

# Preparing for Adulthood: Pointers for Parents and Carers



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Dear Parents and Carers

This booklet has been produced as a starting point with information and prompts for the things that should be considered when supporting your young person to plan for adulthood.

It includes a list of questions for you to consider for yourself, for your young person, your family, friends and community. There are also helpful questions for you to ask the professionals and services around your young person: education, health and social care, for example.

There is a lot of information contained in the following pages and you may wish to consider this as an investment in your young person's future planning. There is a helpful section at the back where you can make your own notes and start to record plans.

For the young person's version of this information see the [Preparing for Adulthood Wiki](#).

We worked with the West Sussex Parent Carer Forum and other partners to produce this booklet. Whilst we know it won't answer all your questions, we hope it will be useful, relevant and help to signpost you to information from other sources.

Happy reading!

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## Preparing for adulthood pointers for parents and carers



Preparing for adulthood starts at home and in school when children are young, through the skills and values we teach them. At 14 years of age, we need to start having conversations with young people, planning the future and building independence. Hopefully, by 16 years of age, plans are becoming firmer and we have a clearer direction of what their future will look like. Young people need to be involved and at the heart of their planning and, where they are able to make decisions, will be the decision makers in their own lives.

The Children With Disabilities (CWD) teams use a core assessment, care planning and review document for children. A young person's views, wishes and plans can be captured using linked My Views and My Path documents and can be written into this by the allocated CWD worker. The My Path template can also be found in the [Preparing for Adulthood Wiki](#), and the Wiki itself can support young people to think about and talk about their wishes and plans.

Not all young people with lifelong disabilities will have been supported by CWD. Some children with lifelong disabilities may have had support from [Early Help services](#) or other specialist or mainstream social care teams, schools and health care provisions.



The best outcomes in education, health and social care happen when the young person and their family are already working to prepare and play an active role in building the future they want. We value creating independence, but human lives are interdependent and we are stronger when we have circles of support and different networks in our lives.

It is important to recognise doing with young people rather than for them empowers young people to reach their potential. Taking risks, making mistakes and doing things in an imperfect way are all part of learning, growing and enjoying life.

In preparing young people for adulthood, parents and carers often say, 'I didn't know what to ask, or what was possible' and 'I didn't consider how I could do things differently, as a parent carer at home it was just easier to do it myself'.

We believe young people with all levels of disabilities can be supported to have more involvement, more choice, more responsibility and more control in their own lives, and they will have happier lives for it.

This booklet is written for parents and carers of young people whose disabilities meet the eligibility for CWD teams and Adult Lifelong Services (LLS), although may also be helpful for others. It includes a list of questions for you to ask of yourself as a parent carer, to ask of your young person, your family, your friends, your community, and to ask of education, health and social care services. It is designed as a prompt, for things that should be considered when supporting a young person to plan for adulthood.

The questions have been grouped under the same headings used in the core Children With Disabilities assessment, planning and review document.

There is a place for you to keep notes at the end of this document.



## Looking after myself and where I live

### What things can you stop doing for your young person or do less of to help them be more independent?

Independence is taken in little steps. Maybe ask your young person to bring down their own dirty clothes to the washing machine, get them to put it into the washing machine and together decide which programme to use. It might be helpful to talk about why it is important for them to learn how to do the laundry and all the household chores.



Doing this with your young person rather than for them is an investment in their future. People with learning disabilities take longer to learn skills, so don't wait. Think about who else can help with this.

### How can you help your young person to transfer independence skills taught at school to home and the community?

Your young person should be practising independence skills in school or college. We know people with learning disabilities need to practise skills in the real environments they are going to use those skills. If your young person is practising shopping or travel training at school, make sure they practise these with someone at home too. If your young person has a personal assistant (PA), they should also support development of independence.

