

## Lifestart Co-operative Ltd



### Response to the Productivity Commission's Draft Report *Disability Care and Support*

Lifestart Co-operative Ltd welcomes the Productivity Commission's Draft Report *Disability Care and Support* on long term care and support for people living with disability. Lifestart hopes that the National Disability Insurance Scheme (NDIS) will provide an entitlement to support for all people who live with disability which impacts on their daily life. The recognition of the person as the primary focus of service provision is an essential driver to ensuring that the person and their family/carers can have more choice and more control in their lives.

Lifestart acknowledges the Commission's powerful statement in its draft report ('the report') that:

**the disability support system overall is inequitable, under-funded, fragmented and inefficient and gives people with a disability little choice. It provides no certainty that people will be able to access appropriate supports when needed... The central message of this draft report is that a *real* system for people with a disability is required with much more and better-directed money, a national approach, and a shift in decision making to people with a disability and their carers. (p. 5 Overview).**

The statement clearly accurately describes disability service provision in Australia in 2011 and the possibility for a NDIS as set out in the report paves a way for the future and gives hope to many families and carers who face a massive battle navigating the disability service system upon receiving a diagnosis for their child. The first paragraph in the above statement is presently a frightening one for a young family, trying to work out how to establish a future for their child and family. The second part of the statement flags the need for certainty which people with a disability and their family should be afforded to over their lifetime. In the case of a child living with disability the family's opportunity to exercise individual choice and seek the 'best fit' for their child should be available with the implementation of the NDIS.

#### **A ABOUT LIFESTART**

Lifestart, a not for profit organisation, provides early childhood intervention and school age services to infants and children with additional needs and their families and carers. Lifestart provides therapy, education and family support services through seven branches across Greater Sydney and the Lower Blue Mountains. Lifestart provides family centred services through a transdisciplinary approach to meeting the needs of children living with disability and developmental delay and their families/carers. It is based on the concept of partnership with children and families/carers to assist and empower them to participate meaningfully and inclusively in our community. Therapists and special educators, along with a team of support staff, work with the child and their families/carers to assist and empower them to participate meaningfully and inclusively in the community. Lifestart is partially supported by government but also relies heavily on the generosity of the community

to provide its services, through philanthropy, donations, fundraising and volunteering. Lifestart's mission is to enable children who have a developmental disability or delay to achieve their potential.

An investment in the early life of a child with a disability or delay, and their family and carers is an investment for the future. Research shows that early childhood intervention ensures the best possible start in life and supports the enhancement of skills for ongoing learning and development. Strong investment in early childhood intervention, in many circumstances, can reduce the costs imposed by demand for services across the broad spectrum of services later in a person's life, and that of their family and carers.

## **B GENERAL COMMENTS**

Lifestart's response to the report will focus mainly on early childhood intervention although it is important to comment on some general thrusts of the paper. The Commission's recognition of the importance of the connectedness between the disability service system and other mainstream service systems such as education, health and housing is well received by Lifestart. The intent of the NDIS to focus on meeting '*disability related needs*' reinforces the need for strong relationships between the NDIS and other service systems. This requires a clear enunciation of supports which will be available under the scheme so that the community is clear about entitlements and other service systems and governments do not renege on appropriate provision for mainstream or generic services, resulting in cost shifting and a diminution of disability services. The intersection of the NDIS with the National Disability Strategy must reflect these safeguards.

### **1 National policy setting and local decision making**

Lifestart supports a future disability service system approach based on national policy setting and decision making at a local level. The decision making at a local level is essential to build capacity, provide flexibility and be responsive to the needs of people with a disability, their families and carers. Families who support a young child with a disability rely on the formal and informal networks in their local and regional areas to ensure that they can access a range of specialist and mainstream services.

