

Response to the NDIS Consultation Paper: Interventions for children on the autism spectrum

Response Summary

Lifestart welcomes the opportunity to respond to the NDIA Consultation Paper: Interventions for Children on the Autism Spectrum.

The principle that every child is unique, including those children with autism or any other developmental delay or disability, underpins this response. Each child and their family/carers have their own individual strengths, interests, relationships, values, preferences and needs. Individualised family-centred planning is therefore a critical element in ascertaining a child's support needs. We agree that “there is no ‘one size fits all’ approach to intervention during childhood, and there is no one intervention that improves all developmental outcomes for all children” (Autism CRC, 2020 Interventions for children on the autism spectrum, and their application in the Australian community (Summary 1 of 2: Narrative review)).

Whether or not a child has functional support needs that require an NDIS plan, families need information about interventions and supports that is readily understood and accessible and that they can easily apply to their own child. This should include information about how mainstream services can contribute to positive outcomes through holistic planning. When a child accesses a funded plan, choice and control can only be exercised when informed decision making is facilitated. In what is largely an unregulated marketplace, the NDIA can support this through considering the current programs delivering best practice, the cost of delivering these supports and the outcomes they achieve, and communicating this information to families and the sector more broadly.

In reviewing the tables on indicative levels of funded support, we have concerns that the descriptors of functional impact and what this might look like for a child with autism do not necessarily represent the spectrum of presentations that children may have. While Lifestart broadly agrees with the seven principles and seven standards outlined in the consultation paper, it is unclear how these have been applied to the indicative levels of support and what evidence and/or assumptions underpin these.

We agree that achieving outcomes for children on the autism spectrum relies on the support of mainstream services, particularly the early education/education, health and family services sectors. However the assumption that these supports are accessible to all families and robust and inclusive across the board cannot be made. Despite many examples of good practice, it is well documented that gaps in these service systems have impacted on holistic family supports. Investment by the NDIA in collaborating with these sectors to plan strong capacity building over the medium to long term is required.

Our response therefore makes the following recommendations:

1. Further research is undertaken to better understand interventions and supports, including lived experience and practitioner perspectives.
2. That the NDIA commissions the development of a suite of independent and impartial information that is accessible and easily understood by families and that incorporates Autism CRC and best practice principles.
3. Assumptions underpinning functional levels and funding ranges are further tested.
4. Assessment of a child's strengths and needs is a collaboration with families so that the choice of intervention is best suited to that individual child.
5. That the NDIA identifies and costs models of support that are considered best practice, links these to reasonable and necessary supports and communicates this clearly to families.
6. That the NDIA develops a comprehensive plan to build the capacity of mainstream services to better support all children with disability and developmental delay, including those with autism.

About Lifestart

Lifestart is a not-for-profit organisation and registered charity. We support children and young people aged 0-24 years living with a broad range of disabilities and their families/carers. Our vision is that all children and young people can participate inclusively and meaningfully in their community.

Lifestart is a registered NDIS provider of Specialist Behaviour Supports, Therapeutic Supports and Early Childhood Supports. Lifestart is also an Early Childhood Partner with the National Disability Insurance Agency (NDIA), delivering the Early Childhood Early Intervention (ECEI) approach (for children 0-6 years) in 5 regions of NSW. In addition, we deliver programs under grant funded initiatives on behalf of the NSW Department of Education and the Department of Social Services (Information, Linkages and Capacity Building). Lifestart currently employs approximately 240 staff including 150 specialist staff (for example, allied health professionals and educators). Lifestart maintains a strong investment in learning and development across all its teams and secures a strong return on investment with this commitment. During 2020 Lifestart supported approximately 10,500 children and young people across all our teams.

Lifestart also has been a part of the evolution of the Early Childhood Early Intervention (ECEI) approach for some time, including as:

- One of four Early Childhood Partners in the original ECEI Pilot conducted in the Nepean Blue Mountains region of NSW in 2015/2016.
- One of two organisations funded to act as Transition Advisors in NSW. This role was to advise and support NSW Early Childhood Intervention Providers to act as Transition Providers in transitioning children and families to the NDIS.
- An ECEI Partner in the Community from 2018 under the NDIS in 5 regions of NSW.

