



JFA  
Purple Orange

## **Submission**

**In response to the Joint Standing  
Committee on the National  
Disability Insurance Scheme  
Provision of Services under the  
NDIS Early Childhood Early  
Intervention Approach**

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## **About the Submitter**

JFA Purple Orange is a non-government, social profit organisation. Anchored on dialogue with people living with disability, their families, service providers, government and other stakeholders, we seek to identify policy and practice that has the prospect of advancing peoples chances of a good life. Our work is anchored on the principles of Personhood and Citizenhood. Our work includes research, evaluation, capacity building, consultancy, and hosted initiatives.

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## 1.0 Summary

The National Disability Insurance Scheme (NDIS) is a critical social welfare reform in Australia. A focus on achieving the best outcome via a family-centred approach that supports greater inclusion in mainstream settings and builds child and family capacity is proven to have positive effects in early childhood intervention. The NDIA has designed the Early Childhood Early Intervention (ECEI) approach using this strong research and evidence base.

This approach will help identify the type and level of early intervention support each child needs to achieve their best outcomes. Research has shown providing children and families with timely, comprehensive and well integrated early intervention support leads to better longer-term outcomes for children, fostering inclusion and participation in their environment. As an insurance scheme, the NDIS also uses effective early intervention to reduce its medium to long-term liability.<sup>1</sup>

## 2.0 Purpose

JFA Purple Orange welcomes the opportunity to contribute to the Joint Standing Committee on the National Disability Insurance Scheme Provision of Services under the Early Childhood Early Intervention (ECEI) Approach. This submission is based on the views of JFA Purple Orange. This submission provides an outline of the views of JFA Purple Orange on early investment in general, with specific reference to the following terms of reference:

- (a) the eligibility criteria for determining access to the ECEI pathway;
- (f) the evidence of the effectiveness of the ECEI Approach;
- (h) the adequacy of information of potential ECEI participants and other stakeholders;
- (j) the principle of choice of ECEI providers;
- (l) any related matters

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<sup>1</sup> <https://www.ndis.gov.au/html/sites/default/files/documents/Research/NDIA-ECEI-Approach-1.pdf>

### 3.0 Introduction

JFA Purple Orange is the social policy agency of the Julia Farr group, a trio of social profit, non-government organisations based in South Australia, working to improve the life chances of people living with disability. The Julia Farr group (JFA Purple Orange, Julia Farr Housing Association, and the Julia Farr Trust and Julia Farr MS McLeod Benevolent Funds) and its predecessor organisations have been involved with the disability community, older people and other vulnerable groups for more than 130 years.

We are an independent, non-government organisation that fosters innovation, shares useful information, and promotes policy and practice that support and improve the life chances of people living with disability.

### 4.0 Overarching Principles

It is clear from the available research there is a wide range of endeavours being undertaken in an attempt to deliver an early (timely) intervention (investment), borne out of a desire to be helpful to people and families early in their experience of disability.

First, a comment about terminology. The word intervention implies the removal of personal control from person and family, and professionals taking over. If the goal of intervention is to grow a person's or family's capacity, resilience and life chances, then the word intervention is ill-suited. No one would routinely described learning, a living-waged employment opportunity, joining a club, buying a car, taking a vacation, starting a family, and so on, as interventions. Good lives, good life chances, are not characterised by intervention, but by investment. Therefore, the phrase Early Investment will be used for the remainder of this submission.

JFA Purple Orange's work on early investment<sup>2</sup> includes a conceptual framework for thinking about early intervention, which interprets 'intervention' as 'investment' and which encompasses the following 'process' characteristics:

- a Radar (timing) – effective mechanisms for early detection of emerging issues/circumstances where a person is likely to need assistance
- a Compass (orientation) – a values framework that ensures that mechanisms are orientated towards 'front-foot' capacity-building or capacity-recovery in the context of ordinary valued life roles and milestones
- a Map (strategy) – an early intervention technique/ methodology needs to give detailed measurable guidance on how to move a person's circumstances from A to B
- an Engine (resource) – an early intervention technique needs adequate competent resourcing (grunt, muscle) to get the job done.

Importantly, this early investment framework is further underpinned by JFA's Model of Citizenhood Support.<sup>3</sup> The Model presents four main outcome areas against which an early intervention initiative may be measured for its effectiveness in capacity-building, capacity-recovery or capacity maintenance. The four 'content/outcome' areas are:

- Personal Capital
- Knowledge Capital
- Material Capital
- Social Capital

Personal Capital refers to the person's characteristics, strengths, and outlook. Applied to the topic of Early Investment, endeavours that increase Personal Capital would include clinical interventions that create a lasting change, but would also include endeavours that build a child or family's outlook on their own strengths and what might be possible in their life.

