

Operational Guideline – Access – Early Intervention Requirements

Legislation

 Read ss.21 and 25 of the <u>National Disability Insurance Scheme Act 2013</u> (NDIS Act) and Parts 6 and 7 of the <u>National Disability Insurance Scheme (Becoming a Participant) Rules 2013</u> (Becoming a Participant Rules).

Becoming a participant

2. To become a participant a person must meet the age and residence requirements, **and either** the disability **or** the early intervention requirements.

See s.21 of the NDIS Act.

The early intervention requirements

- 3. There are four requirements to be met before determining that a person meets the early intervention requirements set out in s.25 of the NDIS Act.
- 4. First, **as a matter of fact**, the person:
 - a. Has one or more identified intellectual, cognitive, neurological, sensory or physical impairments that are, or are likely to be, permanent, or
 - b. Has one or more identified impairments that are attributable to a psychiatric condition and are, or are likely to be, permanent, or
 - c. Is a child who has developmental delay.
- 5. Second, the delegate is **satisfied** that provision of early intervention supports for the person is likely to benefit the person by reducing the person's future needs for supports in relation to disability.
- 6. Third, the delegate is **satisfied** that provision of early intervention supports for the person is likely to benefit the person by:
 - Mitigating or alleviating the impact of the person's impairment upon the functional capacity of the person to undertake communication, social interaction, learning, mobility, self-care or selfmanagement, or
 - b. Preventing the deterioration of such functional capacity, or
 - c. Improving such functional capacity, or
 - d. Strengthening the sustainability of informal supports available to the person, including through building the capacity of the person's carer.

See s.25(1)of the NDIS Act.

- 7. Fourth, there is one more step. Even if a person meets the test above, that person does **not** meet the early intervention requirements if the delegate is satisfied that early intervention supports for the person:
 - a. Is not most appropriately funded or provided through the National Disability Insurance Scheme (NDIS), and
 - b. Is more appropriately funded through:
 - i. Other general systems of service delivery or support services offered by a person, agency or body, or
 - ii. Systems of service delivery or support services offered as part of a universal service obligation or in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

See s.25(3) and 34(1)(c) of the NDIS Act.

- 8. In determining whether the early intervention supports would be more appropriately provided by a different service system delegates should consider the supports outlined in the <u>National Disability Insurance Scheme (Supports for Participants) Rules 2013</u> (Supports for Participants Rule).
- 9. For all children under 6 years of age, the delegate is to first consider whether the child meets the early intervention requirements, prior to any assessment of their eligibility under the disability requirements above, unless they have a diagnosed condition listed in List C at Appendix A.

A permanent impairment

- 10. The test in the NDIS Act is whether the impairment 'is, or is likely to be permanent'.
- 11. In some cases it will require a very careful assessment of the facts to determine whether an impairment is, or is likely to be, permanent. The Becoming a Participant Rules set out in legislation the circumstances in which an impairment is not permanent and also some guidance on when an impairment may be permanent.
- 12. Under the <u>Becoming a Participant Rules</u> an impairment is, or is likely to be, permanent **only if** there are no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment.

See r.6.4 of the Becoming a Participant Rules.

13. Under the <u>Becoming a Participant Rules</u> an impairment may be permanent notwithstanding that the severity of its impact on the functional capacity of the person may fluctuate or there are prospects that the severity of the impact of the impairment on the person's functional capacity may improve.

See r.6.5 of the Becoming a Participant Rules.

- 14. Under the <u>Becoming a Participant Rules</u> an impairment is, or is likely to be, permanent **only if** the impairment does not require further medical treatment or review in order for its permanency or likely permanency to be demonstrated (even though the impairment may continue to be treated and reviewed after this has been demonstrated).
- 15. What is required is information that is sufficient to demonstrate to a delegate that the impairment is permanent or likely to be permanent. This is a matter of judgment but what the Becoming a Participant Rules are trying to do is rule out cases where the permanency or likely permanency has not been established because the person requires further medical treatment or review before the permanency or likely permanency can be demonstrated.
- 16. This does not mean that an impairment will not be permanent or likely to be permanent if it requires further medical treatment or review. In some cases an impairment may require medical treatment



and review before a determination can be made about whether the impairment is permanent or likely to be permanent. In some cases an impairment may continue to be treated and reviewed after it has been demonstrated that it is permanent or likely to be permanent.

