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A brief history and user's guide to the Australian National Disability Insurance Scheme

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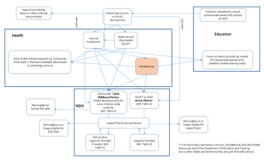

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A brief history and user's guide to the Australian National Disability Insurance Scheme

"The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments." p2. 2010 Productivity Commission report on Disability Care and Support in Australia [1]

The National Disability Insurance Scheme is currently being rolled out in Australia and significantly changes the way disability is supported. This article provides an overview for paediatricians of how the scheme came about and how it works, including key terms and access pathways. The companion article provides a discussion of some of the challenges and opportunities faced by paediatricians [2].

Rationale for the NDIS

Disability support in Australia in 2010

For some time professionals and advocates working with children with disabilities and their families in Australia have been aware that services were not sufficient, were poorly coordinated and that many parents were struggling to provide the care their children needed at substantial emotional, physical and financial cost. There was also awareness that services were inequitable, with some children supported while children with the same needs but different diagnoses were not, and with unacceptable geographic and age-related differences.

In many parts of Australia today there exists a range of funding or service options for individuals with disability and their families/carers. Some are national and others state or territory funded, and some are provided as funding with service choice. Others are public services based on

needs or an individual's place of residence, or services provided by non-government organisations. Support options are also divided by type of services (e.g. equipment versus clinician input), type of issue addressed (e.g. continence versus mobility) and by age group, with separate services for early life and adult care. For example, the parents of a child with cerebral palsy may receive AU $12,000 through Better Start Funding together with specific funding for equipment or orthotics (e.g. State-Wide Equipment Program (SWEP) funding). For a child with autism, they may have received AU $12,000 for early intervention through the federal Helping Children with Autism Program.

In 2010 the Productivity Commission undertook an inquiry for the Australian Government into disability support and reported that the current disability system was flawed and unsustainable [1]. The Australian National Disability Insurance Scheme (NDIS) was devised to overcome the failings of the previous system and provide sustainable long term care and support for individuals with significant disabilities, aged between 0 and 65 years. The step-wise introduction of the NDIS began in July 2013 as a trial in four locations and the full roll-out to all states and territories commenced in July 2016.

Aims of the NDIS

The goal of the NDIS is to fund lifetime care for those with a disability, maximising their independence and social and economic participation [3]. It is designed as a national scheme with different service providers but one source and mechanism of funding. This design can potentially overcome some of the previous issues of inequity and provides an opportunity to understand the interaction between different needs and suitable services at any one time. For example, following early intervention services in the preschool years there are opportunities for ongoing therapy and resources from school-age through to adulthood. In short, it is designed to minimise gaps created by age based services and resultant unmet need for families, and can also cater to some parent/carer and sibling needs, with the aim of ensuring optimal care, as well as individual and community productivity.

What is the NDIA?

The National Disability Insurance Agency (NDIA) is the assessor and funder of the scheme but not the provider of support services. Support services are provided by non-government and government organisations, including disability service organisations, state and territory disability service providers and private businesses. This is a significant shift in the way service providers in Australia operate. The scheme provides people with disabilities and their carers with the capacity to choose their providers and to tailor their support packages to meet their unique needs.

The NDIS uses insurance principles rather than a welfare model of disability [4]. This includes considering needs over a lifetime, rather than the short to medium term. The rationale for needing a lifetime approach is to remove short term funding for disability support that is vulnerable to economic, tax and competing portfolio changes [3]. The insurance model controls for the future lifetime costs resulting in an incentive to make short term investments that reduce long term costs, by increasing an individual's independence and ability to participate in society [4].

How much will it cost?

The NDIS is expected to cost around $22 billion annually when fully rolled out in 2019-20. During the planning it was anticipated that for the NDIS to operate, government expenditure on disability services would need to double from 0.5 per cent to approximately 0.9% of Gross Domestic Product (GDP) for under 65 year olds. The NDIS is funded from taxation revenues and an increase in the Medicare levy [4]. However, it is expected that although the national expenditure on disability will increase, the NDIS will result in an additional 320,000 people with a disability and 80,000 carers being employed. This is anticipated to increase GDP by 1 per cent by 2050 thus offsetting the costs of the scheme. Preliminary reports indicated that the project was on budget [5], however, the most recent quarterly report notes higher than expected numbers of children entering the scheme, and benchmark package costs created at the outset of the scheme not matching actual package costs [6]. For example, annual Early Childhood Early Intervention (ECEI) levels of support were initially

estimated at $16,000 for high needs but some families are being provided with annual ECEI support that exceeds this upper level. A working group has been established to address these cost pressures.