### Who will make decisions about where your young person will live and the type of support they will have?



From 16 years of age, if you or others think your young person would have difficulties in making important decisions in their life, such as where they live and what support they have, they will need to have an assessment of their mental capacity by the allocated worker. This will show whether your young person is able to make specific decisions. The Mental Capacity Act says we have to presume everyone can make their own decisions, unless we can evidence a person can't because of their disability.

If your young person lacks capacity to consent, they will need a best interests decision to decide. Your views as a parent carer are very important and will be needed to inform the best interests decision process.

## **What does your young person need to learn about to be able to make their own decisions about care and support and where they will live?**



Best interests decisions about care and where people live are only needed for people who can't understand their own needs and options.

Talk to your young person - where do they want to live when they are grown up, what do they want it to look like? You can help them to develop the understanding they need to make their own decisions, such as understanding their own needs, the consequences of them having care or not having care, and choices about where they will live.

## **Is the care and support of your young person more restrictive than usually expected for someone of their age?**



If the answer is yes, this might be the best thing to keep your young person safe and well.

Ask yourself, could it be made less restrictive?

Consider what would happen if you removed the restriction or support, and how you can give your young person more control, even if it's just a little bit. Don't be alarmed if your young person's allocated worker talks about restrictions and deprivations of liberty. These are terms used in the Mental Capacity Act. We know some young people require restrictions in place to keep them safe and well. To respect young people's human rights, we need to identify restrictions and deprivations, consider if they are necessary or if they can be done in a less restrictive way.

## **When will your child's benefits change?**

There may be changes in your young person's benefits between ages 16-19. You will need to consider how to maximise their benefits. For example, when Personal Independent Payment will replace Disability Living Allowance, and which benefit will replace Child Benefit. Some of this is affected by education. Benefits can be complex, and you should probably speak to someone for [benefit advice](#).

## **How can your young person practise saving, budgeting and spending money?**

It is a good idea to separate your young person's money from the family money. For example, using a separate or joint bank accounts, limited bank cards for practising skills, using pictures to plan a budget. They can still contribute towards the household. Even if you know your young person will never be able to manage their money on their own, they will benefit from being more involved and practising these skills.

## How is your young person's DLA or PIP benefit being used to meet their disability related needs?

For example, accessing social clubs, care or transport. Where Children's Services may have funded short breaks for some children, Adult Lifelong Services will only consider funding things like clubs and activities in exceptional circumstances. You can search for subsidised services through the [Local Offer](#), and for [discounts and grants](#).

## When do you think your young person will move out of home? What does your young person think?



Support your young person to think this through. Consider using the My Path document to plot it out with your young person, involve siblings or ask a PA to do it with them. The My Path can help to inform the young person's assessment, planning and review document if shared with the CWD allocated worker.

## Have you discussed it with social care or education services?

Residential school placements need to be agreed by the [SENAT](#) team and by CWD and LLS managers. It is a good idea to check if they are coming to the next review.

Options for young people to move out of the family home will depend on the level of the young person's needs. Many young people continue to live at home with their family. However, there are supported living placements and Shared Lives placements. Some people have support in their home or community. Some people have respite breaks or access support groups like [My Network](#). Other people just need signposting to community services which are already available. For young people with the most complex needs, a placement in a residential home may be offered.

Adults are usually expected to pay a contribution towards the cost of their care from their benefits (after a financial assessment). People in residential care, for example, usually only have a personal allowance of £30.65 a week in addition to any mobility allowance. The rest of their benefits are put towards the cost of their residential care.

Up to date leaflets and publications, including easy read information, are available [online](#) and will tell you all you need to know.

## What are your young person's views? How are they different to yours?



Everyone has a different view, recognising this demonstrates a healthy regard for individual autonomy and leads to good discussions. The My Views and My Path documents can be used by anyone to capture the young person's views and be used to inform the young person's assessment, planning and review document if shared with the allocated CWD worker. These don't need to be written and can use pictures to tell a person's story.

They are not to capture the views of the parent carer, just the young person. You can discuss your own views with the allocated worker.