See r.6.6 of the Becoming a Participant Rules.

 Under the <u>Becoming a Participant Rules</u>, where an impairment is of a degenerative nature, the impairment is, or is likely to be, permanent if medical or other treatment would not, or would be unlikely to, improve it.

See r.6.7 of the Becoming a Participant Rules.

Factors to consider – is there a benefit to the person with disability

- 18. The second and third of the four requirements in determining whether a person meets access for early intervention both deal with whether a person is likely to benefit from early intervention. The delegate must be satisfied that the provision of early intervention supports is likely to benefit the person.
- 19. In deciding whether the provision of early intervention supports is likely to benefit the person (either by reducing future support needs, mitigating or alleviating the impact on functioning, preventing deterioration of or improving functioning, or strengthening the sustainability of informal supports) the delegate should consider:
 - a. The likely trajectory and impact of the person's impairment over time, and
 - b. The potential benefits of early intervention on the impact of the impairment on the person's functional capacity and in reducing their future needs for supports, and
 - c. Evidence from a range of sources, such as research or information provided by the person with disability or their family members or carers. The delegate may also in some cases seek expert opinion.

See r.6.9 of the Becoming a Participant Rules.

20. The Becoming a Participant Rules allow delegates to consider evidence from a range of sources, including from the person with disability, family members, carers and from experts. Delegates are to make judgments about the weight or value of particular pieces of evidence. The sources of the evidence and the purposes for which it is being used will have an impact on the weight or value of the evidence. For example, evidence from a doctor on a specific medical matter would be given considerable weight just as evidence from family members on the impact of a support on the informal support they provide would be given considerable weight. When considering if a person is likely to benefit from early intervention supports, the delegate may also wish to consider factors such as the time elapsed since the onset or diagnosis of the disability and whether there has been a recent, or there is an impending, significant change in the person's impairment or disability. As a guide, early intervention supports generally provide a greater benefit to a person if they commence within 2 years of onset or diagnosis of the impairment or immediately after a significant change in the impairment.

See r.6.9(c) of the Becoming a Participant Rules.

Developmental delay

21. Under the <u>Becoming a Participant Rules</u>, the delegate is taken to be satisfied that provision of early intervention supports for a child under 6 years of age is likely to benefit the child in the ways mentioned in rs.6.2(b) and (c) of the <u>Becoming a Participant Rules</u> (paragraphs 5 and 6 above) if

one or more of the child's impairments is a mental or physical impairment which, by itself or in combination with other mental or physical impairments, results in developmental delay.

22. Developmental delay is defined by s.9 of the NDIS Act as:

developmental delay means a delay in the development of a child under 6 years of age that:

