



Connect and Relate for Autism Inc - CARFA

A group of RDI Consultants Australia wide who provide the RDI Program to families.

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Provision of services under the NDIS Early Childhood Early Intervention Approach

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Early Childhood Early Intervention Approach

Joint Standing Committee on the NDIS
PO Box 6100
Parliament House
Canberra ACT 2600

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Connect and Relate for Autism Inc (CARFA) welcomes this opportunity to provide a submission to the Joint Standing Committee Inquiry into the provision of services under the NDIS Early Childhood Early Intervention Approach. This submission will address key issues from the perspective of the members of CARFA who are all certified Relationship Development Intervention Consultants working as sole practitioners in various states and territories of Australia (Tas, Vic, ACT, Qld).

Connect and Relate for Autism Inc (CARFA) is an Australia wide consortium of Relationship Development Intervention (RDI™) Program Certified Consultants formed in 2008. CARFA has been delivering cost effective and highly regarded Relationship Development Intervention services to families eligible for support under the Helping Children with Autism funding for the past 9 years.

RDI™ is a neurodevelopmental, evidence based, family centred intervention approach focused on restoring the parent child guiding relationship that is impacted when a child is diagnosed with a neurodevelopmental disorder, such as, but not exclusively, an Autism Spectrum Disorder (ASD).

Our Mission:

- Empower family relationships, so parents can act as the primary guides of their children's mental, social and emotional development.
- Create powerful learning relationships, that seamlessly integrate home and centre based programs, teachers, parents and students in a productive learning environment
- Enable growth promoting experiences, through carefully understanding each learner's unique bio-psycho-social needs
- Design dynamic curriculum/programs that engage learners in productive cognitive challenges that stimulate neural integration

TERMS OF REFERENCE ADDRESSED

E - Costs associated with ECEI services;

Harnessing the immense power of the family to influence a child's growth and development is a very cost effective way to address a child's needs. Children with a neurodevelopmental disorder, such as ASD have lifelong impairments that can result in the need for many costly and intensive supports later on in their life (ie intensive behavioural programs), if appropriate developmental services are not provided in a timely manner. The provision of specialized, family centred, individualized supports to restore the parent child guiding relationship

- empowers parents
- improves family functioning
- increases the child's capacity for growth and overall competence
- increases the child's independence in learning and activities of daily living
- reduces the types and level of downstream impacts (family breakdown, mental health problems, challenging behaviours)
- reduces the need for costly compensatory supports (ratios of one to one support).

Participant Feedback

The constant stress that we go through every year in the review process, and the lead up to that, has been perhaps the worst aspect of transitioning to the NDIS. We are incredibly grateful for the funding that we receive, but the stress that goes with not knowing whether we are going to get funded to an adequate level every year gives me many sleepless nights and much financial worry. It is very hard making ends meet (we also undertake biomedical and dietary interventions, which are outside the realm of the NDIS, but very costly), without the added stress of having to fund your child's RDI therapy, and this year we did not get as much funding as we needed, meaning that we had to cut one of the two planned 'face-to-face' immersion times with our RDI therapist.

Added on top of this, is the requirement to get re-assessed before the age of 8, to receive continued funding for 'life' (with a diagnosis of ASD under DSM V). As a parent with a child who is not aware that they have autism, this is a very confronting process to go through to receive ongoing funding that is not contingent on functional assessments (and therefore likely diminishing each year, as the child can do more). It is also an expensive process. Our children have already been diagnosed under DSM IV. It is frustrating and expensive to have to go through another diagnosis process.

Concern

Early Intervention costs are increased as a result of delays in the development of plans and families not being given choice to access a family centred model of support such as RDI™. A 'one-size fits all' approach is not individualized and costs more. RDI™ is an extremely cost effective model of intervention for families who are either close to diagnosis or with an eligible child in the 0-6 age range.

Action

More streamlined processes from the point of diagnosis to the plan meeting and provision of funding will reduce costs as the earlier intervention commences the better the outcomes for children and families. NDIS planners need to be better informed and trained in listening to

parents goals and offering a wide range of service models to families needing early intervention, including family centred services such as RDI™.

