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Family &
Community
Services

Supports for children and young people 9–18 years and their families

Framework for Service Providers | July 2015



Contents

Introduction	3
About this framework	3
The seven guiding principles	5
Objectives of the framework	6
Context	8
Experiences of children and young people with disability	8
Experiences of families	11
Supports provided to children and young people with disability in NSW	11
Policy context of the framework	15
The seven guiding principles	19
1 Deliver person-centred, family-centred and strengths-based supports	20
2 Strengthen decision-making capacity and opportunities to exercise choice and control	23
3 Provide early intervention and holistic support across transitions	27
4 Provide coordinated and integrated supports	32
5 Promote participation and inclusion	35
6 Support the development of social relationships	40
7 Follow culturally appropriate practices	43
Future directions and opportunities	46
Participant Capacity	46
Strategies to support capacity building	50
Provider and community capacity	52
Conclusion	54
Endnotes and references	56

Introduction

Every child and young person, regardless of their needs, has the right to participate fully in their community and to have the same opportunities, experiences and choices as other children. Children and young people with disability should be recognised as children and young people first and foremost, and be supported to participate, enjoy, learn and play alongside their peers.

The *Ready Together* reforms have seen an unprecedented expansion in the range, availability, quality and flexibility of support services for people with disability in NSW. This investment is building a lifespan approach that creates long-term pathways, embedding early intervention and prevention across a person's whole life. At the same time, there have been widespread changes to the way that specialist supports are provided. People with disability are increasingly supported in everyday settings in their community, rather than in segregated specialist settings. Early childhood intervention has been prioritised in these reforms, with a significant investment made in the non-government sector to increase support and inclusive pathways for children with disability aged 0–8 years and their families.

About this framework

The 9–18 years life stage is another important stage in the development of children and young people with disability. It is in this age group that many exciting things happen. Children leave primary school and commence the high school journey. They develop as individuals, learn skills to interact with their peers, identify areas of interest and gain independence as they become young people. The NSW Department of Family & Community Services (FACS), Ageing, Disability and Home Care (ADHC), has therefore developed this framework to set out guiding principles for service providers (ADHC direct services and ADHC-funded NGOs) to use in increasing the participation and inclusion of children and young people with disability in everyday settings.

The framework focuses on all children and young people with disability aged 9–18[†] and their families living in NSW, recognising that this is a broad group with different needs at different ages and stages of development. This includes children and young people living in the community who may or may not require specialist supports.

[†] The framework covers children and young people aged 9 to 18, in recognition that under the Children and Young Persons (Care and Protection Act) a child means a person under 16 years, and young person means a person under 18 years.



This life stage provides significant opportunities to support children and young people to build and maximise their capacity and skills in order to help them achieve their goals and live good lives on their journey to adulthood.

The NSW Government has committed to an early transition of the National Disability Insurance Scheme (NDIS) in the Nepean Blue Mountains District for children and young people aged 0–17 years, with participants starting to receive packages from September 2015.

The framework will be a useful tool for service providers as they develop their capacity to support the inclusion and participation of children and young people through their service approach both now and into the future during the transition to the NDIS. It identifies important principles for supporting this age group and opportunities to develop models of support, and evaluates the effectiveness of strategies for families and providers alike as NSW continues to transform the current system and prepare for transition.

The seven guiding principles

The framework sets out guiding principles that can be used by FACS districts and service providers (including both ADHC direct services and ADHC-funded non-government organisations) to guide and support local service delivery and decision-making.

Like the NDIS, the framework is broader than specialist supports children and young people need. It focuses on how service providers can incorporate inclusive practices in the way they deliver services across a range of settings – at home, at school and in their community.

The framework looks at strategies to build the capacity of mainstream[†] and community services to be accessible, supporting and enabling participation and inclusion. It also includes ways for service providers to support and build the capacity of children and young people with disability and their families to exercise choice and control and to be at the centre of decision-making regarding self-directing supports along their journeys to adulthood.

The framework begins by looking at the context within which the development of children and young people takes place, as well as providing an examination of the policy context and service system in NSW. Then, at the core of the framework, lie the seven guiding principles:

1. Deliver person-centred, family-centred and strengths-based supports
2. Strengthen decision-making capacity and opportunities to exercise choice and control
3. Provide early intervention and holistic support across transitions
4. Provide coordinated and integrated supports
5. Actively promote participation and inclusion
6. Support the development of social relationships
7. Follow culturally appropriate practices.

Accompanying each guiding principle is an examination of supporting evidence and strategies. ADHC has endeavoured to use the best available research and evidence throughout the framework, but acknowledges there are considerable

[†] For the purposes of this initiative, mainstream settings are considered those which are available to anyone in the community. Examples include preschools, schools, community health centres, hospitals, playgroups and community groups. It is acknowledged that people working in mainstream settings have a diverse range of skills, including some people with specialist skills. In this document the specialist system refers specifically to the disability sector.

gaps in the evidence base. In the absence of available local research and evidence, the framework draws on international and national research and evidence.

The framework concludes with a look at future directions and opportunities during the transition to the National Disability Insurance Scheme (NDIS). The areas covered here are:

- increased access to individualised funding arrangements
- capacity-building
- improved pathways to supports in the community, and
- promotion of participation and inclusion.

A Resources Guide included as an appendix to this framework includes additional information, tools and resources that service providers may find useful in applying this framework.

The framework and Resources Guide may be useful to a range of community and mainstream service providers.

Objectives of the framework

The objectives of the framework are that children and young people with disability aged 9–18 years and their families will:

- participate and be included in their local community, with opportunities to choose and engage in a mix of meaningful social, recreational and cultural activities that help them determine their strengths, passions and interests
- access therapy and other supports in their natural environments,* where they are incorporated into everyday tasks and routines, including integrating specialist supports in a way that complements their life in a functional manner rather than treating it as an isolated event
- develop positive and meaningful social relationships and networks in their community
- access the necessary supports to build resilience, increase capacity and improve their quality of life
- build and maximise their capacity, appropriate for their age and stage of life, to plan and make decisions regarding their life, including activities they pursue and supports they access that best meet their life goals, aspirations and needs

* Natural environment refers to everyday places, environments and activities within the community or home settings where all children and young people are typically found.

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- access a variety of education, life skills and vocational development opportunities based on their goals, aspirations and strengths to maximise independence and socio-economic participation
 - have choice, control and access to a range of flexible and inclusive supports in their local community and mainstream settings and be less likely to rely on specialist disability supports to meet all their needs.

Additional objectives are that:

- families will have the necessary skills and supports to self-advocate and address challenges that may arise along their child's journey towards independence
- mainstream services and local communities will provide inclusive and welcoming environments that foster inclusion and participation of children and young people with disability and their families
- information in the framework will assist service providers to have a targeted approach to supporting this age group in a way that is specific to their needs as they prepare for transition to the NDIS.

Context

This section outlines the context and rationale for developing the framework. It describes some of the experiences of children and young people with disability, provides an overview of the current service system in NSW, and examines the policy context of the framework.

Experiences of children and young people with disability

According to estimates, 3.4 per cent of children and young people aged 5 to 24 in NSW (a total of 65,500 individuals) have a profound or severe core activity limitation, and 2.4 per cent (45,100 individuals) have a moderate to mild limitation.¹ Aboriginal children and young people have higher rates of disability, and poorer outcomes, than non-Aboriginal children and young people.²

Children and young people with disability are often considered primarily in reference to their disability, rather than as children and young adults.³ Their disability is just one part of their life; they want to be known for who they are – as a person with abilities, talent and potential.⁴

'To have a healthy and happy life, I need acceptance, inclusion, to be seen as a person with potential and for help to reach that potential'

12-year-old boy⁵

Children and young people with disability have the same hopes, ambitions and aspirations as their peers – to make friends and have relationships, to study or go to work, to have hobbies and a social life, and to be part of their community.⁶ They want to be involved and included, to participate in activities that are fun and give a sense of belonging. They also want to have control over these choices and desire to be independent.⁷

'To lead an independent life – if possible'

10-year-old boy⁸

As children and young people move from childhood to adulthood, they experience many challenges dealing with periods of rapid growth and development.⁹ This significant life stage involves preparing for a range of transitions that can be challenging for all children to navigate, such as moving from paediatric to adult health services, moving to and from high school, finding employment, or engaging in further studies and living independently.¹⁰ This transition process continues well

into adulthood. It is also a time when young people focus on building peer-focused relationships while establishing a sense of identity.¹¹

Children and young people with disability can experience additional challenges that impact on their outcomes as they transition to adulthood, as outlined below. Yet it is important to remember that, despite these challenges, there are many ways to create positive, lifelong opportunities for children and young people with disability in their community so that they can live good lives and achieve their goals as they transition to adulthood.

Limited involvement in decision-making

Young people with disability want more opportunities to be involved in decision-making about their lives, particularly at crucial points on the journey to adulthood.¹² For example, a survey of young people with disability in Victoria found that over 50 per cent of young people with disability had limited or no opportunities to share their views and opinions, and that over 70 per cent said that they would like more opportunities to have their voices heard.¹³

Social exclusion

Children and young people with disability can be vulnerable to social exclusion, with fewer opportunities to engage in recreational and social activities, develop social relationships and positively engage with peers.

One study found that 37 per cent of children and young people with disability never took part in organised physical activity in the community, compared with only 10 per cent among their typically developing peers.¹⁴ Exclusion has a profound effect on a child and young person's development and attitudes towards life and, if not addressed effectively, can set up a negative pattern for later life.¹⁵

'I am important, ask me what I think, I want more choices, I have good ideas, sometimes I need help, everything is good, I am the same as other kids, I want to do the same activities, I am clever.'

9-year-old girl¹⁶

Poorer education and employment outcomes

All children aged 6 to 17 years must attend school or be registered in home schooling.¹⁷ In NSW, approximately 90,000 students, or 12 per cent of the total public school population, have disability and/or additional needs relating to learning or behaviour.¹⁸

Research shows that children and young people with disability have lower levels of participation in education and employment than their peers. In 2009, 38 per cent

of young people aged 15 to 24 years with disability were fully engaged in full-time or part-time study or work, compared with 56 per cent of young people without disability.¹⁹ In 2012, just over 50 per cent of people with disability aged between 15 and 64 were participating in the labour force, compared with over 80 per cent of people without disability.²⁰

Higher rates of physical and mental health issues

It is common for children and young people with disability to have other long-term and complex conditions. They also experience higher rates of physical and mental health issues than those without disability,²¹ including emotional distress, anxiety and depression.²²

Children and young people with intellectual disability have higher rates of behaviour and emotional issues. One study²³ found that around 40 per cent of children with intellectual disability had a severe degree of behaviour and emotional issues, which is three to four times higher than in typically developing children and young people.