- is attributable to a mental or physical impairment or a combination of mental and physical impairments; and
- results in substantial reduction in functional capacity in one or more of the following areas of major life activity:
 - i. self-care;
 - ii. receptive and expressive language;
 - iii. cognitive development;
 - iv. 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.
- 23. In determining whether a delay has led to a substantial reduction in functional capacity delegates may be assisted by considering the result for the child in comparison to the result for other children of the same age. For example:
 - a. The child requires more assistive technology, equipment (other than commonly used items such as glasses, non-slip bath mats, simple adapted kitchen utensils and dressing aids) or home modifications (other than common modifications such as bathroom grab rails, hand rails at stairs and age appropriate child safety locks) to participate in one or more of the activities listed in s.24(1)(c) of the NDIS Act than most other children of the same age, or
 - b. The child usually requires more assistance than most other children of the same age to participate in one or more of the activities listed in s.24(1)(c), or
 - c. The child is unable to participate in the activities listed in s.24(1)(c) that would usually be expected of most other children of the same age.
- 24. Generally, a delegate would be satisfied that there has been a delay that results in a substantial reduction in functional capacity where:
 - a. The child is older than 12 months and under 6 years old and has a delay greater than 12 months in one or more functional areas, or
 - b. The child is 12- 24 months of age and has a delay greater than 6 months AND their developmental trajectory is likely to result in delay greater than a 12 months delay, or
 - c. The child is 12- 24 months of age and has a demonstrated a delay greater than 6 months AND the child is at high risk of a substantial developmental delay due to significant risk factors such as:
 - i. having a sibling who has autism spectrum disorder, or
 - ii. having a delay between 9 and 12 months in multiple areas.
- 25. Where standardised tests are either not available or other assessment methods are considered best practice, milestone inventories or other functionally based assessments performed by a qualified professional may be used provided they are reported in full to the NDIA.
- 26. Reporting of these assessments must be comprehensive and include clear evidence of the child's current level of functioning, and comparison to normative data on the domain of development.

Conditions where the delegate will generally be satisfied without further evidence

27. The provision of early intervention supports for a child under 6 years of age is likely to benefit the child in the ways mentioned in paragraphs 6.2(b) and (c) of the Becoming a Participant Rules (paragraphs 5 and 6 above) in the circumstance that one or more of the child's impairments results from a condition which is on a list of conditions published by the CEO for which evidence has established that early intervention supports will have these benefits. This list is at Appendix A and titled List C 'Permanent Impairment/Early intervention, under 6 years – no further assessment required'.

Use of information

- 28. In considering whether a person meets the early intervention requirements the delegate should develop a comprehensive view of the person's circumstances including by:
 - Examining all relevant available information provided by the participant (such as the selfassessment in My Access Checker and any diagnostic or assessment information provided), and
 - b. Talking with the person and (with the person's consent) the person's family, or carers.
- 29. Diagnostic information will generally be required to determine whether a person has an impairment and whether that impairment is permanent.
- 30. Where the available information is not sufficient for a sound decision, the NDIA may request information reasonably necessary to decide whether a person meets the access criteria. Planners can also request the prospective participant to undergo an assessment or examination.
- 31. Where further information is being sought from the participant the request should clearly identify what information is being sought and by when it must be provided. If the request is to a third party, the delegate should inform the prospective participant of the reason for the delay in making the decision.

See Operational Guideline - Information Handling - Overview and s.26 of the NDIS Act.

General considerations for delegates

- 32. A decision tree designed to assist decision makers in making and recording their decisions has been developed and is attached. The decision tree should be completed for each prospective participant except prospective participants who:
 - Have a condition listed in List A at Appendix A of the Operational Guideline Access –
 Disability Requirement, or
 - b. Have been found eligible for a program at Appendix C of the *Operational Guideline Access Disability Requirement*, or
 - c. Are children under 6 years of age who have developmental delay, or
 - d. Are children under 6 years of age who have a condition listed in List C at Appendix A to this Operational Guideline.

See Operational Guideline - Access - Decision Tree Disability Requirements and Early Intervention Requirements.

APPENDIX A

List C – Permanent Impairment/Early intervention, under 6 years – no further assessment required

Synonyms for conditions are also shown (e.g. condition/synonym/synonym)

1. Conditions primarily resulting in Intellectual/ learning impairment

- Intellectual disability
- Global Developmental Delay
 - Autism Spectrum Disorders
 (diagnosed by a specialist multi-disciplinary team, pediatrician, psychiatrist or clinical psychologist experienced in the assessment of Pervasive Developmental Disorders/Autism Spectrum disorders, and assessed using the current Diagnostic and Statistical Manual of Mental Disorders (DSM-V) diagnostic criteria)
 - Autism
 - Asperger's disorder
 - Childhood disintegrative disorder
 - Pervasive developmental disorder not otherwise specified /Atypical autism