F - Evidence of the effectiveness of the ECEI Approach;

Families of newly diagnosed children who would like to receive choice about their services are being given a 'one size fits all' response by planners. It is difficult for them to access information about the range of services that they could potentially access, causing long delays in finding private, innovative and family centred models of intervention such as RDI™. Recent research evidence depicting the pathway of autism for children indicates that no child is born with ASD, instead they reach a critical tipping point in their development which impacts the parent child guiding relationship. Family based interventions that focus on optimising parent child interactions delivered as early as possible are quoted by Dr Andrew Whitehouse in his recent journal article as showing promising outcomes. (*Elizabeth Usher Memorial Lecture – Rethinking the clinical pathway for autism spectrum disorder and challenging the status quo, International Journal of Speech-Language Pathology, 2017; 19: 208-217*). It is therefore of concern to have a service system requiring long assessment processes and plans that only reflect more traditional models of service delivery (ie multidisciplinary allied health teams working with the child only) adding stress to family functioning. The RDI model of intervention incorporates many aspects of best practice in delivering early childhood services as outlined in the ECIA National Guidelines for Best Practice - RDI™ meets the following criteria

- Natural learning environment of the child
- Developmental framework
- Key worker model

Participant Feedback

As a family who received funding under HCWA, as well as the NDIS, the set up under HCWA was better, as we had direct contact with an Autism Advisor, who really linked us with the field of ASD and enabled us to feel connected. Under the NDIS, we feel very disconnected from anyone else with Autism, and from the ASD field in general.

Planners from the NDIS seem mostly professional, but the relationship seems somewhat distant and impersonal, given that most communications are now done through telephone (and often the planner isn't the same as when the last review was done = lack of relationship and continuity). In the early days of the NDIS, the face-to-face meetings with the planner (even in our home, in the early days) were appreciated – it really gave the connection that most people value, particularly when they have been isolated from the community through disability.

Concern

Families feel more isolated, are not being given choice and there is a lack of innovative supports being made available to parents of newly diagnosed children, or children in the 0-6 age range. Private practitioners operating in this sector are being impacted by the preference being given to a key agency or larger organisations.

Action

NDIS planners should have more time to meet with families and should be aware of and disseminating information about a range of effective interventions to families, including the RDI™ model of intervention. Communication channels between NDIS staff and participants need to be improved and more continuity achieved.

I - Accessibility of the ECEI Approach, including in rural and remote areas;

Families living in rural and remote locations are often disadvantaged due to being able to access a more limited range of specialized service supports locally compared with people living in more densely populated areas. The RDI model of intervention is fully accessible to families living in rural and remote locations. It can be delivered through a Telehealth service model reducing the demands and costs associated with families needing to travel long distances with young children to access services. Parents of a child with ASD are able to access specialised and individually tailored intervention directly in their own home. The RDI model empowers parents to support their child's growth and development in their own environment, tailoring it to the individual child and family's needs. Both parents are typically involved in the intervention which builds family cohesion and results in a unified approach using a consistent developmental framework. It is also a portable service, meaning that if the family moves to a different location, they can maintain continuity of support and continue to work with the same professional receiving a consistent model of intervention.

Concern

High costs associated with families or services needing to travel to rural and remote locations exist. There are limited alternatives being offered to these families as planners are unaware of models of services that operate through Telehealth, such as RDI™.

Action

Information about RDI™ should be made available to NDIS planners working with families in rural and remote Australia.

J - Principle of choice of ECEI providers;

Under the HCWA model of funding, parents were provided with a choice of agency and service model, (ie centre based, individual therapy, family centred intervention) which included working with a certified RDI™ Program consultant. The implementation of the new ECEI pathway under NDIS is resulting in a backward step, whereby families are not being given choice and control over service options. Planners are not adequately informed about the range of available services and from our experience, provide more limited information than in the past under the Autism Advisors and HCWA Provider Panel.