Vulnerable to abuse and neglect

There is considerable evidence that children with disability are much more likely than their peers to be vulnerable to:

- bullying or victimisation²⁴
- neglect
- mental, physical and/or sexual abuse,²⁵ and
- homelessness and exclusion.

Children and young people with disability are often more likely to be victims of bullying. Bullying can affect a child or young person's self-esteem, mental health and wellbeing, contributing to mental health issues such as depression and anxiety.²⁶ One study reported that 62 per cent of students with autism spectrum disorder report being bullied once a week or more.²⁷

In NSW in 2011–12 there were 23,175 substantiated cases of significant harm, with 34 per cent experiencing neglect, 31 per cent emotional abuse, 19 per cent physical abuse and 16 per cent sexual abuse.²⁸ Children with an intellectual disability are four times more likely to experience all four types of maltreatment. Children and youth with behaviour disorders are seven times more likely to experience neglect, physical abuse and emotional abuse, and five-and-a-half times more likely to be sexually abused.²⁹

Abuse and neglect can lead to a wide range of adverse consequences for children and young people; it is important that further research in this area be undertaken.³⁰

Vulnerable young people with disability are at higher risk than their peers without disability of instability and homelessness, disengagement from school, exclusion from services, and poverty. Young people with disability, and particularly young Aboriginal people with disability, are overrepresented in the juvenile justice system.³¹

Experiences of families

Research shows that having a child with disability has a significant impact on the whole family.³² Families can experience difficulty in maintaining family routines, loss of social support, and financial stress due to loss of income or additional costs.³³ Parents** of children and young people with disability also experience higher levels of stress and lower levels of wellbeing than other parents,³⁴ including increased reports of anxiety, depression and feelings of hopelessness.³⁵ Caregiving can be challenging and demanding,³⁶ causing stress due to the child's behaviour of concern, complex medical or high caring needs, as well as the limited availability of informal (natural unpaid) or formal supports.

Families can experience a range of barriers when trying to access specialist, mainstream and community supports and activities. These can include barriers accessing information, attitudinal barriers, and barriers dealing with a complex service system. It can be difficult for families to know their rights and have the skills and/or confidence to advocate for the inclusion of their children in mainstream and community settings. They may struggle to meet challenges arising across various transition points and may need support to develop the skills needed to meet these challenges.

While families of children and young people with disability may experience barriers such as these, many adapt and overcome them, using their own personal resources, the support of family and friends, and the help of services.³⁷

Supports provided to children and young people with disability in NSW

ADHC-funded supports

For most children and young people with disability, their families provide most of the support they need. Some children and young people with disability and their families may require additional supports to improve their quality of life and wellbeing and to live independently in their community. The supports they access will depend on their goals and needs and on what is available in the local

** 'Parents' refers to parents and carers.

community, such as community organisations, non-government organisations (NGOs) and government agencies.

ADHC funds a diverse range of supports for children and young people with disability across a continuum of need. These supports are flexible, individually tailored and responsive to the needs of each child and young person with disability and their family. While some are delivered directly by ADHC, they are predominantly delivered by NGOs. These include the following:

- [Information, referrals and advice](#) to access supports in the community that will suit the needs and goals of children and young people and their families
- [Advocacy and information services](#) to help them access community and disability supports and promote community awareness
- Support planning and [coordination](#) to support their planning and decision-making, and to access services in their community that help them to meet their needs and goals
- Everyday living support, including [specialist supports](#) (such as therapy and behaviour supports) to help improve independence, quality of life and wellbeing
- [Behaviour supports](#) for families, service providers, school staff and other professionals who may need help supporting children and young people who have behaviours of concern
- [Self-care supports](#) for young people with moderate, severe or profound disability who need assistance with self-care tasks and daily living activities so they can continue to live in their community and maintain their independence
- Supports to [develop skills and transition from school](#) to employment and further education
- Supports to provide opportunities for them to build relationships and positively engage in recreation, leisure and social activities in their community
- Support to build skills that help them transition to [independent living](#)
- [Support options](#) that provide positive and meaningful experiences, such as recreation and social activities, while also providing families with planned short-term, time-limited breaks from their usual caregiving roles
- A range of [supports for families](#) designed to build their capacity, resilience and ability to cope during times of stress or crisis.

In 2013/14 a total of 9,281 children, young people and their families accessed 14,114 ADHC services (funded and direct services), including:

- specialist supports, particularly therapy, behaviour support, case management and local coordination services – the most accessed supports for this age group, accounting for 54 per cent of all supports accessed, and

- respite services, accounting for 35 per cent of all supports accessed, particularly flexible respite delivered by NGOs, which accounted for 20 per cent of all supports accessed.

In 2013/14, approximately 1,757 children and young people aged between 6 and 17 accessed ADHC Behaviour Support Services.³⁸

For a detailed overview of the diverse range of supports ADHC funds for children and young people with disability and their families, see Appendix 1 – Resources Guide.

Mainstream and community supports

Children and young people with disability, like their peers, access a range of services from mainstream organisations, NGOs, community providers and other government providers that are available to all members of the public, such as health services to address health needs and education youth services, transport, sports and recreation. The following examples show the range of such services.

Children and young people with disability and special needs attend government (public) and non-government (Catholic or independent) schools, with support tailored to their educational needs. All education providers are required to provide reasonable adjustments for students with disability where needed so that they can access and participate in education on an equitable basis, under the Commonwealth *Disability Discrimination Act 1992* and its associated [Disability Standards for Education](#) (2005). Planning for reasonable adjustments for individual students with disability is undertaken in consultation with the student and/or their family through each school's planning processes.

A wide range of programs and services support students with disability in NSW public schools. These include:

- additional support in regular classes
- specialist support classes that operate in special schools and some regular schools across the state, and
- a wide range of specialist education staff that support students and their teachers including, school counsellors, teachers with specialist expertise in transition, vision and hearing impairment, and educational consultants.

The Learning and Support Team in each school assists teachers to address the educational needs of students with additional learning and support needs, including disability.

[Youth health services](#) are specialist services that provide multidisciplinary primary health care to young people. Focusing on engaging disadvantaged young people,

they deliver flexible and unique services in relaxed and comfortable youth-friendly environments. Youth health services work in partnership with other government and non-government services.

[Child protection, wellbeing and sexual assault services](#) provide a range of services, including:

- Family Referral Services, which link vulnerable children, young people and their families with appropriate support services in their local area
- Child Protection and Counselling Services, which provide tertiary, trauma-informed specialist treatment for families with children and young people where there is significant child protection concern due to parental/carer abuse and neglect, and
- NSW Health Sexual Assault Services, which provide crisis and ongoing counselling services for victims of sexual assault (child and adult) and non-offending family members.

Service gaps

As NSW will continue to operate in a rationed system until the NDIS comes into effect, children and young people with disability and their families may experience some difficulty accessing timely supports that meet their needs and goals. The availability of supports varies across NSW and can be particularly limited in rural and remote areas.

Specialist supports are not always well integrated within a child's or young person's natural environment, such as at home or where they play and learn. Mainstream services have an important and ongoing role in continuing to support and build their skills and capacity to support the participation and inclusion of children and young people with disability.

Additional barriers include fragmentation of services, particularly at key transition points and particularly for children and young people with complex health and support needs. Families may also experience limited access to appropriate transport and face barriers accessing local facilities, such as parks, playgrounds and buildings.³⁹ Aboriginal families and families from culturally and linguistically diverse backgrounds may experience additional barriers to access supports due to a lack of culturally appropriate models of services that are flexible and culturally responsive.⁴⁰

Policy context of the framework

This framework is supported by a number of key international, national and state policies that work to ensure that children and young people with disability have the right to actively participate and be included in their community, and have opportunities to reach their full potential at all stages of their lives.

International context

The [*United Nations Convention on the Rights of the Child*](#) recognises the right of a child with disability to enjoy a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community.⁴¹ Article 23.3 obliges states to ensure effective access to education, training, health care services, preparation for employment and recreation opportunities to enable the child to achieve the fullest possible social integration and individual development.⁴²

Commonwealth and NSW context

The Commonwealth [*Disability Discrimination Act 1992*](#) seeks to eliminate discrimination, as far as possible, on the grounds of disability and promotes recognition and acceptance of the principle that persons with disability have the same fundamental rights as the rest of the community.⁴³

The Commonwealth [*Disability Standards for Education*](#) outline the rights of students with disability to access and participate in education and training, and give education providers guidance on how they can meet their obligations under the *Disability Discrimination Act*. Education providers must make reasonable adjustments to ensure that students with disability are given opportunities to participate in education and training on the same basis as students without disability. All education providers are bound by the Standards: preschools and kindergartens, public and private schools, education and training places and tertiary institutions, including TAFEs and universities.

The NSW Department of Education and Communities' (DEC) [*Every Student, Every School: Learning and Support*](#) initiative provides better learning and support for every student with disability, learning difficulties or behaviour support needs in public schools through specialist services and programs targeted for individual students, as well as professional learning and support for teachers and support staff.

The NSW [Disability Inclusion Act 2014](#) replaces the Disability Services Act 1993. It sets out a coordinated, whole-of-government approach to creating a more inclusive community in which mainstream services and community facilities are accessible to people with disability to help them achieve their full potential. The Act:

- makes it clear that people with disability have the same human rights as other members of the community and that the State and the community have a responsibility to facilitate the exercise of those rights
- promotes the independence, social and economic inclusion of people with disability
- enables people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports and services
- provides safeguards for people accessing NSW funded disability supports
- works to build capacity of people with disability, service providers and the NSW Government by focusing on individualised funding arrangements, safeguards and quality control mechanisms in readiness for the NDIS.

The [National Disability Strategy 2010–2020](#) sets out a national policy framework for improving life for Australians with disability and their families and carers. It recognises that, while some people with disability need specialist supports, social inclusion and full participation cannot be addressed by the specialist service system alone. It argues that it is essential for the broader community, and mainstream services and facilities such as health services, schools and transport, to be fully accessible for people with disability.⁴⁴ This framework is also aligned with the range of reforms underway to transition the NSW disability service system towards person-centred approaches that promote choice, control and the inclusion of people with disability.