Chromosomal abnormalities resulting in permanent impairment

- Aicardi syndrome
- Aicardi-Goutières syndrome
- Angelman syndrome
- CHARGE syndrome
- Cockayne syndrome/ Types I and Type II / Cerebro-oculo-faciao-skeletal (COFS) syndrome/ Pena Shokeir syndrome Type II / Weber-Cockayne syndrome/ Neill-Dingwall syndrome
- Coffin-Lowry syndrome
- Cohen syndrome
- Cornelia de Lange syndrome
- Cri du Chat syndrome
- Dandy-Walker syndrome
- DiGeorge syndrome/ 22q11.2 deletion syndrome/ Velocardiofacial syndrome/ Shprintzen syndrome/ Conotruncal anomaly face syndrome
- Down syndrome
- Edwards syndrome/ Trisomy 18
- Fragile X syndrome
- Kabuki syndrome
- Lesch-Nyhan syndrome/ Nyhan's syndrome/ Kelley-Seegmiller syndrome/ Juvenile gout
- Leigh syndrome/ Leigh's disease/ subacute necrotizing encephalomyelopathy
- Menkes disease
- Patau syndrome/ Trisomy 13
- Prader-Willi syndrome
- Rett syndrome
- Seckel syndrome/ microcephalic primordial dwarfism/ Harper's syndrome/ Virchow-Seckel dwarfism
- Smith-Lemli-Optiz syndrome
- Smith-Magenis syndrome
- Sturge-Weber syndrome
- Trisomy 9
- Tuberous sclerosis
- Williams syndrome

Wolf-Hirschhorn syndrome

2. Conditions primarily resulting in Neurological impairment

Systemic atrophies primarily affecting the central nervous system:

- Friedrich's ataxia
- Hereditary spastic paraplegia/ Infantile-onset ascending hereditary spastic paralysis/ L1 syndrome/ spastic paraplegias types 2 and 11
- Louis-Bar syndrome/ Ataxia-telangiectasia
- Niemann-Pick disease (Types A and C)
- Progressive bulbar palsy of childhood/ Fazio-Londe disease

The following spinal muscular atrophies:

- Spinal muscular atrophy Type I/ Werdnig Hoffmann disease/ infantile SMA
- Spinal muscular atrophy Type II/ Dubowitz disease
- Spinal muscular atrophy Type III Kugelberg-Welander disease/ juvenile SMA
- Spinal muscular atrophy lower extremity dominant/ SMA-LED
- X-linked spinal muscular atrophy

Extrapyramidal and movement disorders:

 Hallervorden-Spatz syndrome / Pantothenate kinase-associated neurodegeneration (PKAN)/ neurodegeneration with brain iron accumulation 1 (NBIA 1)

Other degenerative diseases of the nervous system:

 Alpers disease/ Alpers syndrome/ Grey-matter degeneration/ Progressive sclerosing poliodystrophy/ Progressive infantile poliodystrophy

Demyelinating diseases of the central nervous system

- Adrenoleukodystrophy / X-linked childhood cerebral form
- Alexander disease
- Canavan disease
- Krabbe disease/ Globoid cell leukodystrophy
- Pelizaeus-Merzbacher disease

Episodic and paroxysmal disorders

- Lennox-Gastaut syndrome/ Lennox syndrome
- West's syndrome

Polyneuropathies and other disorders of the peripheral nervous system

- Dejerine-Sottas disease/ Dejerine-Sottas syndrome/ Dejerine-Sottas neuropathy/ progressive hypertrophic interstitial polyneuropathy of childhood/onion bulb neuropathy
- Infantile Refsum disease

3. Conditions primarily resulting in Physical impairment

- Amputations
- Diamond-Blackfan anaemia
- Epidermolysis bullosa
- Harlequin type icthyosis
- Hay Wells syndrome/ ankyloblepharon/ ectodermal dysplasia/ clefting [AEC] syndrome
- Joint or limb deformities resulting in impaired mobility
- Juvenile arthritis/ Stills Disease