## Does your young person have a Care Act assessment?



If a young person has adult social care needs, they will need a Care Act assessment. The allocated worker will look at what resources you and your young person can access that are already available within your family, close network and in the community. Young people generally have better lives when they have support from friends, family and networks within their local area.

The allocated worker will consider the needs of the young person, what needs they are likely to have when they turn 18 and the outcomes they want to achieve in life. LLS Adults' [Supporting Lives Connecting People](#) approach will help your young person identify their strengths and those in their family and community. They will build a support plan around these strengths, contributing with a funded service where eligible outcomes cannot be met in any other way.

The Local Authority will decide if a personal budget is needed in addition to what other support is available to the young person. More information about adult service providers can be found on the [Care Guide](#) and [Connect to Support, Adult Social Care Publications](#).

## Do you need to register your young person for housing with your Local Council?



Councils have waiting lists so it is best to do this as soon as you know your young person will need to move. Some adult care placements are only accessible to people on the housing register so your young person might miss out if they are not registered. Your young person has the same housing rights as everyone else, so unless they can afford to rent or buy, you should check what age your young person can register from.

The council will want to understand your young person's specific needs. If they have a CWD assessment, planning and review document you could consider sharing this or ask your young person's allocated worker to write a supporting letter.

## Are you managing a direct payment for your young person?



Because the law says everyone from 16 years of age will make their own decisions, your young person will either need to manage their own direct payment, nominate someone to do it for them, or will need a mental capacity assessment and best interests decision to appoint a suitable person. If you are already managing the account and are willing, this will probably just mean a new contract so you continue to manage the direct payment.

Direct payments [prepaid card](#) system makes it easier to manage and means you no longer have to send in bank statements.



## **Do you need the Independent Lives admin service or just payroll to manage a direct payment?**

Social Care does not have to fund the administration service. Except in exceptional circumstances, Adult Lifelong Services expect people managing budgets to manage the administration themselves or fund the administration services themselves.

## Employment, education and learning



### Where will your young person go to college post 16?

Will this be the sixth form of their current school or somewhere else? It is important you are aware of what the plan is, what agreements are in place in the Education, Health and Care Plan (EHCP), and which college you and your young person feel are going to be able to meet their educational needs. Check that the [SENAT](#) team are attending the Year 9 school review.

### Is there a plan for further education post 19?

Education can continue until the young adult is 25, if they are still achieving their educational goals. It is helpful if you and your young person are clear about long term plans and what learning is needed for these, and where this learning could take place. This would usually be possible in a local Further Education College. The [SENAT](#) team are responsible for issuing Education Health and Care Plans which will name the educational provision required. Be aware, in West Sussex education and social care budgets are separate. Make sure you are aware when the current college placement will end and that agreements are in place. Check that the SENAT team are attending the Year 11 school review.

### How will your young person get to college?



If your young person is receiving transport to school, once they are 16 years of age, they will need to pay £826 a year towards it. Young people in low-income families can apply for [help](#).

It is important to be preparing your young person to build their skills and travel independently.

If you, someone in the family or a PA are going out with your young person, why not practise getting the bus rather than using the car to build up travel training confidence and skills? Consider if you can work towards meeting them at a location. When the young adult would not be able to get to college because of their disability and there is no one able to help them, it may be possible for Adult Lifelong Services (LLS) to make arrangements for travel to college.

## Does your young person have a bus or rail card?

Find links on the [Preparing for Adulthood Wiki](#) to get a free bus pass and subsidised rail travel. Also:



- [Travel discounts](#)
- [Rail discounts for students](#)
- [Assisted travel](#)
- [Helping Hand scheme](#)
- [Free bus pass](#)
- [Railcard](#)

## Has your young person been referred to employment support services?



Explore Local Offer information about [preparing for and finding employment](#) or [Gov UK support](#). Young people need to have meaningful lives and meaningful occupation. Talk to your young person about who they want to be when they grow up, help them to identify their ambitions. It is important we help our young people have ambition and have professionals listen.

