National Best Practice Guidelines for Early Childhood Intervention

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The Dietitians Association of Australia (DAA) is the national association of the dietetic profession with over 5800 members, and branches in each state and territory. DAA is a leader in nutrition and advocates for food and nutrition for healthier people and healthier nations. DAA appreciates the opportunity to provide feedback on the National Best Practice Guidelines for Early Childhood Intervention by the Early Childhood Intervention Australia for the National Disability Insurance Scheme.

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DAA interest in this consultation

DAA is concerned about the identification and treatment of nutrition issues for infants and children with disabilities. Early intervention for children and their families with respect to safe intake and adequate food and fluids supports growth and development[1] and gives children the energy to respond to other therapies.

DAA is responsible for the Accredited Practising Dietitian (APD) program as the platform for self regulation of the dietetic profession. APDs are the dietetic and nutrition professionals who are qualified and credentialed to support infants and children with disabilities, along with their families. APDs aim to work with other professionals in a collaborative approach to assist children with disabilities and their families to achieve their goals.

Recommendations

DAA recommends that the NDIA institutes a process to engage all professional contributors to early childhood intervention (ECI)

- to tighten the model of teamwork presented in this consultation and recognise the roles of all contributors to ECI ,
- to agree on terminology for this model to promote mutual understanding and collaboration between contributors, and
- to inform development of a robust evaluation methodology of the model.

Summary or key messages

DAA supports early intervention but is concerned that the Early Childhood Intervention Best Practice discussion paper has been developed using an incomplete evidence base. The transdisciplinary key worker model outlined has the potential to place children at risk and to force professionals or support workers to practice beyond their scope of practice.

Discussion

Introduction

DAA supports the concept of early intervention through the NDIS to enable children with disabilities to thrive. DAA considers that the NDIS has the potential to improve opportunities for infants and children with disability to enjoy greater participation in the community, and ultimately to contribute productively to the community. Children, their families and carers stand to benefit from the opportunities under the NDIS.

While it is early days for implementation of the NDIS, reports from members indicates that the inability of some children to consume food and fluids in adequate amounts and safely is not well recognised by the NDIA, planners or service providers. Early intervention with respect to nutrition guided by qualified and credentialed professionals, i.e. APDs, is essential to ensure that children grow and develop to their potential. Sufficient protein, energy and other nutrients are needed to learn in school and other environments, and to respond to interventions implemented by other professionals.

DAA supports professional collaboration and collaboration with families to meet the needs of the child with disability. However DAA has considerable reservations about the teamwork models described in the document. Insufficient recognition is given to models involving various disciplines which have resulted in desirable outcomes for individuals with disability, there is inadequate description of the proposed transdisciplinary key worker model and incomplete evidence offered for the loosely described keyworker model.

DAA is particularly concerned that the transdisciplinary approach to service provision[2] has already been implemented by the National Disability Insurance Agency regardless of limitations, and that there is no apparent mechanism in place for a rigorous evaluation of this approach.

Importance of early childhood intervention

DAA considers that specialised services for infants and children with disabilities and their families with diverse needs should be accessible. Professionals such as APDs should work in partnership with children and their families, and with other service providers as much as possible to meet the needs of the child in order to promote development, wellbeing and community participation.

APDs have a unique role in assisting infants and children with their families to achieve adequate nutrition and maximise nutritional status through assessment and intervention. Adequate nutritional intake allows children to grow to their maximum potential, to develop the skills and knowledge for wellbeing, to fight illness. Without adequate energy and protein intake children are unable to respond to interventions from other disciplines or therapy, to learn and participate in school or to fully enjoy family life.

Early Intervention Seven Key Principles

DAA agrees in general with the principles listed on page 4 of the discussion paper but not with Principle 6. At this point there is insufficient evidence to support the statement that “the family’s priorities needs and interests are addressed most

appropriately by a primary provider who represents and receives team and community support. Further discussion is provided under the section on Teamwork.

Limitations of NDIS to date

The remarks made about the NDIS in section 2.2 on page 2 suggest the NDIS will cover all children with disability, and will ensure "that there is a single consistent scheme for the provision of disability support services across all Australian states and territories."

DAA recommends that the content of this section is reviewed by the NDIS. At this stage it appears eligibility for support depends on the variable interpretation of planners employed by the NDIA against a tiered structure. This and the nature of funding directly to individuals will lead to considerable variability in the implementation of the scheme.

Remarks are also made that there will be an "end to 'block funding' from government to service providers." As to block funding, it appears too early in the scheme to say how services identified as 'Tier one' related to activities such as advocacy will be funded. DAA considers that block funding may be needed to fund programs which build the capacity building of people with disabilities living in group accommodation and support workers with respect to food, nutrition and lifestyle programs. This will be particularly important for people who were previously living in institutions which had well organised food service systems to provide for their special dietary requirements.

