Independent Advisory Council to the NDIS

NDIS support for participants who are parents

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Introduction

Article 23 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) underpins this IAC advice on the role of the NDIS in supporting participants who are parents with dependent children in their care. Affirming the right of persons with disability to marriage, family, parenthood and relationships, on an equal basis with others, the UNCRPD spearheaded a sociocultural shift in the way in which parents with disability are seen, with a shift from questioning their capacity to raise children to a focus on contextual models of parenting[1] recognising the role of support networks in enhancing wellbeing.

Parents with disability are however a relatively invisible group and too often, their right to parent is challenged directly and indirectly by attitudinal barriers and environmental factors such as poverty, unemployment, social isolation, stress and relationship difficulties that impact on their capacity to care for their children.[2]

In addition, parents with disability often face unresponsive service systems where embedded prejudices can be seen in discriminatory attitudes and prejudicial assumptions, lack of access to information, services and support, lack of knowledge and understanding of needs.[3] These factors add to vulnerability and place parents with disability at higher risk of coming to the attention of child protection agencies than other parents with greater risk of removal and/or threat of removal of their babies and children.

Evidence confirming the relationship between effective support networks and positive outcomes for parents and their children[4] affirms the maxim, *it takes a village to raise a child.* Children facing hardship are more resilient when they have support from at least one caring adult. Families are more resilient when they are surrounded by caring communities. Resilience is not forged in isolation; it is forged by interdependence with others.[5]

In NZ, practice guidance [6] aimed at achieving positive outcomes for parents with disability and their children starts with the imperative of recognising the support needs of parents in relation to parenting. In Australia however, to respond to participants' support needs as parents, participants and practitioners must navigate the interface between the NDIS and mainstream child protection and family support systems that operate in different assumptions and models.

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[1] Schuengel , C., Kef, S., Hodes MW et all (2017) Parents with intellectual Disability *Current Opinion in Psychology* 15:50-54 reported in Koolen, J., Verharen, L., van Oorsouw, Embregts (2019) "Support needs of parents with intellectual disabilities: systematic review on the perceptions of parents and professionals, *Journal of Intellectual Disabilities,* 1-25

[2] Lamont, A., & Bromfield,L.,(2009) Parental intellectual disability and child protection: Key issues *National Child protection Clearing House* p11 Accessed https://aifs.gov.au/cfca/publications/parental-intellectual-disability-and-child-protection-key-i 16 April 2019

[3] Frohmader, C., Parenting Issues for Women with Disabilities in Australia: A policy Paper by Women With Disabilities Australia, Women With Disabilities Australia, 2009

[4] Darbyshire L V & Stenfert Kroses, B (2012) Psychological wellbeing and social support for parents with intellectual disabilities: risk factors and interventions *Journal of Policy and Practice in Intellectual Disabilities,* 9:

[5] Raffensperger, M., Morton, M., Gage, J., Caldwell, F., Penfold-Green, C., Raffensperger, R., & Fulop, K. (2012), From our perspective p6 Accessed https://www.superu.govt.nz/sites/default/files/RF-from-our-perspective.pdf 16 April 2019

[6] Families Commission 2012, Disabled parents: diversity, experiences and support needs, Accessed at http://carers.net.nz/wp-content/uploads/2012/12/disabled-parents_0.pdf 16 April 2019

In this context, the best outcomes for participant parents and their dependent children may be diminished in the tensions associated with interface negotiations.

Analysis[7] of 2015 SDAC data shows that 340,000 Australians have a disability and are primary carers. Some are NDIS participants who are parents.

This paper seeks to understand the role of the NDIS in supporting participant parents to fulfil their goals and develop resilient families. The paper uses insights from research and case studies in Appendix 1 to critique NDIS practice along the participant pathway and finds that the Scheme lacks a formal consistent approach to:

- intervene early
- acknowledge the parenting role and responsibilities of participants
- negotiate with mainstream family support and child protection services to ensure they meet their responsibilities to NDIS participants; and
- build effective informal support.

It must be stressed that all participants are individuals and their need for support will be shaped by many factors including those related to their disability, their heritage, their environment and their personal preferences.

The paper recommends that the NDIA:

- strengthens NDIS practice to intervene early, build capacity and negotiate with mainstream services on behalf of participant parents
- provides reasonable and necessary support that is:
  - o person centred, family focused acknowledging the central role of participants to children in their care
  - o can be used to develop support networks around the participant
- makes representation to ensure:
  - o child protection agencies make an urgent referral to the NDIS for a plan review of participants who are notified
  - o mainstream agencies make adjustments to fulfil their responsibilities to NDIS participants.

Insights from research and practice

A NZ study[8] that examined the strength and resilience of families that included a parent with different disabilities, explored how to tailor research and practice to better meet the needs of these families. Acknowledging that families faced many challenges which are often ongoing, the study described resilient families as those that adapt and change to move on with their lives amidst their challenges.[9] The study identified five principles to underpin engagement with families that include a parent with disability. The principles are:

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[7] By Professor Ann Kavanagh, Chair, Disability and Health, Melbourne School of Population and Global Health
[8] Raffensperger (2012) op cit
[9] Raffensperger (2012) op cit p5

- Each family is unique
- Disabilities co-exist with abilities and strengths
- Spending time together having fun helps to build family resilience
- Families function as a unit
- Poverty and social isolation are challenges in themselves and when families that include a parent with disability experience challenges, the root cause may be the underlying poverty or social isolation rather than the disability.

The study concluded describing the relational component of resilience, supporting inter-dependence by nesting a vulnerable person in the context of significant others and families in the context of caring communities.