Young people tell us they want paid jobs. Most of us don't end up in the dream jobs we envisaged when we were young, but hopefully we are able to find work we find interesting. In reality, we probably did jobs we didn't like to get work experience and build up our skills and employability.

Use the My Path document to help map education and skill development to ambition. Not all work needs to be paid. Help your young person to look for voluntary work and work experience. It is important to have ambition, set realistic goals to achieve that ambition with, and for, your young person.







## Are you having conversations with your young person about healthy relationships and consent?



Love and sex are facts of life and that means for our young people too. We all develop at different rates and will have different ways of meeting those needs. It is important to recognise your young person has needs too. To be happy in life we all need to be able to talk about it and express ourselves in a healthy way. [Healthy relationships - West Sussex County Council](#). Have a look [online](#) for easy read information about relationships and sexual health.

## Does your young person have a Health and Care Passport, completed and ready just in case?

[Health and Care Passports](#) are a great way to tell health staff what they need to know, to make your young person's appointments or time in hospital run as smoothly as possible. It is a document which tells them the things a young person might not be able to say themselves and means you don't have to keep repeating yourself when professionals can just read it. It is a good idea to share a copy with social care so they can help to make sure the right people have it if your young person goes into hospital.

## Does your young person have an annual health check?



All young people with learning disabilities 14 years old+ are entitled to an [annual health check](#). This is because people with learning disabilities often have more complex health needs, and often are not able to identify if they have a health problem. Annual health checks are usually completed by the GP.

Check with the GP practice if your young person is on the doctor's learning disability register, and ask for them to go on this register if not.

Your young person may already have a paediatrician. Once they become an adult, health reviews and management and referral to specialists will be completed by the GP. It is a good idea to start annual health checks before your young person turns 18 so the GP can get to know your young person. Look at this [video from Misfits Theatre Company](#).

## Are you aware of the support of the Health Facilitation Team?

The [Health Facilitation Team](#) is a specialist team for people with learning disabilities who are 14 + years old. They provide nurse liaison support in hospitals and the community and can help make sure your young person's needs are being met.

They help health professionals to make reasonable adjustments to get the right support and can provide information and help to access health care. If your young person refuses to have treatment, won't sit in the chair or go into an appointment, they can help arrange desensitisation activities to help your young person feel more relaxed to get their health needs met. Part of their job is to help make sure everyone with a learning disability can have an annual health check, so if the GP said they don't do health checks the Health Facilitation Team can tell you who will.

## Have you looked for easy read information online?

Information about health can be found online in easy read formats. Finding these and teaching your young person where to find these will mean you don't need to wait for health professionals to get the information you need. Try searching online for other helpful sources.

## Are you supporting your young person to practise having time alone at home or in the community?

Your young person wants to be able to grow up, to have more responsibility and more independence. Technology can be used to provide reassurance to help young people grow and live their lives in the way they want to. Think about what needs to be in place to help your young person learn how to do this safely.

Practise staying safe at home alone for short periods, or being out and about, practise contingency plans, such as going to a neighbour or into a shop or phoning for help. Practise what to do in an emergency.

There are [alert cards for people with autism](#), and [Pegasus card](#) for people with communication difficulties, to help the police understand their needs, also [emergency cards for carers](#).

Some phones have GPS tracking and an SOS button if your young person gets lost or needs help. Technology can be used to help recognise problems or call for help, for example smoke, flood and gas alarms can be linked to telecare to ensure there is always an appropriate response. There are providers for specialist technology, such as care alarm services and [Carers Support West Sussex](#) offer advice and help on equipment. Don't forget however to have a look at the technology you already have and use at home, for example, smart phones and smart watches are great for setting reminders, and home voice control devices can be linked to automated lights and curtains. There are so many different types of coffee machines and kettle tippers, you no longer have to handle boiling water to make a hot drink. Have a look online, in Motability and phone shops for all sorts of equipment you can buy which make it possible to do more things without help.



