

Meeting the challenge **7**

How do my family member's rights change as they become an adult?



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This factsheet will provide you with information about some of the main changes that will occur when your son/daughter moves from childhood to adulthood.

Words in **green** are explained in more detail in the glossary at the end of the factsheet.

The transition period from childhood to adulthood can be a complicated time and cause anxiety for the person and their family. Changes occur in support and care packages; there are differences in which agencies are involved in supporting your family member; and the welfare benefits that can be claimed are different.

Understanding what's involved can help to ensure a smooth transition for your family member.

What happens when my family member leaves school and what are the options?

Leaving school can be a challenging time for all young people, and can be particularly difficult for young adults with a learning disability and their families.

There are important new laws that will affect the lives of young people with learning disabilities and their families. The two pieces of legislation that will have the greatest influence on support for disabled young people as they reach adulthood are:

1. The Children and Families Act 2014, which focuses on Special Educational Needs and Disability (SEND); and
2. The Care Act 2014, which focuses on the care and support of adults with care and support needs (implemented April 2015).

The Children and Families Act introduces a system of support, which extends from birth to 25 for some people. The Care Act deals with adult social care for anyone over the age of 18.

“Disabled young people tell me they want the same things as everyone else: paid work, a place to call their own, good health, friends and relationships, and to be part of the society they live in.”¹

¹www.preparingforadulthood.org.uk/media/312574/pfa_delivering_oct_2013.pdf



Top Tip

There will be a group of young people aged 18-25 who will be entitled to support through both the Children and Families Act 2014 and the Care Act 2014.

The two Acts have the same emphasis on outcomes, personalisation, and the integration of services. It is essential that the planning and implementation of both of these Acts are joined up at a local level.

More about the Care Act 2014

The Care Act changes the way that young people move from the children's social care system to the adults' social care system.

First, it enables families to ask for an assessment of someone's likely needs under the adult system before they are 18. This allows families and local authorities to more effectively plan what support someone will receive when they are an adult.

Second, the changes mean that young people can continue to receive children's social care services beyond the age of 18 if the adult system cannot meet their needs. This will continue until adult care and support is in place to take over – or until it is clear after a **needs assessment** that adult care and support does not need to be provided. See factsheet 2 for more on assessments and planning in adult services, and what good support looks like.

More about the Children and Families Act 2014

This law has introduced **Education, Health and Care plans (EHC Plans)** to replace statements of Special Educational Needs (SEN). They apply to young people from birth to age 25. This support is available while someone is in education or training, for example a **supported internship** or **travel training**, as well as traditional education courses.

The government has stated that eligibility for an EHC Plan has remained the same as for statements of SEN, but with the notable difference that it now applies to a 0-25 age range.²

From Year 9 onwards, the child/young person and their parents will be involved in deciding what the child/young person wants to achieve when they are an adult (e.g. independent living,

employment, etc.) They should then get the support they need to make this happen written into the EHC plan.

The extension of the SEND system into further education also means that there is now a single system running throughout early years, schools and further education.

Each local authority must have a Local Offer that sets out the local support and services available to children and young people with special educational needs and disabilities (SEND) to help them and their families prepare for the future. The local offer will be available on the local authority's website and in other formats.

²www.gov.uk/government/uploads/system/uploads/attachment_data/file/414952/SEND_Reforms_transitional_advice_March15.pdf (paragraph 2.3/2.4)



Top Tips

A local Information, Advice and Support Service (IASS) will be in each local authority area to help advise children, young people and parents and carers about their options as they approach or reach adulthood. To find out more about your local IASS, see:

www.iassnetwork.org.uk.

Parents can also get support from groups like Parent Carer Forums which are available in each local area. The National Network of Parent Carer Forums (NNPCF) has a list of all parent carer forums on their website: www.nnpcf.org.uk.

Those families going through an EHC needs assessment and the process of developing an EHC Plan, can request the help of an Independent Supporter. These are accredited professionals from private, voluntary and community sector organisations and can be recruited locally.

Care plans and EHC plans and how they work together

When someone moves into the adult social care system and they have a EHC plan, the social care section of their EHC plan is likely to become their adult care and support plan (see **factsheet 2** for more on assessments and planning). This will continue even if an EHC plan ceases, though a reassessment must take place. Some young people with a plan will be able to continue to receive children's social care services after their 18th birthday (as mentioned above in the Care Act section).

An EHC plan will cease if a young person no longer requires the support offered by the plan, if they are over the age of 18 and decide to leave education or training, or they enter paid employment or higher education. A plan cannot cease purely because someone is aged 19 or over, but there is also no absolute right for young people to be in education or training, or to receive an EHC plan up to age 25.

Where a local authority knows a young person will soon be completing their time in education or training, they should use the annual review of their EHC plan, before it ceases, to agree what support will be in place afterwards.

Even if an adult does not have an EHC plan, they may still be entitled to a needs assessment and care and support plan in relation to meeting their social care needs.