Practice guidance[10] aimed at supporting parents with a psychosocial disability as parents emphasises the importance of documentation and plans to help parents feel in control and children to feel more secure and settled. Documentation of when episodes of mental illness are likely to occur is used as a strategy to reduce the severity, duration and recurrence of an episode and help minimise disruption to a family's daily activities and routines. Professionals and supporters are encouraged to help parents to plan ahead and develop:

- a family crisis or care plan that includes working with family members, carers and community support services and agencies
- a schedule to ensure a parent is receiving adequate sleep, has a healthy diet and is performing regular physical exercise.

Peer support is a valued intervention for parents with mental illness. Trained parent peer specialists able to empathize with and relate to the needs of parents seeking services are shown to be effective in helping parents achieve their goals.[11]

Pregnant women and mothers with physical disabilities are encouraged to find the right doctor, do their homework, connect with other mothers with disabilities, be assertive and prepare for pregnancy, child birth and beyond.[12] In practice however, peer support and good information are hard to find. Interaction with the health system is negative or patchy[13], and general practitioners lack knowledge.

There is a body of research relating to parenting with an intellectual disability. Whilst the challenges faced by parents with other disabilities is often quite different, many general insights may be derived from research in this field.

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[10] Accessed https://www2.health.vic.gov.au/mental-health/working-with-consumers-and-carers/supporting-parents-with-a-mental-illness 16 April 2019

[11] Nicholson J & Valentine A (20118) Defining peerness: developing peer supports for parents with mental illness *Psychiatric Rehabilitation Journal*, 2018, 41(2) 157-159 Accessed http://heller.brandeis.edu/parents-with-disabilities/research-briefs/nicholson-defining-peerness.html 16 April 2019

[12] Mitra, Long-Bellil, Iezzoni, Smeltzer & Smith (2016) Pregnancy among women with physical disabilities: Unmet needs and recommendations on navigating pregnancy, Disability and Health Journal *9(3) 457-63* Accessed http://heller.brandeis.edu/parents-with-disabilities/pdfs/mitra-self-advocacy-pd-1.pdf 16 April 2019

[13] Salthouse, S., and Moore, C., *Submission to the Inquiry into Maternity Services in the ACT,* WWDACT, January 2019, https://www.wwdact.org.au/publications/

Parents with intellectual disability depend on their support network; those who have little support have lower levels of wellbeing of both parents and children and poorer developmental outcomes of children.[14] Conversely adequate support is important to enhance parenting and to keep families together.[15]

Studies show that the manner in which informal social support is provided by a diverse range of supporters shapes the ways in which mothers understand, learn about and carry out mothering. In a study of the lived experience of becoming a mother for women with intellectual disability,[16] 17 expectant mothers strategically negotiated support networks prior to the baby's birth, aligning themselves with a key person in their social network who advocated for and supported them as the central figure in the life of their babies.

Mothers with intellectual disability preferred people who provided practical assistance without taking over their roles as mothers,[17] identifying their greatest unmet needs as help with understanding child development and increasing community participation (work options, making friends, knowing what services are available).[18]

The high rate of parents with intellectual disability involved in the child protection system suggests that there is a significant gap in effective services for parents with intellectual disability.[19] The same can be said for parents with psychosocial disability and cognitive impairment. Research confirms that child protection practitioners focus on deficits at the expense of recognising strengths and competencies in parental capacity[20] and that services rarely meet the needs of parents with intellectual disability with parents describing the support offered as often not helpful.[21]

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[14] Darbyshire L V & Stenfert Kroses, B (2012) Psychological wellbeing and social support for parents with intellectual disabilities: risk factors and interventions *Journal of Policy and Practice in Intellectual Disabilities,* 9: 40-52; Llewellyn G & Hindmarsh G (2015) parents with intellectual disability in a population context, *Current Developmental Disorders reports,* 2: 119-126 reported in Koolen et al (2019)

[15] Aunos M & Pacheco L (2013) Changing perspectives: workers' perceptions of interagency collaboration with parents with intellectual disability. *Parents with Disabilities in Child Welfare* 7: 658-674; Booth T and Booth W (1999) Parents Together: Action research and advocacy support for parents with learning difficulties *Health & Social Care in the community* 7: 464-474; Llewellyn G (1997) Parents with intellectual disability learning to parent: the role of experience and informal learning, *International Journal of Disability, Development and Education,* 44:243-261 reported in Koolen et al (2019

[16] Llewellyn, G., Mayes, R., & McConnell, D., (2008) Towards acceptance and inclusion of people with intellectual disability as parents, *Journal of Applied Research in Intellectual Disabilities,* 21, 293-295

[17] Mayes, R., Llewellyn, G., & McConnell, D., (2008), Active negotiations: mothers with intellectual disabilities creating support networks, *Journal of Applied Research in Intellectual Disabilities, 21(4), 341-350*

[18] Llewellyn, G., McConnell, D., & Bye, R., (1998) Perception of service needs by parents with intellectual disability, their significant others and service workers, Research in Developmental Disabilities 19(3):245-26

[19] Llewellyn, McConnell & Bye (1998), Perception of service needs by parents with intellectual disability, their significant others and their service workers, *Research in Developmental Disabilities,* 19 (3) 245-260; Mildon et al 2003 *Understanding and supporting parents with learning difficulties* Melbourne Parenting Centre in Lamont & Bromfield (2009) p14

[20] NSW Dept of Community Services, 2007; Kriese, Hussein, Clifford & Ahmed 2002 in Lamont

[21] Stenfert Kroses, B BS, Hussein H, Clifford C, (2002) Social support networks and mothers with intellectual disability, *Journal of intellectual Disabilities* 14:324-240

Research suggests that to improve service delivery for parents with intellectual disability, interventions should be family centred, focused on family and parental strengths[22] and help at home with practical tasks such as transport.[23] Interventions should focus on specific skill development [24] through performance based rather than knowledge-based programs.[25]

In a systematic review of research on parents with an intellectual disability, Koolen et al[26] reported the different perceptions of parents with intellectual disability and professionals in relation to support needs. A summary of the different perspectives is presented in Table 1 followed by a discussion of the implications of the findings.

