

# 'DON'T HOLD BACK'

**Achieving the best** for young people  
with **learning disabilities**



## 'Don't hold back': Transitions to adulthood for young people with learning disabilities

### Summary of the report by Sally Holland, Children's Commissioner for Wales



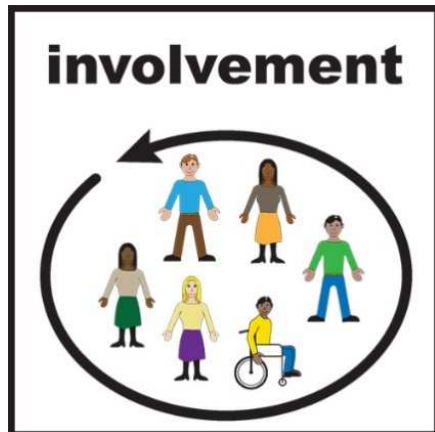
The human rights of young people with learning disabilities are protected by United Nations conventions and Welsh legislation.

This means that there are laws to make sure young people with learning disabilities are protected, supported and listened to.

The laws are failing to give the right help to many young people with learning disabilities as they become adults. Sometimes people call this transition to adulthood.

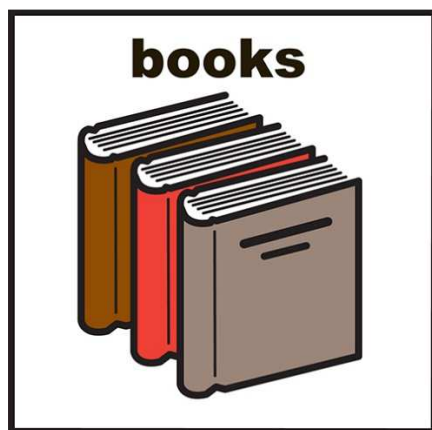
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Young people with learning disabilities get the right support when they have participated in decisions about their future. It also helps if they have one professional or key worker who can support them with making decisions.

## **What did we do to find out about the experiences of young people with a learning disability as they become an adult?**



We asked Edge Hill University to look at all of the research that has already been written about this subject. They found 58 different research studies that had looked at this topic. They wrote a report for us about all the things that these studies had in common.

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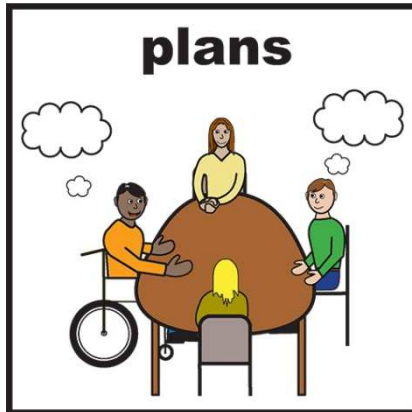
We asked C.A.R.P. Collaborations to do some research. They met with 99 young people with learning disabilities. They asked 187 parents and carers to do a questionnaire. They spoke to 43 professionals and 6 national charities. They wrote a report about what they had found out.

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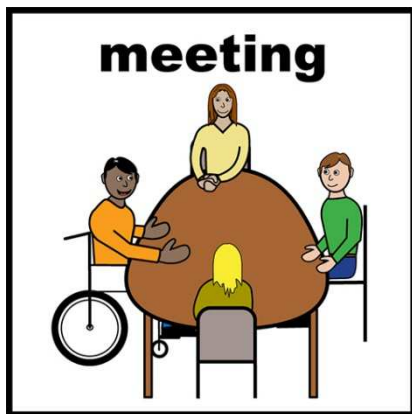


- 1. We found out about whether young people were involved in decisions about their own futures.**



Transition plans help young people with a learning disability plan for becoming an adult. Only a few young people knew about their transition plan.

Many young people thought that a transition plan was about moving from school to college. They did not know it can include other things like keeping friends or having a personal support worker.



Many of the young people said they had not been involved in decisions about their support in school. Most said they were not involved in social work reviews.

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This means that most young people with learning disabilities are not being involved in decisions about their futures. They are not being listened to.

## 2. We found out about family life



Parents of young people with a learning disability have caring responsibilities. They balance supporting their child to become an adult with continuing to meet care needs.

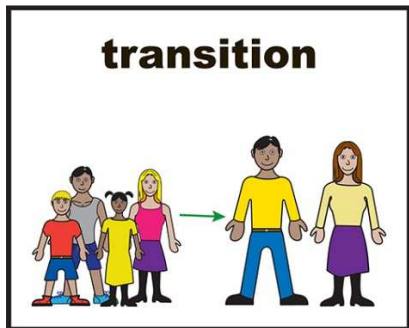
A small number of parents had to give up work because of caring for their child. This means that the family had less money to live on.