The NSW Government's [Ready Together](#) reforms continue the NSW Government's Stronger Together 2 reforms, which committed \$2 billion in new funding for disability services from 2011/12 to 2015/16. Ready Together focuses investment on what people say they most want – more flexibility, more choice and more control – implemented through the [Living Life My Way](#) (LLMW) framework.

Ready Together also prepares NSW for the transition to the [National Disability Insurance Scheme](#) (NDIS) by July 2018. The NDIS is a generational reform that will deliver a national system of disability support focused on the individual needs and choices of people with disability. The NDIS will replace the current system of shared provision and funding of disability services by the Commonwealth and state and territory governments with a nationally consistent scheme. The scheme will provide people with disability, including children and young people, with reasonable and necessary supports to live life their way, achieve their goals and

participate in social and economic life. The NDIS, which is about more than just the specialised supports people need, has three key components:

- *Mainstream* – services that are available to all members of the public, including people with disability, such as healthcare, education, transport and housing
- *Information, linkages and capacity-building* – funded activities which interact with mainstream and funding packages to strengthen informal and mainstream responses, build the capacity of people with disability, communities and mainstream service sectors, and minimise the impact of disability
- *Individual Funding Packages* – for people with significant disability, to enable them to exercise choice and control and engage as equal partners in decisions that will affect their lives.

The NDIS is being introduced gradually in order to ensure a smooth transition for people with disability and for providers. The scheme is being trialed in the Hunter.

The NSW Government committed to an early transition of the NDIS in the Penrith and Blue Mountains area for children and young people aged 0–17 years, with families starting to receive packages from September 2015. This is a year ahead of the planned 1 July 2016 rollout of the NDIS across NSW.

Once the scheme is fully implemented, by July 2018, funding for disability support in NSW will more than double, and approximately 140,000 people will directly benefit.

NSW will continue to transform the current system to be NDIS-ready, expanding individual funding arrangements to give people with disability more choice, control and flexibility over how supports are delivered, and opportunities to plan for their future. The expansion of individualised funding is being implemented through the LLMW framework, which is:

- redirecting investment towards increasing the number of individualised arrangements that are portable, flexible and self-managed
- expanding the use of individualised funding arrangements within existing programs, and reducing constraints on the scope and nature of the supports they provide, and
- increasing opportunities for people receiving support under a number of programs to amalgamate their support into a single funding arrangement.

This transition process will focus on ensuring people with disability are able to build their capacity, skills and experience in preparation for the NDIS. It will also enable service providers to increase their NDIS readiness by gradually adapting to more individualised funding arrangements.



The NSW Quality Framework for disability services is built on the National Disability Quality Framework and based on the NSW Disability Services Standards (NSW DSS). The NSW DSS directly aligns with the National Standards for Disability Services (2013), maintaining quality of practice in NSW consistent with other states and territories of Australia. To meet the requirements of the framework, service providers are required to implement a quality management system and attain Third Party Verification to confirm performance against the Standards.

The [Standards in Action](#) manual is a practical guide for service providers in implementing the NSW DSS and to support the transition to a person centred service system. ADHC has recently prepared the [Guide for services working with children and young people with disability and their families](#) as an addendum to the Standards in Action manual, in order to provide additional guidance, including practice examples and tips, for services working with children and young people with disability and their families.

Against this broad policy context, there is an increasing need for service providers to reorient the way they support children and young people with disability and their families to ensure they are supported in inclusive mainstream settings, while being able to participate in their community. There is also a growing need for providers to support and build the capacity of children and young people with disability and their families to self-direct supports in preparation for the NDIS.

The seven guiding principles

At the core of this framework are seven guiding principles:

1. Deliver person-centred, family-centred and strengths-based supports
2. Strengthen decision-making capacity and opportunities to exercise choice and control
3. Provide early intervention and holistic support across transitions
4. Provide coordinated and integrated supports
5. Actively promote participation and inclusion
6. Support the development of social relationships
7. Follow culturally appropriate practices.

These guiding principles are consistent with key NSW and national policy frameworks and best practice and can be used by Districts and service providers to underpin service provision for children and young people with disability and their families.

This section describes each principle then provides supporting evidence and strategies that service providers may be able to use in applying the principles in practice and in guiding future service delivery and decision-making at the local level.

1

Deliver person-centred, family-centred and strengths-based supports

Service providers should deliver supports that are person-centred, family-centred and strengths-based.

Person-centred approaches recognise that children and young people with disability are children/young people first and foremost. The needs and interests of each child and young person is different, and not necessarily the same as those of their families and carers.

Family-centred approaches[†] involve working with each child or young person and their whole family as equal partners to identify their needs, goals and vision for the future. They provide flexible and individually tailored supports to achieve these goals and meet the family's needs as they change over time.

Strengths-based approaches build on the strengths and capabilities of the person, their family and others in their support network. Resources should complement the child's or young person's strengths and build their capacity, rather than focusing on their deficits or on what they can't do.

[†] Family may include parents, siblings and carers.



Evidence and strategies supporting this guiding principle

Key elements

The key elements of person-centred and family-centred practice are:

- working with the child or young person and their family as equal partners in a partnership based on mutual trust and respect
- considering the needs of the child or young person as well as the needs of the family as a whole
- being flexible and tailoring supports that are based on the needs and preferences of the child or young person and their family as these change over time
- focusing on the strengths and capacities of the child or young person, their family and others in their support network, letting the individual's strengths and capabilities guide the setting of goals and activities
- meeting family needs through a broad range of informal, community and formal supports and resources, rather than solely through formal supports alone.

The role of parents

Parents play a key role in supporting children and young people with disability to realise their potential. The parents' role in the life of their child is to be respected and valued. The principle contained in section 4(11) of the *Disability Inclusion Act 2014* (NSW) supports this. It states that 'the crucial role of families, carers, and other significant persons in the lives of people with disability, and the importance of preserving relationships with families, carers and other significant persons, is to be acknowledged and respected'. Parents may need support to fulfil their caring role and responsibilities.

Family-centred approaches focus on supporting, building and maintaining the capacity of families to be the main support for the child, while strengthening family relationships.⁴⁵ As young people grow and increase their levels of independence, family relationships remain important, and providers need to combine family-centred and person-centred approaches, especially with older children and young adults.

Families may need capacity-building and empowerment strategies to help them meet the needs of their child and to manage challenges when they arise. They may also need guidance and specific strategies so they can effectively advocate for their child's needs and priorities, particularly within mainstream services and the community. Rather than using a 'doing for' approach, it is critical that this support empowers the family and builds their capacity, confidence, coping strategies and ability to advocate for themselves.



The US-based Evidence Network⁴⁶ suggests that coping skills training is most effective when it involves training parents in coping strategies, including positive self-statements, relaxation, and developing social and problem-solving skills. It also suggests that training parents in behaviour management skills considerably benefits both parent and child, reducing the child's behaviour of concern and enhancing parents' sense of competence.

Further information on Australian approaches to capacity-building can be found in the Resources Guide.

2

Strengthen decision-making capacity and opportunities to exercise choice and control

Children and young people with disability and their families should be given the necessary information and support to empower them to participate in decision-making that affects their lives, in ways that are appropriate to their developmental stage.

As children and young people grow and increase their levels of independence, their involvement in planning and decision-making activities should also grow. Providers should maximise their choice, control and decision-making in support planning and funding to ensure that the supports they access best meet the needs, goals and aspirations of children and young people with disability.

Evidence and strategies supporting this guiding principle

UN Convention on the Rights of the Child

Under the *UN Convention on the Rights of the Child*, children and young people have the right to be involved in decisions that affect them in ways appropriate to their age and stage of development.

Article 7(2) highlights that children's and young people's best interest need to be a primary consideration in decisions that concern them. What 'best interest' means needs to be determined on an individual basis, taking into account factors such as the child or young person's level of maturity, disability and vulnerability, their views, their characteristics (including age, social and cultural context, family relationships and safety), and their physical, emotional, educational and other needs. An adult's judgment of the child's or young person's best interest cannot override the obligation to respect all of their rights under the Convention.

Support at each life stage

It is important that children and young people are genuinely involved in decision-making at crucial points in the journey to adulthood.⁴⁷ As they grow and increase their levels of independence, their involvement in planning and decision-making should also grow. They should be put at the centre of planning and decision-making processes regarding the supports they receive and how they are delivered, based on their needs and goals.⁴⁸

Given that children and young people with disability can be vulnerable to exclusion, bullying and abuse, they need to be supported to build their confidence and skills to speak out and have a voice, and to be empowered to make decisions about their future⁴⁹ based on what is important to them. Capacity involves more than just traditional skills such as motor or cognitive skills; it includes attributes such as understanding and using one's abilities, being involved in problem-solving and decision-making, being in control of one's life and directing others to provide supports.⁵⁰

Strategies to build decision-making capacity

Supported decision-making provides support for people with disability to exercise their legal right to make their own decisions where possible, rather than having decisions made for them. Children and young people with disability should be able to access the information and support they need to build their skills, confidence and capacity to make their own decisions and exercise control in implementing these decisions. The types of support a person and their family may require will depend on their individual circumstances; supports may include communication tools, support planners, local area coordinators, training and capacity-building.

It is important that children and young people and their families build their capacity, skills and experience in self-directing supports. Providers need to ensure that children and young people and their families have genuine choice and control over how resources are used and choose the supports that will best suit their needs, including who provides the support. For example, many young people prefer support workers who are of a similar age to themselves, particularly when support is being provided for social and recreational outings.⁵¹ It is important that they are able to have a say in selecting support workers who are of a similar age or have similar interests. It is also important that they have the support to take reasonable risks and make mistakes through a process of trial and error, in the pursuit of their goals and the planning and delivery of their supports.⁵²

Strategies to increase the capacity and participation of children and young people with disability in decision-making processes include the following:

- When undertaking support planning, listen to the child or young person and ask what is important to them and what their goals are which research shows is a foundation for participation in wider decision-making processes⁵³. Participation by young people with disability is most successful when their views are respected.
- Foster trust with the child or young person and focus on the mutual benefit of increasing their participation in decision-making processes.
- Provide children and young people with opportunities to learn about decision-making processes.
- Work with children and young people to establish a clear understanding of the expectations, roles and parameters of the decision-making processes.
- Support the child or young person and their family to practise decision-making, to learn and solve problems by trial and error, and to reflect back on these processes.
- Use a variety of approaches that best suit the child or young person, particularly making use of technology, social media and communication tools.
- Involve the child's or young person's support network (which may be an individual or network of family members, friends, community members, etc) to help them gather, understand and consider relevant information about the decision in question, weigh up the pros and cons, predict likely outcomes, consequences and risks, and evaluate the available options and support them to implement their decision.