Table 1: Perceptions of parents with intellectual disability and professionals in relation to effective support

	Parents' views of effective support	Professionals' views of effective support
Type of support	Practical help with children (child care, bathing, feeding, washing, cooking meals)	Help with cooking
	Help with child raising (setting boundaries, playing, homework, sex education)	Help with child raising (setting boundaries, discipline, stimulating)
	Support to deal with services (understand what they're saying, fill in forms, go to court with me, tell me what to say)	Help parents contact services
	Emotional support (a shoulder to cry on, a supporter who babysits)	No studies mentioned emotional support
	Disability awareness (understanding limitations, becoming better at receiving help)	"Of great importance was that these parents were aware of their limitations and the kind of consequences that ID had on their everyday lives"

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[22] NSW Department of Community Services (2007), *Parental intellectual disability/Learning difficulties vulnerability,* Brighter Futures Practice Resource; Wade, C.,Mildon, R. & Matthews, J (2007) Service delivery to parents with an intellectual disability: family centred or professional centred? *Journal of Applied research in Intellectual Disabilities, 20:87-98*

[23] Wade, (2007) Wade, C.,Mildon, R. & Matthews, J (2007) Service delivery to parents with an intellectual disability: family centred or professional centred? *Journal of Applied research in Intellectual Disabilities*, 20:87

[24] Wade, C (2007) ibid;

[25] McGaw, S, & Newman, T (2005) *What works for parents with learning difficulties* (2nd edition), Ilford: Barnados, reported in Lamont, A & Bloomfield, L., (2009); Mildon, R., Matthews, J., & Gavidia-Payne (2003) *Understanding and supporting parents with learning difficulties*, Melbourne: Victorian Parenting Centre

[26] Koolen, J., Verharen, L., van Oorsouw, Embregts (2019) "Support needs of parents with intellectual disabilities: systematic review on the perceptions of parents and professionals, *Journal of Intellectual Disabilities,* 1-25

	Parents' views of effective support	Professionals' views of effective support
		Help with budgeting and shopping
Source of support	Role of family members and partners valued for practical child care and emotional support and as best alternative to/protection from child protection	Grandparents as crucial safety net No study identified role of partners, family members other than grandparents or informal network members
	Moral support from other parents in similar situations	Contact with other parents
	Friends, neighbours and volunteers as source of practical support (less mentioned)	No studies mentioned informal supporter networks
	Advocates who helped: represent parents in court, keep their child and maintain contact with their child when in foster care	Advocates to ensure voice of parents heard and maintain contact when children in foster care
	Practical and emotional support of social workers	With isolated parents, service providers took on a role that might otherwise be provided by a mother, grandmother, friend or neighbour
	Support of health professionals such as midwives and psychologists in post birth period	No study identified role of health professionals
Conditions of successful support	Services should always offer 'someone being available' Support preferably long term and ongoing Tailored to individual need	Services structured, long term, and ongoing Proactive, at home and tailored to individual need
Characteristics of support members	Honest and straightforward Available and accessible when needed Understanding not patronising Friendly and helpful	Interested in the parent, be honest and open about their role Accepting parents as they are Supporters preferably involve parents, ask what needs they have and ensure information is understood

	Parents' views of effective support	Professionals' views of effective support
	Ability to be a good listener Parents wanted supporters to ask what they wanted, break down the tasks "People like to interrupt and say "I'll do it for you" and that is not right … do it together" Importance of receiving positive feedback	Variety of communication skills are suggested such as break down tasks, listen to parents' opinions, simplify explanations, take into account reading ability, use repetition, 'demonstrate and teach skills instead of doing things for them'

Implications for NDIS practice

Whilst much of the literature focuses on parents with an intellectual disability, it is broadly agreed that the implications for practice extend to parents with the full range of disabilities especially those with cognitive and psychosocial disability.

Parents and professionals seem to describe support needs in different ways

Parents used a variety of concrete descriptions about how to act (fill in forms, go to court with me) whereas professionals used more abstract terms for the same needs (introduce parents to agencies). It is questionable for example, whether the (only) description of professionals regarding the importance of listening (i.e. listen to the opinions of parent) fully captures the meaning of the broad variety of descriptions of listening from parents (e.g. 'listen to me', sit there and listen', 'listen and not interrupt'). [27]

Awareness of differences in the way people describe support needs is important to facilitate clear communication and as a precursor to a successful working relationship and an improved fit between parents' wishes and the intention and interpretation of staff. Many parents with disability start on the backfoot when communicating with people in authority. Their disability is perceived as a deficit by health, welfare and child protection workers and their ability to anticipate their needs and represent themselves may be diminished in the context of poverty, social isolation and their own experience of the out-of-home care system.

The IAC recommends that the NDIA:

- allocates a specialised Support Coordinator skilled at working with participant parents to negotiate with mainstream services and facilitate clear understandings, in behavioural language, of service requests, outcomes sought and communication preferences between the participant, providers and support staff.
- develops practice resources aimed at improving communication between participants and staff.

