
13 Early intervention

Key points

- Early intervention can potentially improve outcomes for people with disabilities as well as yield benefits for the National Disability Insurance Scheme (NDIS) and the wider community.
 - Early interventions seek to reduce the impact of disability for individuals and the wider community, for example, by mitigating or alleviating the impact of an existing disability, and/or preventing a deterioration in an existing disability. They may occur: as soon as the disability is first identified or appears, where there is a discrete change in the disability, or at particular lifetime transition points.
- Analyses of early interventions can provide valuable information to people with disability, the National Disability Insurance Agency (NDIA), and others about whether they are safe and lead to improved outcomes, and are ‘value for money’. There is a particular need for undertaking cost-effectiveness analyses.
- Funding of early interventions under tier 3 of the NDIS should be based on good evidence of effectiveness and an initial analysis of likely cost-effectiveness. Absent such evidence and initial analysis, the NDIA should not fund the intervention.
- Where there is evidence to support funding of an early intervention approach, this funding should be in addition to funding provided for ongoing care and support and not be able to be ‘cashed out’ by people with self-directed care packages.
- The NDIA should commence building an evidence base on early intervention and develop linkages with relevant agencies responsible for other early interventions as well as interventions to reduce the risk of disability (such as injury and health prevention measures).

13.1 Introduction

An important deficiency of many Australian disability services is their predominantly static and crisis-driven approach to funding needs. This frustrates a longer-term approach to achieving beneficial outcomes for individuals and the community generally.

Australian governments have in recent years attempted to address this deficiency by seeking to incorporate ‘early intervention’ in their disability services. At the national level, governments have agreed to develop a framework for ‘early intervention and prevention’ within the context of disability services (National Disability Agreement 2009 and CDSMC 2010). Governments have also agreed to a

five year program that, among other things, seeks to divert younger people with disability who are at risk of admission to residential aged care into more appropriate forms of accommodation (COAG 2006a).¹ Many individual governments have also funded early interventions in their disability services, including those targeting children with disability and their families (box 13.1).

Box 13.1 Some recent government early intervention initiatives

- Australian Government initiatives include: the Better Start — Early Intervention for Children with Disability initiative, Helping Children with Autism Program (including the establishment of an early intervention service provider panel); the establishment of six autism-specific early learning and care centres; and the Outside School Hours Care for Teenagers with Disability Program.
- The NSW Government's Stronger Together: a New Direction for Disability Services in NSW 2006–2016 sought to increase (among other things): intensive, innovative and flexible support packages for children and young people with disability and their families; therapy places for children with disability; respite places for children and young people with disability. Associated funding programs include the NSW Intensive Family Support Program, Families First Program, Family Assistance Fund, Family Solutions Pilot Program and Early Childhood Intervention Coordination Program.
- The Queensland Government's Growing Stronger: Investing in a Better Disability Service System, 2007–2011 and Disability Services Queensland Strategic Plan 2008–2012 committed the Government to pursuing early intervention. For example, there has been: more funding support for people at key lifetime transition points of an individual's life — by expanding accommodation support, family support, post-school services, support to young adults leaving State care, and respite and day services; more funding support for children with a disability (through Building Bright Futures Action Plan for Children with Disability 2010–2013 and the Early Intervention Initiative) through education and information services for families, exercise programs, social skills programs, therapy services and programs, and support to access local play groups and other education and care services; and support for autism early intervention in regional Queensland. Associated funding programs include the Family and Early Childhood Services Program, Family Support Program, and the Autism Early Intervention Initiative.

Sources: FaCHSIA (2010d); NSW Government (2006; sub. 536); Queensland Government (2010a, b, c, d, e; 2007).

¹ In addition to these examples is COAG's 2008 National Partnership on Preventive Health. This agreement seeks to address the rising prevalence of lifestyle-related chronic diseases through social marketing efforts and the national roll out of programs supporting healthy lifestyles, and 'enabling infrastructure for evidence-based policy design and coordinated implementation.' An element of the agreement is the Australian National Preventive Health Agency, which was subsequently established in November 2010.

In this inquiry, many participants have noted the benefits of ‘early intervention’ and called for its incorporation in a new national scheme (for example, Anglicare Australia, sub. 594, p. 20; Down Syndrome Victoria, sub. 492, p. 6; National Disability Services, sub. 454, p. 13; Victorian Government, sub. 537, p. 18). The NSW Government said:

A national disability service system should have an early intervention and prevention focus. Research highlights the importance of early intervention and prevention in preventing problems escalating, for the person with a disability and families. The outcome for individuals can be seen in a reduction in the impact of disability and improved transitions through life stages. (sub. 536, p. 76)

The Commission has proposed that people with a disability that is, or is likely to be, permanent who are in an early intervention group would be able to receive individualised funded support under tier 3 of the National Disability Insurance Scheme (NDIS) (chapter 3).

This chapter considers further:

- the nature and benefits of early intervention
- how it might be possible to identify and target beneficial early interventions for individualised funding, including how such funding would ‘sit’ with individualised funding for ongoing care and support.

Many early interventions (and, indeed, interventions to reduce the risk of disability — such as health and injury prevention measures) are the responsibility of agencies outside of the disability services sector. For example, there are established bodies within the mental health sector (for example, early psychosis prevention and intervention centres) that specialise in the provision of early interventions that are typically clinical in nature. The Commission does not see the NDIS as being the primary funder or coordinator of such interventions. Nonetheless, as considered at the end of this chapter, there is potential for forming linkages between the National Disability Insurance Agency (NDIA) and other agencies responsible for such interventions.

Early intervention is just one aspect of the care and support provided to people with disability. In taking such a focus, the Commission wants to emphasise that ongoing care and support for people with disability is also crucial (and dealt with in other chapters). As Brain Injury Australia observed:

... whilst early intervention does bring measurable gains, recovery from a “severe” or “profound” ABI [acquired brain injury] may take considerable time and service support needs will be long-term. This is particularly the case with those who experience an ABI early in life: a study [Tate et. al 2003] has shown that service use is high even 20–26 years post-injury, with 85% having used at least one service, such as financial,

transport, home support in the previous 12 months. Therefore, a potential limitation to the emphasis on “early intervention” in the Commission’s thinking could be that the episodic and lifelong needs of people with an ABI will be forgotten. For some people with an ABI, no amount of early intervention will alter those service requirements. (sub. 371, p. 18)

In one sense, tiers 1 and 2 functions of the NDIS — such as the tier 1 function of promoting opportunities for people with disabilities and the tier 2 function of referring people with disabilities to relevant agencies for support — can be viewed as early intervention. For example, KPMG said of tier 2 activities:

... while some early intervention will be provided within the NDIS for some specific disabilities, there will also be intervention that sits outside the scope of Tier 3. ... Early intervention will affect (and perhaps limit) Tier 2 participants transitioning into Tier 3 as their disability progresses. This will have a direct impact on costs. Whether or not sufficient early intervention is being provided outside of Tier 3, may well impact the sustainability of the NDIS. (sub. DR973, p. 2)

This point is covered further in chapter 4 on the role of the community in relation to the NDIS.

Throughout this chapter, the Commission has used examples of early interventions provided by participants to illustrate particular points — such as the nature of early intervention or how a particular method can be used to assess a particular intervention. While the Commission has endeavoured to verify with participants that the examples provided have been subject to an analysis or evaluation, this has been difficult to do in every case. That the examples are given should thus not be seen as representing the Commission’s endorsement of their effectiveness or cost-effectiveness.

13.2 Nature and scope of early intervention

It became evident to the Commission from participants’ comments and from government policy documents and reports that ‘early intervention’ is not easy to define precisely in relation to disability care and support.

The Commission found it helpful to ‘unpack’ the meaning of early intervention by addressing the following questions. Figure 13.1 captures the Commission’s view.

