

Ten Top Tips for Transition to Adult Services

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1. Start Early

Many families say the earlier you and your son/daughter start to plan and think about the future the better. This is especially important if they might need support in their adult lives. Make sure your child's needs are assessed fairly and appropriately so any support in adult life can be planned effectively.

You can ask for a Child's Needs Assessment at a time of "significant benefit" when preparing for adulthood. This means that not all children will need to be assessed at a particular time-this can be during year 9 if you think that's appropriate.

2. Don't wait to be asked.

Find out about Person Centred Plans. What process is used to put your son/daughter at the centre of their transition? Talk to family and friends and get their ideas about what is important for your son/daughter. Is there any information from the Local Authority (LA) about their transition process? Is there a transition team? How will they meet and get to understand the needs of this young person? Do they know anything about fragile X and its effects? Think about ways of explaining some of the difficulties such as not able to manage change and transition well, the heightened anxiety that this can cause and the difficulty communicating your choices. Basically give you and your son/daughter a head start!

3. What things should you and your son/daughter be thinking about?

There will be lots of talk about "outcomes" and "goals" during this process. These will relate to

- Further education and training opportunities
- Community inclusion and leisure/social pursuits
- Independent living or future living options
- Employment
- Keeping safe and well.

4. Talk to other families and contact organizations.

Talk to other families about their experiences. There should be a "local offer" which is like a marketplace for what services are available in the local area. This should be on the LA website. Find out as much as you can about service provision from social enterprise schemes to day services, from friendship schemes to local clubs, from voluntary agencies to college courses. Contact your local carer centre for more help with this. They should have knowledge of the local Learning Disability Partnership Board and may have workers specializing in learning disability in your geographical area. They certainly will have knowledge of local support groups that might be helpful. Think about ordinary life too such as- getting to the

cinema, going shopping or using the local library that kind of thing, how would these be accessed, would some 1:1 time or using a personal assistant be the right way.

5. What decisions are made in adult life?

Start to think about the kind of decisions that participation in adult life brings. For example, making decisions about money and where to live. Adult services will talk about these kinds of issues and will assess whether the young person is able to make these decisions. You will hear people talking about "capacity" and the Mental Capacity Act (England and Wales). In Scotland the legislation is Adults with Incapacity. This is legislation put in place to protect the interests of vulnerable people who are unable to make their own decision about a specific life choice-for example where they want to live or how they want to spend their money. For England and Wales this may result in someone applying for Deputyship and in Scotland this is termed Guardianship. In Northern Ireland this is known as Controllership which comes under the Office of Care and Protection.

Please contact the office for more information if you feel capacity maybe an issue. Some young people with fragile X will be able to make some decisions about their life and some will not be able to. Even if a person is unable to decide they should be included as much as possible, and the decision must be made with their best interests as the focus.

6. Have your say.

As a parent you can be the advocate for your son/daughter. You know them after all and you should not feel excluded in the transition process or when adult services become involved. As a carer you should be listened to but if you do feel uncomfortable in any meetings take someone with you for support. Write down questions before the meeting and give yourself time in between meetings to look at and consider any options discussed.

7. What resources might be helpful when thinking about the future?

There are a lot actually but be careful that you look at up to date ones. Refer to your child's Education, Health and Care plan (EHC Plans) which are used in England. In Wales this may still be a statement although there will be changes in the future to an Additional Learning Need. In Scotland your child may be seen as needing Additional Support for Learning. In Northern Ireland your child may have a statement. For more information about Wales, Scotland and Northern Ireland please go to the Contact website www.contact.org.uk

EHC plans in England can last until a young person is 25 but only if they remain in education or training. Its also worth saying that social care needs identified during a Child's Needs Assessment must be added to the EHC plan along with an indicative Personal Budget amount. This is supposed to minimize the whole assessment process.

"Thinking Ahead: a planning guide for families" from The Foundation for People with Learning Disabilities is very useful. You can download this from-

www.togethertomorrow.org.uk/thinking-ahead-planning-guide-pdf Although it looks forward to a long-term future it has some very useful templates that help you think about any future support for your child in a practical everyday sense. This could be a starting point when considering a support plan for adulthood. For a resource that is more focused on the transition from children to adult services itself have a look at this website <https://www.preparingforadulthood.org.uk/>

8. What is a care or needs assessment?

In adult social care services this is what will determine the support your son/daughter will receive. The local authority have a duty to assess an individual, but, there is no automatic right to services or support because you have a learning disability or diagnosis. It is the impact your disability has on your independence and wellbeing that is assessed. This is done by identifying and evaluating the needs that they have and what would happen if the presenting needs were not met. If the outcome was of significant risk to their independence and wellbeing, then these needs would be seen as eligible unmet needs and the authority would have a duty to meet them.

Even if your level of need is not sufficient to generate support your son/daughter should be offered relevant information that might be helpful.

Carers are also entitled to a Carers Assessment. This examines the impact of your caring role in your everyday life. It also focuses on wellbeing as does the persons needs assessment. There is a duty to assess you as a carer. If you need short breaks or respite emphasize this in your carers assessment as well. Please think carefully about the support you give on a daily basis. You will always be doing more than you think and don't be afraid to say what you are not going to do. This is very important. A carers support is not supposed to be considered when the assessment is being completed but it will be when the support plan is being made. The support from a carer has always had a significant impact in self directed support. This is when someone is allocated through a Resource Allocation System money to buy their own services. They may be allocated less as their carer is meeting some of their unmet eligible needs. Please think about this.

There is relevant legislation here to refer too. Please go to Carers UK and look for the acts of law for where you are in the UK. Carers UK also have very good information about assessments.

9. Think about the practicalities.

The practicalities should never be ignored. For example how would you son/daughter get to college, their work experience, go shopping etc. Could they travel independently or would they need help to learn this-do they need a taxi?

You will be asked about using a Personal Budget or accepting Direct Payments. Are you happy to become an employer and recruit personal assistants? Or do you want an agency to help with this? Or do you want the social worker to take more control over service provision? Don't be afraid to get help around these issues.

Do not sign any assessment or support plan unless you are happy and agree with it!

10. Charges for services.

Your local authority will have information about charging for adult services. This is standard in adult services. Basically your son/daughter's finances will be assessed to see if they can make any contribution towards the costs of their support. It is not a financial assessment on the whole family's finances. Information will be online but you should have a visit from a financial officer who will explain it to you. Please think about all the extra expense that the person's disability incurs. This is Disability Related Expenditure. For example, do they need a special diet, frequent clothes /bedding washed and replaced, aids/assisted technology. You need to mention anything like this as these should be considered when they figure out the contribution towards the costs of someone's care.

Please note that across the UK there are some differences in how services are charged for. Please see this factsheet for more detailed information about charging for community care in your region of the UK www.disabilityrightsuk.org/charging-community-care