[27] Koolen (2019) op cit p22

Potential support of friends, neighbours and volunteers

The strengths-based NZ study[28] noted that resilience is not forged in isolation but by interdependence with others and that families are more resilient when they are surrounded by caring communities. Research into parenting with an intellectual disability identifies the pivotal role of support networks in supporting positive outcomes for parents and their children.[29]

In the more deficit-based studies comparing the perceptions of parents and professionals, professionals appeared not to be aware of the potential support of friends, neighbours and volunteers. The researchers noted that whilst the informal support networks of many parents with intellectual disability are small, this does not mean that other informal supporters might not be willing or are not already supporting parents with intellectual disability in practice. The researchers recommended strategies to strengthen the involvement of an informal network noting that in cases of (perceived) isolation of parents, professionals take on roles that might be better provided by a friend or neighbour, and as a result, maintain the (perceived) absence of informal network members.'[30]

NDIS plan implementation talks about strengthening informal support. The IAC has critiqued NDIA practice in this area, finding it lacking the skill, depth and duration of support necessary to facilitate enduring unpaid relationships in the lives of people who face societal barriers.

The IAC recommends that the NDIA:

- strengthens practice guidance as to the value of and requirements in relation to developing networks of informal support around participant parents
- encourages the use of capacity building to develop networks of informal support around participant parents including around those who have no informal support. This would include the use of reasonable and necessary support to establish and facilitate circles of support and similar strategies
- funds services in the ILC that focus on building informal support.

Peer support

An important area of commonality between perceptions of parents and professionals is the value of support from other parents in a similar situation. The IAC has also written on many occasions about the value of peer support hosted by DPFOs.

The IAC recommends that the NDIA:

- ensures all parent participants are aware of options for advocacy and peer support.
- identifies parents with disability as a priority target group for peer networks in the DPFO program.

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[28] Raffensperger, M., et al (2012) op cit
[29] Koolen, J., Verharen, L., van Oorsouw, Embregts (2019) op cit
[30] Koolen (2019) op cit p21

Help me to do it for myself

The observation of one parent "People like to interrupt and say *I'll do it for you,* and that is not right*… Do it together*"[31] is a perfect epithet for the NDIS approach. Where a parent is able to learn to undertake a task, it is critical that paid support assists the participant to learn the skill to become competent at that task.

The IAC recommends that the NDIA:

- provides capacity building support in relation to all tasks that a participant could learn to undertake.

Families function as a unit

In a family situation, a parent's disability is not theirs alone; family members adapt and work together to meet the demands of family life. Support and interventions targeted at individuals alone do not harness the strengths within a family unit.

The IAC recommends that the NDIA:

- adopts a person-centred family focused approach for participants who are parents.

Poverty and social isolation are challenges in themselves

When families that include a parent with disability are facing numerous challenges, the root cause may be underlying poverty or social isolation rather than the disability itself. When families are well resourced, financially and socially, they are better able to meet day-today challenges posed by the disability.

The IAC recommends that the NDIA:

- incorporates information about the contextual barriers to good parenting into practice guidance and represents the interests of the participant in negotiating with mainstream services
- considers capacity building of mainstream family services as a priority area for ILC mainstream capacity building investment.

Nature of support

Consistently, research demonstrates that parents want services that are family centred and solution focused, draw on family and parental strengths, do not take over their roles as parents and provide practical help at home as well as transport. Parents with intellectual disability identified their greatest unmet needs were help with understanding child development and increasing community participation (work options, making friends, knowing what services are available).

Research suggests that interventions should focus on specific skill development through performance based rather than knowledge-based programs and the early provision of such

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[31] Strike, R.,& McConnell, D., (2002), Look at me, listen to me, I have something important to say, *Sexuality and Disability* 20:53-63 reported in Koolen (2019) op cit p20

support may prevent the over-representation of parents with intellectual disability in the child protection system.

Assistance of this nature is part of the NDIS reasonable and necessary options with performance-based skill development a key approach to capacity building.

The IAC recommends that the NDIA:

- provides evidence-based support for participant parents.

Role of NDIS as defined by interface principles

The Interface Principles[32] outline supports that are the responsibility of the NDIS. These are described below and relate to:

- *Development of daily living and life skills* – *where the participant, or the participant's family, require support specifically related to the functional impairment to live as autonomously as possible, including, skills in daily life activities, communication and social skills, problem solving and managing funding of supports. This assistance can be for participants who are children with disability and also to assist participants who are parents with disability.*

- *Participation in community, social and civic activities* - *to assist the participant to participate in community activities, which can also assist to sustain caring arrangements as an alternative to previous supports funded as in-home/facility-based care. This assistance can be for participants who are children with disability and also to assist participants who are parents with disability.*

- *Disability* - *specific parenting training programs which are specifically designed for the participant's needs and are not available as a mainstream service. This can include intensive training such as one-on- one or in-home training for parents with disability or training that is specific to a participant's disability (e.g. a program specifically addressing barriers to parenting for parents with impaired hearing)*

The challenges described below have been identified through discussion with participant parents and people working with participant parents. In this section, NDIA practice on the participant pathway will be reviewed in relation to core NDIS themes of intervene early, build capacity, develop support networks, ensure mainstream does its part to make reasonable and necessary decisions about support.

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[32] https://www.ndis.gov.au/about-us/operational-guidelines/planning-operational-guideline/planning-operational-guideline-appendix-1-table-guidance-whether-support-most-appropriately-funded-ndis

Challenges

Access

Current practice

Information about access is widely publicised online describing how to make a request and the nature of evidence required.