An [Advocacy and Information Service Directory](#) is available online to assist people to locate a funded advocacy and/or information service near them.

Technology and social media

Technology and social media play a key role in the lives of all children and young people, in terms of social communication, entertainment, education and learning. According to the Australian Communications and Media Authority, 90 per cent of young people between 12 and 17 years use social network services.⁵⁴

For children and young people with disability, technology and social media are important communication tools that help them express themselves and make informed decisions.⁵⁵ Research has found that young people with disability get a range of benefits from social media, helping them to build an online community that offers friendship, support, information and advice.⁵⁶ Social media can reduce social isolation and can help young people share experiences, explore identity, build new friendships and engage in discussion with other young people without a family member or support worker present.⁵⁷

For service providers, social media is an indispensable tool for engaging with and building the capacity of young people with disability, as it:

- is often the first place young people will go to get information, advice and support
- is accessible and easy to use for young people
- can increase engagement with young people who might face other barriers to connecting with a service or organisation
- is an effective way to increase young people's awareness of the supports available.

Social media is also a valuable tool that providers can use to engage young people in respectful, purposeful two-way dialogue using mechanisms they like to use, rather than making young people 'come to them'.⁵⁸ For example, the Youth Disability Advocacy Service has incorporated social media into its youth advocacy work, using Facebook, YouTube and Twitter to promote events, activities and advocacy services more directly than has been possible in the past.

It can also be used to build the capacity of young people to make decisions. For example, Speakout Advocacy Tasmania has produced a YouTube video called [Decisions, Decisions, Decisions](#), which is designed to teach young people with intellectual disability about choice and decision-making in preparation for the NDIS.

Children and young people should be given the support they need to access and effectively use technology and social media, with consideration being given to their different communication needs. They may require assistive technologies to use social media, such as a screen reader for a person who is blind, an on-screen keyboard for a person with a mobility impairment, or playback of captioned videos for a person who is hearing impaired. They may also require tailored support to build their technical, social and literacy skills to safely access and use social media and the internet.

3

Provide early intervention and holistic support across transitions

While evidence clearly shows that one of the most effective times to intervene is in the early years, it is important that the outcomes achieved in these years are sustained over time as children and young people transition into adulthood. This is an important development period that provides opportunities for intervening early to maximise capacity, skills and lifelong functioning.

Supports should be flexible, holistic, tailored and responsive to the changing needs, priorities and aspirations of children, young people and their families as they make key transitions.

Transition planning should commence early, with a focus on identifying goals and supports that maximise the child's or young person's lifelong functioning, skills and capacity. Supports should be well coordinated so as to ensure seamless transitions between them.

Families should be able to access the supports they need as early as possible, in order to build their capacity and to prevent and reduce family issues and stressors before they reach 'crisis point'.

Evidence and strategies supporting this guiding principle

Early intervention

Intervening early in the lives of children and young people with disability leads to better outcomes for children and their families over the long term. Identifying and responding to need as early as possible, particularly at key transition points, helps achieve positive outcomes, reduces the adverse impacts of disability and reduces the need for intervention later in life.

Parents play a significant role in their child's development. A key goal of early intervention is to build upon parent-child relationships and improve home learning environments.⁵⁹ Service providers should work with families to build more supportive environments that minimise negative patterns or experiences and build informal supports and networks.⁶⁰

For families to successfully adapt to stressful events, there is a need for both strategies that come from within the family (such as cognitive and communication strategies) and external supports and resources outside the family, including support from social networks and professional supports.

Flexible and individually tailored respite can be a positive experience for a person with disability while providing a break for families, helping them build resilience and supporting primary caregiving relationships. In some instances, it plays an important role in preventing the occurrence or escalation of crisis, as well as providing a break for the family if a crisis does arise.⁶¹

It is important to put support strategies in place as early as possible to meet a child's or young person's unmet needs and address emerging issues. This may involve making changes to their environment, improving communication, supporting positive relationships and enhancing active engagement in meaningful activities. Early intervention approaches should include family members so they can work alongside professionals and learn how to help and support their child.

Service providers can use positive behaviour support strategies as a prevention and early intervention approach to helping a child or young person learn new skills and acceptable behaviours. This can be achieved through strategies such as role-modelling, positive reinforcement, skill development and collaborative and inclusive approaches.⁶²

Transition processes

The transition to adulthood is a gradual process, rather than a discrete event, and the length of this process varies for each individual.

The literature highlights the need for a holistic approach to transition, setting goals that focus on maximising the child's or young person's lifelong functioning, rather than simply preparing them to shift to new service systems. Transition processes are more than just a service approach; they involve 'a process of gradual adoption of new roles and modification of existing roles'⁶³ for all children and young people and their families.

Successful transition between services is often the result of early planning and collaboration between education services, health services, NGOs and community supports, and it should commence in the years leading up to the transition.⁶⁴ It is essential that support is continued through the transition process into adult services, by coordinators, primary care physicians, parent-to-parent networks, community facilitators, peer mentors and others. Some families may need assistance to see the importance of helping their family member transition to a more independent life and may need support to do so.

Research identifies 'navigators', such as coordinators or key workers, as a key element of best practice approaches to transition support. They support children and young people and their families in planning for transition and navigating systems and resources.⁶⁵ Navigators who are community based and outside of the service system can help build the capacity of communities to be inclusive and to reduce the child's or young person's reliance on services.⁶⁶

It is vital that providers consider the additional challenges faced by children and young people and their families in rural and remote areas, including geographic isolation and transportation and access needs, when they are undertaking planning and delivering supports. Children and young people living in rural and remote parts of NSW have limited access to supports and to recreation and social activities.

Transition from paediatric to adult health services

Significant interactions with health services will have been a normal part of life for most children and young people with chronic conditions and disabilities. Transition from paediatric to adult health services is another of the many transitions they face during late adolescence.

Young people face many challenges during adolescence, and it is often a time of uncertainty and change. They want more autonomy and independence at this time, and making the right choices means they need access to the right information, the right people to talk to and the right services that can help.

Successful transitions can have a significant positive effect on lifelong engagement with health services, but for this to happen they require planning, coordination and support. Early planning is key to a successful transition and to ensuring the young person is at the centre of transition planning. Empowerment, advocacy and enabling self-management are important aspects of transition planning, as they can help reduce the incidence of unplanned hospitalisations during transition and can improve wellbeing.

For more information on NSW health services that can assist young people and their families with these health transitions, see the transition from paediatric to adult health services section of the Resources Guide.

Transition to and from school

Transitions can be challenging for any student, including students with additional or complex needs,⁶⁷ yet successful transitions can have a significant positive effect on students' current and future educational experiences.

Transitions to and from school are most effective for children and young people with disability when positive relationships are established between them, their family, the school and other relevant service providers involved in the transitions.

Strategies to support the child or young person and their family to prepare for school transition include making resources available for family members to support transition planning, enabling families to visit the new school, and having child-specific instructional activities. An advocate or support person for students with disability can help make important transition decisions to ensure they are receiving the most appropriate education.⁶⁸

Specialist staff within mainstream services can provide advice and assistance with transition. For example, Transition Support teachers employed by the NSW Department of Education and Communities (DEC) help students with disability in NSW public schools and their families to plan for transition to post-school options. This may include advising on curriculum pathways in senior years of schooling and connecting young people with services outside the school.

Transition to further education and employment

Research shows that many young people with disability can transition to meaningful post-school pathways when they have someone, in addition to their family, who can support them in identifying their career plan and help them navigate the school and post-school environment. This would typically be a coordinator or key worker. Such support should be underpinned by collaborative service provision between schools and disability and other support providers, so that there is a range of options and supports to sustain effort over time.⁶⁹

School-sponsored work experience, vocational education enrolment and after-school jobs are all linked to more favourable employment outcomes during early adulthood.⁷⁰ Key elements to improved post-school education and employment outcomes are:⁷¹

- providing opportunities for real work experience, internships, work placements and volunteering, commencing in early adulthood
- designing a job to suit the individual, rather than squeezing them into an existing vacancy
- being aware of and accommodating employers' needs
- setting up individualised programs, planning and services, and
- providing assistance for employees to help them understand the best ways to support a colleague with disability.

Strategies to ensure that children and young people with disability have successful and coordinated transitions

- Commence transition planning and decision-making early, in the years leading up to transition to adult services.
- Focus on long-term goals and supports for a child or young person that are incorporated into their everyday life.
- Ensure the child or young person and their family have enough information to make informed decisions and are at the centre of transition planning and decision-making, in partnership with their school and other specialist services such as therapy supports and health services.
- Provide long-term cross-sector collaborative planning and coordination, including the sharing of relevant information and data, to ensure continuity of service provision across transitions and to reduce the complexities that children and young people and their families experience.
- Support families to facilitate transition for their child, including building their skills and capacity to address challenges that may arise along the way.

4

Provide coordinated and integrated supports

Service providers should work with children and young people with disability, their families and a range of mainstream and specialist support providers to facilitate seamless, coordinated and integrated access and support to meet their needs.

Evidence and strategies supporting this guiding principle

Cross-sector collaboration

Children and young people with disability and their families are likely to have a range of needs that cannot be met by a single provider. Mainstream and specialist support providers should therefore work with the child or young person and their family and other providers to ensure that supports are coordinated, integrated and holistic. Service providers should encourage families to be involved in the process, at a level they find comfortable, with the aim of building their skills and capacity.

Cross-sector collaboration helps children and young people with disability and their families to transition between services, such as education, health and community supports. It is also important in responding to the needs of young people and families with complex needs (co-occurring issues such as mental health, cognitive impairment, disability, trauma and drug and alcohol misuse) which require a holistic response.

Single point of contact

Research⁷² has found that providing a consistent, single point of contact to help families coordinate supports across systems is a key aspect of effective models of support. Receiving this connected and informed support reduces the need for the child or young person and their family to tell their story multiple times. It also ensures the child or young person is at the centre of holistic planning and support.