### **2 Social capital engendered by not for profit agencies**

Lifestart recognises that the NDIS does not demand that the not for profit sector be the sole providers of disability services in Australia. In Lifestart's experience there are often excellent relationships between private therapy providers, education services and not for profit agencies, all of which are committed to providing complementary services to young children, their families and carers. However, it is important that the social capital engendered by not for profits in the supply of community services is not eroded by a strong emphasis on allowing market forces to prevail in service provision. This contribution by the not for profit sector was clearly identified by the Productivity Commission in its report on the contribution of the sector in 2010. Early childhood intervention services offered by not for profit disability providers such as Lifestart are cost effective while ensuring that a high level of service quality is maintained as well as a strong commitment to innovation.

Lifestart's service provision is built on the notion of empowerment of families/carers to support each other as well as be supported in their service delivery. The value of this empowerment has far reaching effects on the family and the infant or child with disability. Such a commitment is not necessarily going to be forthcoming in an agency where the profit motive is the primary driver.

### **3 Differentiation between Tiers 2 and 3.**

Lifestart is concerned about the gap between Tiers 2 and 3 and that delivery of appropriate supports for some children who may fall into Tier 2 is deleterious to their actual functional support needs. This could be particularly difficult if children with developmental delays are going to be placed in this category rather than in Tier 3 based on the eligibility criteria developed for Tier 3 (b). There could be a massive gap between the receipt of information and referral services as specified in Tier 2 compared with delivery of more extensive and appropriate levels of services and supports available to those falling into Tier 3 (b). The concern is that, for many children with developmental delays and more marginal disabilities, they will once again fall through the cracks and miss out on services as they transition through their life stages. Too often such children can appear later in the juvenile justice and justice systems, fail to secure employment and be socially excluded from opportunities to lead meaningful and valued lives. Surely it can be possible for some people to have access to a range of options which can support them in a proactive way which is not necessarily at the same high cost level as some other services? This would be cost effective long term. Opportunities would also need to be available for people to move into Tier 3 (b) supports should their needs change.

### **4 Tier 3 (b)**

Lifestart requests that the definition of Tier 3 (b) be redefined to include people who may fall outside of the definition of intellectual disability eg children with autism or developmental delay. Children with an early diagnosis of global developmental delay may go on to receive a diagnosis of intellectual disability.

Lifestart requests that consideration be given to defining eligibility for Tier 3 (b) based on functional need rather than a specific diagnosis. This could combat criticism about inequity such as that recently applied to the rolling out of the Federal Government's Better Start initiative whereby five disability types have been identified for eligibility based on level of disability or disability type, rather than the functional needs of a wider cohort of children with disability including rare genetic disorders whose needs may indeed be much greater than say a child with Down syndrome or cerebral palsy. Lifestart supports many children with both these disability types but it also supports many children with other disabilities whose functional needs are sometimes far greater. Delineation based on disability type is discriminatory and marginalises even more some children and their families within a service system which is already marginalised from the community.

### **5 Health**

Lifestart supports many families whose child frequently requires complex health care intervention. This is often costly, has an impact on the general wellbeing of the family both financially, emotionally and often on the employment prospects of the principal carers of the child or infant. Negotiating appropriate arrangements for the provision of health care will be an important aspect of the NDIA. Also ensuring that

health staff have adequate training in the needs of a person with a disability accessing the health system is important.

## **6 Education**

Families with young children with disability or delay often have major concerns about the ongoing education of their child once the child transitions to school. There is much evidence about the failure of the Australian education system to adequately support children with disability or delay in schools. Lifestart welcomes the report's view that *partnerships are essential for achieving positive outcomes for students with a disability. These include partnerships between families, communities and schools that are effective in identifying and responding to the needs of individual students as well as inter-agency approaches through collaborative planning and delivery of services.* (pp 4. 17-19).

Often families have had very positive experiences during the period of early childhood intervention with early childhood education providers, and suddenly they find that the school system is very different. A collaborative approach by the NDIS to ensuring that the education system delivers is essential to supporting young people to become active members of their community. Children with disability have the same rights and entitlement as other children to good educational outcomes at all stages of their education.

