

Lifestart Response to Consultation Paper on supporting young children and families early to reach their full potential

About Lifestart

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

Lifestart is a registered National Disability Insurance Scheme (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.

Lifestart currently employs more than 240 staff, including 150 specialist staff including educators and allied health professionals. During 2020 Lifestart supported approximately 10,500 children and young people across all our teams.

Lifestart was one of four Early Childhood Early Intervention Partners in the initial Pilot conducted in the Nepean Blue Mountains region of NSW in 2015/2016 to implement the original ECEI Approach. Lifestart was also one of two Transition Advisors in NSW to advise Early Childhood Intervention providers, funded by Family and Community Services (Ageing, Disability and Home Care) Department to transfer as Transition Providers services across to the National Disability Insurance Scheme, as well as transitioning in its own right. In 2018 Lifestart commenced as an ECEI Partner in the Community under the NDIS.

Lifestart maintains a strong investment in learning and development across all its teams and secures a strong return on investment with this commitment.

Lifestart Response

Lifestart welcomes the opportunity to provide feedback on the National Disability Insurance Agency (NDIA) proposal to bring about a number of changes to the delivery of Early Childhood Early Intervention across Australia through its ECEI Reset (the Reset). As Lifestart has been actively engaged in all aspects of the ECEI Approach since its inception, and was active in its original co-design, we believe that we are well placed to comment on our experience as an early childhood partner. This response will address those matters that we see as a positive approach to change, identify challenges that we have encountered and make suggestions for a renewed focus on the original intent of the ECEI Approach.

For the purposes of this submission 'family/ies' refers to both families and carers.

There are many examples of how the implementation of the ECEI Approach has not reflected its design as rolled out in the pilots, and the Reset represents a way to go back to the original intent and build on that to enable children and families/carers to achieve more positive outcomes regardless of whether a child does go on to receive a funded plan. The recognition of identified particular 'pain points', challenges and gaps should lead to improvements in the implementation of the ECEI Approach.

We note that many of the recommendations contained in the 2019 Review of the National Disability Insurance Scheme Act 2013 completed by David Tune (the Tune Review) are also reflected in the ECEI Reset papers and recommendations.

Lifestart accepts the NDIA's concerns around scheme sustainability and agrees that there should be a commitment to improvements in efficiencies and effectiveness of service delivery. Efficiencies cannot be at the expense of improved outcomes for children and their families. If we hold true to the UN Conventions and Protocols on the *Rights of People with Disabilities* and the *Rights of a Child*, we need to be careful not to conflate scheme sustainability with the rights of all children who are deemed eligible to access funding under reasonable and necessary supports based on their individual needs. A rights-based focus built on equity of access is essential for all children to participate meaningfully and inclusively in their community. Likewise, the lack of consistency in size of plans also needs to be addressed.

We note that the NDIS Quarterly Reports continue to show trends with increasing numbers of young children, and in particular children with a diagnosis of Developmental Delay or Autism Spectrum Disorder being assessed as being eligible for reasonable and necessary funded NDIS plans.

We support the Reset intention to create a distinct ECEI Implementation model which is strongly differentiated from the general adult-centric Scheme, with a focus on a family centred approach aligned with best practice. Lifestart agrees with the intent of the Reset that the 'right children receive the right mix of support for the right period of time'. This must include children from the point when families may have concerns about their child's development to receipt of supports under Short Term Early Intervention (STEI), being supported in mainstream services and settings, planning and implementation of funded plans to possible transition out following appropriate supports. The position that a child does not require a funded plan should be equally valued with the child who may receive ongoing funding due to a lifelong disability. There needs to be improved recognition that some children may need NDIS funded support for a time but not throughout their lives.