The key worker model is one approach that gives families coordinated and comprehensive support by ensuring access to, coordination of and delivery of services by different agencies. In essence, the key worker pulls together all the elements of the child's or young person's life.⁷³ They can act as the single point of contact for the family and other support providers working with the family – facilitating joint planning, assessments and meetings to address shared outcomes more efficiently.⁷⁴

The NDIS has recommended the [transdisciplinary, family-centred and key worker approach](#) in the early childhood intervention sector and has recommended the key worker model for scheme participants.

Strategies to build collaboration and coordination⁷⁵

- Commit to communicating regularly and sharing information through attendance at key meetings and through multi-agency planning.
- Organise joint professional learning and development (training, workshops or seminars) for mainstream and specialist staff so they can share knowledge and gain an understanding of the different roles which can contribute to a multi-agency response. This helps build connectedness and respect for each other's work.
- Give staff regular opportunities to 'shadow' (work alongside) staff from other services so they can build professional connections and learn from each other.
- Showcase examples of specialist services that are connected to or integrated with mainstream services.
- Seek buy-in from managers and practitioners to facilitate co-working, joint commissioning and pooling of budgets.
- Appoint coordinators, such as key workers or lead professionals, who are trained for and supported in their pivotal role as the single point of contact for young people and as coordinators of appropriate packages of support.

5

Promote participation and inclusion

Inclusion is a continuing process of increasing the participation of children and young people in everyday environments, building their knowledge and skills through active involvement and participation.

Children and young people with disability and their families should have opportunities to actively participate in and contribute to all aspects of community, social and economic life, and to live as valued and equal members within their community. Specialist supports should be provided within the child's or young person's everyday environment – at home, in school or in the community – to enable their participation in these settings.

Evidence and strategies supporting this guiding principle

Specialist supports in mainstream settings/natural environments

Children and young people with disability should be able to participate in everyday activities that all children and young people participate in. This participation is vital to their developmental outcomes, helping them to learn skills, interact socially, develop friendships, express creativity, become self-determined and have a sense of purpose, meaning and improved wellbeing.^{76, 77}

Children and young people with disability are recognised in the *Disability Inclusion Act 2014* as a group that has particular needs, and the Act places additional responsibilities on the providers of supports to this group, including the need to:⁷⁸

- respect the needs of children with disability as they mature, and their rights as equal members of the community
- respect children's rights, including the right to be involved in decisions that affect them, as outlined in the [UN Convention on the Rights of the Child](#)
- respect the role and responsibilities of parents for children aged less than 16 years and young people aged between 16 and 18 years
- support children, particularly young children, in the context of their families
- support children, young people and their families through the many transition points that occur between birth and 18 years.

One of the objectives of the *Disability Inclusion Act 2014* is to 'promote the independence and social and economic inclusion of people with disability'.⁷⁹ Participating in everyday environments is vital to the health, development and quality of life of children and young people with disability. For children and young people with disability who need additional specialist supports, such as therapy and behaviour support, evidence shows that the best outcomes are achieved when these supports are provided within their everyday environment – at home, in school or in the community.⁸⁰

Specialist supports for children and young people with disability should:

- be participation based and incorporated into everyday tasks, routines and recreational activities, providing real-life experiences that enable them to learn new activities and develop skills
- be goal orientated, responsive and directly linked to the needs and goals of the child or young person as they change, particularly in transition from childhood to adolescence and adulthood, across a range of life settings such as home, school, work and leisure

- be reinforced in the child's or young person's life through cross-skilling of relevant people, such as parents and teachers
- be responsive and tailored to the needs of the child or young person
- facilitate access to recreation and other social activities for children and young people with disability in their local community through awareness-raising, training and support.

In practice, the specialist will be a consultant who provides outreach supports and collaborates with the child or young person, their family and their mainstream or community provider to enhance inclusion in mainstream settings.⁸¹ The specialist should share information and provide education in ways that build the capacity of the child or young person, their family and the community. They can also provide itinerant professional support to mainstream services.

Specialist supports play a key role in supporting mainstream schools to include students with disability by:

- working in partnership with schools to plan and support a student's transition to and from high school, to provide specialist advice to school staff to tailor the learning support plans to the student's needs, and to embed therapeutic supports within these plans, and
- providing support and training to school staff to build knowledge and skills to include therapeutic approaches into the daily routine to support the participation of students in education activities and learn about positive behaviour management strategies, communication tools, mealtime management and safe transport for students with disability.
- It is essential that service providers work in partnership with schools and build collaborative, respectful relationships with teachers to ensure that the delivery of specialist supports in school settings, where agreed with the school principal, is consistent with the curriculum and other legal requirements in schools.
- These approaches should be planned and implemented in a way that can be integrated into the daily work of teachers and education staff to support curriculum access and outcomes.

Building the capacity of communities and mainstream settings to be inclusive

For a child or young person with disability, being physically present in a community or mainstream setting does not automatically result in inclusion.⁸³ Their participation and inclusion in everyday activities and environments depends largely on these environments being accessible, enabling and supporting participation.

Strategies to build the capacity of mainstream settings and community organisations to 'open up' include:

- making modifications to facilities so they are physically accessible, such as ramps, doorways, pathways, equipment and proximity to accessible public transport
- raising awareness in the community about the experiences of people with disability in order to address negative attitudes and stereotyping, and to foster inclusiveness of children and young people with disability, and
- investing in training for staff, such as training to act as role models or champions within their organisation, and mentoring other staff within an organisation on inclusion strategies.

Disability awareness intervention

The research shows that children and young people without disability can have negative attitudes and low acceptance of their peers with disability.⁸³ It is important that they have ongoing opportunities to learn about social inclusion and to get to know people with disability in supportive environments.⁸⁴ Well-designed disability awareness interventions can improve their knowledge and acceptance of people with disability. Forming positive attitudes towards disability is vital at this stage, and it is important to build on the foundations that have already been put in place during the early years. Key elements of successful awareness-raising interventions are:

- improving knowledge, breaking down stereotypes and creating awareness using a variety of formats, such as simulations, multimedia and multi-component approaches, class activities, discussions and stories
- undertaking activities over time and targeting whole-of-school interventions, which have been shown to be effective in reducing bullying, and
- providing opportunities for students to have social contact with a person with disability over a period of time so they develop understanding and friendships.

Case study: Social Inc.

The [Social Inc.](#) project seeks to increase inclusion and challenge the stigma and social disadvantage around disability in high schools. It challenges young people to help change the perception of disability in their school through awareness, active social networks and engagement. The project uses a diverse range of strategies to improve awareness, understanding, acceptance, belonging and inclusion of young people with disability in high schools, including:

- [Annual Inclusion Surveys](#), designed to build understanding of what the needs are for individual schools and to monitor how students and staff experience inclusion
- the [Social Inc. Kit](#), designed to increase awareness of disability and inclusion in schools through offering units of education that can be used by teachers to improve awareness
- Social Inc. Groups, made up of students with a range of abilities in school supported by trained community volunteers
- [Social Inc. Projects](#), in which young people work in small groups in their school community to inspire inclusive relationships, and
- inclusion councils, which aim to develop the leadership skills of young people with disability.

6

Support the development of social relationships

Providers should facilitate and support the participation and inclusion of children and young people with disability in their chosen recreation and social activities, enabling them to enjoy, learn and play alongside their peers in natural settings and to develop social relationships⁸⁵.



Evidence and strategies supporting this guiding principle

Social relationships and supports

Social relationships and supports have an impact on all aspects of a person's life. They are a major contributor to quality of life, as well as being a major factor in reducing stress and preventing mental health issues for children and young people with disability and their families.

Research shows that being able to participate in meaningful social activities and recreation provides opportunities to develop social connections and friendships, develop skills, feel part of the community, find meaning and improve quality of life.⁸⁶ It enables children and young people with disability to enjoy, learn and play alongside their peers in natural settings and is a key part of facilitating their inclusion in the community.

The provision of a supportive environment by service providers, families and caregivers is critical to enabling children and young people with disability to be included in recreation and other activities.

Paving the way for community participation

Like most youth, children and young people with disability often need the support of adults (parents, attendants and other caregivers) to enable their participation. Providers play a key role in providing this support so they can choose and access a range of recreation and social opportunities (at home, in school and in their community) that are fun, give a sense of belonging, and help them build positive and meaningful connections.⁸⁷

Support workers can, for example, provide information, targeted training and support to local sporting, recreation and community organisations to improve their understanding of disability. They can also advise on making adjustments to meet the child's or young person's needs or to address any behaviour of concern that may emerge.

In the Hunter area, Aspect has provided individualised autism and disability awareness training to a range of local community organisations, such as the Hunter Valley Martial Arts Centre (HVMAC), to enable the participation of children with disability. One parent commented:

'I am very impressed at the training that the HVMAC has taken in supporting the students on the autism spectrum. The change in the approach to direction for my child in training has helped his understanding of his hits and kicks. Thank you to all staff!'

Providing ‘taster days’⁸⁸ is a good way to give children and young people with disability a chance to try new activities, such as trying out local sporting and arts activities. This can help them make decisions about trying new activities and hobbies.

The importance of recreation

Research suggests that young people with disability can sometimes be ‘over-theraped’, receiving a range of specialist supports that take time away from recreation and activities that provide important opportunities for them – having fun, choice and a sense of belonging.⁸⁹ A child’s or young person’s environment plays a key role in influencing their participation across a range of settings, so it is important that specialist supports work to increase participation in these settings.

For families of children and young people with disability, having informal social supports and participating in social activities in the community helps them to adapt, feel less isolated, feel supported when problems occur and develop relationships that do not focus on their differences.⁹⁰

Providers should support children and young people with disability and their families to build and maintain informal social supports and networks in their community. For example, they can help them build a network or [circle of support](#) made up of a group of people (such as family members, friends, community members) who regularly come together to help the young person accomplish their personal goals.

See the Resources Guide for more information.

Building supportive environments

Strategies designed to build supportive environments to enable social participation of children and young people in recreational activities should be:

- *physically and attitudinally accessible and welcoming* – e.g. local sports clubs welcoming new members with starter packs and introduction/taster days, as well as offering training for beginners
- *accommodating* – reducing barriers to participation by making adjustments to sporting programs and educating sports providers to be inclusive
- *socially supportive* – involving family, friends and teachers
- *resource ready* – having suitable funding, equipment, support staff and time
- *appropriate* – based on the needs, preferences and goals of the child or young person and their family, and providing genuine choice.