## **C EARLY CHILDHOOD INTERVENTION**

Lifestart requests that the NDIS clearly distinguishes the delivery of early childhood intervention services from other models of early intervention in terms of assessments and eligibility. There is clear evidence that many infants and young children will have support needs which will vary over a short time frame even with the most rigorous assessment of a potential or obvious diagnosis. Families often require a high level of support to navigate the early years. Care needs to be taken with the implementation of the NDIS that early childhood intervention service provision is not based on a medical model precluding family centred practice which promotes enablement and empowerment of families and carers to support their child's learning and development in generalised settings and environments.

Chapter 11 of the report deals with early intervention across a number of levels. Lifestart acknowledges the importance of early intervention from when the disability first arises and at various transition points in a person's life.

Lifestart welcomes the commitment by the NDIS to *commence building an evidence base on early intervention*, as well as the development of *linkages with relevant agencies responsible for other early interventions.* (11 p.11.1). Evidence based research in the early childhood intervention sector has clearly demonstrated the value and cost effectiveness of high quality early intervention and demonstrates clear sustainable outcomes for many children, their families and carers. Early childhood intervention services already provide both national and international strong evidence based research through which interventions and models for service delivery for infants and children can be determined. (p.10 Overview and Recommendations).

Intervening early, even prior to formal diagnosis is essential for the child, the family and the community as a whole, as well as setting the scene to boost a child's capacity to participate in education and later adult activities meaningfully and inclusively.

Lifestart supports the NDIS in the need to fund early childhood interventions which are based on good *evidence of effectiveness and an initial assessment of cost effectiveness*. (11 p.11.1). Families and carers often report to Lifestart on the high cost of some therapy and other interventions and this has been particularly the case in Helping Children with Autism (HCWA) programs. Sometimes families, who are overwhelmed by the ways they can navigate the service system, are made to feel that the more expensive the therapy treatment or intervention the more efficacious that service will be and should they not choose that model of service they are denying their child the 'best service available'. Many families are invited to sign up for services for protracted lengths of time and informed that they cannot withdraw if this service does not suit their family and or child.

## **1 Eligibility**

Lifestart recognises that particular eligibility criteria must be applied judiciously or the NDIS is not sustainable. (p. 13 Overview). However, in the case of early childhood intervention there should be strong recognition of the benefits of application of assistance across a wide range of disabilities including developmental delays.

Lifestart is of the view that early childhood intervention, based on sound assessment practices, should be available to the child and their family even prior to formal diagnosis of a particular disability or delay. A protracted delay, pending the availability of diagnosis can result in valuable time being lost which can have profound consequences for the child, their family/carers and support network. Lifestart offers some services to families while they are waiting for a diagnosis to enable them to have access to funded support. Results of this practice demonstrate clearly the value of such an approach to empower the family and achieve outcomes for them and their child. There is, however, a limit to the number of programs where this can be done while such intervention remains unfunded. Families are supported with information and referral services so that they can access other specialist disability and mainstream services but there remains a clear need for early childhood intervention within transdisciplinary or multidisciplinary approaches. Stop gap measures should not be an option for children living with disability or developmental delay.

Lifestart endorses the statement that most people currently receiving specialist disability services would receive more service under an NDIS but has concerns that there is a clear articulation defining the scope and demarcation of services between the federal scheme and state funded services. An example of existing confusion has been the rolling out of the HCWA funding where families have been confused as to whether such funding provides an early intervention service for their child or is meant purely as supplementary funding. The differing application of such funding, by both private and not for profit provider, has also added to this confusion. It is hoped that there is not a repeat of this situation with Federal Better Start funding or indeed the provision of early intervention services under the NDIS.

Comments on the gap between Tiers 2 and 3 above highlight some of Lifestart's concerns on eligibility.