Lifestart is of the view that a funded plan should be seen as a strategy to achieve improved outcomes in a child's life, as well as their family. Too often the funded plan is seen as a goal in its own right. The NDIS does not equal a funded plan and we hope that the Reset will improve sector and community understanding of this premise. The view that the NDIS equals a funded plan needs to be changed in the early childhood/ education and care, disability, school education, health and housing sectors, along with mainstream government and community sectors and the wider Australian community. This broad perception has been a failure of the Scheme and one can see how it emerged. The result is the marginalisation of many of those people living with disability who are not eligible for a funded plan yet still need supports to live an ordinary life. Such marginalisation can commence in the early years of a person's life trajectory. Education of families, as well as the broad service system, is essential if there is going to be any change in the expectation that only a funded plan will make a difference in a child's life. Families need to feel empowered to question the barriers which they encounter or the push from some parts of the NDIS service system that the bigger the plan, the greater the success for their child and their family.

The concept of choice and control in the early years has failed to deliver an understanding that choice for participants new to the scheme often requires the proviso of 'informed' choice. That is part of the intent of the ECEI Approach to work with the family/ carer to build their capacity

to support their child and at the same time recognising that they are the expert in their child's life.

Families need to feel confident that, should their child's needs change over time during their early years, they can re-enter ECEI if they have transitioned out to mainstream supports.

While there have been a number of reviews of the ECEI Approach since the commencement of the pilots across States and Territories, the current review is the most extensive and considered; and provides a way forward that can result in positive outcomes for children living with delay or disability, along with the families and carers.

The ECEI Approach when first designed and implemented was hailed as a strong investment in the trajectory of a child's life to enable them to participate more meaningfully and inclusively in their community, whether or not a child went on to being assessed as eligible for a funded plan. Lifestart endorses much of what is articulated in the proposed ECEI Reset.

Recognised Areas for Improvement

Lifestart agrees with the 8 areas which have been recognised as requiring improvements. In particular Lifestart recognises the following as critical for reform:

Social versus medical model of disability

Lifestart agrees that the rollout of the NDIS, including ECEI, has resulted in an inadvertent focus on a medical model of disability rather than a social model as was the intent of the underlying principles for the NDIS under the National Disability Strategy.

In our ECEI experience we have seen the dismantling of years of evidence-based practice because parents often do not and cannot be expected to understand what they should be purchasing as they implement their child's plan. Where a child does not require a funded plan based on assessment there is frequently a sense of failure that the family has not managed to secure funds for their child.

An essential underlying principle of the ECEI Approach is to build the capacity of the child and of the family to support the child. This investment has been a casualty in recent years with the strong focus on planning and reviews and little capacity for Early Childhood partners to invest time in what is now being referred to as STEI.

It has been disappointing to see the change from the period when the pilots commenced at which time there was a focus on outcomes for the child and their family. The conversation has shifted from outcomes needed to increase participation and inclusion to *how much support can I get for my child* and secure funds for therapy services that will 'fix' or 'cure' a child. This observation is in no way meant to detract from those children who require reasonable and necessary supports as determined through the ECEI process.

Workforce

Early Childhood Partners need to be able to undertake front end service delivery and provision of short term early intervention supports for children who may not require an NDIS individualised reasonable and necessary support funded plan. To undertake this work, Early Childhood Partners need experienced and well credentialed qualified staff to undertake clinical assessments and make recommendations about appropriate supports required. Educators and allied health professionals undertaking this work need to be well supported

through clinical governance arrangements. This work cannot be done by generalist services and providers that do not have the experience and knowledge in delivering effective ECEI services. The proposal to increase the focus on STEI supports will require the NDIA to allocate appropriate funding to attract and retain such a workforce.

Lifestart acknowledges that there is also a need to invest in suitably trained program support workers or generalist allied health assistants, along with peer support workers, to assist the specialist team enable successful delivery of ECEI. None of these should be considered as a cost saving for replacement of the specialist but rather as an adjunct to these staff to enable a highly competent and effective workforce.

Resetting the ECEI Approach

Recommendation 1

Explain, rename and promote the NDIS Early Childhood Approach – and stop using the term “gateway” – so families understand and follow a clear pathway with a mix of early childhood support options available.

Lifestart agrees that the ECEI Approach be renamed the Early Childhood Approach and that the descriptor “pathways” replace the term “gateway”.