## What if you can't afford a piece of equipment or activity you know would be helpful?

If you need a piece of equipment or help to buy something for your young person there are different charity sources. For example, [Turn2us](#) is a directory of all sorts of charitable funding, [Family Fund](#) will help up to the age of 17 years old.

## Do you need a social worker to get support from an occupational therapist?

If your young person needs support at home from an [occupational therapist](#) for assessment or equipment, you can refer directly and don't need to go through a social worker. Referrals for both children and adults are managed through the Adult CarePoint.

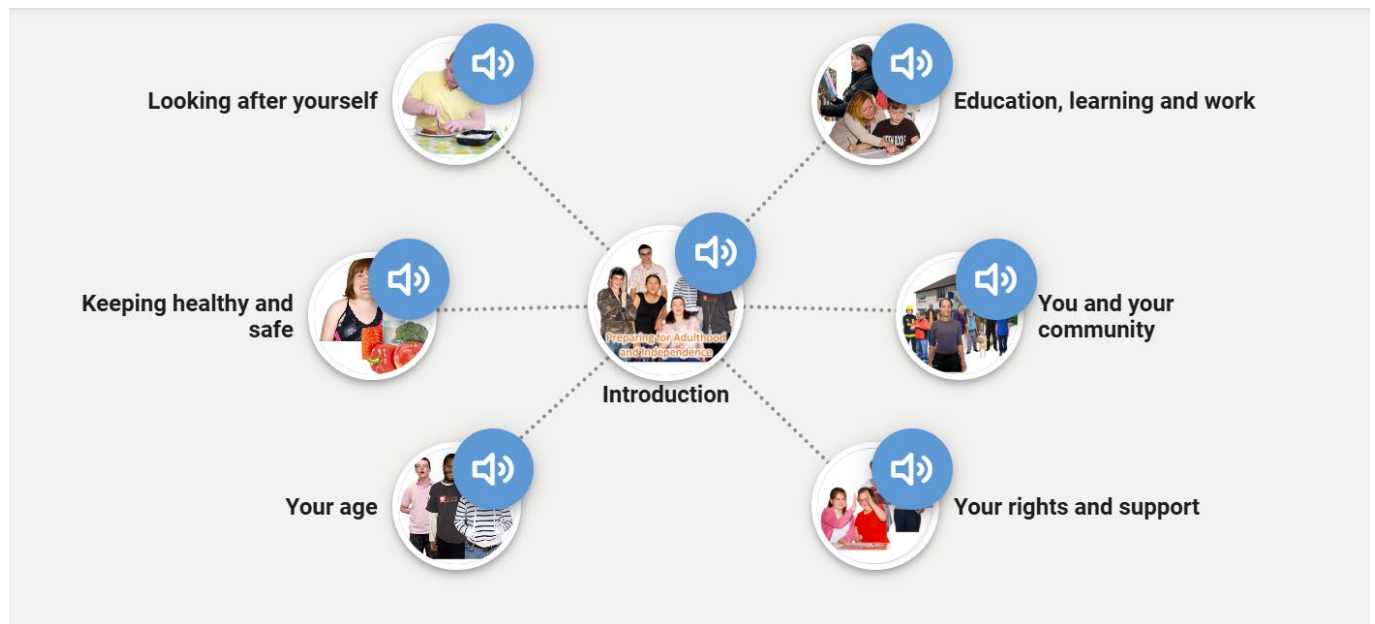
[How to get adult social care support - West Sussex County Council.](#)  
[Occupational therapy support for children - West Sussex County Council.](#)

## Does everyone need a Social Worker?

No, some people just need some advice to think about what is already out there in the community and some people just need some support to think about what they can do for themselves. West Sussex [Supporting Lives Connecting People](#) initiative in Adult Services includes 6 area 'My Network Hubs' offering information and advice.