More Information

The Transition Information Network (TIN) is an alliance of organisations and individuals who aim to improve the experience of disabled young people's transition to adulthood. TIN is a source of information and good practice standards for disabled young people, families and professionals:

www.transitioninonetwork.org.uk

Children and Families Act 2014:

SEND Code of Practice

www.gov.uk/government/publications/send-code-of-practice-0-to-25

Detailed government guide for parents and carers about the SEND reforms

www.gov.uk/government/publications/send-guide-for-parents-and-carers



More Information

Guide for young people about the SEND reforms (Council for Disabled Children)

www.councilfordisabledchildren.org.uk/resources/cdcs-resources/information-for-children-and-young-people-on-send-reforms

Easy read guides for young people and parents about the SEND reforms (Mencap)

www.mencap.org.uk/EasyReadGuides

Information about getting an Education, Health and Care Plan (The Challenging Behaviour Foundation)

www.challengingbehaviour.org.uk/education-housing-social-care/getting-an-ehcp.html



More Information

Care Act 2014:

Government factsheets on the Care Act

www.gov.uk/government/publications/care-act-2014-part-1-factsheets

Preparing for Adulthood Programme Resources

www.preparingforadulthood.org.uk/resources/pfa-resources/delivering-support-and-aspiration

Will I still be involved in decisions about my family member when they become an adult?

The law is clear that every adult (when a young person turns 18), whatever their disability, has the right to make their own decisions, where they have capacity to do so, and should be supported to do so wherever possible.

Under the SEN reforms, young people will become primary decision makers about their

educational support from the age of 16. If the young person has capacity to make these decisions it does not mean parents cannot be involved – young people can continue to have their parents involved as much as they want.

The law also recognises that some people may not be able to make their own decisions. **The Mental Capacity Act (2005)** is the law that outlines how decisions are made concerning adults. It applies to people over the age of 16. When a person is unable to make their own decision because they do not have the **mental capacity** to do so, other people have to decide what is in that person's '**best interests**'.

It is important to remember that a person may have capacity to make some of the decisions in their life but not all of them. Deciding if someone has capacity is always decision specific.

Family members can continue to make many decisions for their adult child in their best interests. However, this will not automatically be the case in all aspects of their child's life.

Importantly, however, the Mental Capacity Act requires professionals to consult with family members when an adult lacks the mental capacity to make a decision for him or herself. Family members can challenge professionals if they feel that they are not being involved. Ultimately, families can ask for things to be referred to the **Court of Protection** if they

feel that their involvement is being limited or decisions are being taken that are not in the family member's best interests.

There are some options that a family member can consider if they want to seek legal power to make certain decisions on behalf of their adult child, including applying to become a **Deputy** through the Court of Protection. This can be in relation to things like financial or welfare matters.



More Information

Find out more about decision-making and the Mental Capacity Act:

Guide to the Mental Capacity Act (for family and friends of people with learning disabilities) by HFT

www.hft.org.uk/Supporting-people/Family-carers/Resources/Using-the-Mental-Capacity-Act/



More Information

Mental Capacity Act resource pack for family carers from Mencap

www.mencap.org.uk/sites/default/files/documents/mental%20capacity%20act%20resource%20pack.pdf

Best Interests Decision Tool – template letters for families to help ensure their involvement in Best Interests decisions by Irwin Mitchell Solicitors

www.irwinmitchell.com/activities/best-interest-decisions-tool

Getting legal authority to make decisions on money, property and welfare by the Challenging Behaviour Foundation

www.challengingbehaviour.org.uk/learning-disability-files/18_Getting-legal-Authority-to-make-decisions-about-money.pdf

How do welfare benefits change?

There are adult welfare benefits that you and your family member may be entitled to.

Parents/ legal guardians receive child benefit for every child they are responsible for who is under the age of 16 or under the age of 20 if they are in approved education or training. They can also claim tax credits. There are 'top-up' amounts for these benefits if the child / young person has a disability and meet the eligibility criteria. Families might be eligible to claim Carers Allowance but it is means tested on your weekly income.

The main benefits for adults with a disability are:

Disability Living Allowance (DLA) or Personal Independence Payment (PIP)

DLA and PIP are benefits paid to cover the extra costs of a person's disability or health needs. They are both split into two components: Daily living/care, and mobility. DLA is available to children under 16 and until recently was available to new adult claimants too.

PIP started to replace DLA for people aged 16 – 64 from April 2013. Anyone 16-64 will now apply directly for PIP, not DLA. People on DLA aged 16-64, and those turning 16, are being slowly transferred from DLA on to PIP, and all claimants will be transferred to PIP by 2018.

Employment and Support Allowance (ESA)

Once your family member leaves full time education and is over 18 they will be entitled to apply for ESA if they are unemployed, which is for those who cannot work because of a disability or illness. If they are not eligible for ESA, they will be entitled to apply for Jobseeker's Allowance (JSA) instead, which is the benefit claimed by most people who are unemployed.