Lifestart welcomes promotion of a clear pathway with a mix of early childhood supports options being available, including in mainstream and community settings. Families require information that is relevant, useful and clear to help them make informed decisions about what they want for their child.

A key driver for the Reset is the need to improve the experience for children and their families to enable them to obtain more support earlier in their lives and ensure that these are the right supports that meet their individual needs. Another imperative is that families will gain knowledge of how they can take part in their child’s supports and use other supports in their community. This then can start an understanding of family centred practice and a social rather than medical model of supports.

Recommendation 2

Clearly and consistently, communicate the intent of the new Early Childhood approach and the Agency’s support for best practice, so families understand how the approach informs positive outcomes for young children.

Lifestart endorses the above recommendation. The concept of the ECEI Approach can be very confusing for some families as they navigate their concerns about their child’s development or may have received a recent diagnosis of disability for their child. The need for clarity and consistency in its communications has been identified continually as a priority for the NDIA to address. The constant changing or amendment of information has made it extremely difficult for families and other stakeholders to gain an understanding of the ECEI Approach and how it can inform positive outcomes for young children. While partners can work diligently to promote best practice to families and the wider community, this needs to be also clearly articulated by the NDIA.

Recommendation 3

Develop and publish new Early Childhood-specific Operating Guidelines – so our decision-making processes and best practice evidence are transparent and implemented consistently by partners and NDIS planners.

Lifestart endorses this recommendation. The lack of consistency and transparency of decision-making processes has been an ongoing issue for Lifestart as an Early Childhood partner.

Families need to be reassured that decisions are based on equity and fairness.

Recommendation 4

Create a distinct delegate/planner workforce that is exclusively focused on young children and their families, to improve the way families are supported.

From Lifestart's experience over the life of the ECEI Approach to date there is a clear need for delegates (NDIS Planners) and Early Childhood partners to be well trained in understanding best practice in early childhood. NDIA planners making decisions about reasonable and necessary supports for children 0 - 7 years need to be appropriately qualified to make decisions which reflect best practice. A planner making decisions about what is considered reasonable and necessary for older children and adults does not necessarily have the skills and competencies to apply this to young children.

Recommendation 5

Continue to work with federal, state and territory governments to identify gaps and strengthen the role of mainstream services, so all young children receive support from the appropriate system when they need it.

Lifestart agrees with this recommendation.

The NSW Government has abrogated much of its responsibility for provision of wrap around and more broad supports as an adjunct to NDIS funded supports. Colleagues and other providers have shared similar stories of what is happening in their State / Territory. The review of the National Disability Strategy will hopefully change the community view that the NDIS covers everyone living with disability and all are in receipt of funding. The National Disability Agreements should be driving this in a spirit of co-operation.

Recommendation 6

Consider a range of mechanisms that will enhance compliance of providers with the NDIS Practice Standards on Early Childhood Supports and increase awareness by families of providers that adopt that best practice framework.

Lifestart agrees with this recommendation. This should be applied to both registered and non-registered providers.

Lifestart was involved in the provision of feedback in the development of the Early Childhood Practice Standards. We saw it as a driver to ensure best practice in the early years so that children and their families would have access to high quality evidence-based practice driven

by a commitment to recognising that this investment in the right supports at the right time could make a significant difference in a child's life and that of their family.

Families need to be provided with increased awareness of the value of all providers being accredited against the Early Childhood Practice Standards.

Concerns about cost of registration processes should not be an impediment to mandating that all providers, whether a not-for-profit organisation, for profit businesses/ partnerships or individual practitioners, need to be accredited against the NDIS Practice Standards (the Standards). In Lifestart's view, registration with a professional association or peak body should not replace a requirement for accreditation against the Standards. They are two completely different processes with very different outcomes. As with Specialist Behaviour Support, the accreditation against the Standards should not be tied to a professional body based on qualifications.

The accreditation process should demonstrate to families and other stakeholders that a provider has the skills, experience and knowledge to work effectively with children and their families, as well as others significant in the child's life.

Lifestart is of the view that the Agency can establish a unit to manage the accreditation process or embed it in the Early Childhood Services Branch. Alternatively, the process could be managed by the NDIS Commission.