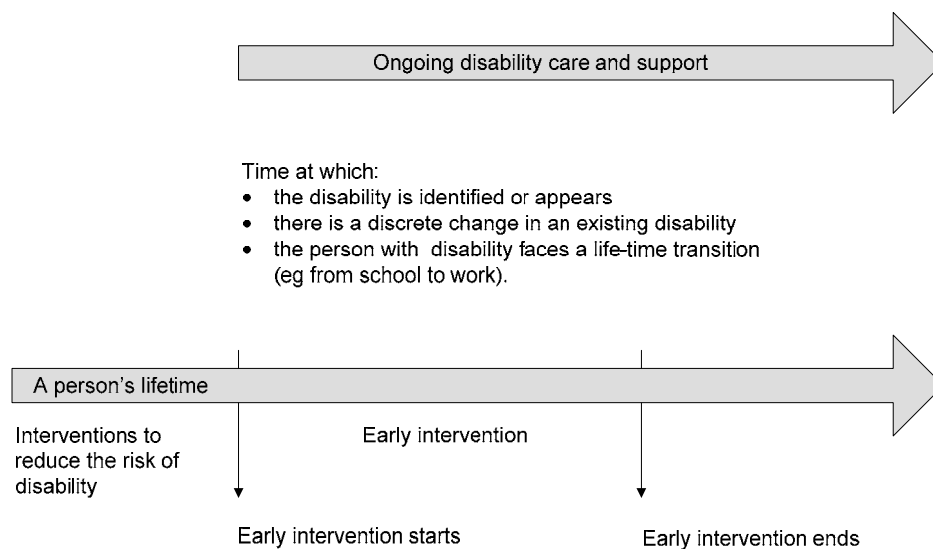
What does early intervention seek to do?

In general, the overarching objective of early intervention is to incur expenditure on a particular intervention today that, not only improves individual outcomes beyond that which would occur in the absence of the intervention, but lowers the costs and

impacts associated with the disability for individuals and the wider community over the longer-term.

This is an objective that should apply to all care and support for people with disability. It should not be restricted to specific interventions just because they occur at a certain time relative to (say) the identification or appearance of a disability.

Figure 13.1 A depiction of early intervention



More fundamentally, early intervention seeks to reduce the impact of disability for individuals and the wider community — for example, by:

- mitigating or alleviating the impact of a newly acquired, newly diagnosed or an existing disability, and/or
- preventing a deterioration in an existing disability.

Early intervention may also be seen as including interventions to reduce the risk of a new or secondary disability. For example, providing advice to pregnant women to avoid alcohol can reduce the risk of their babies suffering from foetal alcohol syndrome, and early diagnosis of foetal alcohol syndrome in their babies can reduce the risk of secondary disabilities down the track such as mental health problems (Disability Information and Resource Centre 2008). However, in this chapter, the Commission has mainly considered those interventions that seek to reduce the impact of a new or existing disability, rather than seek to reduce the risk of a new disability.

What types of services would early intervention cover?

Early intervention within the NDIS would encompass the full range of disability services and supports funded under the scheme (described in chapter 5), including: accommodation support; aids and appliances; behaviour and specialist interventions; and case management, local coordination and development; and home and transport modifications.

Early intervention could be provided as a package of these services and in a range of settings including in hospitals, residential care facilities, community health centres, and in a person's home, school and workplace.

Some examples of early intervention approaches are given in box 13.2.

What should be the timing and duration of early intervention?

The precise timing and duration of early intervention will need to be informed by good evidence, such as from studies on efficacy and effectiveness (section 13.3). Moreover, it will depend on a range of factors including the particular disability, the type of intervention and the individual's particular circumstances.

For example, the Victorian Coalition of Acquired Brain Injury Service Providers and Victorian Brain Injury Recovery Association said:

There are several aspects to the timing and nature of rehabilitation and disability support [for people with acquired brain injury]:

- People who are poorly managed in the beginning of care and support can require increased costs and experience poorer outcomes. This is particularly so with people with severe physical impairments who, if they do not have access to treatment and therapy shortly after their injuries are more likely to develop severe contractures of their limbs – which results in increased care needs, equipment needs and them experiencing pain.
- It is important not to reduce support too early as this may also prevent maximum recovery. (sub. 320, p. 11)

... It is also clear that every individual's recovery process is unique and is built upon a whole range of pre-injury skills, connections, family supports (or lack of them), and is highly aligned to the age when the injury was received (paediatric, juvenile, and adult injuries are very different in the way they effect recovery patterns). (sub. 320, p. 32)

Box 13.2 Examples of early intervention approaches

Autism Behavioural Intervention (NSW) — Footprints Program

The Footprints Program is a home-based early intervention program for families with autistic children, covering a 20 week period. It provides training for families and any other person that a child may interact with, the development of an individualised assessment and behaviour plan, and the implementation of that plan to achieve the family and child's goals. Individualised assessment and planning are done in collaboration with the child's family and may cover such target areas as: challenging behaviour, communication skills, attention, school skills, play schools, socialisation and relationship building, gross and fine motor skills, self help/independent living skills and community access skills. The Program has been subject to a service review in 2007. A longitudinal study of the Program funded by the NSW Department of Ageing, Disability and Home Care is expected to commence in 2011.

Brightwater Care Group — Oats Street Program

The Brightwater Care Group provides residential, rehabilitation and respite accommodation services for people with predominantly neurological disabilities between the ages of 18 and 60 in Western Australia. Its Oats Street Program is a 27-place rehabilitation facility for people aged 16 and over with an acquired disability as well as cognitive impairment, which aims to facilitate return to community living, with an environment suitable to each client's needs. Clients are expected to participate in the Program for a period of one to two years with a short end phase of community integration. This Program has been subject to an evaluation of its benefits and costs (box 13.8).

New South Wales Brain Injury Rehabilitation Program

This Program (BIRP) was established by the NSW Department of Health and the Motor Accidents Authority in 1990 as a specialist network of agencies that provide services to people suffering from traumatic brain injury and to fill gaps left by general rehabilitation services. Services provided include inpatient treatment, community outreach support and a transition living program. The BIRP has early intervention 'as a key principle to maximise spontaneous recovery and the multi-intra disciplinary approach to the client, their family and environment reduces activity limitations and achieves social participation' (sub. 93, p. 6). The BIRP also operates as a continuum of care model for community resettlement and ongoing support. There has been no evaluation of the early intervention component of the BIRP. However, there are, or will be, projects on particular aspects of the BIRP — for example, a scoping project has been commissioned by the Lifetime Care and Support Authority to assess the fees charged to it by NSW Health for services, including BIRP services; an evaluation of the Transitional Living Program under the BIRP will commence in mid-2011; and a report on rural and remote rehabilitation service delivery is expected in early 2011.

(Continued next page)

Box 13.2 (continued)**New Zealand Burwood Hospital Spinal Unit — Kaleidoscope Program**

The Spinal Unit implements the Kaleidoscope Program, which is a vocational rehabilitation program of which an element is to make initial contact with people with spinal cord injuries within a week of acute hospital admission to identify their future employment and other expectations. The rationale of this approach is that without this, the client has no framework or target through which to judge and engage with services or interventions that were offered (or just applied to them). There is no published evaluation of the Program. However, Dickson et al. (2010) said that their findings on the employment experience of people following spinal cord injury, including return to work outcomes, endorsed the Program's 'founding principle', which is to 'foster hope that employment is both realistic and likely' following spinal cord injury (p. 2).

Novita Children's Services — early childhood services

Novita Children's Services provides a wide range of services to children and young people with disabilities in South Australia. Its early childhood services, for example, involves a Welcome Program (which provides information about services to parents, links to other families through a parent-to-parent initiative, and the establishment of goals and intervention programs with families). Dependent on the family need, a case manager or contact person is allocated to the family. The family is then also allocated a therapy team and services ranging from home and school visits, and group programs, to referral to specialist service teams where complex equipment or post medical intervention follow up is required.

Victorian Transport Accident Commission (TAC) — claims management

Over the past fifteen years, TAC has instituted changes in the management of its claims from clients with severe injuries from road traffic accidents. In 2009, TAC announced TAC 2015, which included an 'independence' initiative relating to claims management for seriously injured clients. This initiative seeks to help seriously injured clients achieve individual goals and independence. Characteristics of this initiative include the development of a single 'one plan model' and of a 'claims practice framework' that features 'early, proactive interventions' in the initial post-accident period. TAC considered that this initiative will enable decisions to be made in consultation with the hospital and improve discharge processes. The Institute for Safety and Compensation and Recovery Research is currently undertaking an evaluation of the TAC's 2015 new claims model.