Pathways to services

Access eligibility

Access to the NDIS is not means tested and is under two streams – Early Childhood Intervention stream for those six and under, and the general disability stream for those aged over six up to 65 years (those aged 65 years and older may be eligible for support under the Commonwealth Continuity of Support Programme). To be eligible a participant must be an Australian citizen or hold a permanent visa or a Protected Special Category visa.

Early Childhood Early Intervention (ECEI) Requirements. ECEI is for children with a developmental delay or disability and aims to provide local support services that use a family centred approach [7]. By design ECEI through the NDIS is available based on functional impairment or a medical diagnosis. Functional assessment is used to understand the level of support needed as the child enters the scheme. Entry based on functional impairments is not new for many states/territories' early childhood intervention services for more generic purposes, but is a change from diagnostic entry required by national ECEI funding schemes such as HCWA and Better Start. This functional approach aims to provide timely intervention which is monitored to ensure it is effective and provided for the appropriate duration. The goal is to provide "early investment in achieving functional outcomes for children and minimising long term dependence and support costs" [8].

Table 1 highlights the ECEI eligibility criteria under the NDIS. There are a list of permanent conditions (List D) which do not require further assessment to receive support under NDIS other than the diagnosis itself [9]. For other presenting problems evidence must be provided about the impact of a child's differences on their life, including "any impact on their mobility, communication, social interaction, learning, self-care and self-management", including evidence of the degree of

delay in development relative to same age normative data [9]. Support is specifically available for developmental delay, as defined by NDIS in Table 1 [9].

<insert Table 1 about here>

Although clinicians may question the appropriateness of the term developmental delay (refer Table 1 for definition), the underpinning principle, to allow entry to ECEI when difference in development is noticed and prior to a diagnosis being made, is laudable and suited to the aim of minimising later functional and participation difficulties. Not surprisingly some parents have found it difficult to accept that funding for their child's therapy for what they are hoping is a transient problem comes under a 'disability' scheme. Paediatricians and other health professionals can play an important part in explaining to families that some developmental and behavioural differences may be transient, requiring a period of early intervention, with this intervention now funded under the NDIS model.

Disability Requirements for those aged over six years. Diagnostic information is required as part of the assessment of whether a person's impairment is causing a disability [10]. The NDIS disability access criteria are defined in Table 1. The NDIS provides two lists of conditions: List A eligible conditions which generally do not require further assessment and List B "conditions for which permanent impairment/functional capacity are variable and further assessment of functional capacity generally is required" [11]. It is stated that "a person does not need to have a condition on List A or List B to become a participant in the NDIS" [10] but rather these lists are provided to streamline the process. Regardless, the use of listed diagnostic categories will inevitably facilitate easier access to the NDIS for some individuals but not others [12].

Referral pathways

ECEI uses the existing referral pathways via maternal child health, paediatricians and GPs, or families can self-refer to an early childhood partner (roles described in Table 2). Figure 1 highlights

the referral pathways. Medicare diagnostic codes still trigger access to individual Medicare rebated therapy and paediatricians should still provide advice to families about priorities for use of these, as these rebates for services are available in addition to NDIS ECEI.

<Insert Figure 1 about here>

<insert Table 2 about here>

As the NDIS is implemented in each region existing sources of information about individuals with a disability are being utilised to expedite access to funding. For example, in Victoria NDIA is ensuring those on the Disability Support Register are contacted. As such it is important to ensure all children who are eligible are known to existing disability services in their state or territory. Anyone receiving Commonwealth Disability Support services should be automatically transitioned across to the NDIA [13]. Examples include those on ECIS, Limbs for Life, and Disability Support Registers.

Documentation requirements

Documentation regarding an individual's disability is required and can be provided either by completing NDIS forms or in the form of letters, reports and test results from medical professionals including paediatricians, as well as teachers and other therapists. Treating doctors or specialists may be required to complete the Professional's Report section in Part F of the Access Request Form (available from an NDIS office) or the NDIS Supporting Evidence Form. Alternatively, the same evidence can be provided in a different format, such as copies of existing assessments and reports but must be attached to the NDIS form. Families/carers and people with a disability will also provide information about their disability as part of accessing the NDIS [14].