Implementation of the accreditation for all providers of supports to children in the early years would ensure some controls over and accountability for the quality of services and supports being offered to families for their child. If the ECEI Approach is linked to delivery via a key worker model and family centred practice where there is a strong focus on capacity building for families, then this can be followed up by providers with a sound knowledge of best practice. Such a strategy is going to lead to improved outcomes for children and families as well as the communities in which they belong.

The enablement of self and plan managed plans for children in the early years lacks the rigour of accreditation against the Early Childhood Practice Standards. The removal of self and plan management in the first year of a child's plan could also have a strong influence on building families' awareness of best practice and a family centred approach. There also needs to be increased awareness raising of the benefits of the key worker model and a transdisciplinary team. This could be delivered through Agency plan management.

Recommendation 7

Improve sector wide understanding of how to identify families and young children experiencing disadvantage or vulnerability and tailor culturally appropriate services and resources so they can benefit from early intervention support.

Lifestart agrees with this recommendation. This improvement should be a collaboration among families, the NDIA, Early Childhood partners, providers and other stakeholders. There needs to be a commitment to tailoring culturally appropriate services and resources in a manner which has long term benefits and is not impeded by short term funding and lack of appropriate timeframes to actually make a difference in people's lives or the community which supports them.

The NDIA must recognise the urgency for reviewing current arrangements with States and Territories to ensure that STEI can be successfully delivered in those natural environments and settings where young children spend most of their time. This urgency also needs to be addressed in terms of other sectors across Commonwealth and State jurisdictions appropriately fund those services and supports for which they are responsible for children and families.

Recommendation 8

Implement tailored methods of delivering supports for young children and their families living in remote and very remote areas to strengthen access to services.

Lifestart agrees that tailored methods to recognise diverse needs of young children and their families living in remote and very remote areas to strengthen access to services need to be implemented within the context of place-based support and linked in innovative and collaborative ways to other supports. Lifestart, like other organisations, has had some success in delivering supports in innovative ways. Such place-based supports need to be developed beyond the concept of telehealth. There are a number of learnings from Aboriginal and Torres Strait Island health programs which could be applied to the disability sector and in particular to supporting young children.

Recommendation 9

Implement a tailored Independent Assessments (IAs) approach for young children to support consistent access and planning decisions.

Lifestart agrees with this recommendation.

The introduction of IAs in the early years will need to include a heavily nuanced recognition of the individual needs of each child and their family if we are committed to best practice using a Key Worker model and wanting to maximise outcomes for all children supported through the ECEI Approach. We need skilled and appropriately qualified staff to conduct the suite of assessments which will be available. If this rigour is not in place there will be future impact on Scheme sustainability as well as the provision of reasonable and necessary supports within a child's plan.

Lifestart believes that Early Childhood Partners, provided they have specialist staff trained and / or accredited to appropriately utilise a range of identified tools (e.g., those listed in the Assessments Tools Appendix attached to the ECEI Reset Consultation documents), are well positioned to conduct independent assessments.

Recommendation 10

Increase Early Childhood partner capacity to identify and help young children and families from hard-to-reach communities or those experiencing disadvantage or vulnerability, so they can connect to – and benefit from – early intervention supports.

Lifestart agrees with this recommendation. Please see notes in Recommendation 7 above.

Recommendation 11

Increase Early Childhood partner capacity to connect families and young children to local support networks and services in their community.

Lifestart agrees with this recommendation.

Recommendation 12

Increase Early Childhood partner capacity to provide Short Term Early Intervention (STEI) support to eligible young children and families for longer.

Lifestart agrees with this recommendation. From our experience in the Nepean Blue Mountains pilot, solid and well informed investment in supports (now described as STEI), made a difference in the capacity of some families to be able to be supported in mainstream services and settings. Implementation of STEI needs to be resourced appropriately and cannot be governed by Early Childhood partners having to balance competing demands of plan building, plan implementation and plan reviews. Each function of the ECEI Approach needs to be considered as part of a continuum of supports and appropriately resourced.