Sources: Autism Behavioural Intervention NSW (sub. 331; pers. comm.); Brightwater Care Group (sub. 398; pers. comm.); ISCRR (2010b); Kaleidoscope Consulting International (pers. comm.); Novita Children's Services (sub. 560); Agency for Clinical Innovation (NSW) (sub. 93; pers. comm.); TAC (pers. comm.); Tech4Life (sub. 261).

CASA said:

Early interventions should be provided as soon as possible after diagnosis or acquired brain injury, in order to secure the best outcomes and should be continued as long as

the intervention is deemed helpful, not cut off at a certain age, no matter what the person's ability or progress. For example, the school leaver age is nonsensical for people with intellectual disabilities, as they continue to learn slowly, and often, at the time they are required to leave, are just starting to mature and pick up on language and other skills. As there is nowhere else for them to go, and work is not usually an option, remaining in a school or learning environment is sensible, would provide structure and purpose, and allow the person to continue to develop life skills. To cease therapy at a particular age, with no regard for the individual's circumstances, is also nonsensical and continued therapy could often lead to maintaining mobility, for example, thus keeping the person with a disability out of a hospital or a more intensive care facility. (sub. 54, pp. 3–4)

Thus, it is not possible for the Commission to be prescriptive about the timing and duration of early intervention for particular types of disability — even though some participants (for example, Autism Victoria, sub. DR624, p. 2) sought further detail.

That said, there are several broad aspects about the timing of early intervention that need clarification.

Early in life or early relative to the identification or appearance of a disability?

In relation to early intervention, 'early' can broadly be understood in two ways — namely, early in the life of a person (for example, newborns, children and youth — sometimes also described as early childhood intervention or support for children) or early relative to the identification or appearance of the disability.

The main implication of defining early intervention as early in life is that the duration of the intervention could be fairly lengthy and potentially last from birth to age 18 years.

A large number of participants emphasised the importance of focusing on early in life intervention (such as Anglicare Sydney, sub. DR700, pp. 19–20; Association for Children with a Disability Victoria, sub. DR1022, p. 4; Cerebral Palsy League Queensland, sub. DR809, pp. 3–4; Early Childhood Intervention Australia, sub. 450, p. 2 and sub. DR840, pp. 1–2; Friends of Brain Injured Children ACT, sub. DR810, p. 2; Guide Dogs NSW/ACT and Guide Dogs Australia, sub. DR828, p. 6; Jackson Ryan Partners, sub. DR717, p. 7; Lifestart Cooperative, sub. DR1037, p. 4; Montrose Access, sub. DR684, p. 2; National Disability Services, sub. DR836, p. 26–7; Novita Children's Services, sub. 560, p. 25; Technical Aid to the Disabled ACT, sub. DR706, p. 1; Yooralla, sub. 433, pp. 69–70 — see box 13.3).

Box 13.3 Participants views: the need to focus on early in life intervention

Cerebral Palsy League Queensland:

... you need to think about children totally differently and have a separate strategy for children, because it links in with the early intervention that comes through so strongly in the [draft] report, as well as that investment strategy. We believe that the investment will ensure that these children will grow up into adults that will be able to be in the best position to maximise their independence and, in a very real sense, create the highest possible effectiveness of that three tiered system that is proposed. (trans., p. 435)

Early Childhood Intervention Australia:

The provision of appropriate supports and services for young children with disabilities and their families has personal benefits and potential longer term savings from improved educational outcomes, better labour market participation, reduced dependence on public assistance and lower levels of criminal activity.

Access to timely and adequate early childhood intervention ... has been demonstrated to improve outcomes for children with developmental delays and disabilities and their families. (sub. 450, p. 2)

Lifestart Cooperative:

Evidence based research in the early childhood intervention sector has clearly demonstrated the value and cost effectiveness of high quality early intervention and demonstrates clear sustainable outcomes for many children, their families and carers. Early childhood intervention services already provide both national and international strong evidence based research through interventions and models for service delivery for infants and children can be determined. (sub. DR1037, p. 4)

MontroseAccess:

Many of the children supported by MontroseAccess have degenerative conditions or disabilities that significantly impact their physical, social and emotional functioning. Early diagnosis, referral and intervention are critical to prevent or reduce physical deformity, loss of function and psychological harm. Failure to intervene early is likely to lead to increased care requirements and reliance on the service system in the future and a reduction in the potential for people to live economically and socially independent lives. ... Evidence demonstrates the benefits of early intervention in literacy and language skills and preparation for families about the progression of the condition. (sub. DR684, p. 2)

Their views were generally founded on studies into the factors affecting child development and wellbeing, as well as benefit-cost and cost-effectiveness studies into specific interventions in respect of children and their families.²

² These are principally studies from the United States into models of early education and care, including the Perry Preschool project, the Caroline Abecedarian project and Chicago Child Parent Centres — see Hilferty et al. (2010) and Katz and Valentine (2007) for reviews of these and other studies.

These studies suggest that early intervention applied in many different service sectors — family and community services, health care, the justice system, education services as well as disability services — and potentially involved the coordination of all of them. This raises the question of the specific role for the NDIS in this area.

The Commission considers that early intervention under the NDIS should generally encompass interventions occurring early relative to the identification or appearance of a disability rather than only early in life. For children with disability, this, in effect, means early in life. In any event, funding under the NDIS of either types of these interventions should be evidence-based.

When there is a discrete change in the disability

Some disabilities such as multiple sclerosis, Parkinson’s disease, motor neurone disease or muscular dystrophy involve a progressive deterioration in the person. There might also be a discrete change in a person’s condition — such as a sudden deterioration or change in mobility, vision or brain acuity. In these cases, early intervention can occur not only after the disability is identified or appears, but soon after there is discrete change.

An example of early intervention of this kind is the Continuous Care Pilot run by MS Australia and Calvary Health Care Bethlehem (2009) (box 13.4). This program sought to ‘re-route’ the pathway into aged care for young people with progressive conditions through a set of interventions. An evaluation of the program suggests that it has led to benefits for participants — for example, the program ‘almost certainly’ prevented between two and five admissions to aged care.

Early intervention might not necessarily be one-off, but periodic or episodic (for example, the Association for the Blind WA, sub. DR703, p. 4; National Disability Services, sub. DR836, pp. 26–7; the Royal Blind Society, sub. DR826, p. 9). The Association for the Blind WA said:

Typically ... someone with a vision impairment will require relatively short-term assistance, for example, the provision of a particular aid or item of equipment or training in the acquisition of a new skill. These short-term interventions are directed towards successfully enabling a person to live independently and continue his/her participation in community life. The episodic nature of such services mean that people with vision loss only seek the intervention required when their vision or circumstances change or when they have a need for something different. This might be: the uptake of a new piece of equipment or a software upgrade requiring further training; or moving house requiring orientation and mobility training in a different environment. (sub. DR703, p. 4)

What about lifetime transition points?

As advocated by several participants (for example, Anglicare Australia, sub. 594, p. 20; Disability Council of NSW, sub. 489, p. 16; Life Without Barriers, sub. 512, p. 7; Uniting Care Queensland, sub. DR776, p. 24), the Commission considers that early intervention should also encompass interventions to help people with disability to transition to typical lifetime milestones — such as beginning school, leaving education and entering the workforce, retiring and ageing.

Box 13.4 The Continuous Care Pilot

The objective of this program is to ‘re-route the pathway into aged care for young people with progressive conditions through the implementation of a comprehensive set of interventions’ (MS Australia and Calvary Health Care Bethlehem 2009, p. 2).

There were 19 participants in the program, under 50 years of age, who had a diagnosis of a progressive neurological condition (such as spino-cerebellar ataxia, cerebral palsy/cervical dystonia, and multiple sclerosis) and who lived in Victoria.