Lifestart Response

The understanding and delivery of best practice in early childhood intervention supports is essential for all children with disability and developmental delay, including children who have been diagnosed with autism spectrum disorder. Lifestart welcomes the information provided in the recent Autism CRC Paper (2020) *Interventions for children on the autism spectrum: A synthesis of research evidence* which was commissioned by the NDIA and referenced in this current consultation paper. However, we note that the Autism CRC has clearly stated that its paper did not consider levels of funding and that there are knowledge gaps related to interventions for autism. Lived experience and practitioner perspectives have been highlighted as requiring further research. This additional information will provide a much greater understanding of the level of support and intervention suited to children, their families and what the cost benefits are. This information should be used to drive best practice and support offerings from providers. Other research was also recommended to increase an understanding of:

- How child characteristics (e.g., age, core autism characteristics, and communication skills) may influence the effects of interventions.
- How the way an intervention is delivered may influence the effects of interventions, and how this differs between children and families.
- The amount of intervention that may maximise the effects of interventions on outcomes, and how this differs between children and families.
- The costs and benefits of interventions including unintended consequences, negative impacts, and opportunity costs that can occur when time and money is spent on less effective interventions.
- How interventions may improve broader areas of child and family wellbeing, such as quality of life.

Recommendation 1: Further research is undertaken to better understand interventions and supports, including lived experience and practitioner perspectives.

Lifestart remains concerned that families do not have access to easily understood and impartial advice as to what best practice is and how it can be applied to their child. Our experience is that families do not have a robust understanding of best practice and may be provided with conflicting information from multiple sources, or with information that is difficult to interpret. These sources of information can vary but include Early Childhood Partners, Local Area Coordinators, service providers, health professionals such as doctors, reputable and non-reputable internet sites, brokerage services and other families.

Even though Lifestart ECEI Coordinators have been supporting and educating families about supports and services for their children for some years, we consistently find that many families have already investigated supports and services through these other sources and are often still being sold on the 'cure'. Families may understand and often agree with the advice the Early Childhood Coordinator is providing but worry about missing the opportunity to 'fix' their child and consistently convey concerns about missing opportunities. They will often comment that

they do not want to look back in 5 years' time and regret that they did not try a particular intervention or support. The provider chosen by families may or may not be delivering supports consistent with what is understood to be best practice and our experience as a Partner is that we have limited influence on their decisions. We are also aware that Early Childhood Partners are not always seen as being impartial because of their contracts with the NDIA.

Service providers may consciously or unconsciously promote information to families that is not best suited to their needs or that does not reflect good practice. Currently the marketplace is completely unregulated. Registered NDIS providers must meet the NDIS early childhood intervention standards but providers are not required to be registered and the largest participants self-managing plans are children 0 – 6 years of age. It is entirely left up to families to exercise choice and control and the onus is on the family to identify best practice. There are many services promoting and delivering best practice supports and services but there are just as many that are not. Requiring service providers to complete NDIA proformas reporting on their services will not increase service quality or alignment to best practice. Service providers will quickly understand what is required in these reports and will write whatever is required by the NDIA. This further confuses decision making by families about what interventions are most appropriate. It is unrealistic to think that the marketplace and how it informs about and delivers best practice can be shaped in this way.

In addition, there are now services emerging in the marketplace that provide free advice to participants and their families. Families provide a copy of their child's plan to the service and they link the child and family to a provider in their local area. This service is 'free' to the family as providers pay a fee to this business for the referrals they receive. This commission-based servicing is indeed concerning and adds another level of complexity in assisting families get access to what is known to be best practice support and significantly diminishes choice and control.

In this context, it is imperative that there is more easily accessible and practical information available for families to inform the intervention choices they make for their child. The responsibility and onus cannot sit only with the families to understand best practice. The NDIA could commission experts such as Professor Andrew Whitehouse from the Autism CRC to create information related to the core principles they have developed. Short videos and accessible information could also be developed and promoted by peak Autism organisations such as Amaze and Autism Awareness Australia. The NDIA would have responsibility for ensuring that the availability of this information was constantly promoted to families, the sector more broadly and to mainstream service sectors including education, early education, health and child and family services.