Challenges

Advocates observe that many people with intellectual disability who are 'on the margins' do not have access to support to complete an access request and do not have the documentation required to demonstrate eligibility. Without persistence and advocacy, many eligible people with disability would not become participants. In addition, when women with intellectual disability become pregnant, their need for support is exacerbated.

Recommendation

The IAC recommends that the NDIA:

- continues to work with mainstream agencies connected to people who are on the margins with intellectual disability, cognitive impairment and psychosocial disability to ensure eligible people are supported to make an access request.

Streaming

Streaming is a key threshold to NDIS support: early identification of increased vulnerability increases access to skilled system navigation and if reasonable and necessary, to increased support.

Current practice

Streaming decisions take into account multiple factors including complexity in the participant's life and the capability of informal support in assisting the participant with decision-making, engaging in the planning pathway and with services (including mainstream). In general, where a participant has minimal or no informal support and is involved with the child protection system, the participant would be directed to the intensive or super-intensive stream.

Challenges

Pregnancy is a life stage that adds significant complexity to a participant's life. Given that for most, being an NDIS participant is lifelong while pregnancy is a short episode, pregnancy generally occurs after the streaming decision. When a participant becomes pregnant and may require additional assistance to identify and negotiate with mainstream services, their first point of call is their LAC or planner. People who work with parents with intellectual disability report that pregnant women with intellectual disability are unable to access NDIS support to negotiate with mainstream services. They are also not offered options of:

- a transfer to a participant pathway that offers more intensive or specialised assistance in negotiating with mainstream services or

- a plan review that will provide increased capacity building and core supports.

In some states and territories, a pregnancy confirmation for people with identified vulnerabilities requires a mandatory notification to child protection. This places the pregnant participant under child protection supervision and increases the risk of child removal. Speak Out Advocacy in Tasmania used ILC funds to facilitate conversations between mainstream health workers and parents with intellectual disability to change the stereotypical perceptions of parents. Their slogan *Support Before Report*, emphasised the importance of seeing a parent with intellectual disability beyond stereotypes and to give them a fair go to become a capable parent.

For participants at risk of a notification to child protection agencies, an urgent plan review is essential to secure the support required to meet expectations of the child protection agency and better risk assessment tools are required to appropriately guide child protection workers to view parents in the context of supports.

Participants who are pregnant or are parents are a small cohort within the NDIS and many NDIA planners do not have experience in working with this group and understanding the challenges they face.

Recommendations

The IAC recommends that the NDIA:

- identifies pregnancy in participants most at risk of notification to child protection agencies as a complexity that requires a transfer to a different participant pathway (including the Complex Participant Pathway) with planners and Support Coordinators experienced in working with this target group.

- responds to a participant request for plan review on the basis of a new pregnancy as urgent to gain additional assistance in negotiating with mainstream agencies as well as additional core and capacity building support as reasonable and necessary.

- facilitates frequent plan reviews so that the needs of the parent can be adjusted as the needs of the child change with age

- makes representation to State and Territory child protection agencies:

  o that if they receive notification of an NDIS participant (including pre-birth), that an urgent referral is made to the NDIS for a plan review and the participant is notified of this referral for review and the reason that it is requested.

  o to review their risk assessment tools to guide child protection workers to view parents in the context of supports.

Plan review

<u>Current practice</u>

The NDIA recognises pregnancy as a change of circumstance however pregnancy is not a flag for a plan review on its own. Similarly, notification to child protection agencies is not a flag for a plan review. NDIA practice guides participants to use funded supports as intended in an approved plan and if circumstances change, lodge a request for plan review.

<u>Challenges</u>

Delay in securing a plan review, delays the opportunity for skilled assistance in gaining access to:

- additional mainstream and community support that may be useful to a pregnant participant or a participant parent at risk of losing their child including

    o pre-birth education

    o negotiating with parent education programs to make reasonable adjustments

    o 'specific parenting training programs which are specifically designed for the participant's needs and are not available as a mainstream service'[33]

- additional capacity building supports related to her role as mother

- additional core supports related to any change in functional impairment or circumstances related to pregnancy to minimise negative effect on both the mother and the unborn child. (Note that women are unable to predict how the pregnancy will interact with their physical or chronic health condition).

<u>Recommendations</u>

The IAC recommends that the NDIA identifies pregnancy in participants most at risk of notification to child protection agencies and/or notification to child protection as reasons for an urgent plan review (if sought by the participant) and for increased support to negotiate with mainstream agencies.

Supports in the plan
General

<u>Current practice</u>

Reasonable and necessary supports must:

- be related to the person's disability support needs
- support the participant to pursue their goals

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[33] as identified as an NDIS responsibility in Appendix A Operational Guidelines of the Interface Principles

- facilitate social and economic participation
- represent value for money
- be effective and beneficial for the participant having regard to current good practice
- take into account what is reasonable to expect families, carers, informal networks and the community to provide
- not provide supports that are appropriately funded or provided by another service system.

In the context of the interface with child protection and family support systems,[34] reasonable and necessary support for a participant who is a parent may include:

- support specifically related to the functional impairment to live as autonomously as possible, including, skills in daily life activities, communication and social skills, problem solving and managing funding of supports

- assistance with actions which are not physically possible for the parent in attending to the child's physical needs

- support to participate in community activities, which can also assist to sustain caring arrangements

- specific parenting training programs which are specifically designed for the participant's needs and are not available as a mainstream service. This can include intensive training such as one-on- one or in-home training for parents with disability or training that is specific to a participant's disability (e.g. a program specifically addressing barriers to parenting for parents with impaired hearing)

Capacity building support to learn parenting skills

Current practice

Skill building for parenting is the responsibility of mainstream services.