The program had six steps: transition to the program, specialist health and social assessment, information sharing and knowledge transfer, decision making and implementation of plans, planning to meet contingencies (including the provision of brokerage funds); and monitoring and review.

The step covering transition to the program involved:

- defining criteria for different diagnostic groups to identify the point at which a person with a chronic neurological condition should be offered a continuous care program
- identifying ‘red flags’ for this ‘at risk’ group and educate health and community providers to recognise risks
- informing public and consumers (including consumer groups).

An evaluation of the program (Batterham 2009) found, among other things, that the program:

- ‘almost certainly’ prevented between two and five admissions to residential aged care during its period of operation
- achieved ‘other substantial benefits’ for a number of participants including resolving problems with service providers, accessing additional or more appropriate services, accessing larger and more adequate funding packages, identifying and resolving outstanding equipment issues, establishing more acceptable respite arrangements (pp. ii–iii).

Sources: MS Australia and Calvary Health Care Bethlehem (2009); Batterham (2009); Calvary Health Care Bethlehem (sub. 436).

13.3 The benefits of early intervention

Many participants emphasised the benefits of early intervention, and considered these to include:

- reduced public expenditure on the lifetime costs of care and support for people with disability (for example, Australian Rehabilitation Providers Association, sub. 523; Down Syndrome Victoria, sub. 492; Melbourne City Mission, sub. 283; Rehabilitation Counselling Association of Australasia, sub. DR737; Scope, sub. 432; Victorian Government, sub. 537)
- reduced public expenditure on welfare, health services and other programs outside of the disability services sector (for example, Cerebral Palsy League Queensland, sub. 505; NSW Government, sub. 536)
- greater independence for the individual with disability (for example, Centacare Townsville, sub. 485; MND Australia sub. 264; Rehabilitation Counselling Association of Australia, sub. DR737; Vision Australia, sub. 352)
- improved quality of life (for example, MND Australia sub. 264; Melbourne City Mission, sub. 283; Rehabilitation Counselling Association of Australia, sub. DR737)
- improved health outcomes (for example, Insurance Council of Australia, sub. 553; Rehabilitation Counselling Association of Australasia, sub. DR737)
- reduced impairment, secondary disablement and risk of injury (for example, Queenslanders with Disability Network, sub. 166; Scope, sub. 432; Melbourne City Mission, sub. 283; Rehabilitation Counselling Association of Australasia, sub. DR737)
- improved rehabilitation outcomes (for example, Insurance Council of Australia, sub. 553; Rehabilitation Counselling Association of Australasia, sub. DR737)
- improved school or educational performance (for example, NSW Government, sub. 536; Novita Children's Services, sub. 560)
- better employment outcomes, such as higher employment and skill levels (for example, Australian Rehabilitation Providers Association, sub. 523; Brain Injury Australia, sub. 371; Cerebral Palsy League Queensland, sub. 505; Queenslanders With Disability Network, sub. 166; Rehabilitation Counselling Association of Australasia, sub. DR737)
- greater community participation, reduced community exclusion and reduced loss of established networks (for example, Cerebral Palsy League Queensland, sub. 505; Down Syndrome Victoria, sub. 492; Queenslanders with Disability

Network, sub. 166; Vision Australia, sub. 352; Rehabilitation Counselling Association of Australasia, sub. DR737)

- lower criminality rates, reduced child abuse and neglect notifications (for example, NSW Government, sub. 536)
- reduced breakdown in family relationships (for example, Rehabilitation Counselling Association of Australasia, sub. DR737; Scope, sub. 432).

These and other participants provided the Commission with examples of their own experiences, or of particular studies, as evidence of the benefits (box 13.5).

Box 13.5 Participants' views: benefits of early intervention

Slow stream rehabilitation for people with acquired brain injury

... We have a documented model of practice entitled the Community Approach to Participation (CAP). Three articles on the CAP provide both case study and group data evidence regarding the potential of people with severe to catastrophic brain injury to benefit from community based, slow stream rehabilitation, both in terms of reducing long term care and support and increasing participation and community living skills [Sloan et al. 2009a, b; Sloan et al. 2004]. In contrast, for people who do not receive this targeted rehabilitation, we found that, over an eight-year period, hours of support remained the same. However, there was a shift from paid care to gratuitous support, with associated increasing caregiver burden [Sloan et al. 2007]. (Callaway, Sloan and Winkler, sub. 526, p. 9)

Transition planning

Paediatrics is well supported until the young person reaches adolescence. The problem really start once they leave paediatric care. Transition planning is increasingly being shown to provide long term solutions for young people with chronic illnesses. Transition clinics for conditions such as diabetes, spina bifida, cerebral palsy improve health and social outcomes. ... [The] State-wide Spina Bifida Adult Resource Team ... (210K/annum) ... has in one year of operation connected 185 young people to adult services who had not previously been connected or who have fallen through the gaps. This early intervention approach potentially saves hundreds of thousands per year in preventable admissions through early detection and treatment of shunt problems, renal complications and pressure areas. (Agency of Clinical Innovation (NSW), sub. 93, p. 6)

Early provision of assistive technologies

.... Independent Living Centre of Western Australia ... put forward a submission [to the Western Australian Government] to trial early provision of AT [assistive technologies] based on predictive prescription to prevent hospitalisation and reduce carer burden. This is based upon evidence that AT devices such as the introduction of mobile hoists can impact significantly on the ongoing health of the carer and to prevent breakdown of the [carers]. (Occupational Therapy Australia, sub. 510, p. 7)

The method used matters

In examining evidence from participants and other sources on the benefits of early intervention, it is necessary to distinguish among the different methods of analysis. As noted in chapter 12, there are many possible methods, depending on the particular issue being addressed. Analyses based on these methods can provide valuable information to persons with disability, the NDIA and others about whether a particular intervention is safe, works, or represents ‘value for money’.

Financial (or actuarial) modelling measures any discrepancies between expected and actual costs, and the adequacy of revenues to meet expected costs over the long-term. Such modelling generally occurs as part of monitoring the financial sustainability of the scheme but can be used to identify interventions that are low cost and yield beneficial outcomes for people with disability. Box 13.6 presents an example of financial modelling of the 1999 changes to the NSW Compulsory Third Party (CTP) scheme to the handling of whiplash claims, which included early intervention approaches. The modelling found that the changes led to lower claims costs (as expected) as well as improved outcomes for claimants.

Box 13.6 Actuarial modelling of changes to the handling of whiplash claims under the NSW CTP scheme

Walsh et al. (2007) assessed the impacts of changes in 1999 to the NSW compulsory third party (CTP) scheme on long-term health outcomes and on the cost for claimants with whiplash from motor vehicle accidents.

The main changes to the scheme were: the removal of payment for non-economic loss for claims; the introduction of clinical practice guidelines for whiplash treatment; earlier acceptance of claims; and earlier access to treatment for all types of injury.

The analysis was based on claims data as well as on data collected from telephone interviews with claimants (on their health outcomes). Three independent groups of claimants were compared in 1999 (before the changes took place), 2001 and 2003.

The primary measure of health outcomes used was the Functional Rating Index (FRI), which has 10 items that measure disability due to neck and back pain. A FRI score of 25 or less indicates recovery. Two secondary health outcome measures used were the Medical Outcomes Study Short Form (SF) 36, which measures physical and mental health status, and the Core Whiplash Outcome Measure (CWOM), which measures symptom ‘bothersomeness’, interference with normal work, attitude if injury lasted for life, normal activities cut down, and work absence.

(Continued next page)

Box 13.6 (continued)

Walsh et al.'s findings included the following:

Long-term health outcomes

- Using FRI, at 2 years after injury, there were improvements in recovery from whiplash and reductions in disability due to whiplash for the 2001 and 2003 groups compared with the 1999 group.
- After adjusting for age, the physical component scores of the SF 36 for the 2001 and 2003 groups were significantly higher than for the 1999 group, but there was no significant difference in the mental component scores.
- There were significant improvements in the CWOM item measuring global perceived change in whiplash symptoms in the 2003 and 2001 groups at 2 years after injury compared with the 1999 group. There were significantly more favourable outcomes in 4 of the 5 items of the CWOM for the 2001 and 2003 groups compared with the 1999 group.
- At least half of the claimants in the 2001 and 2003 groups were not recovered at 2 years after injury. The main predictor of non-recovery for this group was high initial disability. Psychological factors or claim-related factors were not as relevant. Thus 'greater emphasis should be placed on assessing disability soon after whiplash and, if high, directing resources to these patients' (2007, p. 25).