Recommendation 2: That the NDIA commissions the development of a suite of independent and impartial information that is accessible and easily understood by families and that incorporates Autism CRC and best practice principles.

Reasonable and necessary capacity building supports for children with autism have been organised in the consultation paper into tables on indicative levels of funded support, which contain descriptors of functional impact across four levels. While Lifestart acknowledges that the levels are designed to provide guidance, they do not necessarily represent the spectrum of presentations that children may have. The descriptors are linked to a funding range for each level. Many assumptions appear to have been built into the examples and Lifestart recommends that these should be tested. These assumptions include that:

- families are functioning with the ability to implement all strategies and be coached over short time periods.
- a child's functional capacity necessarily correlates with the level of support that may be required. For example, a child with well-developed expressive communication skills, can have complex repetitive behaviours requiring more intensive support.
- higher functional capacity should result in a lower funding level. However, evidence may inform that long-term outcomes in this context may be enhanced by a higher level of support in the early years.
- a child has been diagnosed early. Many children are diagnosed with autism in their school years and may therefore require higher levels of support in this life stage.
- one visit a term will result in capacity building practices for a child in a preschool or school environment.
- functional needs will necessarily reduce during transition times e.g., starting school.

Recommendation 3: Assumptions underpinning functional levels and funding ranges are further tested.

It is also best practice that any assessment of a child with autism or any other developmental disability is holistic and properly informs functional capacity. As previously mentioned, all children are unique and there is no "one size fits all" approach to intervention.

Recommendation 4: Assessment of a child's strengths and needs is a collaboration with families so that the choice of intervention is best suited to that individual child.

The consultation paper does not make it clear how the four funding levels have been arrived at. The Autism CRC have stated that they were not consulted or involved with this process. The lowest levels of \$2,400 per annum equates to 12 visits by a key worker or allied health worker. It is uncertain how these lower levels of funding may interface with what is available through the proposed short term early intervention (STEI) that will be made available through the Early Childhood Partners. We also note that although reference has been made to supporting children in their natural environments, there has been no funding budgeted in any amounts to cover the cost of travel or any other indirect supports.

The NDIA has previously applied funding ranges to levels of support when there were three levels of transdisciplinary support packages. These were replaced as a more individualised approach was considered desirable and more aligned to a return on investment. If an insurance approach is to be delivered into the future with an appreciation of return on investment, then

research into current programs delivering best practice, the cost of delivering these supports and the outcomes they achieve must be understood. A starting point might be to identify high quality support programs and the costs of delivering the programs. Funding value for money support focuses on the lifetime value for participants. Supporting high quality early childhood intervention supports will reduce lifetime costs of participants. It is important that NDIA clearly signals the types of supports and services that families can spend their funds on, so that the investment for the child and family will be realised. The marketplace cannot be relied on to do this and the NDIS should have stewardship over a significant investment that could be life changing for children and their families.

Recommendation 5: That the NDIA identifies and costs models of support that are considered best practice, links these to reasonable and necessary supports and communicate this clearly to families.

The consultation paper assumes that mainstream support services are also supporting children with autism well and we know that this is not the case. It is well documented that gaps in these service systems have impacted on holistic family support. Many of these gaps existed prior to the NDIS transition, however a significant number of gaps developed during transition due to altered funding arrangements at State and Federal levels. Lifestart acknowledges that the NDIA cannot take responsibility for funding services that are not in its scope. However it cannot obfuscate its responsibility for investment in early childhood intervention through a reliance on mainstream services that do not exist or that are not accessible or appropriate for children with autism. A medium-long term strategy targeting sector capacity building (especially in education, health and child and family services) is required to build knowledge and supports for all children with disability and developmental delay. This could commence with a smaller pilot program that can be evaluated for effectiveness and then scaled. There are learnings from initiatives across the States that could be used to form a joined-up strategy with relevant mainstream support services. Examples of this in NSW include the Sector Capacity Building initiative for community preschools, funded by the NSW Department of Education and the First 2000 Days Framework by NSW Health.

Recommendation 6: That the NDIA develops a comprehensive plan to build the capacity of mainstream services to better support all children with disability and developmental delay.

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