DAA is concerned that the pricing framework of the NDIS provides for service delivery, but not for collaboration with other professionals. Teamwork models should align with funding models to achieve both collaboration to meet the needs of children and families, and adequate reward for professionals.

Outcome-focused approach

DAA agrees there may be advantages in an outcome-focused approach. If this is to be implemented under the NDIS then the full range of professionals supporting children and their families in early childhood intervention should be involved in defining developmental and functional outcomes, and developing measures for these outcomes.

Child engagement practices

The statement is made on page 9 that "the research and evidence base regarding a child's ability to learn has shifted from being focused on genetics, health and physiological functioning and exposure to risk factors, within family and community environments towards an understanding that places children's proximal

environments and experiences as central to shaping their learning and development."

No doubt children's proximal environments and experiences are important. But health, physiological functioning, and exposure to risk factors remain equally important and should not be dismissed. Unless issues such as adequate food and fluid intake are addressed the child will not be able to fully appreciate their proximal environment and experiences. The importance of health and physiological functioning is easily demonstrated by public health changes to protect the intellectual development of children in Australia i.e. the necessity to fortify the food supply to promote adequate iodine[3] intake in the population, and the changes to the blood lead levels which are acceptable in Australia[4].

The statement suggesting a move away from a focus on health etc underlines the limited scope of the discussion paper and the limited involvement by mainstream allied health practitioners in the development of the model.

Teamwork models of practice

DAA does not agree with the expression of teamwork models in Figure 1 on page 11. There is no justification provided for the relationships between various forms of teamwork in this figure.

DAA does not agree with the descriptions on page 12 with respect to multidisciplinary and interdisciplinary teamwork, and finds that these descriptions are contrary to the experience of many APDs working cooperatively with children and their families, other professionals and support workers.

The description of transdisciplinary teamwork suggests that the technical skills of one, or indeed more, professions such as APDs, can be easily and safely assumed by a keyworker to meet the complex needs of a child with disability and their family. Without adequate negotiation of professional roles, training of keyworkers in specific skills and building of trust this model may put the child and family at risk. In fact DAA has reports from APDs that this is happening. One member reported,

> *"a special ed teacher was the key worker for a child with Down syndrome and epilepsy. She kept reporting that the child was fine and she was giving the mother dietary advice because it was just basic parenting. Our physiotherapist went to see the child and came back to the office to report that the child was skeletal".*

Clearly the child in this example was malnourished and the family would likely have benefited from nutrition assessment and intervention. The absence of an APD in the example highlights the safety and quality gaps when there is no suitably qualified

and credentialed health professional providing assessment, advice and intervention. DAA argues that the family's needs should be addressed by appropriately qualified and credentialed professionals working collaboratively with the family and other support workers. Sharing roles across disciplinary boundaries must consider the qualifications of professionals, additional training, governance frameworks, experience within the working environment and the specific needs of the family in question. Without this, and the professional trust which results from these foundations, children and their families will be at risk of harm. Furthermore professionals and support workers are placed in a difficult position by being forced to practice outside their scope of practice.

The discussion paper refers to the possibility that some professionals may work independently but that this carries the risk of lack of continuity of care and families being stressed by the interaction with multiple professionals. DAA agrees that this is undesirable and is very concerned that this is highly likely to happen under the NDIS with a market driven model. As an illustration of this the Canberra Times carried a supplement jn June 2015 with paid advertisements from a number of providers marketing their services for people with a disability. A telephone call to providers demonstrated that none of the providers employ APDs, so that consumers will need to find those services elsewhere and there will be no mechanism in place to support team care.

Evidence base

It was difficult to access the source documents used for this paper because of incomplete referencing on pages 17 and 18. The source articles found using search engines indicate that the evidence base for this paper is incomplete.

There is an absence of references to dietitians, and it seems very few references from other allied health professions such as physiotherapy. Thus the evidence from professionals working collaboratively with children and families in various health and disability agencies for many years has not been considered.

It appears the evidence is drawn more from a literature base related to education, social science, psychology, social work and child development. This is problematic given early intervention in disability may require a range of professionals and the model of care adopted by the NDIA should have included as many of these as possible in researching and designing the preferred model.

Very few source documents which could be located were trials, studies or interventions and there was no evaluation of the quality or applicability of the reviews in the way recommended by the Australian National Health and Medical Research Council.[5]

The term 'Best practice' has been used liberally throughout the document, starting from the Introduction on page 1 i.e. 'It is envisaged that consultation with the sector will capture current best practice'. Consultation is an ambiguous term and does not mean that the practice is based on scientific data[6], and is not enough to satisfy safety and quality concerns in vulnerable populations such as children with disability. Children and their families, and the funders of the NDIS should expect that there is an evidence base gained from rigorous review of the literature.

References

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