## **2 Assessments**

Lifestart agrees that assessment should be focused on needs and the identification of reasonable needs. The importance of recognising that needs over time can change, warranting fluctuations in levels and types of support is also acknowledged as important. Assessments for early intervention need to be timely to ensure that valuable opportunities for the family and child are not lost. A balance between the rigour of assessments and the needs for support services is required.

Lifestart acknowledges the need for the application of carefully designed and valid assessment tools and the need for independence. Formal reassessments in a non-intrusive manner can monitor the need for ongoing intervention. Evidence of effective intervention and schedules should form the basis of intervention availability and duration.

Issues relating to assessment in early childhood years have been long debated. There is a need for different types of assessments to reflect the needs of the child, family and the purpose of the assessment.

In the case of early childhood intervention, some families may not have had appropriate assessments and a formal diagnosis at the time of seeking service for a variety of reasons. The child may have an identified developmental delay, or rare genetic disorder or syndrome which is taking some time to identify, and the family is seeking a diagnosis. It is often a period of great stress, anxiety, isolation and uncertainty and families need support. The families frequently present for services seeking intervention and can access some family based services pending the formal diagnosis. Intervention at this time can be crucial to maintaining the family as it copes with addressing the needs of the child and their family needs and navigates the assessment/diagnosis process.

## **3 Individualised Funding**

Lifestart welcomes the inclusion of person centred planning, individualised support packages and self directed funding models. However, in the case of early childhood intervention it is essential that appropriate supports and resources are applied to ensuring that families and carers are equipped to be active in planning, implementing and evaluating their support package. Lifestart works closely with families to develop an Individual Family Service Plan which is the core of Lifestart's service provision.

There are a number of functions of service providers which fall outside the ambit of the individualised funding model. These include communications, training and staff development, production of educational resources, equipment, technologies, development of new intervention strategies and research activities. It is essential that these are recognised within the NDIS and are funded appropriately. The development of resources to be used by families in provision of early childhood therapies and strategies in their home and community environment is critical to the success of the program and is a costly component.

## **D WORKFORCE**

Successful early childhood intervention services using a transdisciplinary approach rely heavily on the successful teaming of therapists and special educators who can bring a family focused holistic approach to supporting a child and his/her family. From the family's perspective, the NDIS can provide the means to choose supports which will best meet their individual needs. Good training and support is an essential component of an engaged workforce which can meet the needs of the person with a disability and their family and carers.

Demand for allied health professionals and early childhood special educators is exceeding supply, particularly in early childhood intervention services. These intervention services rely heavily on the employment of therapists and special educators to work with infants and young children. Both these professional streams are contracting seriously in the disability sector and there are many factors impeding attraction and retention of these staff. Not for profit agencies are unable to pay wages offered by the public or private sectors. Unlike some service provision in the disability sector, early childhood intervention services have a funding and model of delivery imperative to employ qualified professional staff to deliver services. In many instances these staff have to be licensed by a professional body. However, the implementation of the NDIS will exacerbate demand for allied health professionals.

There needs to be some form of support articulated between the NDIS and the education systems and reflected in the National Disability Strategy, which will highlight training and recruitment of specialist staff. One example would be an increase in the number of therapy places in universities and promotion of take up of studies in early childhood education with a particular focus on working with infants and children with disability or delay.

Traineeships for aides and other professional support staff need to be addressed in the VET system through promotion of employment opportunities in early childhood intervention and other specialist disability services. Enhancement of skills for therapy aides could be used to maximise intervention modes by therapists and special educators.

There needs to be a national promotion of disability as a meaningful professional career and this promotion needs to begin in the high school years. The CareCareers project in NSW, ([www.carecareers.com.au](http://www.carecareers.com.au)) is an excellent example of how this can be managed in the disability sector.

## **CONCLUSION**

The implementation of the NDIS will have a profound impact on the lives of many Australians and their families and carers who are living with disability. The capacity for change is strong. Lifestart looks forward to a world where all children with disability or developmental delay can access services and supports that meet their individual needs and support their families and carers as they support their child to develop as an active and socially included citizen.

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