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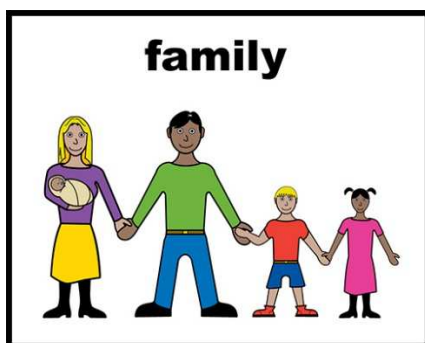


Some parents have to prepare for meetings and make appointments with different services. Some found it difficult to get the different services to talk to each other.



These difficulties can mean parents become anxious and Most parents are very supportive of their children. If they are involved in planning for the future a young person often has a good transition to becoming an adult.

### **3. We found out about the support that families have and what else they want.**



Parents and young people get most of their help from family members.

Some families also get help from key workers and teachers in schools and colleges.

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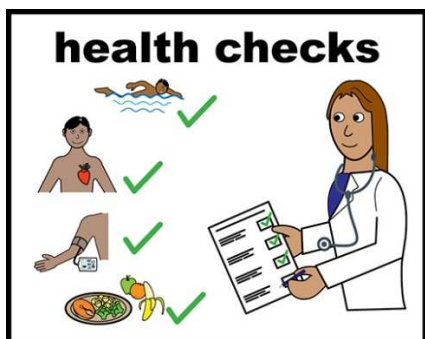


Young people wanted help with practical things. This included help to use public transport, help to fill in forms for jobs and help to understand finances and money.



Parents wanted help with their caring roles. They spoke about the need for having a break from being a carer and getting better advice. Parents need help that is flexible; so it fits around family life and work.

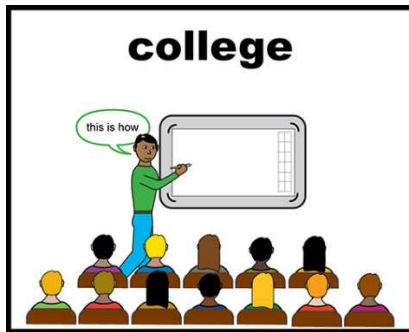
## 4. **We found out about the services that families use.**



Half of the families that used specialist health services said decisions were made too slowly. Young people at residential school faced a number of problems in getting appointments and help from health services.

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Most parents were worried about trying to get the right college placement for their child. Getting a place at a college was particularly difficult for young people who had high support needs.



Services for children used different assessments to services for adults. This meant that often young people stopped getting the help they need when they reached a certain age.



Becoming an adult is a complicated experience because decision making is too slow. Decisions are not flexible and can be based upon how much things cost.



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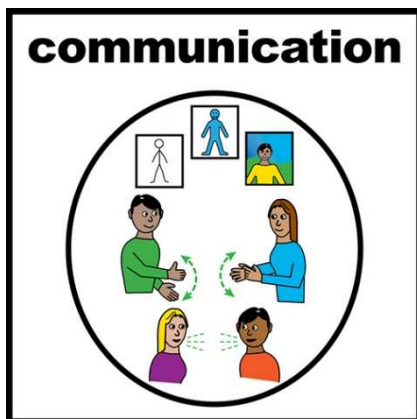
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## 5. We found out from families about the different services in Wales



There are a lot of differences between services in Wales. The help you get depends upon the community and area in which you live.



Professionals and families spoke about problems with services. They said that services did not communicate well and that decisions were made too late. Families felt that education did not prepare young people to live independently in adulthood.

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Professionals and families spoke about what was working in services. They said that the best support happens when staff are person centred and listen to the young person and their needs.

It works well when there is one person who helps families with the changes that happen when you become an adult.

## 6. We found out about friends and social lives

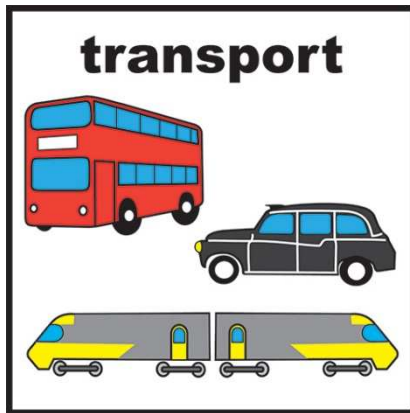


Young people said friendship was the most important thing in their lives. But many young people were isolated which meant they felt lonely and did not have many friends.

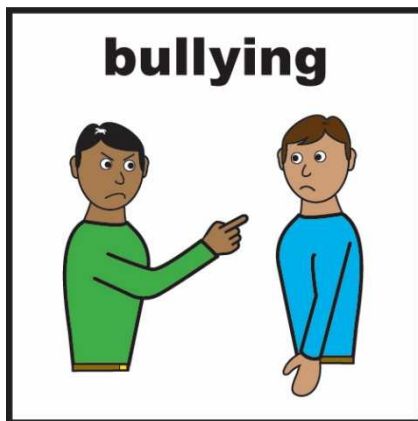
Young people spent a lot of time socialising with their family.