Cost outcomes

- Estimated average claim size on all claims (using case estimates) declined by 40 per cent from \$47 768 in 1999 to \$28 824 in 2001.
- The pattern of costs changed, reflecting the changes to the scheme, namely earlier access to treatment, reduced legal fees and reduced non-economic loss payments.
- Small claims finalised faster after the changes. For example, 12 months after injury, 17 per cent of 1999 claims were finalised compared with 43 per cent of 2001 claims, and 44 per cent of 2003 claims.
- The changes were 'effective' in reducing the average size of the smaller claims that finalised relatively quickly, yielding 'substantial savings' to the scheme due to their high frequency.
- For large slow to finalise claims, there were higher medical and economic loss payments after the changes.

Effectiveness (or outcomes) studies consider the extent to which intervention, when used under usual or every day conditions, has a beneficial effect on the course or outcome of a disease or disability compared with an alternative. Box 13.7 presents an example of an effectiveness study in 2010 of the Western Australian Government's early intervention services for children with intellectual disability

and their families. The study concluded that the services met families needs to at least a moderate extent for most ‘measures of process care’.

Box 13.7 Evaluation of the effectiveness of the Western Australian Government’s early intervention services

Wilkins et al. (2010) examined the quality of Western Australian Government early intervention services for young children with intellectual disability (including Down syndrome and autism), which are based on a ‘family-centred care model’.

The specific objectives of Wilkins et al.’s study were to evaluate parental perceptions of the processes of family-centred care for children aged 0 to 6 years who were registered with the Western Australian Disability Services Commission because of the presence of, or potential for, intellectual disability. The study aimed to describe the pattern of service utilisation and compare differences in the results of evaluation between groups defined by the type and frequency of service provided.

The results of the study were based on the responses of 165 families to a postal survey. The survey questions covered the frequency and type of services received as well as perceptions of services using a ‘Measure of Processes of Care (MPOC) questionnaire (which looks at five areas of care — ‘enabling and partnership’, providing general information, providing specific information, coordinate and comprehensive care, and respectively and supportive care). MPOC scores range from 1 to 7, with 1 indicating the family’s needs are never met, 4 indicating that the family’s needs are only sometimes met, and 7 indicating that the family’s needs are met to a great extent.

The main results were the following:

- Contact with disability professionals. Over two thirds of families had contact with both speech pathology and occupational therapy at least once per month, while under half had contact with a physiotherapist at least once a month. Contact with other health professionals (medical doctors, clinical psychologists and dentists) were less frequent. Just over 15 per cent of families had contact with their local area coordinator at least once a month.
- Measure of processes of care scores. Mean scores for the five MPOC areas were 3.97 for the provision of general information, 5.20 for provision of specific information, 5.28 for coordinated and comprehensive care, 5.44 for enabling and partnership, 5.76 for respective and supportive care.

Wilkins et al. concluded that early intervention services for young children with intellectual disability in Western Australia are implementing family-centred care to a standard that meets families’ needs to at least a moderate extent for most aspects of care. They said that the ‘perceptions of families receiving family centred care are generally positive and provide an argument for retaining and strengthening family-centred practice’ (2010, p. 716).

Economic analyses consider whether an intervention is value for money. There are different types of these analyses.

Benefit–cost analysis identifies all the benefits and all the costs of an intervention, and measures them in monetary terms compared with the alternative. Box 13.8 presents a benefit–cost analysis of Brightwater Care Group’s Oat Street program in 2010. The analysis estimated a benefit–cost ratio for the program of around 4:1.

Cost-effectiveness analysis focuses on the costs of achieving a particular type of benefit (or outcome) through an intervention compared with an alternative. Box 13.9 presents a variant of cost-effectiveness analysis — cost utility analysis — in 2010 of an early intervention program in Zambia for young children at risk of neuro-developmental disability. The analysis estimated an incremental cost of around \$8.50 per DALY (avoiding a disability-adjusted life year) for the program.

Cost savings analysis compares the financial costs (usually government outlays) of a service or intervention compared with an alternative. (An example of such an analysis is given later in box 13.10 of a rugby injury prevention program.)

Box 13.8 Benefit-cost analysis of a rehabilitation program for people with acquired brain injury

Brightwater Care Group, a Western Australian service provider, commissioned a benefit-cost analysis (ACIL Tasman 2010) of expanding its Oats Street program (described in box 13.2). The expansion would involve the construction of a new 43 bed residential facility to house a cohort of 20 clients with acquired brain injury over one year. (Currently the program houses around 20 clients over two years.)

Key assumptions of the analysis were: 20 new clients a year, the counterfactual being either no rehabilitation or rehabilitation as in an outpatient setting, an hourly cost of care of \$33.50, a value of statistical life year at \$166 603, a reduction in disability burden as a result of rehabilitation of 10 per cent, a real discount rate of 7 per cent, and a daily cost of rehabilitation per client of \$400.

The client base was divided into five types and the outcomes from the program for each type were examined using case studies.

The analysis found that the:

- net present value of benefits for a cohort under the program was estimated at \$25.67 million, comprising of a reduction in costs of care, improvements in employment opportunities and improvements in the quality of life of clients.
- net present value of costs was estimated at about \$6.2 million (assuming a daily cost of rehabilitation of \$400 per client).
- benefit cost ratio was around 4:1.

Box 13.9 Cost-effectiveness of an early intervention program for young children at risk of neuro-developmental disability

Wallander et al. (2010) undertook a block-randomised controlled trial — the *Brain Research to Ameliorate Impaired Neurodevelopment — Home-based Intervention Trial* — to evaluate the effects of an early developmental intervention program on young children in low- and low-middle income countries (India, Pakistan and Zambia) who were at risk for neuro-developmental disability because of birth asphyxia.

Birth asphyxia is a leading specific cause of neonatal mortality in low and low-middle income countries and the main cause of neonatal and long-term morbidity, including mental retardation, cerebral palsy and other neuro-developmental disorders.

The early developmental intervention program was delivered in home visits every two weeks by parent trainers from two weeks after birth until age 36 months. The primary outcome of the trial was cognitive development, and secondary outcomes included socio-emotional and motor development. These outcomes were measured at child ages of 12, 24 and 36 months.

The trial enrolled 174 children with birth asphyxia and 257 without peri-natal complications. The control group received health and safety counselling only.

The authors compared the incremental cost of sustaining a home-based early intervention program with the willingness to pay for a disability adjusted life year (DALY). The authors noted that maintenance of a home-based intervention program had a relatively low incremental cost. The incremental cost per year once the program was established consisted of the salary of a full time trainer, training equipment, transportation and supplies. For example, the research data for Lusaka, Zambia showed that, if the rate of mental disability index less than 70 due to birth asphyxia was reduced from 7 to 3.5 per cent, the incremental cost of the early intervention program would be around \$8.50 per DALY — consisting of \$22 000 divided by 2590 (3.5/100 absolute risk reduction x 2000 survivors of asphyxia enrolled per year x 37 years life expectancy). The authors considered that this cost compared favourably with that of other medical procedures.

Performance indicators measure how well an intervention is performing against a specific benchmark. The Victorian Transport Accident Commission uses client satisfaction and ‘actuarial release’³ as performance indicators for the management of its claims by persons with serious injury. The Australian Government’s Early Intervention Services Provider Panel also uses performance indicators in assessing outcomes for children with a diagnosis of autism spectrum disorder (box 13.9 later).

³ The difference between the actuarial projected claims incurred and the actual claims incurred.

What does the economic evidence say?

The Commission's internet-based searches of websites such as PubMed, BioMedCentral, Social Care Online, NHS Evidence and NHS Economic Evaluation Database revealed what appears to be a large number of efficacy/effectiveness studies of a wide range of interventions to reduce the impact and risk of disability for many different types of disabilities.