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<sup>2</sup> Robbi Williams, Julia Farr Association

<sup>3</sup> Williams, R. (2013). Model of Citizenhood Support, 2<sup>nd</sup> Edition. Julia Farr Association Inc. Adelaide.

Knowledge Capital refers to the presence of information that can assist the person to make informed choices towards a good life. Early Investment endeavours that support this include, for example, information to families about programs, or the work of a well-informed case coordinator who can pass on a mine of practical relevant information to a person or family.

Material Capital refers to the presence of tangible material resources that are demonstrably helpful to the person and family. Early Investment endeavours that support this include schemes focusing on aids and adaptations, home and transport modifications, accommodation support, and direct personal supports arranged through case coordination. Critically, it also includes access to public resources that most people will take for granted – public transport, public buildings and spaces, education, and health.

Social Capital refers to the connection (the opposite of isolation) and fellowship (the opposite of loneliness) that deliver natural supports and a sense of belonging to a person and family. Throughout human society it is easy to find examples of people with common interests or concerns coming together for mutual support and advancement. Early Investment endeavours that support Social Capital include family/carers supports that build peer support networks for people with a common experience of disability, where people can gain hope, knowledge, practical support and fellowship from others on a similar journey.

## **5.0 Key issues**

JFA Purple Orange supports early investment as it can reduce costs to the NDIS in the long term. The Early Childhood Early Intervention (ECEI) pathway is the gateway for a child 0-6 years with a disability or developmental delay to enter the Scheme. Under the ECEI approach a family seeking support for their child is connected to an ECEI partner in their local community who can assess the child's and family's needs.

### **5.1 Commissioning of ECEI Partners**

There appears to be no nationally consistent approach on selection and implementation of the ECEI approach with different options for ECEI Partners in each state. For example, in South Australia the 2016 tender was for one organisation for the whole state and excluded

any organisation that was a registered NDIS provider. Currently there is no ECEI Partner in SA and a temporary system is in place. This is of concern given that SA was the trial site for children coming onto the NDIS and would have been an opportunity to test the ECEI approach. The situation in other states varies: in Victoria there is one ECEI Partner for each rollout area whereas in NSW 57 current ECEI providers are funded.

As with the Local Area Coordinator, it is important that the ECEI Partner is knowledgeable about the local community and services. This reinforces the importance and benefit of selecting local, well-established, deeply embedded, highly knowledgeable community agencies to undertake the ECEI work.

This is particularly important as the ECEI Partner has several roles and depending on the child living with disability and their family's needs this can be:

- Information and linkages to mainstream support and services
- Timely short to medium term supports such as family based education, parenting support services and therapy
- Access to an NDIS Plan

In JFA Purple Orange's 2015 report on planning<sup>4</sup> commissioned by the National Disability Insurance Agency we describe the planning elements the disability community prefers. As discovered through an extensive consultation, people's preferences are to plan in a timeframe that suits them, using a methodology they find accessible, and undertaken with someone they trust.

This arrangement also sets up the opportunity to ensure the participant has genuine choice over where they get their planning assistance from. Noting that such assistance often includes a blend of information, peer connection and capacity-building, this sets the scene for the NDIS to invest in the role and value of Disability Support Organisations (DSOs) - agencies

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<sup>4</sup> JFA Purple Orange (2015) *About pre-planning: An advisory report to the National Disability Insurance Agency (NDIA) on how people can best be assisted to prepare for the NDIS*



that provide information, peer connection and capacity building, and whose role was contemplated in the original Productivity Commission work in 2011.

**Recommendation**

That ECEI Partners should be local, well-established, deeply embedded and highly knowledgeable.

## **5.2 Access to a NDIS Plan based on need**

We note that it is critical that each child and family receives the right support and timely support. The ECEI approach should not be used to restrict entry into the NDIS where this is the appropriate response to the child's needs. Further, there is a risk that children living with disability who are ineligible for the NDIS will be diverted to mainstream early childhood services that do not meet their needs. Commonwealth funding for programs such as Helping Children with Autism and Better Start are being closed to new applicants. State and territory funding is also likely to dry up because:

- a) explicit calculations underpinning bilateral agreements mean those funds are gathered up as part of the agreement and generically transferred to NDIS, or
- b) implicit assumptions at the state/territory level that anything relating to disability and disability service delivery is now the business of the NDIS.