7

Follow culturally appropriate practices

Support services should be accessible, culturally appropriate and tailored to the needs of children and young people from various cultural backgrounds.

Service providers should recognise diversity and the choices of each individual, family and community. They should work in partnership with local communities and organisations, including Aboriginal community controlled organisations and culturally and linguistically diverse organisations, to implement strategies that ensure services are culturally appropriate and responsive.



Evidence and strategies supporting this guiding principle

Aboriginal children and young people, as well as children and young people from culturally and linguistically diverse backgrounds, may have limited access to supports that are culturally appropriate, accessible and meet their needs.

Aboriginal children and young people

To improve access to and uptake of supports for Aboriginal children and young people with disability, providers should establish partnerships with Aboriginal communities and with organisations that come into frequent contact with Aboriginal families.⁹¹ They should also build networks with a range of service providers, including:

- local Aboriginal community controlled services which provide a range of supports to Aboriginal families, such as [Aboriginal medical centres](#), and which are well placed to identify and link families to necessary supports
- Aboriginal education officers, who are employed in many schools and are in an excellent position to work with providers to identify Aboriginal children who may have disability and to educate families and encourage them to access support services⁹²
- [Aboriginal Education Consultative Groups](#), which are a key source of advice on behalf of Aboriginal communities on issues relating to education and training
- Community Services, particularly for young Aboriginal people in out-of-home care
- Juvenile Justice, for young Aboriginal people with disability at risk of entering the criminal justice system.

Strategies to ensure supports are accessible, culturally appropriate and responsive to the needs of Aboriginal children and young people include:

- running programs with local Aboriginal and organisations, such as sharing assessment and/or coordination responsibilities and pairing workers to provide mentoring
- employing Aboriginal people in both identified and non-identified positions
- consulting with the community in partnership with local Aboriginal organisations, Aboriginal Elders and community leaders
- adapting how services are delivered so they target Aboriginal communities more effectively, including providing outreach supports in rural and remote areas
- seeking input and advice from Aboriginal Elders, e.g. through appointment to boards
- designing promotional material and information using Aboriginal artwork and input from local Elders to make it culturally appropriate

- building culturally competent staff through strategies such as cultural competency training.

Children and young people from culturally and linguistically diverse backgrounds

A range of issues can affect how children and young people from culturally diverse backgrounds engage with service providers. These may include proficiency in English, a range of cultural and religious backgrounds, recent arrival in Australia, and educational and socio-economic issues. In addition, recent migrants to Australia may not understand how the service systems work, or they may have been discouraged by previous efforts to engage with disability services. Service providers should remember that this group is not homogenous, and so, when developing approaches, one size does *not* fit all.

Strategies to ensure that supports are accessible, culturally appropriate and responsive to the needs of children and young people from culturally and linguistically diverse backgrounds include:

- finding out about the languages, cultures and religions in the community
- being aware that people's migration experiences may be very varied
- consulting with multicultural and community groups, as well as other service providers, on the needs and barriers of this group
- adapting how services are delivered to be more accessible for culturally and linguistically diverse groups, using strategies such as cultural competency training for all staff, employing bilingual staff or delivering services in partnership with multicultural agencies
- promoting awareness of support services at local youth, sporting and community events, e.g. putting posters and pamphlets in local services, libraries and TAFEs, or sponsoring youth and disability events
- using plain language and visuals that are inclusive of cultural diversity, providing multilingual information, using social media to get messages across, and using interpreters, when needed, to communicate with children or young people with disability and their families.[§]

[§] The NSW government requires that funded NGOs identify a budget for interpreting and translating services. Go to ADHC'S [Language Services Guidelines](#) for more information.

Future directions and opportunities

This section outlines some of the future directions of disability supports in NSW. It also describes some of the opportunities to increase the system's capacity to support the inclusion and participation of children and young people with disability and to help them make the most of the opportunities they have now and into the future during the transition to the NDIS.

During transition and into the full roll out of NDIS a number of components of the system will change. However, the strategies identified in this paper will provide a useful platform for providers to consider how best to support this age group. The perspectives of participant capacity, provider and community capacity are useful lenses through which to view this paper.

The NSW Government has committed to an early transition of the NDIS in the [Nepean Blue Mountains District](#) for children and young people aged 0–17 years. This will involve delivering early intervention services for around 2,000 children and young people by 30 June 2016, with children and young people starting to receive packages from September 2015. This is a year ahead of the planned 1 July 2016 date for the rollout of the NDIS across NSW. This early transition provides an opportunity to test some of the principles of this paper and to also reflect on the effectiveness of strategies and specifically the types of supports that are most effective for families and providers in being prepared for transition.

Participant Capacity

Children, young people and their families will be well placed to benefit from the NDIS. A number of strategies are in place in NSW to develop their exposure to making choices and exercising greater control over their supports.

Increased access to individualised funding arrangements

NSW is continuing to transform the current system to be NDIS-ready. During this transition, children and young people with disability and their families are likely to have more choice, control and flexibility in the way they plan and access supports, including increased access to individualised funding arrangements.

Through the Living Life My Way (LLMW) framework (see earlier Policy Context section), ADHC is expanding individualised funding arrangements for people with disability and their families by:

- expanding the flexibility and scope of supports available within existing programs

- working with people with disability and providers to individualise current disability supports, making them flexible and tailored to individual needs and goals (e.g. families can now access individualised and portable flexible funding that enables them to choose respite services that will provide the supports they need at the times they need them)
- making supports more integrated by offering people the option to amalgamate multiple supports into a single individualised funding arrangement, and
- increasing the availability of flexible and portable individualised funding packages.

While access to individualised funding arrangements is currently limited, it is expected to increase over time as growth funding is rolled out and people continue to express their interest in individualising their current supports.

Providers can encourage people with disability to register their interest in individualising their current supports with ADHC. For more information, go to the [ADHC website](#).

It is important to note that people with disability who are seeking to make support arrangements with their current service provider(s) more flexible or tailored do not need to register with ADHC unless they wish to individualise their funding. These people can contact service providers directly to negotiate changes to their supports.

Support planning

A support plan is a written record that describes the supports a person requires based on what they want to achieve in their life. It may also set out how they will use their individual funding to reach their desired outcomes. It should explore all support options, including paid supports, informal (natural unpaid) supports, community services, other sources of funding and private services (e.g. cleaning, gardening).

Support planning is vital to the success of any approach to supporting people with disability that is to be based on choice, flexibility and control, particularly for people wanting to individualise their funding and support arrangements. It helps people think creatively by encouraging them to look at informal, mainstream and specialist services, as well as services or supports that are not currently available but which could be created or developed.

To meet growing demand in the lead-up to the NDIS, FACS is building the capacity of the NGO sector and ADHC staff to undertake support planning activities. In particular, FACS is investing in a small number of NGOs to trial a new model of support planning across NSW. Access to these support planning resources is by referral from FACS. These organisations are independent of service delivery and

are already involved in delivering capacity-building activities. This approach to support planning will have three components: aspirational planning, goal setting/initial support planning, and detailed support planning. Involvement in support planning will assist people in their preparation for the NDIS by having conversations about their goals and aspirations. More information on support planning can be found in the Resources Guide.

Case study

Vision Australia

The following case study demonstrates the excellent outcomes that can be achieved for children and young people with disability and their families when they are supported to self-direct their supports to best meet their goals and needs in everyday settings and within their community.

Stern is a 15-year-old student who lives with his parents and sister and has the support of an itinerant teacher for vision. Stern has an interest in meteorology and is keen to explore this further. He also enjoys playing soccer.

Vision Australia has provided Stern and his family with a range of supports over the years, including vision assessments, orientation and mobility services. He has attended group programs during the school holidays.

Recently, with the assistance of a support planner, Stern's family developed a comprehensive support plan and received an individualised funding package of \$5,000. This has enabled them to self-manage the purchasing of supports and equipment to best suit their needs and goals. Stern's goals were to have good educational opportunities that provide career options for him on completion of high school, and to pursue his interests in sport and meteorology.

At the end of the 12-month period, these goals were met, providing a foundation to Stern to meet his long-term goal of a post-school career. The outcomes of the support plan were as follows.

Outcome 1	improved results at school – Stern’s family were able to purchase equipment that allowed Stern to access his work more easily at home. This has increased his motivation at school and helped him work more easily, especially at exam time. Having improved academic results should increase Stern’s long-term employment opportunities.
Outcome 2	Access to sport for physical and social wellbeing – Stern reported that he is enjoying both the physical and social aspects of soccer, while also seeing his overall health and wellbeing improve.
Outcome 3	Part-time work – Stern’s involvement with the soccer group has resulted in part-time employment; every Saturday he sets up the fields prior to the game. This provides him with income as well as enhancing his employability skills, including communication, teamwork and problem-solving.
Outcome 4	Being a budding meteorologist – Stern was able to purchase a small weather station, which he mounted in the backyard. This specialist interest may lead to specific technical employability skills in the meteorology field.
Outcome 5	Using technology to move around safely – funding was used to purchase supports from an orientation and mobility instructor, who gave Stern an introduction to travel-related iPhone apps. Stern said he is confident to use these in real-life situations. Having access to accessible information can improve safety and allow Stern to use his time more effectively.

Strategies to support capacity building

Service providers play a key role in helping prepare children, young people and their families to make the most of the opportunities they have now and into the future during the transition to the NDIS. A range of 'Getting Prepared' capacity-building projects have been funded until 30 June 2016 to help people with disability participate confidently in individualised arrangements and connect and share with other people with disability and their families and carers.

Service providers can support children and young people and their families to access these initiatives, which include:

- [My Choice Matters](#) – an initiative of the NSW Consumer Development Fund which delivers a range of projects to help people get the most out of person-centred supports through workshops, tools, online learning, videos, leadership development programs, capacity-building projects, story sharing and information resources
- [Living Life My Way Through Technology](#) – a project being delivered by Community Connections Australia to support people with disability and their families and carers in developing skills and confidence using technology
- [Resourcing Families](#) – a project which provides workshops and other strategies to build the skills and capacities of people to participate in and maximise the benefits of individualised disability arrangements.

The shift towards individualised funding will impact on how service providers support people with disability, including how they negotiate service arrangements and receive funding.