The interface principles make provision for the NDIS to provide specific parenting training programs which are specifically designed for the participant's needs and are not available as a mainstream service. NDIA practice however specifically prohibits support for specific parenting training programs for pregnant participants because they are not yet parents.

When a parent participant continues to have challenges following participation in a mainstream parenting program, reasonable and necessary capacity building supports of a time limited, step down nature can be provided. Examples include daily, in-home skill building support to assist the participant parent to implement skills and strategies developed in the mainstream program. A step-down approach reduces the frequency and duration of support until the participant parent has achieved their goal.

Challenge

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[34] Appendix A – Table of guidance on whether a support is most appropriately funded by the NDIS. Accessed at https://www.ndis.gov.au/about-us/operational-guidelines/planning-og/appendix-1-table-guidance-whether-support-most#child-protection-and-family-support on 14 April 2019

Almost universally, mainstream parenting classes are not adjusted to enable participants with cognitive or psychosocial disability to gain core competencies. NDIA staff argue that any role for the NDIS must wait until it is demonstrated that the mainstream option is shown not to be working.

Evidence from advocates working with parents with disability suggests that information about reasonable and necessary daily, in-home skill building options is not widespread and that the child has often been removed prior to additional NDIS support being put in place. The principle of early intervention will be both cost effective, result in development of better parenting skills, and have a positive outcome for the child, even including the unborn child.

Core support to assist with challenges related to pregnancy and dependent children

Current practice

Pregnant participants and participant parents can access reasonable and necessary additional core support if they need assistance to understand information related to pregnancy and parenting, attend appointment and undertake tasks of daily living that are challenging as a result of parenting responsibilities.

Challenges

There is variable experience in relation to the availability of reasonable and necessary support for assistance with actions which are not physically possible for the parent in attending to the child's physical needs. Some parents are rebutted saying that assistance with practical tasks of raising children, such as feeding and bathing a child, are a mainstream responsibility. Some parents with disability who are assisted by advocates or skilled committed Support Coordinators have been able to access Special Child Care Benefit to assist with these core tasks. Participant parents without such assistance in negotiating with mainstream agencies are left without support.

Some pregnant participants and participant parents need assistive aids and supports to participate in mainstream classes or access mainstream services where available. The principle of value for money, might mean that the supports provided are better and cheaper than accessing mainstream classes.

Building informal support

Current practice

NDIA guidelines indicates that LACs and Support Coordinators work with the participant to strengthen informal support.

Challenges

Strategies undertaken by LACs and Support Coordinators do not build enduring relationships that make a difference in the lives of participants.

Equipment

Current practice

NDIA guidelines require assessments for the purchase of assistive technology.

Challenge

Participants with physical disabilities report that requests for specialised equipment to enable them to care for their children are responded to in a framework that inhibits solutions rather than an enabling problem-solving framework. Parent participants report that they are forced to find volunteers prepared to modify equipment so that it is fit for purpose. Case study A describes the modifications that enabled a parent with cerebral palsy to care for her baby.

Recommendations

The IAC recommends that the NDIA:

- provides additional reasonable and necessary core support in acknowledgement of the need to attend additional appointments, the potentially reduced ability to undertake some tasks of daily living and the practical child care tasks that parents may not be able to undertake as a result of their functional impairments.

- makes specific parenting training programs available to participants who are pregnant and their partners

- allocates reasonable and necessary support to develop networks of support around participant parents who face societal barriers

- allocates reasonable and necessary capital resources for new equipment or to modify equipment to enable participant parents to care for their children

- prioritises peer support for parents with disability in the DPFO grant program

Plan implementation

Current practice

For participants in the general and supported stream, the LAC assists the participant to implement their plan, including connecting the participant with funded supports and mainstream and community services. For participants in the intensive and super intensive streams, where there is an identified need to negotiate with multiple service systems, the level of Support Coordination added to the plan as a capacity building support is a reasonable and necessary decision.

Challenges

Where child protection services are involved with pregnant participants and participant parents, very skilled Support Coordination assistance is required to help the participant meet the requirements of child protection, develop informal support and source good support. In

addition, a specialised Support Coordination role is required to navigate the complexity of sometimes conflicting tensions between representing the parent and mandatory reporting.

Participants are often not connected to a participant pathway that provides the level of skilled understanding and negotiation required. As a result, they miss out on the negotiation and advocacy needed to have a chance of using mainstream services essential to reduce the risk of the child being removed.

Recommendations

The IAC recommends that the NDIA:

- transfers a pregnant participant or participant parent lacking informal support to a Participant Pathway with the knowledge, skills and experience in assisting the target group

- develops specialised planners and Support Coordinators who are experienced in working with parents involved with child protection systems

- provides information about and where appropriate, refers participant parents to advocacy services and peer support

- works with advocates experienced in working with parents with disability to review existing practice guidance to assist planners and Support Coordinators navigate their appropriate roles and responsibilities.

Where parent and child are participants

Current practice

Where there are multiple participants who are co-resident in the one family, NDIA practice allocates participants to the intensive stream and facilitates a planning cycle so that the plans are approved around the same time. Where the child participant is over 7 years, NDIA practice aims for one planner to work with each participant in the family to develop their plan.

Challenges

Feedback from the community suggests that NDIA practice identified above is not always implemented. In addition, advocates recommend the same practice is applied to participant parents and their dependent child participants for whom they are responsible.