- Osteogenesis imperfecta
- Sjogren Larsson syndrome

Diseases of myoneural junction and muscle

- Congenital muscular dystrophy
- Congenital myotonia / Thomsens disease/ Becker myotonia
- Distal muscular dystrophy
- Duchenne muscular dystrophy
- Emery-Dreifuss muscular dystrophy
- Facioscapulohumeral muscular dystrophy
- Myotubular myopathy
- Oculopharyngeal muscular dystrophy
- Paramyotonia Congenita

Cerebral palsy and other paralytic syndromes

- Cerebral palsy
- Diplegia
- Hemiplegia
- Monoplegia
- Paraplegia
- Quadriplegia
- Tetraplegia

4. Conditions resulting in Sensory and/or Speech impairment

- Permanent blindness in both eyes, diagnosed and assessed by an ophthalmologist as follows:
 - a. Corrected visual acuity (extent to which an object can be brought into focus) on the Snellen Scale must be less than or equal to 6/60 in both eyes; or
 - b. Constriction to within 10 degrees or less of arc of central fixation in the better eye, irrespective of corrected visual acuity (i.e. visual fields are reduced to a measured arc of 10 degrees or less); or
 - c. A combination of visual defects resulting in the same degree of visual impairment as that occurring in the above points.

(An optometrist report is not sufficient for NDIS purposes.)

- **Deafblindness** confirmed by ophthalmologist and audiologist and assessed as resulting in permanent and severe to total impairment of visual function and hearing
- **Deafness/hearing loss** a 45 decibels or greater hearing impairment in the better ear, based on a 4 frequency pure tone average (using 500, 1000, 2000 and 4000Hz)

5. Conditions resulting in multiple types of impairment

- Aceruloplasminemia
- Addison-Schilder disease/ Adrenoleukodystrophy /
- Albinism
- Arginosuccinic aciduria
- Aspartylglucosaminuria
- Cerebrotendinous xanthomatosis/ cerebral cholesterosis
- Congenital cytomegalovirus infection
- Congenital hypothyroidism
- · Congenital iodine-deficiency syndrome /cretinism
- Congenital rubella syndrome
- · Galactosaemia with long term learning disabilities and neurological impairment
- Glycine encephalopathy/ non-ketotic hyperglycinaemia

- GM1 gangliosidosis
- Hartnup disease
- Homocystinuria
- Lowe syndrome/ Oculocerebrorenal syndrome
- Mannosidosis
- Menkes disease
- Mucolipidosis II / I-cell disease
- Mucolipidosis III / pseudo-Hurler polydystrophy
- Mucolipidosis IV
- Neuronal ceroid lipofuscinosis
- Niemann-Pick disease
- Phenylketonuria
- Pyruvate carboxylase deficiency
- Pyruvate dehydrogenase deficiency
- Sialidosis
- Sulfite oxidase deficiency

The following mucopolysaccharidoses:

- Hurler syndrome/MPS1-H
- Scheie syndrome/ MPS 1-S
- Hurler-Scheie syndrome/ MPS 1 H-S
- Hunter syndrome/ MPS II
- San Fillipo syndrome/ MPS III
- Morquio syndrome/ MPS IVA
- Maroteaux-Lamy syndrome/ MPS VI
- Sly syndrome/ MPS VII

The following lysosomal storage disorders:

- Gaucher disease Types 2 and 3
- Niemann-Pick disease (Types A and C)
- Pompe disease
- Sandhoff disease (infantile form)
- Schindler disease (Type 1)
- Tay-Sachs disease (infantile form)

Congenital conditions – cases where malformations cannot be corrected by surgery or other treatment and result in permanent impairment:

- Chiari malformation/Arnold-Chiari malformation
- Congenital absence of limb(s)
- Congenital hydrocephalus
- Fetal alcohol syndrome
- Fetal hydantoin syndrome
- Microcephaly
- Spina bifida
- VATER syndrome (VACTERL association)