Top Tip

make sure you claim all the Benefits you and family member are entitled to:

Guides on different benefits by the Department for Work and Pensions. (DWP)

www.gov.uk/government/collections/dwp-detailed-benefit-guides

The Carers UK website includes information about benefits and tax credits.

www.carersuk.org/help-and-advice/financial-support



Top Tip

An easy read guide for people with learning disabilities about the Employment and Support Allowance (ESA) (Mencap):

www.mencap.org.uk/node/5994

Guide to transition and family finance (Working Families):

From child to adult: a guide to disability, transition and family finance - part 1

www.transitioninonetwork.org.uk/media/2234/from-child-to-adult-part-1.pdf

From child to adult: a guide to disability, transition and family finance - part 2

www.transitioninonetwork.org.uk/media/2240/from-child-to-adult-part-2.pdf

Becoming an appointee for someone claiming benefits

You can apply for the right to deal with the benefits of someone who cannot manage their own affairs because they are 'mentally incapable' or severely disabled. For more information about becoming an appointee, see: www.gov.uk/become-appointee-for-someone-claiming-benefits

How does support from health and social care services change?

In adult services, the support offered to your son / daughter will be determined through a needs assessment, which is usually carried out by your local authority. Health and housing needs should be considered as part of the assessment process.

A person's package of support may be funded in different ways. Some people's package of care may be funded solely through social care by the local authority, whilst others may have a package of care funded jointly by the local authority and health (NHS) if there are specific health needs that need to be met, and others may have their whole package of care funded by the NHS (NHS Continuing Healthcare). Some people with behaviour that challenges may meet the criteria for NHS Continuing Healthcare.

There are ways that people can manage their own care and support. This allows people to have more choice and control over the services they receive to meet their needs. This is often referred to as 'self-directed support'.

A Personal Budget means that the person is allocated a pot of money to choose and pay for the care and support they want. It is important that people with behaviour that challenges are given the opportunity to have a Personal Budget. It could be funded by a Local Authority or it could be a Personal Health Budget (if the person is funded by NHS Continuing Healthcare) or it could be a joint (integrated) personal budget combining health and social care funding.

There are different ways you can take and manage a Personal Budget. You can take it as a Direct Payment – which is where you are given a payment instead of services, to buy the services you want – or you can leave it to the local authority or NHS with the responsibility for commissioning services (whilst still choosing the services you want). Or, people can have a combination of both. Young people can receive direct payments from the age of 16.

Carer's Assessment

Your Local Authority also has a duty to you in your caring role. Carers' assessments are undertaken to assess the needs of a family carer in their own right. A Carers assessment is not to assess how well you are providing care and support. It is to assess what support and services you could be provided with to help you in your caring role - for example, to get practical support. See **Factsheet 2** for more information.



More Information

Information about carers' assessments (Carers UK):

www.carersuk.org/files/helpandadvice/2589/factsheet-ew1020--assessments.pdf

See **Meeting the challenge: Frequently asked questions about the law** written by Irwin Mitchell Solicitors for more information about your family member's legal rights: www.irwinmitchell.com/meetingthechallenge

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Glossary

Needs assessment - the assessment that is carried out by the local authority to work out what someone's needs are. An individual is entitled to one if they have social care needs. Once a 'needs assessment' has been carried out, the local authority will determine which of the person's needs are "eligible" for support using "eligibility criteria". The Care Act has introduced national eligibility criteria, which local authorities must use.

Education, Health and Care plans (EHC Plans): For some children and young people who need support to achieve their potential in education. An EHCP will look at all the needs a child or young person has across education, health and care. Professionals from each area, along with parents, will consider what outcomes are desired and what is needed to achieve them. The plan should describe all of the different types of support the young person needs, who is responsible for providing it and when the plan will be reviewed with the young person.

Supported internship: They enable young people aged 16-24 with an Education, Health and Care plan to achieve sustainable paid employment by equipping them with the skills they need for work, through learning in the workplace. Supported internships are unpaid, and last for a minimum of six months. Wherever possible, they support the young person to move into paid employment at the end of the programme.

Travel training: Travel training refers to a scheme or programme that is aimed at providing tailored and practical help in travelling, including by public transport. It aims to help people travel independently and is predominantly aimed at people who are less able or less inclined to travel independently, including people with learning disabilities.

Mental Capacity Act: A law designed to protect and empower people who may lack capacity to make decisions, for example decisions about their own care and support, property or finances, because of a mental health condition, learning disability, brain injury or illness. 'Mental capacity' is the ability to make decisions for yourself. The law applies to people aged 16 or over.

Best interests: Under the Mental Capacity Act, decisions made in a person's best interest are made after weighing up all the evidence to decide what is best for a person. Best interest decisions are made when it is deemed that the person does not have the mental capacity to make the decision themselves. The MCA provides a non-exhaustive checklist of factors that decision makers must work through in deciding what is in a person's best interests, including involving the person as fully as possible.

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Court of Protection: The Court which is responsible for making decisions on applications which involve people who lack mental capacity. This can include decisions around people applying to become someone's deputy to make decisions on their behalf. There are two sorts of deputy: (i) those regarding decisions about the management of a person's property and financial affairs, and (ii) those regarding decisions about personal welfare (e.g. decisions about medical treatment).

For more information visit
www.mencap.org.uk/meetingthechallenge

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