However, the Commission found much fewer economic analyses of early intervention, particularly in Australia.⁴ (The results of some recent economic analyses of interventions relevant to disability are summarised in table 13.1.)

Those that it uncovered involved different types of interventions for different disabilities using different methods of analysis. This makes it difficult to reach any general conclusions about whether an early intervention constitutes value for money.

That there is a poor evidence base of economic analyses of early intervention in particular, was corroborated by the views of some participants and by a 2006 report on early intervention in autism. The Victorian Government said:

Early intervention is a relative new focus in health care, and the evidence of what is effective and yields a return on investment is still under-developed. (sub. 537, p. 18)

A report commissioned by the Australian Government Department of Health and Ageing on early intervention in autism noted:

To date, no studies have examined the cost-effectiveness of treatment programs provided in Australia. Consequently, there is no evidence to suggest that one program is more effective than another based on cost versus benefit ... (Roberts and Prior 2006, p. 79)⁵

Given the potential for early intervention to yield beneficial outcomes not just for persons with disability but also yield cost-savings for the NDIS, the Commission considers that establishing an evidence base that encompasses economic analyses should be a matter of priority for the NDIA. How this could be done is considered next.

⁴ Rehabilitation Counselling Association of Australasia drew attention to research on Australian workers' compensation schemes that, although limited as a source of evidence, indicated that early intervention and early return to work result in lower overall claims costs (sub. DR737, p. 4).

⁵ Also noted in a later article on early intervention in relation to autism by Roberts et al. (2011, p. 2).

Table 13.1 Some recent economic analyses

<i>Study (date, country)</i>	<i>Type of intervention</i>	<i>Economic method/s used</i>	<i>Alternative/s</i>	<i>Economic analysis of intervention</i>
Access Economics (2008a, Australia)	Early intervention for people with psychotic illness (involving low-dose atypical antipsychotics, CBT, programs for vocational recovery, continuing care, relapse prevention and substance misuse harm reduction, family based intervention services, and services to families).	Cost utility analysis and cost savings analysis (with data from 3 Randomised Control Trials — RCTs).	Treatment as usual.	Cost savings over 5 years of \$39 934 per patient. Cost savings over five years of \$212.5 m (\$82.5 m in financial savings and \$130 m reduced disease burden).
ACIL Tasman (2010, Australia)	Expansion of Brightwater Care Group's Oats Street Program (involving residential and rehabilitation services for people with mainly neurological disabilities in Western Australia) to accommodate 20 new clients a year	Benefit–cost analysis.	No expansion — accommodate 20 new clients over two years.	Net present value of benefits of \$25.6 million. Net present value of costs of \$6.2 million. Benefit-cost ratio of 4 to 1.
Chasson et al. (2007, Texas, US)	Early intensive behavioural intervention for children with autism.	Cost savings analysis.	18 years of special education.	Cost savings of \$US208 500 per child Cost savings of more than \$US2 billion.
McDermott et al. (2010, Australia)	NSW Integrated Services (Pilot) Project for Clients with Challenging Behaviour (eg people with intellectual disabilities, mental health problems and other disabilities who have accommodation and criminal justice problems). Support is for 18 months.	Form of cost effectiveness analysis.		Recurrent cost per client of \$207 000 that achieved improved outcomes for clients (eg reduced challenging behaviours and reduced hospital use and costs).
Roberts et al. (2011, Australia)	Early intervention delivered to preschool children with an Autism Spectrum Disorder — Aspect's Building Blocks Program. The Program draws on a variety of approaches, including naturalistic play-based intervention, behavioural and developmental theory, structured teaching, the development of functional communication skills, positive behaviour support, assessment of sensory processing issues, and extensive use of visual supports.	Primarily and outcomes comparison as well as cost-effectiveness analysis.	Two variations of the Program are considered: a home-based service (involving 1:1 work with child and parent) and a centre-based small group centre based service (involving 5 to 6 children and two staff and a parent group). Both variations of the Program involved 2 hours of direct service per week over 40 weeks.	Staff cost per child was estimated at \$6383 regardless of Program variation.

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Table 13.1 (continued)

<i>Study (date, country)</i>	<i>Type of intervention</i>	<i>Economic method/s used</i>	<i>Alternative/s</i>	<i>Economic analysis of intervention</i>
Romeo et al. (2009, UK)	Health check intervention for people with intellectual disabilities, involving a nurse reviewing a patient's GP records against a semi-structured form, discussing findings with specialist GP, then issuing report with recommendations to patient's GP.	Cost savings analysis.	Standard care.	Cost of care savings was £37 569 per annum.
Wallander et al. (2010, US)	BRAIN-HIT. Early intervention program for children at risk of neuro-developmental disability because of birth asphyxia. Program delivered in home visits every 2 weeks by parent trainers from 2 weeks after birth until age 36 months.	Cost utility analysis (with RCT).	Control group received health and safety counselling only.	For a site in Zambia, \$US8.50 per DALY.

13.4 Targeting beneficial early interventions under the NDIS

The NDIS as proposed by the Commission will have many features that are likely to be conducive to improved early intervention.

- A more thorough, consistent and timely needs-based assessment (chapter 7) would include an analysis of the scope for early intervention. In effect, the NDIS would search for cost-effective interventions across all people with disability, regardless of their age or severity of condition. Many participants pointed out the importance of interventions over the whole life of a person where they produced good outcomes (Anglicare Australia, sub. 594, p. 20; Life Without Barriers, sub. 512, p. 7).
- Individualised support packages and greater self-direction over care funding (chapter 8) would enable individuals themselves to have greater control in initiating interventions suited to their own specific needs. In the United Kingdom, for example, a woman with a disability was able to use her funds to buy an air conditioner, which reduced her subsequent hospitalisation rates and quality of life (Leadbetter et al. 2008, p. 39).
- The public reporting and modelling of future expected liabilities as a key performance indicator, rather than just of current claims (chapter 14) would allow decision-makers to estimate the effects of early investments on future liabilities.
- Systematic data collection on outcomes for people with disability (such as employment, education, and self-care capabilities) and on the inputs and processes that may have led to these (such as aids and appliances, self-directed

support, particular programs, and case management approaches) (chapter 12) would help build up an evidence base for assessing which particular interventions work well, as a basis for their greater diffusion or withdrawal.

- The replacement of fault-based injury insurance arrangements with no-fault systems would encourage improved rehabilitation outcomes (chapters 17 and 18).

A particular challenge for the NDIA (and for people with disability) is how to choose or target early interventions that should be funded or purchased under tier 3 of the NDIS. Undertaking analyses based on the methods described in section 13.3 would in principle indicate those interventions that are safe and work, and that are most likely to yield the highest benefits or lowest costs for people with disabilities and the wider community.

However, from a pragmatic perspective, there are the following inter-related issues.

- What standard of evidence is required in deciding whether or not to fund or purchase a particular intervention?
- How should the evidence be obtained?
- How would the funding of proven interventions sit with the funding of other disability supports?

What standard of evidence?

Some participants expressed a range of views about the standard of evidence necessary to support the funding of early intervention (box 13.10).

The most robust standard of evidence — a combination of a systematic review of randomised controlled trials on effectiveness and benefit-cost analysis — is likely to be the most costly and slow to obtain (apart from where there are already international studies) (chapter 12, table 12.1).

Accordingly, the Commission considers a selective evidence-based approach is appropriate for deciding whether or not to fund or purchase a particular early intervention under the NDIS. This approach would consist of the following.

- As a minimum, there should be good evidence of the effectiveness of the intervention — that is, the intervention is safe and achieves improved outcomes for people with disability. Without such evidence, there should be no funding of the intervention.

Box 13.10 Participants' views: what should be the standard of evidence for early intervention?