Whilst understanding that each participant has reasonable and necessary support in his/her own right, research suggests that the best outcomes for all are achieved when individual reasonable and necessary support also supports family function. A person-centred family focused approach is more likely to support the development of a resilient family.

Recommendations

The IAC recommends that the NDIA:

- implements practice guidance that where desired by participants, one planner is used for all co-resident participants in the one family and for participant parents and the participant children for whom they are responsible

- coordinates the plans of parent participants and their children who are on the ECEI Pathway

- implements a person-centred family focused approach to planning for parents with disability and families with multiple co-resident participants.

Where child is removed

Current practice

The NDIS can provide capacity building support in the area of relationships (Individual Social Skills Development)[35] to assist the parent to respond appropriately to their child and Assistance with Social and Community Participation for support to accompany the parent participant to visit their child if that is their priority.

Challenges

Many parent participants are not informed of the reasonable and necessary support for which they may be eligible to gain the skills to relate to the child in an appropriate way and to maintain contact with their child.

The NDIA does not take into account the trauma experienced as a result of child removal, or the re-traumatisation experience at each contact-visit occasion. The planner and Support Coordinator need to identify appropriate trauma-informed mainstream services to address this impact on mental health and support the parent to enable the child to return home.

Recommendations

The IAC recommends that the NDIA:

- showcases reasonable and necessary options that are available to parent participants to maintain contact with children not in their care

- refers the parent to advocacy services and peer support

- assists with access to appropriate mental health services and supports.

Mainstream and NDIS registered provider experience with target group

Current practice

"Mainstream agencies are responsible for general family support including counselling, parenting programs and adjustments, for families with disability that are not directly as a result of the child's disability"[36].

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[35] Price catalogue Ref No 11_024_0117_7_3 costed at $57.32 (2018/19)
[36] Interface principles

Some parent participants use services funded under the Special Child Care Benefit.

NDIS takes a market approach to the delivery of reasonable and necessary support. Parents with disability are a small but important part of the market in which it would represent value for money to invest in supporting participant parents and building capacity upfront.

<u>Challenges</u>

Mainstream providers

Feedback from advocates working with parents with intellectual disability strongly suggests that mainstream agencies do not make reasonable adjustments that enable participants with cognitive impairment to gain the skills they need. There are few specialised programs and even those that exist do not appear to prioritise those in greatest need on the basis that *'families with the most need were not necessarily those with the greatest capacity to benefit from the program'. For example, some people with intellectual disability may not be able to sustain learnings in the longer term.*[37]

Services funded under the Special Child Care Benefit focus on the child and often replace the participant as parent rather than assist the participant to be the best parent they can be.

NDIS registered providers

Very few NDIS registered services are oriented to work effectively with participant parents in ways that simultaneously support the participant to be a good parent. Such a capacity building approach would represent value for money and would reduce the long-term costs of care and support by increasing the capacity of participant parents to care for their children. Feedback from the community agencies that work with parents with intellectual disability suggests that many NDIS registered providers are unwilling to work with the participant parent in a person-centred, family focused way meeting the participant's disability support needs in ways that simultaneously enhance their parenting skills.

Advocates report that the practice of support staff working with participant parents in isolation from their family responsibilities has not been effective in enabling the participant to keep her children. The parent cannot be viewed in isolation from her/his parenting role.

At least one advocacy organisation has had success in securing effective support for participant parents with intellectual disability. The provider has welcomed the advocate guiding support workers to support participants in ways that build their capacity as parents. The organisation reports the experience in confidence as if this example of good practice may not be permissible under NDIS guidelines.

<u>Recommendations</u>

The IAC recommends that the NDIA:

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[37] Australian Institute of Family Studies, 2017, Cradle to Kinder Evaluation Summary, p14 Accessed at https://aifs.gov.au/publications/cradle-kinder-evaluation-summary 15 April 2019

- publishes guidance that demonstrates good practice in supporting participants who are parents.

- makes representation to state and territory family support systems in relation to their responsibilities to ensure that services make reasonable adjustments to be inclusive of parents with disability. The inclusion of requirements in funding agreement would provide a clear signal as to expectations.

- identifies parents with disability as a niche group of participants and showcases effective options of support

NDIS experience with the target group

The paper has outlined challenges with NDIS practice in relation to participants who are parents and participants who are pregnant. Improvements will require enhancements to practice, training for planners and LACs and specialisation of Support Coordination to be able to effectively support participants who are parents.

Recommendations

The IAC recommends that the NDIA:

1. Strengthens NDIS practice to:

    a. intervene early

    b. build capacity

    c. negotiate with mainstream services to meet their obligations

2. Provides reasonable and necessary support

    a. that is person centred family focused, acknowledging central role of participants as parents

    b. to develop support networks around parents

3. Develops specialised Support Coordination roles in relation to participant parents at risk of having their child removed

4. Make representations to ensure:

    a. child protection agencies make urgent referral to NDIS for plan review

    b. mainstream agencies make adjustments to ensure they fulfil their responsibilities to NDIS participants.

Appendix 1: Case studies

Karlie: systems failure

This case study demonstrates the impacts of a lack of direct discussion with a parent with disability.

Karlie and her husband John gave birth to their baby daughter 10 years ago, prior to the NDIS. Both Karlie and John are capable individuals who have an intellectual disability. They had experienced prejudice and negativity much of their lives and had 'got by'. They were not aware that the judgemental attitudes toward Karlie's pregnancy would have significant impacts.

They attended anti natal classes but did not get much from them because there were no adjustments to take account of their learning needs.