Guidelines on the NDIS ECEI approach are available and emphasise evidence based interventions using family centred approaches [7]. Specific guidelines to assist with making decisions about the delivery of services to preschool children with autism spectrum disorder (ASD), and their families and other carers have also been developed [15]. To be eligible for autism specific early

intervention services a diagnosis of ASD will be required. A diagnosis will be made, as previously, by health professionals accessing publicly provided or Medicare rebated assessments. However, other ECEI services can be accessed using eligibility criteria noted above as soon as problems with social interaction, communication, and behaviour are identified. Although, some reports from trial sites indicate diagnostic labels are being requested [see the accompayning article for examples 2].

Recommendation guidelines for ECEI and ASD early intervention can assist paediatricians with documenting the support services required by children and their families. For example, when requesting early intervention support it is reasonable to request an early intervention program provided by an early intervention team and also to request support for the parents/carers and siblings. Parents may value advice about local early intervention team options and whether specific issues will require specialist team support, like a feeding or continence service. Specific information should be provided if training for parents or educators and other care providers is required to optimise care, for example for catheterisation or to achieve continence, as this will need funding in the plan.

After access is granted

Once access is granted by the NDIA, an individualised support plan is created for each participant via a meeting with an access planner. For ECEI the access planner is known as the Early Childhood Partner (Table 2). The plan details the amount of funding from the NDIS and how these funds are spent. The support plan also details how individuals can access non-NDIS mainstream services and supports such as existing Medicare-related health funded services and educational supports, such as those provided under state government programs for students with disabilities. Information about local community services that are available to families via the Local Area Coordinator (see Table 2) and during planning "informal supports" are also taken in to account. This may mean that children with equivalent individual needs receive different packages for ECEI or

ongoing support, based on availability of non-NDIS funded care that can cater to their needs. Support plans are reviewed every 12 months.

The experience of paediatricians in regions where the NDIS is fully functional indicates the planner is an important point of contact for the family as they contend with this often complex funding system. However, reports consistently indicate that supports elicited by planners vary. Whether this relates to operational issues associated with the roll-out is unclear. As with existing services some families will require more support than others to access appropriate services for their child. Working with and around NDIS to achieve equitable service raises some challenges [see the accompaying article 2].

Fund Management

Once the support plan is defined funds are provided to the participant directly to self-manage, are managed by the NDIA or an approved third party. If self-managed, the parents of children will purchase their own supports. Participants are given access to the online myGov Participant Portal to manage their documentation and payments to service providers. Health services are able to become registered providers, and if they do NDIS will be billed for the disability (not health care) services they provide which must be part of an individual's support plan. These services could include prosthetics and equipment, early childhood intervention, continence and nutrition support and disability home care.

What is provided?

The NDIS funds "reasonable and necessary" supports. The supports must be related to the disability and help the individual to function and engage in an "ordinary life". Support via the NDIS is provided across the lifespan for as long as it is needed (up to age 65). Table 3 outlines the types of supports available for ECEI and disability requirements [1, 11]. Supports in plans will be categorised according to three purposes: (1) core supports to assist with daily living, transport, consumables and

with social and community participation; (2) capital supports to provide assistive technology, home modifications, and specialist disability accommodation; (3) capacity building including coordination of supports, improved living arrangements, increased social and community participation, finding and keeping a job, improved relationships, improved health and wellbeing, improved learning, improved life choices and improved daily living skills [16]. Most items are quotable which means providers must negotiate a price in a service agreement with a participant. Although the boundaries between health and disability care are not always clear and there is ongoing discussion, it is expected that distinctions will be clarified as the scheme becomes fully operational.

Experience with plans received by some families to date indicate that items for funding are clear but little direction is provided about the specific way the money is spent. A statement like this from one report "I can choose how I spend the amount in each budget listed below by checking the NDIS price list and the matching supports on the NDIS website. Where a support is listed in my plan as 'stated', I must purchase this support as it is described in my plan. I cannot swap 'stated supports' for any other supports." makes the limits of the flexibility clear. The opportunity for variation within the funded plan is indicated by this item that was allocated $8000 of funding: "Improved daily living. 45 hours for OT and PT. Assessment for new bed, cushion and standing frame". Again, it will become clearer over time if the lack of direction is temporary and related to rollout issues.