Association for Children with a Disability (Victoria):

... it will be important that assessments for the NDIS does not get bogged down in securing diagnostic evidence, whilst the 'clock is ticking' and opportunities to benefit from early intervention are quickly fading. (sub. DR1022, p. 4)

Our Association is concerned with the ... inference that 'early intervention' should be assessed on the 'likelihood of cost-effectiveness' will compromise access to evidence-based effective therapeutic interventions. ... some therapies are expensive and highly intensive, however, their proven effectiveness should be the basis for their inclusive in the NDIS or NDIS. (sub. DR1022, pp. 12–13)

Anglicare Sydney:

Rigorous assessment of early interventions (as with all approaches) needs to establish the efficacy and cost effectiveness of these programs. (sub. DR799, pp. 19–20)

Australian Federation of Disability Organisations:

The ... proposal for early intervention services to be funded on the basis of their 'cost-effectiveness' is potentially at odds with the CRPD obligation for States parties to 'reasonably accommodation' supports that will enable full inclusion and participation for people with disability on an equal basis with others. (sub. DR982, p. 8)

... cost utility on its own is an inadequate rationale for the funding of disability supports with respect to CRPD obligations. (sub. DR982, p. 9)

DANA:

Early intervention approaches should be funded by the NDIA if they are likely to yield a benefit to the person with disability in terms of their desired outcomes and well-being. Cost effectiveness is too limited a criteria on which to base a determination about eligibility because it will always fail to appropriately take into account the indirect costs to the person, their families, the government (for example, through additional health costs) and the community (in terms of lost participation and contribution) of failing to provide the intervention. (sub. DR1010, p. 35)

Friends of Brain Injured Children:

Because the science [in relation to neuroplasticity and children with brain injury] is young, conclusive evidence for the efficacy of particular therapies in this area is incomplete, but growing. ...

We ... recognise the validity of the ... caution that funding must not turn into a free-for-all, and that ineffective therapies must not end up funded by the scheme, ... (sub. DR810, pp. 2–4)

Lifestart Cooperative:

Lifestart supports the NDIS in the need to fund early childhood interventions which are based on good evidence of effectiveness and an initial assessment of cost-effectiveness. (sub. DR1037, p. 4)

(Continued next page)

Box 13.10 (continued)

Rehabilitation Counselling Association of Australasia:

RCAA agrees that more Australian research to establish the efficacy and cost benefit of early intervention for the NDIS client population is required. With regard to developing the evidence base for the range of possible interventions, the Commission should consider the value of a broader range of types of evidence commonly generated in different areas of research. For instances, research by Rehabilitation Counsellors is often qualitative and can be applied directly to practice. ... Often such qualitative research has the capacity to identify those questions which most benefit from quantitative research. (sub. DR737, pp. 4–5)

Valued Independent People:

We would hate to see early intervention denied simply due to lack of evidence of future cost-effectiveness. On-going assessment of the client before, during and at the end of the intervention is not only essential for the client but would also help to build the necessary data base for the effectiveness of particular early intervention strategies. (sub. DR932, p. 19)

Victorian Government:

Further consideration [is needed] of how best to balance the desirability of funding only evidence-based early interventions against the need to promote innovation and build the evidence base for safe, effective and cost-effective early interventions. (sub. DR996, p. 29)

- The NDIA would interrogate its own data — available from the electronic database that the Commission proposes in chapter 12 — to examine the cost-effectiveness of interventions that it already funds.
- In relation to new interventions, there should be an initial appraisal by the NDIA of the likelihood of cost-effectiveness of the intervention. This initial appraisal would follow the steps set out in chapter 12 (section 12.6). Where the NDIA found that the intervention was likely to be cost-effective, that would be enough justification to fund the measure, knowing that there was a reasonable low risk of decision error. Subsequent evaluation would determine whether the initial analysis was well founded. On the other hand, where the NDIA assessed the intervention as unlikely to be cost-effective, it should not fund that without further evidence.

How to obtain the evidence?

Chapter 12 canvassed a broad range of matters relevant to the building of an evidence base under the NDIS.

In respect of early intervention, there are at least three ways of building the evidence base.

- As noted, the NDIA interrogates its own data to search out cost-effective interventions.

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- The NDIA commissions or undertakes research on specific interventions. This research could involve systematic reviews of the evidence on existing interventions, or pilots of promising new interventions.
 - Service providers apply for funding of an intervention under the scheme and, as part of that application, submit efficacy, effectiveness, and economic analyses to the NDIA. This is similar to arrangements for the Australian Government's Helping Children with Autism early intervention program, in which service providers must apply to FaHCSIA to seek membership of an Early Intervention Services Providers Panel and demonstrate that their services are 'value for money' (box 13.11).⁶ There would be a need for the NDIA to independently vet the quality of the analyses.

Regardless of what combination of these ways is used, after its establishment, the NDIA should start building an evidence base. It could be guided in identifying suitable interventions for research by considering such factors as the prevalence of the disability that the intervention is intended to assist, the extent of potential improvements in outcomes for people with disability, and the type of future cost that the approach has the potential to alleviate. Consultations with stakeholders would help the NDIA identify suitable interventions for research.

An established evidence base on early intervention could then lead to the development of guidelines to assist the NDIA in its decision making in relation to whether people with disability obtain early intervention support under tier 3 of the NDIS.

Funding a proven early intervention approach

Where the NDIA is satisfied that there is good evidence that a particular intervention is safe and leads to beneficial outcomes for people with a disability, and has assessed the intervention to be likely to be cost-effective, the NDIA should allocate funding to it.

Such funding would:

- be additional to that allocated to people with disability for their ongoing care and support under needs-based assessment
- not be able to be cashed out by people with self-directed care packages (as discussed in further detail in chapter 8).

⁶ Similar arrangements have been established in respect of the Australian Government's Better Start for Children with Disability initiative, which commenced from 1 July 2011 (FaHCSIA 2011a).

Box 13.11 The (autism) Early Intervention Services Providers Panel

The Australian Government Helping Children with Autism package includes funding for early intervention services for children aged 0 to 6 with an autism spectrum disorder of up to \$12 000 (which can be used until the child's seventh birthday to a maximum of \$6000 a financial year).

Early intervention services that are eligible for funding are defined according to Roberts and Prior (2006) as: behavioural interventions; development and social learning interventions; therapy-based interventions; and family-based interventions.

In order to access funding, families must first contact an Autism Advisor in their state or territory for information about their eligibility. Eligibility criteria include the age of the child, the availability of a diagnosis and meeting residency requirements. Eligible families can then access service providers from an Early Intervention Services Providers Panel.

Services providers seeking membership of the Panel must submit an application to FaHCSIA. Their applications will be accepted if the provider meets certain eligibility criteria, which include meeting best practice guidelines on the following:

- demonstrating that its services are 'value for money'
- conducting assessments of the child before, during and at the end of the intervention to determine the effectiveness of the intervention and to inform the decisions made by the family or carer about those interventions that might best suit their child and family
- meeting reporting requirements against performance standards and specified outcomes of the early intervention service including — wait lists, time to receive services, unmet needs, cost of providing services; complaints; staffing; barriers to service delivery; workforce capacity issues; and performance against the purpose and planned outcomes of the strategy
- collecting performance indicator data through client surveys on increased access to early intervention for children aged zero to six years diagnosed with an autism spectrum disorder; improved overall well-being of eligible children; improved strategies and skills of parents and carers to meet the needs of eligible children; and improved capability of eligible children to attend full time formal school and participate in everyday life.
- FaHCSIA has commissioned a review by the Australian Autism Research Collaboration of autism interventions funded under the Helping Children with Autism package. The review seeks to: provide a comprehensive list of autism interventions based on the latest evidence based research; provide a basis for appropriate assessment by FaHCSIA of provider applications; not concerns raised by families and practitioners, based on feedback from peak bodies, about current practices and ineligible interventions; develop a process for FaHCSIA to ensure that children are receiving effective evidence-based interventions and that families are able to make more informed decisions about available interventions.

Sources: FaHCSIA (2010a, b, c); NSW Government (sub. DR922, pp. 14–15).

RECOMMENDATION 13.1

Early intervention approaches used by the NDIA should draw on evidence of their impacts and be based on an analysis of the likelihood of cost-effective outcomes. NDIS funding for early intervention should be additional to that allocated to people in the scheme for their ongoing care and support and should not be able to be cashed out under self-directed care packages.