Service providers will need to have systems in place to support self-directed services and individualised funding arrangements. ADHC is working in partnership with the NGO sector to expand the capacity of the workforce to be ready to meet this demand. More information on these sector reform resources and initiatives are available on the [ADHC website](#).

Improved pathways to supports in the community

A range of initiatives is underway to improve local service coordination and pathways to supports in mainstream and community settings.

Districts are streamlining the way they provide information and referrals to people with disability and their families, making it easier for them to access supports from NGOs and mainstream community organisations.

ADHC has established [Ability Links NSW](#) to drive a new approach to local area coordination. It provides information and planning support for people with disability



aged 9–64 years and their families and carers. As of July 2014, families in every part of NSW can access support from Ability Links Coordinators, known as ‘Linkers’, who will help improve pathways to mainstream supports and strengthen community inclusion.

For children and young people aged 9 years and over, Ability Links NSW will play a key role in supporting them to plan and coordinate access to local community and mainstream supports and build new networks based on their goals and needs, such as accessing local sports, education and employment. This will facilitate their inclusion in the broader community and reduce their reliance on specialist disability services.

Service providers are encouraged to build networks with Linkers and support planners in order to facilitate integrated service pathways for children and young people with disability and their families.

A key focus of the NDIS will be information, linkages and capacity-building supports, which will focus on linking people with disability to community and mainstream supports. While this part of the scheme is still being developed, it is likely that it will focus on community awareness, low-cost interventions and other community-based activities so as to minimise future demand and reduce risks and liabilities.

Provider and community capacity

Disability Inclusion Plan

Under the Disability Inclusion Act 2014, an [NSW Disability Inclusion Plan](#) was released in February 2015. This plan identifies key strategic areas and actions that will lead to tangible outcomes for people with disability. It focuses on whole-of-government goals that support the inclusion in the community of people with disability and will improve their access to mainstream services and community facilities.

Building on the NSW Disability Inclusion Plan, each NSW Government department and local council must now develop, implement and report on its own disability inclusion action plan. These plans must include strategies to increase access and participation. For more information see the [FACS website](#).

Building capacity of NGOs and mainstream services

AHDC is investing in a range of projects and initiatives to build the capacity of the NGO sector and mainstream services to be more inclusive of children and young people with disability and their families.

For example, [FundAbility](#) is a new initiative being delivered by Northcott to build the capacity of mainstream services to support the inclusion of children aged 9–15 years with disability. It offers small grants for NSW-based events, community activities or projects so that they can become more welcoming of children and young people with disability. The project aims to ensure that:

- children aged 9–15 years with disability are included by mainstream services and activities within their local community
- local mainstream communities and services are more aware of including children aged 9–15 years with disability, and
- local mainstream communities and services have the skills, resources and knowledge to include children aged 9–15 with disability in their activities.

For more information on how to apply for funding, or to learn about innovative projects being delivered, visit the [FundAbility website](#).

Another example is the [School Age Years \(SAY\) Inclusion Support Program](#), an initiative developed by Lifestart to support the inclusion of children and young people with disability aged 6–18 years during their school years. The program will build the skills of children and young people and their families to make decisions about their interests and goals, including the activities they want to be involved in, and support them to participate in mainstream settings and environments. These



supports will target key life stages and events, including transition to primary school, high school and life after school.

The program, to be implemented in the Northern Sydney and Nepean Blue Mountains Districts, will involve a range of components such as:

- training and coaching to empower families to manage their own planning and packaging of support
- positive behaviour support, including resources, training and support for key partners in inclusive services
- resourcing children and young people and their families and school environments to engage in positive and successful inclusive practice
- support for universal and community services that are inclusive of children and young people with disability in mainstream social and recreation activities
- working with young people in Years 9 to 12 to prepare them for life after school
- supporting positive relationships for young people so they can develop safe, positive and appropriate relationships with their peers and friends
- support for siblings and other key family members.

ADHC also funded Aspect to develop [Launchpad](#), a website designed to support young people with autism and their parents to plan for and make the journey into adulthood a positive one. The website provides information on this topic and links to a range of useful resources to help young people with leaving school, studying, joining the workforce and managing daily activities.

Conclusion

Children and young people with disability should be recognised as children and young people first and foremost. They have the same hopes, ambitions and aspirations as their peers: to make friends and have relationships, to study or go to work, to have hobbies and a social life, and to be part of their community. It is critical that they are given every opportunity to participate as fully as possible in their community and realise their full potential.

The research shows that the transition to adulthood can be particularly challenging for children and young people with disability and their families. They can experience barriers that limit their opportunities for social participation in the community, at school and in employment, and these barriers can impact on their opportunities and experiences when transitioning into adulthood.

Despite these challenges, this life stage provides significant opportunities to build the skills, capacity and lifelong functioning of children and young people with disability, enabling them to live good lives and achieve their goals on the journey to adulthood. Many families of children and young people with disability can adapt and overcome these challenges using their own personal resources, the support of family and friends, and the help of services.⁹³

The *Supports for Children and Young People Aged 9–18 Years and their Families* framework, with accompanying Resources Guide, has been developed in recognition of the importance of supporting children and young people with disability and their families during this life stage. It is a high-level guide that service providers can use in delivering supports for children and young people with disability to increase their participation and inclusion in everyday settings between now and the transition to NDIS. This information may also be useful to a range of community and mainstream service providers.

There is a growing need to reorient the way that supports are provided to children and young people with disability and their families to ensure they are supported in inclusive mainstream settings while being able to participate in their community.

At the same time, during transition to the NDIS it is essential to prepare children and young people with disability to make the most of the opportunities they have now and into the future. Service providers should build the capacity of children and young people with disability and their families to exercise choice, control and be at the centre of decision-making regarding their lives in their journeys to adulthood. They need to build the skills and capacity to maximise self determination including their ability to identify the supports they need and who will provide these.



Service providers are encouraged to take every opportunity to support this life stage as they prepare to be NDIS-ready. This may be through developing better linkages and service pathways with mainstream and community supports, or through ensuring supports are flexible and tailored to the individual's needs, complementing the supports they receive from other providers to create an integrated package of support.

Endnotes and references

- 1 Australian Bureau of Statistics (2012) *Disability, Ageing and Carers, Australia, 2012: State tables for New South Wales*, analysed on 17 October 2014.
- 2 Australian Bureau of Statistics (2009) *Comparison of Disability Prevalence Between Aboriginal and Torres Strait Islander Peoples and Non-Indigenous Peoples*, taken from Survey of Disability, Ageing and Carers, Australia: Summary of Findings, Cat. No 4430.0, Australian Bureau of Statistics, Canberra, www.abs.gov.au
- 3 Llewellyn, G. & Leonard, L. (2010) *Indicators of Health and Wellbeing for Children With Disabilities: Mapping the Terrain and Proposing a Human Rights Approach*, Australian Research Alliance for Children & Youth, retrieved from www.acys.info/facts/disability/FTF_YouthDisability_briefing.pdf
- 4 Commissioner for Children and Young People Western Australia (2013) *Speaking Out About Disability: The Views of Western Australian Children and Young People with Disability*.
- 5 *ibid.*
- 6 Everitt, G. (2007) 'Transition? How to find your way through. An overview of recent transitions research for parents and practitioners', *Dimensions*, United Kingdom, p.12.
- 7 Commissioner for Children and Young People Western Australia (2013), *op cit.*
- 8 *ibid.*
- 9 NSW Ministry of Health 2010, *Healthy Bodies, Healthy Minds, Vibrant Futures*, NSW Youth Health Policy 2011–2016, North Sydney.
- 10 Office of the First Minister and Deputy First Minister (2009) *Report of the Promoting Social Inclusion Working Group on Disability*, available at http://www.ofmdfmi.gov.uk/report_of_the_promoting_social_inclusion_working_group_on_disability_pdf_1.38mb_.pdf
- 11 Raghavendra, P. (2013) 'Participation of children with disabilities: measuring subjective and objective outcomes', *Child: Care, Health and Development*, Special Issue: Participation of children with disabilities: Measuring subjective and objective outcomes, vol. 39, no. 4, pp. 461–65, July.
- 12 Stokes, H., Turnbull, M. & Wyn, J. (2013) *Young People with a Disability: Independence and Opportunity*, Research Report 39, University of Melbourne.
- 13 Australian Youth Affairs Coalition (2012), *In Your Own Words: The Voice & Opinions of Young People with Disability*, Surry Hills.
- 14 Bedell, G., Coster, W., Law, M., Liljenquist, K., Kao, Y.C., Teplicky, R., Anaby, D. & Khetani, M.A. (2013) 'Community participation, supports and barriers of school-age children with and without disabilities', *Archives of Physical Medicine & Rehabilitation*, vol. 94, pp. 315–23.
- 15 Office of the First Minister and Deputy First Minister (2009), *op cit.*
- 16 Commissioner for Children and Young People Western Australia (2013), *op cit.*
- 17 *Education Amendment Act 2009 No 25 (NSW)*
- 18 NSW Department of Education and Communities 2012, *Every Student, Every School: Learning and Support*, Sydney.