Conclusion

The NDIS is reforming the disability sector in Australia and aiming to provide a lifetime of support for individuals with permanent disabilities under a national system. With an underlying philosophy of making short-term investments to reduce long-term costs, the scheme should drive independence and maximise participation in society for individuals with disabilities. The Royal Australian College of Physicians has released an NDIS policy and associated guidelines to help physicians better understand the NDIS [17]. Paediatricians will soon be using NDIS mechanisms to assist and support children with disabilities and their families to receive the services they need, but

some frustrations are likely especially during the roll-out where multiple systems will be in operation simultaneously, and also during the learning phase and while change within the NDIS is still occurring [2].

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Figure 1. Flowchart for access to the NDIS

Table 1. Eligibility criteria for the NDIS

	ECEI Criteria – aged six or under	Disability Requirements – aged over six years
Type of Problem	One or more intellectual, cognitive, neurological, sensory or physical impairments that are, or are likely to be, permanent; **OR** One or more identified impairments that are attributable to a psychiatric condition that are, or are likely to be, permanent; **OR** Is a child who has developmental delay; as defined as: • attributable to a mental or physical impairment or a combination of mental and physical impairments; • results in substantial reduction in functional capacity in one or more of the following self-care; receptive and expressive language; cognitive development; motor development; • and results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated	The person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition
Other Require-ments	Provision of early intervention supports is likely to benefit the person by: • reducing their future needs for disability related supports; • mitigating or alleviating the impact of the person's impairment upon their functional capacity to undertake communication, social interaction, learning, mobility, self-care or self-management; • or preventing the deterioration of such functional capacity; • or improving such functional capacity; • or strengthening the sustainability of informal supports available to the person, including through building the capacity of the person's carer; Early intervention support for the person is most appropriately funded or provided through the NDIS.	The impairment or impairments are, or are likely to be, permanent, A**ND** The impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities: • Communication • Social interaction • Learning • Mobility • Self-care • Self-management, and The impairment or impairments affect the person's capacity for social and economic participation, **AND** The person is likely to require support under NDIS for the person's lifetime

ECEI, Early Childhood Early Intervention; NDIS, National Disability Insurance Scheme

Table 2. Language of the NDIS

Term	Definition
(Access) Planners	Planners work with the individual and their family to develop a Disability Support plan which includes participant goals and the services funded to deliver each element of the plan.
Early Childhood Partner	The name for (Access) Planners for ECEI. A local community NDIS partner experienced in early childhood intervention and will provide assistance, advice and access to early intervention and support for children and their families. They have additional roles to (1) create community connections and (2) provide initial support. Initial support may be provided if the profile of a child suggests that a ECEI plan is not indicated or if a period of initial support is needed before a decision can be made about the need for an ECEI plan.
Local Area Coordinators	These are case managers for NDIS and will provide assistance with the planning process to coordinate and source participant supports, building community capacity and awareness about disability. If a family decide not to manage the plan themselves the Local Area Coordinator can assist. However, they will not check individual portals to ensure services that have been purchased are being correctly billed.
Participants	People who meet the NDIS access requirements and have been determined 'eligible'.
Plan manager	Can manage the funding from the NDIS documented in the support plan for the participant if the participant does not wish to self-manage the plan.
Providers	An individual or organisation delivering a support or a product to a participant of the NDIS. Organisations or individuals can apply to be a registered provider with the NDIA. Registered providers must meet requirements regarding qualifications, approvals, experience and capacity for the approved supports.
Transdisciplinary (Key Worker)	Key worker allocated by the early childhood intervention provider to coordinate the therapy team.

Table 3. Supports provided under ECEI and Disability requirements

ECEI Requirements (Under 6 years)	Disability Requirements (6+ years)
• assistance with daily living activities, • disability-specific family support (such as post-diagnostic information, referrals and support coordination) • behaviour and therapeutic supports which will increase a child's level of functioning or prevent a deterioration in functioning; • aids and equipment to improve functioning; • assistance with transport; • specialist support and training (for early childhood and care staff and others) [8]	• aids and appliances such as prosthetics and communication aids as well as home and vehicle modifications; • personal care • community access to supports such as continuing education to develop independence; • respite for people with disabilities and their families; • specialist accommodation support such as group homes; • domestic assistance; • transport assistance; • supported employment services and specialist transition to work programs • therapies such as speech therapy, occupational therapy, physiotherapy, counselling and specialist behavioural interventions; • crisis/emergency support; • guide/assistance dogs