There is no guarantee that all current users of such services or newly diagnosed children who would have received support under an existing program will be eligible for an NDIS individualised funding package (IFP). This reinforces the role of continuity of supports for the former and raises issues of potential gap in support for the latter group of children.

JFA Purple Orange recommend that bilateral agreements be reviewed to test the assumptions underpinning the inclusion of the costs of such local services, and that the NDIS work closely with states and territories to ensure the extent of the above 'gap' risks is fully known, scoped and properly managed before local funding is withdrawn.

**Recommendation**

That a review process is undertaken to ensure that children living with disability who do not qualify for an individualised funding package are able to access early investment support.

### 5.3 Assessment process for access to a NDIS plan or early investment service

Access to early investment services delivered by an ECEI Partner or to a NDIS Plan requires appropriate assessment. If the goal of early investment is to reduce the gap between where a child is now and the goal of participation in community life and the economy, the assessment tool used should clearly measure the outcomes expected from the early investment and where the child is now. We refer the Committee to the Citizenship model<sup>5</sup> as a way of framing how to plan for and measure improvements in a person's life chances.

We further note the importance of consistency between outcome measures and assessment measures. It is not coherent to measure outcomes (the hoped-for situation) in one way and undertake assessment (the current situation) in another. Consideration should be given to whether the current assessment tool for young children (the PEDI-CAT) is appropriate. It is recommended the NDIA review its use of PEDI-CAT for children 0 – 7 years of age, and seek sensitive and robust alternatives to the assessment of support needs in young children.

#### Recommendations

That the NDIA review its use of the PEDI-CAT for children 0-7 years of age

That the NDIS assessment instrument(s) be identical to the instrument(s) underpinning outcomes measurement

### 5.4 Knowledge capital

An early investment approach reduces expenses later in life. In JFA Purple Orange's approach to early investment, Radar refers to the timeliness of the initiative, the extent to which it is available to the person and family at the time when it will be most helpful. This raises questions about how the ECEI is brought to the attention of potential beneficiaries, and when. An initiative will be no use to a person or family if they don't know it exists, or aren't sufficiently informed of its intentions and benefits, or if it is not available (or is withdrawn) at times when it might be most prized.

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<sup>5</sup> Williams, R. (2013) *Model of Citizenship Support 2<sup>nd</sup> Ed.* Julia Farr Association, Adelaide

JFA Purple Orange recommends that the NDIA build the evidence base on early investment for children and families. The evidence base should include the valued role of peer support and connections in information sharing and capacity building. This will assist parents to choose supports for their children based on good information and knowledge and that early investment supports improve outcomes for children living with disability and their families.

#### **Recommendation**

That the NDIA build the evidence base on early investment for children living with disability/developmental delay and their families.

### **5.5 DSOs and peer support**

The Australian government fund local community based DSOs to provide pre-planning support to participants of all ages and their families, through peer support networks which provide good up to date information about the ECEI and its approach under the NDIS. These peer networks will emphasise a family-centred approach that supports greater inclusion in mainstream settings and builds the capacity of young children and the family which is proven to have positive effects in early childhood intervention.

### **5.6 Measuring outcomes**

To provide greater coherence between people's circumstances entering the ECEI pathway and measurement of subsequent return on investment, we refer to our earlier remarks about the importance of the outcome measurement framework being identical to the assessment framework, and being anchored on measuring the gap between a person's circumstances and ordinary valued life chances.

## **6.0 Conclusion and recommendations**

JFA Purple Orange supports the ECEI approach to investment in children living with disability early in their life to build their and their family's capacity. This approach will help identify the type and level of investment support each child needs to achieve their best outcomes. Early

investment will maximise future opportunities to assist them into valued roles in community life.

JFA Purple Orange recommends the following to ensure that the ECEI approach provides timely, comprehensive and evidence-based supports which lead to better longer-term outcomes for children and their families:

- That ECEI Partners should be local, well-established, deeply embedded and highly knowledgeable
- That a review process is undertaken to ensure that children living with disability who do not qualify for an individualised funding package are able to access early investment support
- That the NDIA review its use of the PEDI-CAT for children 0-7 years of age
- That the NDIS assessment instrument(s) be identical to the instrument(s) underpinning outcomes measurement
- That the NDIA build the evidence base on early investment for children living with disability/developmental delay and their families

## **7.0 Request to meet**

We would welcome the opportunity to meet with the Joint Standing Committee to discuss the submission contents in more detail, and to provide additional information/perspective as required.

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