## Where can you find accessible information about preparing for adulthood?

We have created a [Preparing for Adulthood Wiki](#), to provide accessible information about preparing for adulthood to help you and your young person.



Adult Lifelong Services also have online information in the Connect to Support web pages, for example:

[Transition to adulthood | How to live well with a health condition or disability | West Sussex Connect to Support](#)

[Supporting Lives, Connecting People | Community-led support | West Sussex Connect to Support](#)

This list is not exhaustive, there are so many resources for information and practical help, in your own family, online and in your community.

## Notes

Year 9 EHCP review date

Year 11 EHCP review date

Education agreements in place

Education placement will end

**List of Colleges to visit**

## **Short-term plan**

Home

Education and work

Community

Health

Support and care

## **Medium-term plan**

Home

Education and work

Community

Health

Support and care

## **Long-term plan**

Home

Education and work

Community

Health

Support and care



**People contacted**

**People in our network who can help**

## Preparing for Adulthood Wiki

For the young person's version of this information see the [Preparing for Adulthood Wiki](#). The electronic version of this booklet, Preparing for Adulthood: Pointers for Parents and Carers, with internet links can also be found in the Wiki.

## Adult Lifelong Services (LLS)

### **LLS Transition Teams Duty** (Countywide)

0330 222 7060 [LLSTransitionEnquiries@westsussex.gov.uk](mailto:LLSTransitionEnquiries@westsussex.gov.uk)

### **LLS Northern** (Crawley, Horsham, Mid Sussex, and Storrington)

0330 222 8600 [lifelongservicesadultsduty.northern@westsussex.gov.uk](mailto:lifelongservicesadultsduty.northern@westsussex.gov.uk)

### **LLS Western** (Chichester, Bognor and Midhurst)

0330 222 7888 [lifelongservicesadultsduty.western@westsussex.gov.uk](mailto:lifelongservicesadultsduty.western@westsussex.gov.uk)

### **LLS Coastal** (Shoreham, Worthing, Littlehampton and Lancing)

0330 222 7778 [lifelongservicesadultsduty.coastal@westsussex.gov.uk](mailto:lifelongservicesadultsduty.coastal@westsussex.gov.uk)

## LLS Occupational Therapy - Countywide Children and Adults

01243 642121 [socialcare@westsussex.gov.uk](mailto:socialcare@westsussex.gov.uk)

## Children With Disabilities Teams (CWD)

Referrals to the CWD service are made through the Integrated Front Door/MASH, using the [standard online portal](#).

For young people already known to the CWD service:

CWD **South Team 1 Duty** telephone – 0330 222 4900

CWD **South Team 2 Duty** telephone – 0330 222 2666

CWD **South Teams Mailbox** [South.Child.Disability.Team@westsussex.gov.uk](mailto:South.Child.Disability.Team@westsussex.gov.uk)

CWD **North Teams 1 and 2 Duty** telephone – 0330 222 3600

CWD **North Teams 1 and 2 Mailbox** [cdtn@westsussex.gov.uk](mailto:cdtn@westsussex.gov.uk)

CWD **Review Team Duty** telephone – 0330 222 2633

CWD **Review Team Mailbox** [choice@westsussex.gov.uk](mailto:choice@westsussex.gov.uk)

## Special Educational Needs Assessment Team (SENAT)

**SENAT South** – 0330 222 3120 [SENAT.South@westsussex.gov.uk](mailto:SENAT.South@westsussex.gov.uk)

**SENAT North** – 0330 222 2722 [SENAT.North@westsussex.gov.uk](mailto:SENAT.North@westsussex.gov.uk)

**SENDIAS** - SEND Information, Advice and Support Service - 0330 222 8555

[send.ias@westsussex.gov.uk](mailto:send.ias@westsussex.gov.uk)

## Learning Disabilities Health Facilitation Team

Sussex Community NHS Trust, Horsham Hospital, Hurst Rd, Horsham  
West Sussex – 01403 227000 ext. 7341