In delivering STEI supports it is essential that a well-resourced and experienced tertiary specialist workforce undertake this work, supplemented by ancillary staff. This is a much smarter, efficient and effective way to manage shorter term interventions of up to 12 months and ensure best return on investment and to manage numbers of children going on to receive a funded plan where this may not have been a necessary result in terms of their ongoing needs.

Recommendation 13

Clarify the interpretation of the developmental delay criteria under Section 25 of the NDIS Act (2013) to improve the consistency and equity of Agency decision-making. Establish thresholds for key criteria using Independent Assessments.

Lifestart agrees with this recommendation.

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.

Lifestart agrees with this recommendation. We have noted that for many providers there is a view that early childhood intervention ceases as a child commences school education. Family centred support for children in the beginning years of school will lead to improved educational outcomes for children and enable continuity for children and families. It will require a commitment from the education sector to recognise the positive benefits for all students to access an inclusive education and that some children may require additional supports to achieve this goal. Increasing the age limit also reflects international definitions of Early Childhood.

Recommendation 15

Use the early intervention criteria, under Section 25 of the NDIS Act (2013) to make decisions around access to the NDIS for all young children.

Lifestart agrees with this recommendation.

Recommendation 16

Increase Early Childhood partner capacity and flexibility to tailor the level of support provided to families to implement a child's plan and more quickly connect to the right supports and services.

Lifestart agrees with this recommendation, while recognising that there is a critical issue of supply in some regions across Australia.

Recommendation 17

Introduce a 'capacity building support in natural settings' item in the NDIS Price Guide to encourage families and early childhood providers to prioritise supports delivered at home or other natural settings.

Lifestart strongly endorses this recommendation.

Recommendation 18

Publish new guidance about what is considered 'reasonable and necessary' when making decisions around support for children on the autism spectrum, based on evidence found in the Autism Cooperative Research Centre (CRC) 2020 report.

Lifestart agrees with this recommendation.

Recommendation 19

Empower Early Childhood partners to provide families with clear advice about the best providers for their child and situation so families can make more informed choices.

Lifestart agrees with this recommendation with several provisos.

- There needs to be transparent evidence that providers are accredited against the Early Childhood Practice Standards which would mean that they have been assessed against best practice and demonstrate a commitment to family centred approaches
- There needs to be provision of clear information to families about what they are seeking from a provider to assist in implementing their child's plan.
- There needs to be clear mitigation strategies to minimise any real or perceived conflict of interest.
- While recognising that in some areas of Australia there may be no or very limited access to providers, where there is choice of provider then the Early Childhood partner needs to be able to explain why it has recommended particular providers and not others. The partner needs to be able to rely on critical information from the NDIA to communicate such advice.

Recommendation 20

Undertake further ongoing research and study on the outcomes of young children after receiving early intervention support, to inform future policy and operational changes.

Lifestart agrees with this recommendation

Recommendation 21

Improve the existing annual progress review process for young children, to support families to celebrate the achievement of reaching their goals and outcomes and transition out of NDIS supports to the next stage of their lives.

Lifestart agrees with this recommendation as long as there is clear transparency as to why a child is transitioning out and there are adequate supports in community to support the child and family. This review cannot be applied just for reasons of Scheme Sustainability.

Transition out can only happen if there is something to transition out to and our community needs to ensure that such children and families do not fall through the cracks. Often these cracks are due to lack of other support systems where government agencies have abrogated their responsibilities to vulnerable people.

Recommendation 22

Ensure providers are using the recently introduced ‘provider outcomes report’, as a mandatory measure to evaluate the effectiveness of their supports and services.

Lifestart agrees with this recommendation. This requirement also reinforces the need for all organisations or individual practitioners providing supports to children in the early years and their families to be accredited against the Early Childhood Practice Standards.

Recommendation 23

Offer families of young children a ‘transition out’ plan for up to 3 months’ duration, to support them to transition to the next stage of their lives, if they are no longer eligible for the NDIS.

Lifestart is of the view that the ‘transition out’ plan needs to be extended to up to 12 months’ duration due to the uncertain state of the capacity of STEI supports being delivered

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