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RESPONSE TO QUESTION ON NOTICE

*Joint Standing Committee on the National Disability Insurance Scheme
Provision of services under the NDIS Early Childhood Early Intervention Approach (ECEI)*

Lifestart has welcomed the opportunity to both make a submission and give evidence in person to this Inquiry at the Sydney hearing held on 3 October 2017.

During this evidence, Lifestart was asked by Senator Gallacher to take a question on notice in relation to the closure and scale back of family services in the community that may have traditionally provided additional support to families who have a child living with disability or developmental delay. This question followed Lifestart's evidence that these important supports appear to be diminishing since the transition to the NDIS began in NSW.

By way of background to this response, Lifestart is currently both a Transition Provider, NDIA Partner in Community for ECEI and a Registered Provider of Supports across the Greater Sydney area. Our teams in both service streams are able to provide us with feedback about the community supports available to families in their local areas. In addition, Lifestart is also one of two Transition Advisors in NSW, providing support and advice to 28 ECEI Transition Providers in NSW. In this capacity, we receive feedback from across the state about the challenges that families may face in accessing services in local communities.

The needs and strengths of a child with a disability or developmental delay cannot be separated from the family and it is acknowledged in research that positive outcomes for children are enhanced when families are supported, empowered and resilient.

We are aware that under the Stronger Together 2 initiative in NSW, there were some family services that were funded by Family and Community Services (FACS) NSW through Ageing Disability and Home Care (ADHC). Some of the funding for these family support services for families appears to have been "rolled in" to the NDIS as part of NSW's contribution to the NDIS. In providing the Committee with this feedback, Lifestart would like to acknowledge that we cannot know the exact reasons why these services have been withdrawn or the funding source(s) they relied upon. However the services have all previously been an important part of the jigsaw of supports provided to families so that positive outcomes could be achieved for their child and family.

At the same time, the funding for the ECEI approach is insufficient to adequately provide these wraparound family supports and some of these supports are now the responsibility of other service systems as per the COAG agreed Principles to Determine Responsibilities NDIS and Other Services.

Family Support Services

The following specific information in relation to changes to family supports has been reported to us and represents just a snapshot of the anecdotal reports in the sector:

- closure of Intensive Family Support services, for example In South West Sydney (Uniting) and the Illawarra/Shoalhaven
- closure of the Aboriginal family support program Birrung Gurung (Uniting – South West Sydney)
- closure of Extended Family Support services in a number of areas
- Services our Way (for Aboriginal & Torres Strait Islander families) have all advised that they no longer have any recurrent funding
- Family Assistance Fund has been devolved
- direct referrals from disability services to Brighter Futures not being accepted (for example, in the Illawarra/Shoalhaven)
- closure of the Little Yarns program, which was taking early intervention into local Aboriginal communities to support the closing the gap initiatives (previously run by First Chance, Hunter region)
- Advocacy services facing reduced or no funding. This has also been widely reported in the media, for example <http://www.smh.com.au/nsw/nsw-disability-groups-face-wipeout-new-figures-show-20171011-gyystp.html>. These services often support families to assert their child's right to access mainstream services such as preschools or schools

In addition, there are many reports from Early Childhood Intervention Providers themselves that they are no longer able to run programs including parent support groups, sibling support activities and family education programs since ADHC block funding has ceased. These programs are not available under the NDIS. While Lifestart has continued to run its supported playgroups, some parent support groups and outreach services to some Aboriginal community groups, we are reliant on episodic philanthropic or corporate support to do this .It is however becoming increasingly difficult to obtain funding through philanthropic organisations for these supports as organisations now believe that through the NDIS and the increased Medicare levy these supports are now provided by government.

Health Services

Lifestart's Transition Advisors have also received numerous reports from Transition Providers across NSW that they are having increased difficulty accessing hospital and community health services. Lifestart's service delivery teams have also experienced this in their local areas. Some specific examples include:

- Community health services refusing to accept referrals for children who have received an ECEI service and do not require an individualised NDIS package but would benefit from ongoing mainstream supports (for example, speech pathology). This has been reported multiple times from the North Coast region of NSW
- Hospitals and health services refusing to provide specialised supports which have not been funded by the NDIS. For example, a Transition Provider in the New

England area reported that a child required casting. This is not covered by the NDIS and the family was refused the service from their local health facility. They have now been forced to consider travel of 8 hours to Sydney in order to seek this.

- Community health services refusing to provide services or place children's names on waiting lists for therapy supports (such as occupational therapy or speech pathology) under the following circumstances:
 - a child is seeking access to the NDIS
 - a child has an NDIS number
 - a child is waiting for/receiving ECEI services

This happens even if the child may have previously been receiving health services and it is unknown whether the child will receive an individualised NDIS funding package.

Future Services

During the preparation of this response, the NDIS has released the Partners in the Community Program, Round Three grant process in which organisations can apply to deliver Early Childhood Early Intervention (ECEI) Services in NSW. Lifestart would like to raise its concern that the guidelines provided for the delivery of ECEI services in this grant information do not address the need for organisations delivering ECEI to have sufficient capacity to provide the wraparound support services. This capacity is an essential component for families in accessing ECEI services as well as for building the capacity of local and mainstream services to do this.

In addition, the grant guidelines have indicated preference for the ECEI Partner to not be a Registered Provider of Support except in exceptional circumstances. These exceptional circumstances are not clearly articulated within the guidelines and Lifestart is concerned that if Early Childhood Intervention support providers are unable to undertake this role, it will result in a market supply issue where there is insufficient specialist disability allied health skilled labour force. We are awaiting further clarification on the tender from the NDIA shortly. It is also pleasing to see that the *National Disability Insurance Scheme (NDIS) Costs* report released by the Productivity Commission today has affirmed the strategic importance of capacity building for both individuals and the wider community.

Summary

Lifestart is aware from both its own direct experience and the anecdotal reports of other ECEI providers that there has been a diminution of mainstream family supports available for families who have a child experiencing disability or developmental delay. These supports are critical to enhanced positive outcomes for children and families in the long-term and represent an important investment in the future participation of children and their families in communities.

Lifestart would be happy to answer any further questions the Committee may have or to provide further clarification on any of the points that we have made in this response.