them. Goals setting should be done at current planning process and not after the plan is already drafted.

We are concerned that families will struggle to know what discipline of assessor to choose when their child has complex disability. We feel that some of the proposed assessments would be best performed by a psychologist or educator rather than an allied health professional who has little experience conducting such assessments. In most cases a multidisciplinary assessment will be required to fully understand the functional impact of complex genetic conditions.

More information needs to be provided about how assessments will be conducted when a family has a poor grasp of English or requires Easy English or visual supports. We don't think the NDIA has considered the needs and values of culturally diverse backgrounds prior to proposing the introduction of independent assessments. The proposed changes have just added more anxiety and stress to participants.

The NDIS will still need to rely on multidisciplinary reports from services that support your child, which do identify goals and supports. Reports written by clinicians and allied health providers who are experts in the field should be referred to when creating plan budgets. These experts often have a long-standing relationship and have built trust with them from an early age. They are in a position to identify multidisciplinary supports and goals. The proposed assessments don't do this, instead they allocate a dollar figure to a plan budget which may not be enough to support a participant's needs. We cannot have a one size fits all approach as it does not work with our undiagnosed, genetic and rare disease community.

Assessors without experience, knowledge and expertise in genetic conditiona will not be well placed to conduct these assessments. The NDIS should not rely on an independent assessment to determine plan budgets which may not be enough to support a participant's needs. There is still so much unknown about rare genetic conditions that an assessment such as the ones proposed by the NDIS will not capture our SWAN children and their families' needs.

We are extremely concerned that iIndependent assessments will not be reviewable decisions. There is no avenue to request a review if you disagree with the independent assessment, which could impact eligibility or determine your plan budget. We do not agree with this decision. The assigned budget aligned to your plan as a direct result of these independent assessments may not be enough to support a participant's needs. Furthermore, the NDIA is yet to share evidence that supports functional capacity assessments as proven tools for determining support needs and budgets, or how these assessments would be translated into budgets.

We are concerned it will become harder to appeal a planning decision because support budgets are linked to independent assessment which cannot be appealed at the AAT. If participants do not have the funding in their plan to purchase the supports they need to meet their goals and aspirations, it will be very difficult to gain further funding without another independent assessment which are only allowed under special circumstances.

Greater transparency on providers of best practice

- **What mechanisms do you think could help achieve this?**

  Yearly audits would lead to greater accountability and transparency. They would ensure that best practices standards are being delivered in a timely and appropriate manner. Opportunities and forums where experience is shared – by NDIS consumers and providers. This would provide a very transparent platform where best practice could be established and learnings disseminated. A very simple checklist of what constitutes a best practice experience should be provided to families so they can benechmark their providers.

- **Who would be best placed to lead the development of, and manage, any additional complementary mechanisms?**

  ECEI providers would be in a good position to lead the development and implementation of any additional complementary mechanisms in partnership with families (who have lived experience of disability). ECIE providers have the significant experienced with what constitutes best practice in their field. Nothing should happen without consultation with families with lived experience. A working group engaging all key stakeholders should be established to lead any new mechanisms

- **What do you think of the following ideas for potential mechanisms? What are the benefits or concerns with these potential mechanisms?**

  - **Provide greater information to families about the benefits of using providers registered by the NDIS Commission.**

Benefit	We disagree with trying to influence a choice in the type of provider that a participant can choose. The benefits of both utilising a registered and non-registered provider need to be presented to families, it is about choice and control.
Concerns	Using only registered NDIS providers does not offer choice and control to participants and is not flexible. Time and resources may be wasted by changing provider and good working relationships take time to develop. Participants should be able to use the provider who can best support their child's needs

  - **Establish an industry-led 'best practice accreditation system'.**

Benefit	Providers will be required to become accountable for the service they deliver. They need to be accountable to families as well as the NDIA.
Concerns	Accreditation processes take time to establish and require expertise, money, training and resources. Best practice standards may evolve with time, and there is the risk that accreditation may not keep up.

- **Establish a 'quality feedback / rating system'.**

Benefit	Rating systems make organisations accountable and give families the option to select providers based on their ratings.
Concerns	High rated services may not have the capacity to take on new participants. It may lead to bottlenecks and shortages of reputable allied health professionals. Ratings may not always be an accurate measure of performance and sometimes can be subjective. Providers may spend time and money on influencing their ratings rather than delivering their services. Competition does not always provide a better outcome and can be distracting for providers.

- **Make registration with the NDIS Commission mandatory for all providers operating in the EC space.**

Benefit	We disagree with making EC providers registered with the NDIS for the reasons below.
Concerns	It takes away choice and control of selecting a provider. Participants may want to stay with existing providers who can meet their needs. The NDIS was meant to be about choice and control. It is expensive and time-consuming to become a NDIS registered provider. This will put greater demands on small service providers.Participant might have no choice but to use providers who don't understand genetic conditions or your child's needs. There is already thin markets, particularly in rural areas when it comes to the choice of allied health professionals and selected appointment times. By making registration mandatory, some current providers may leave their industry and it may prevent people from accessing a local services.

- **Require self and plan-managed participants in the new Early Childhood approach to use only registered providers.**

Benefit	We disagree with trying to take away choice and control as this goes against the principles of the NDIS Act 2013, so we cannot support the benefits of this statement.
Concerns	It costs a lot of money to be a registered provider, it is complex to register, and there is a lot of reporting to do, which takes time away from working with families. The same arguments that we have used above apply here. There will be less choice and control for families, and rare disease families may have to change providers to people who don't understand their families or child's needs. Rare disease families may want to work with a therapist experienced with working with children with complex needs. Unless they are a registered provider, families won't be able to use them, which may mean your child is missing out on targeted therapy for their complex needs. Registered therapists may not always be the best match for a child.