On day 3 after the baby was born, child protection services arrived at the hospital to inform Karlie and John that they could not take their baby home unless they had 24/7 support. Karlie made many calls to try to organise 24/7 support but was not successful. Her daughter was removed.

Karlie and John were unaware that a notification to child protection services had been made. They had made efforts to learn to become good parents but without assistance to understand the requirements, they had stumbled along a path that would never have succeeded.

Had Karlie and John been assisted to understand fully what was required, been assisted to learn parenting skills in ways adjusted to their learning needs and been provided with support, especially in the early days, they would have had a much better chance of becoming good parents, devoted to their daughter.

John has died but Karlie continues to maintain contact with her daughter. Her highest goal in her NDIS plan is to be a good mother to her daughter (while acknowledging her daughter will not live with her). The NDIS response is that there is no assistance available because her daughter is not in her care.

Rebecca and Craig: barriers to support

This case study demonstrates the barriers parents with disability face in getting the support they need.

Rebecca is a woman with cerebral palsy married to Craig who has an intellectual disability. They live in a home they are purchasing and have consistent and valued work histories.

Rebecca was treated with negativity and scepticism by doctors, allied health professionals and disability support workers during her pregnancy which made her anxious. She reports that the only real support she received in preparing for parenthood came from key friends in her support network. Accessing specialised equipment was an important part of preparation. Rebecca and Craig wanted a wheelchair accessible cot, and an accessible change table and baby station. These requests were rejected by the state systems (prior to the NDIS) and so members of the informal support network modified a cot, raising it so that Rebecca could

wheel under it and changing the pull up side to a swing out gate that allowed easy access to the baby. They also modified a computer desk to a bathing station.

Rebecca and Craig attended ante natal classes as part of their mid wife program but Craig learnt very little because no effort was made to adjust the content and style of presentation to accommodate his learning needs. Similarly, after the birth, guidance by hospital staff given 'at arms-length' was of little assistance especially in the context of the negative judgements expressed openly by many staff. Rebecca and Craig honed their parenting skills under the guidance of friends.

Rebecca had paid a premium for additional mid wife support at home. The health service provided 3 different midwives who did not form relationships with Rebecca and Craig and provided inconsistent information, thereby increasing their stress. Once again, friends assisted with a roster of people making themselves available if required and the local IGA supermarket happy to deliver items as required.

Rebecca is now an NDIS participant but her challenges continue. When Rebecca's support provider was not prepared to help her to parent (including putting the baby into the car seat), Rebecca chose to self-manage, directly employing a previous support worker who saw the importance of a holistic approach to assist her to care for her baby. Rebecca's request for a new wheelchair to parent independently was not given much weight in the OT assessment, leaving her with a wheelchair that makes her less independent. She awaits resolution of a 'battle between the OT and the NDIS'.

Nahla and Andie: support to parent

This case study demonstrates that participants in similar circumstances appear to have different experiences of the NDIS

Nahla and her husband Andie are both NDIS participants who have physical disability and a large support network. They are proactive people who contacted the NDIS for a plan review in the early stages of pregnancy. They were looking for assistance in sourcing and purchasing specialised equipment they would need when the baby was born. Following an assessment, the OT assisted them to source and the NDIS provided a specialised bassinette, electric cot and a sit to stand desk that could be used as a change table. Nahla and Andie purchased a further table that could be used for bathing. Toward the end of her pregnancy, Nahla encouraged her mid wife and the social worker at the hospital to talk to child services in an attempt to pre-empt a notification by people who were uninformed about their preparation and support for parenting.

Once baby Sarah was born, Nahla and Andie pooled their reasonable and necessary support and together with some additional day time assistance and active overnight shift, the family felt well supported. The planner offered capacity building support but both Nahla and Andie recognised that they were not able to improve their functional abilities to care for Sarah. The active overnight support lasted for 9 months with a plan review every 4 months. Sarah is now 18 months old and at the last plan review, the review period was extended to 6 months without an increase in resources. In other words, as part of a step-down approach, Nahla and Andie are being asked to get by with less resources. They are uncertain whether this will work. They believe that the time to reduce NDIS support is when Sarah is potty trained.

Nahla and Andie have found their NDIS planners to lack experience, especially in understanding the challenges of parenting when you have a disability.

Person-centred, family-focused support

This case study demonstrates an approach to enhance the effectiveness of NDIS support.

An advocate working with participant parents with intellectual disability reports that parents were not receiving responsive NDIS support because providers saw the women in isolation from their parenting roles and were not prepared to support the women to parent. The lack of effective support put their children at risk of removal by child protection agencies.

A new support provider opened in town and the advocate indicated she may have some referrals if the provider was prepared to authorise person-centred, family-focused support. The advocate offered to provide training to the support workers and to support and supervise their work with participant parents. As a result, the advocate reports that the participant parents are getting much more effective support within the same NDIS budget.

Helena: rigid service systems

This case study demonstrates the impact of rigidities in the interface responsibilities that thwart a sense of community and inclusion.

Helena is a woman with cerebral palsy (CP) who uses a wheelchair and who has twin boys (neither of whom have a disability). She is on the DSP and uses a scooter for longer trips to shops and school and/or public transport. The family live in social housing approximately 2km from the children's school.

A married couple who have a child with CP of similar age to the twins live in the unit next door. The father works and they have two cars.

The education department provides taxi transport to the young child with CP to and from the same school that Helena's twins attend. Helena asked for taxi transport to school for the twins (in the same taxi as their neighbour with CP) but was refused and has to transport her twins on her scooter to and from school.

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