When participants meet with planners their goals and needs are not being listened to and flexibly responded to in order to provide them with a range of options or choices about which services they could access. It appears that in the current guidelines, when parents enter the ECIA pathway they are provided with 'the light touch' and are funneled into a large agency provider. This will effectively limit families being able to access private therapists of their choice, including RDI™ Program certified consultants.

Participant Feedback

The evolution of funding arrangements and care arrangements and models under the NDIS has been a continual source of confusion for families. We really have no idea what model is currently in service or is being considered. In regard to the fairly recent model of having a key intervention provider, this model has never worked for us, and will not work for others, who, like us, know which providers we want to deal with, and arrange these services independently of one key provider. We are not interested in going to one provider for all of our services – we know through long experience what works and what doesn't, and we want to stick to it.

Concern

There is inconsistency in the quality of information given to parents in the ECEI pathway. Parents of young children are most vulnerable within the service system at the point of entry/diagnosis. Trust is being given to large agencies with a vested self-interest creating a bias in the way guidance is being given to participants.

Action

Improve flexibility of response in the way that plans are developed and allow greater choice for participants.

K - The application of current research and innovation in the delivery of ECEI services;

Relationship Development Intervention is an innovative model of service provision addressing the parent child guiding relationship using a process of family consultation and an on-line learning system. When the HCWA provider panel was first introduced in 2007, the RDI™ model of intervention was reviewed as evidence based by Monash University and was determined as meeting criteria for inclusion at that time. RDI™ met criteria as evidence based again five years later in the 2012 published review. (*Early Intervention for Children with Autism Spectrum Disorders: 'Guidelines for Good Practice' 2012, Prior and Roberts*)

RDI Professional Training is a unique educational program available to people with a diverse range of professional backgrounds and expertise including allied health practitioners, people with teaching qualifications, lived experience in the field of ASD and parental experience. RDI professional training is

- rigorous, requires 18 to 24 months of clinically supervised practice,
- follows a structured protocol,
- incorporates professional ethics and has a code of conduct.

RDI Consultants are required to meet annual re-certification standards. Ongoing professional development and recertification ensures that RDI™ Certified Consultants keep abreast of the most recent research and trends in the field of neurodevelopmental disorders. The on-line RDI™ Family Consultation Program and Dynamic Intelligence Curriculum remain innovative as they are revised to reflect newer research findings and incorporate the latest thinking from the field of ASD. Continuing to only fund and promote child focused traditional therapy interventions in a multidisciplinary model of service delivery does not uphold the NDIS vision of achieving innovation in the market place, especially in the field of early childhood where research trends support alternative models (ie parent coaching).

Participant Feedback

When we first tried to get funding for RDI under the NDIS, no one knew anything about it. There were many phone calls and emails providing details of the therapy, and substantial consideration about whether this was something that the NDIS might fund (despite being an approved therapy under HCWA). The inconsistency astonished and dismayed us, and provided much stress to an already stressful situation. There was also the added complexity regarding the qualifications of the therapists – anyone who did not have an allied health degree was treated with suspicion, even if they were a certified RDI consultant. Those without a degree but with RDI consultant qualifications were regarded even more poorly (by NDIS planners).

RDI works as an early intervention therapy (and beyond early intervention too). We are seeing great success with our son, and would definitely recommend it to others who are prepared to put in the time with their children to help remediate autism.

Concern

- a) We strongly believe that there is a lack of innovation being promoted or endorsed within the ECEI pathway. There is also a worrying potential for bias and/or a conflict of interest in the way the ECEI partner operates because they are also providing direct services to participants.
- b) The sole qualification of RDI™ Program Certified Consultant is not recognised under the new NDIS provider guidelines, meaning that the ongoing availability of this innovative service to families may be in jeopardy.

Action

Develop effective safeguards to ensure innovation is possible and prevent market monopolies from developing.

Amend the NDIS provider list to recognise in it's own right, the professional qualification of RDI™ Program Certified Consultant.

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