RECOMMENDATION 13.2

The NDIA should build an evidence base on early intervention. It should commence this task by identifying, in consultation with stakeholders, existing or potentially promising approaches for further research.

13.5 Interventions outside the NDIS

Many early interventions and interventions to reduce the risk of disability would continue to be under the control of agencies outside the NDIS. These include agencies responsible for health, mental health, education, early childhood intervention, child protection, housing and criminal justice services, the newly established Australian National Preventive Health Agency,⁷ as well as agencies responsible for accident insurance arrangements.

Interventions to reduce the risk of disability cover a wider range:

- Community awareness campaigns associated with the risk of injury and accidents (like safer sports and driving practices). In some cases, these may be targeted at particularly vulnerable populations (such as Indigenous programs addressing petrol sniffing and foetal alcohol syndrome).
- Regulations prohibiting, or setting standards for, activities associated with significant risks of injury and disability. While many of these are obvious, such as motor vehicle standards and driving laws, and occupational health and safety regulations, some, like mandatory fortification of foods, are less so.
- Regulators taking a precautionary approach to the approval of new products involving potentially high risks and where the effects may take some time to appear (for example, requirements for analysis of the safety of new drugs).

⁷ See footnote 1.

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- Public funding or provision of services — such as better roads, health services or child protection services — that help to avoid or screen for the risk of disability.⁸

Participants identified a variety of potentially beneficial interventions in these areas, including:

- increased investment in effective prevention, early intervention and support services for people with mental illness to reduce the disabling impacts of mental illness (Mental Health Coalition SA, sub. 513, pp. 4, 5)
- priority to oral health care [of special needs' groups], to ensure effective preventative care and early intervention (Australian Dental Association sub. 552, p. 10)
- awareness of macular degeneration risk factors, such as smoking, maintaining a healthy weight, protecting eyes from sunlight, fitness and blood pressure to reduce the risk or slow progression of the disease (Macular Degeneration Foundation, sub. 77, p. 11)
- interventions in the education system (Australian Blindness Forum, sub. 438, p. 19)
- early childhood education interventions (Early Childhood Intervention Australia, sub. DR840, pp. 1–2)
- public awareness campaigns to decrease the possibility of people acquiring brain injury (Headwest Brain Injury Association of WA, sub. DR798, p. 4)
- the timely provision of appropriate accommodation for people with disability, which could lessen the time spent by persons with disability in hospitals and residential aged care facilities and enable families who would otherwise care for them to obtain employment (CASA, sub. 54, pp. 1–2).

Economic analyses of such interventions can also illuminate these benefits. For example, box 13.12 presents a cost savings analysis in 2007 of a New Zealand program to prevent rugby injuries. This analysis estimates (actual) cost savings of up to \$NZ700 000 and a return on each dollar invested of around \$NZ12.70 for the program.

There are many other prospective gains to the NDIS from interventions occurring outside the scheme, some of them not immediately obvious. For instance, child

⁸ Some participants considered that premium-setting and the availability of common law redress for negligence necessary to create incentives for employers and motorists to modify their behaviour to mitigate disability risks (for example, Maurice Blackburn Lawyers & Slater and Gordon, sub. 409 and the Victorian Government, sub. 537). This is discussed in chapter 17.

protection agencies could provide services that target vulnerable families where there is a risk of children acquiring inflicted traumatic brain injury or other disabilities due to physical abuse, such as shaken baby syndrome (BIA 2010).

Box 13.12 Cost savings from a concussion management education program in rugby

Gianotti and Hume (2007) assessed the impacts of a concussion management education program in rugby in reducing the number and cost of moderate to serious concussion/brain injury claims to the New Zealand Accident Compensation Corporation (ACC). The program consisted of a RugbySmart educational video and a sideline concussion check tool developed by the ACC. The tool was designed to be small enough to be carried in the coaches', referees' or match officials' pockets and to be waterproof.

To evaluate the effectiveness of the program, moderate to serious claims for rugby concussion/brain injury in 2004 and 2005 were compared with claims in 2003. A comparison was also made for other groups of moderate to serious claims for concussion/brain injury from 1999 to 2005.

Over the two year period of implementation of the concussion management education program, the authors found that:

- new rugby moderate to serious claims for concussion/brain injury reduced by 11 per cent (actual). Rugby player numbers increased by 14 per cent over this time
- new sport moderate to serious claims for concussion/brain injury reduced by 4 per cent (actual)
- non-sport moderate to serious claims for concussion/brain injury increased by 17 per cent (actual)
- the median number of days between a concussion/brain injury and the player seeking medical treatment decreased from 6 to 4 days.

Gianotti and Hume also undertook an investment and cost-savings analysis of the program. They estimated that the:

- cost savings after the program was implemented were \$NZ690 690 (actual)
- the two year cost of the program was \$NZ54 810, returning \$NZ12.70 (actual) for every \$NZ1 invested.

It is likely to be impractical for the NDIS to fund or coordinate many of the above interventions. This is mainly because many of them often have purposes other than addressing the impact or risk of disability (as in child protection), or the agencies responsible for them already have well-developed expertise (such as health agencies in respect of early and preventative interventions for people with mental illness). Indeed, the Commission considers that early interventions in respect of mental

health conditions would remain the responsibility of relevant agencies outside of the NDIS (box 13.13, chapters 3 and 18).

Box 13.13 Why early interventions in relation to mental health conditions should stay outside of the NDIS

Mental health conditions cover a spectrum of disorders including substance abuse disorders, anxiety disorders, depression and related affective disorders, bipolar disorders and schizophrenia.

Early interventions occur when a person is first diagnosed with a mental health condition, and are designed to prevent further episodes. They can include: pharmacological treatment; cognitive behavioural therapy; family-based supports; substance misuse harm reduction; and vocational support. For example, the early psychosis prevention and intervention centre (EPPIC) program in Melbourne is targeted at people with psychosis and uses cognitively-oriented psychotherapy as well as family therapy.

As part of its national mental health reform initiatives in the 2011-2012 Budget, the Australian Government proposed additional funding for early intervention and prevention and mental health services for children and young people. These consisted of an additional 90 headspace sites, 12 EPPICs and 40 family mental health support services.

Evidence of the cost-effectiveness of early intervention services in managing the critical phase of psychosis is accumulating (Singh 2010; Yap 2010).

There was some divisiveness in the views of participants as to whether the NDIS should fund early intervention for mental health conditions (with some participants such as Valued Independent People, sub. DR932 and AMA, sub. DR875 considering that early intervention should be funded by the mental health system, whereas others such as VICSERV, sub. DR921 considering it should be funded within the NDIS).

The Commission is of the view that the NDIS should not fund early intervention for mental health conditions for the following reasons:

- Interventions are largely clinical in nature (involving therapy or pharmacological treatment) and they would thus be reasonably provided for in the mental health system.
- Where a person with disability also has a mental health condition, that person would be referred to the mental health system under tier 2 of the NDIS.
- There would be potentially a very large population of people who would be eligible for early intervention for a mental health condition and who would thus place financial pressures on the NDIS.

The problem of delineating the responsibilities of the various agencies for early interventions and interventions to reduce the risk of disability is not a new one. It is

notable that the Queensland Early Intervention Initiative, aimed at funding new services or the expansion of existing services for families with children with a disability, expressly excluded the use of the funds for medication, rehabilitation, school and education support and other services (Queensland Government 2007, p. 14).

That said, there are strong grounds for defined linkages between the NDIS and other agencies in undertaking early interventions and interventions to reduce the risk of disability. The linkages might involve consultation in the funding and design of programs (for example, in relation to inflicted acquired brain injury in children, sporting injuries, early childhood intervention services, and preventative health), the provision by the NDIA of data as appropriate, and the referral of people with disability in tier 2 to relevant government agencies and not-for-profit organisations. As an example, people with disability receiving individualised funded support under tier 3 of the NDIS who suffer from co-morbidities such as depression might also be referred to relevant agencies in the mental health sector for early intervention. Such an approach would require the formalisation of links between the NDIS and health, education and other relevant agencies and organisations.