- 19 Australian Bureau of Statistics 2009, Survey of Disability, Ageing and Carers, Australia: Summary of Findings, Cat. No 4430.0, Australian Bureau of Statistics, Canberra <http://www.abs.gov.au>.
- 20 Department of Family and Community Services 2012, Better Lives for Vulnerable Teens FACS Review, Key Findings, 2012.
- 21 Commissioner for Children and Young People Western Australia (2013), op cit.
- 22 Burns, J., Collin, P., Blanchard, M., De-Freitas, N. & Lloyd, S. (2008) *Preventing Youth Disengagement and Promoting Engagement*, Australian Research Alliance for Children and Young People.
- 23 Parmenter, T., Einfeld, S. & Tonge, B. (1998), 'Behavioural and emotional problems in the classroom of children and adolescents with intellectual disability'. *Journal of Intellectual and Developmental Disability*, vol. 23, pp. 71–78.
- 24 McLaughlin, C., Byers, R. & Peppin Vaughan, R. (2010) *Responding to Bullying among Children with Special Education Needs and/or Disabilities, Knowledge Phase: Part 2 – A Comprehensive Review of the Literature*, University of Cambridge, Faculty of Education, London: Anti-Bullying Alliance.
- 25 UN Committee on the Rights of the Child (2007) http://www1.umn.edu/humanrts/crc/crc_general_comments.htm
- 26 Burns et al (2008), op cit.
- 27 Parmenter et al (1998), op cit.
- 28 Australian Institute of Health and Welfare (2010) Australia's Health 2010, no. 12. Cat. no. AUS 122, www.aihw.gov.au/publication-detail/?id=6442468376; Australian Institute of Health and Welfare (2013), *Disability Support Services: Appendix 2011–12, Disability Series*, Cat. no. AUS 173, www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129543840.
- 29 Sullivan, P. & Knutson, J. (2000) 'Maltreatment and disabilities: A population-based epidemiological study', *Child Abuse & Neglect*, 24(10), 1257–73. doi:10.1016/S0145-2134(00)00190-3.
- 30 Robinson, S. (2012) 'Enabling and protecting: Proactive approaches to addressing the abuse and neglect of children and young people with disability', *Children With Disability Australia*, January.
- 31 Indig, D., Vecchiato, C., Haysom, L., Beilby, R., Carter, J., Champion, U., Gaskin, C., Heller, E., Kumar, S., Mamone, N., Muir, P., van den Dolder, P. & Whitton, G. (2011) *2009 NSW Young People in Custody Health Survey: Full Report*, Department of Justice Health, Sydney.
- 32 Department of Education and *Early Childhood Development 2010, DEECD Early Childhood Intervention Reform Project: Revised Literature Review*, Melbourne: DEECD.
- 33 *ibid.*
- 34 *ibid.*
- 35 Valentine, K. & Rajkovic, M. (2011) 'Occasional Paper No. 35: Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers', Social Policy Research Centre, Sydney,.
- 36 Bekhe, A., Johnson, N. & Zauszniewski, J. (2012) 'Resilience in family members of persons with autism spectrum disorder: A review of the literature', *Issues in Mental Health Nursing*, vol. 33(10), pp. 650-56.
- 37 Department of Education and Early Childhood Development (2009), op cit.

- 38 Figures from Ageing, Disability and Home Care analysis of MDS data, December 2014.
- 39 Youth Disability Advocacy Service (2008), *National Disability Strategy Youth Roundtable*, prepared for the former Department of Families, Housing, Community Services and Indigenous Affairs, December.
- 40 Family & Community Services, Ageing, Disability and Home Care (2012), *Valuing and Managing Diversity, Cultural Diversity Strategic Framework 2010–2013*.
- 41 United Nations (1989) *United Nations Convention on the Rights of the Child* (UNCRC), Geneva: United Nations.
- 42 *ibid.*
- 43 *Disability Discrimination Act 1992* (Cwlth).
- 44 Commonwealth of Australia (2011) *National Disability Strategy 2010–2020*, Canberra.
- 45 Family & Community Services, Ageing, Disability and Home Care (2011), *Flexible Respite Policy Position (Disability) for ADHC-Funded Services*.
- 46 Evidence Network (2003) 'Meeting the needs of families with disabled children: What works and what's promising?', Barnardo's, City University & the University of York.
- 47 Stokes et al (2013), *op cit.*
- 48 Stewart, D. (2009), 'Transition to adult services for young people with disabilities: Current evidence to guide future research', *Developmental Medicine & Child Neurology*, vol. 61, iss. s4, pp. 169–73, October.
- 49 Office of the First Minister and Deputy First Minister (2009), *op cit.*
- 50 Stewart, D. (2009), *op cit.*
- 51 Youth Disability Advocacy Service (2012) Submission to *National Disability Insurance Scheme (NDIS) Bill 2012 Inquiry*.
- 52 National Disability Insurance Scheme, Operational Guideline – Planning and Assessment – Risk and Safeguards, January 2014, available at <http://www.disability.wa.gov.au/Global/Publications/For%20disability%20service%20providers/Guidelines%20and%20policies/Behaviour%20Support/Positive%20Behaviour%20Support%20Information%20Sheet%20for%20Disability%20Sector%20Organisations.pdf>
- 53 Bell, J., Vromen, A. & Collin, P. (2008) *Rewriting the Rules for Youth Participation – Inclusion and Diversity in Government and Community Decision Making*, Report to the National Youth Affairs Research Scheme.
- 54 Australian Communications and Media Authority (2009) *Click and Connect: Young Australians' Use of Online Social Media, Qualitative Research Report, July*.
- 55 Commissioner for Children and Young People Western Australia (2013), *op cit.*
- 56 *ibid.*
- 57 *ibid.*
- 58 *ibid.*
- 59 Moore, T. & McDonald, M. (2013) *Acting Early, Changing Lives: How Prevention and Early Action Saves Money and Improves Wellbeing*, prepared for The Benevolent Society, Parkville, Victoria: Centre for Community Child Health at The Murdoch Children's Research Institute and The Royal Children's Hospital.
- 60 Office of the First Minister and Deputy First Minister (2009), *op cit.*

- 61 Ageing, Disability and Home Care (2011) *Flexible Respite Policy Position (Disability) for ADHC-Funded Services*.
- 62 Government of Western Australia and Disability Service Commission (2012) *Positive Behaviour Support Information for Disability Sector Organisations*, available at <http://www.disability.wa.gov.au/Global/Publications/For%20disability%20service%20providers/Guidelines%20and%20policies/Behaviour%20Support/Positive%20Behaviour%20Support%20Information%20Sheet%20for%20Disability%20Sector%20Organisations.pdf>
- 63 King, G., Baldwin, P., Currie, M. & Evans, J. (2005) 'Planning successful transitions from school to adult roles for youth with disabilities', *Child Health Care*, vol. 34, pp. 193–216.
- 64 Stewart (2009), op cit.
- 65 ibid.
- 66 ibid.
- 67 Legislative Council Standing Committee on Social Issues (2012) *Transition Support for Students with Additional or Complex Needs and Their Families*, Final Report, Report 45 - March 2012
- 68 National Disability Services NSW (2011) Submission to NSW Legislative Council Standing Committee on Social Issues, *Inquiry into Transition for Students with Additional or Complex Needs and Their Families*, August.
- 69 Social Inclusion Board (State Government of South Australia) (2008) *Post-School Pathways: How 'It Is' and How 'It Works' for Young People with Disabilities – Background Report*, State Government of South Australia, p. 6.
- 70 Carter, E., Trainor, A., Cakiroglu, O., Swedeen, B. & Owens, L. (2010) 'Availability of and access to career development activities for transition-age youth with disabilities', *Career Development for Exceptional Individuals*, vol. 33(1), pp. 13–24.
- 71 Ageing, Disability and Home Care (2009), *From Protection to Productivity – An Evaluation of the Transition to Work Program*, November.
- 72 Stewart, D. (2009), 'Transition to adult services for young people with disabilities: Current evidence to guide future research', *Developmental Medicine & Child Neurology*, vol. 61, iss. s4, pp. 169–73, October.
- 73 Drenman, A., Wagner, T. & Rosenbaum, P. (2005) 'The key worker model of service delivery', *Keeping Current*, vol. 1, CanChild Centre for Childhood Disability Research.
- 74 Mengoni, S., Oates, J. & Bardsley, J. (2014) *Developing Key Working*, Council for Disabled Children, London.
- 75 Walker, J. & Donaldson, C. (2011) *Intervening to Improve Outcomes for Vulnerable Young People: A Review of the Evidence*, Department for Education, UK Government, January.
- 76 Dijkers, M.P., Whiteneck, G. & El-Jaroudi, R. (2000) 'Measures of social outcomes in disability research', *Archives of Physical Medicine and Rehabilitation*, vol. 81, S63–S80.
- 77 Lyons, R. (1993) 'Meaningful activity and disability: Capitalizing upon the potential of outreach recreation networks in Canada', *Canadian Journal of Rehabilitation*, vol. 6(4), pp. 256–65.
- 78 Ageing, Disability and Home Care (2015) *Addendum to the Standards in action manual: Guide for services working with children and young people with disability and their families*, pp 7-8.
- 79 *Disability Inclusion Act 2014* (NSW), Section 3(b).
- 80 Department of Education and Early Childhood Development (2010), op cit.

- 81 Palisano, R., Chiarello, L., King, G., Novak I, Stoner, T. & Fiss, A. (2012) 'Participation-based therapy for children with physical disabilities', *Disability & Rehabilitation*, vol. 34(12), pp. 1041–52
- 82 De Boer, A., Pijl, S. & Minnaert, A. (2011) 'Regular primary school teachers' attitudes towards inclusive education: A review of the literature', *International Journal of Inclusive Education*, vol. 15(3), pp. 331–53.
- 83 Tavares, W. (2011) 'An evaluation of the Kids are Kids disability awareness program: Increasing social inclusion among children with physical disabilities', *Social Work in Disability & Rehabilitation*, vol. 10, pp. 25–35.
- 84 *ibid.*
- 85 Office of the First Minister and Deputy First Minister (2009), *op cit.*
- 86 Specht, J., King, G., Brown, E. & Foris, C. (2002) 'The importance of leisure in the lives of persons with congenital physical disabilities', *The American Journal of Occupational Therapy*, vol. 56, pp. 436–45.
- 87 Leitch, K. (2007) *Reaching for the Top: A Report by the Advisor in Healthy Children and Youth*, Report for Health Canada, Ottawa: Minister of Public Works and Government Services, Canada.
- 88 Majkit, L. (2010) 'To study innovative, community based models of respite that promote social inclusion of people with an intellectual disability.'
- 89 King, G., Gibson, B., Mistry, B., Pinto, M., Goh, F., Teachman, G. & Thompson, L. (2013) 'An integrated methods study of the experiences of youth with severe disabilities in leisure activity settings: The importance of belonging, fun, and choice and control', *Disability and Rehabilitation*, vol. 36(19), pp.1626–35.
- 90 Centre for Community Child Health (2002), *New Frontiers in Early Childhood Inclusion*, Melbourne, accessed at <http://www.noahsarkinc.org.au/wp-content/uploads/2013/03/New-Frontiers-in-Early-Childhood-Inclusion-2.pdf>
- 91 NSW Ombudsman (2010) *Improving Service Delivery to Aboriginal People with a Disability – A Review of the Implementation of ADHC's Aboriginal Policy Framework and Aboriginal Consultation Strategy*, a special report to Parliament under section 31 of the *Ombudsman Act 1974*, September.
- 92 NSW Ombudsman (2010), *op cit.*
- 93 Department of Education and Early Childhood Development (2009), *op cit.*



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Community
Services