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Some services helped young people keep friends by teaching them how to keep in touch. They also helped them use public transport. Most of the young people did not use public transport on their own because they found this difficult. This stopped them from being able to go out and see their friends.



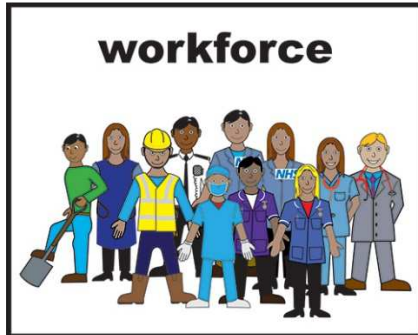
Young people and parents were worried about the amount of bullying that people with learning disabilities experience.

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## 7. We found out about hopes for the future



Finding work was very important to young people. Young people faced a lot of barriers in trying to get paid work.

Some of these barriers were about getting the right qualifications. Other barriers were about getting the right help and advice when looking for work.



The young people said that the second most important part of life when becoming an adult was having things to do and a full life.

This was not mentioned by most of the professionals.

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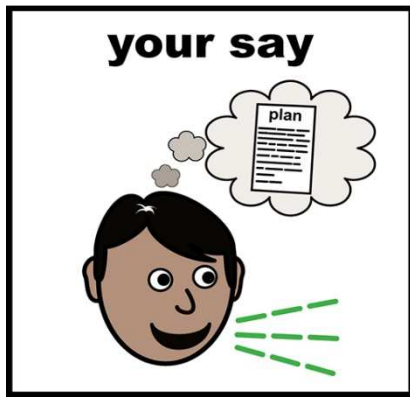
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## What do I think needs to change?



Young people with learning disabilities and their families face a lot of challenges and obstacles which make things difficult as they become an adult. These challenges would be improved if the existing laws were kept to.



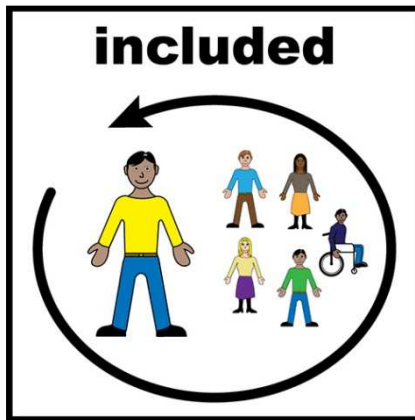
The challenges would also be improved if there was better participation of young people in making plans for their future. There are laws about supporting young people to be involved in planning for their future.



Parents and carers need better support. They need better information about the options available for young people who are becoming an adult.

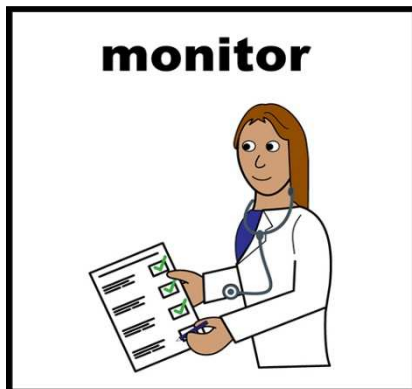
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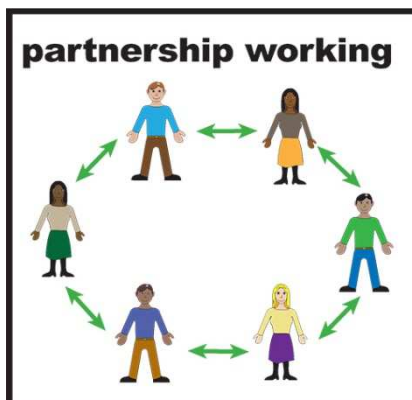


Young people with learning disabilities have equal rights. They need all parts of Government to work together for them to be equal citizens. This must include more chances in paid employment.

## As Children's Commissioner for Wales I will:



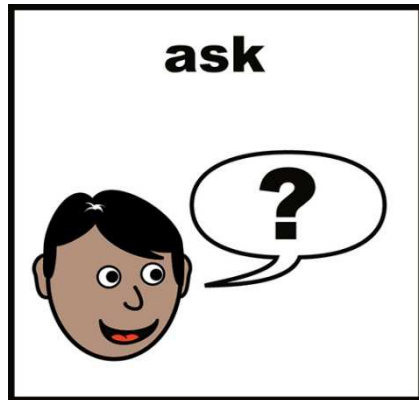
I will monitor the Welsh Government's new programme for making life better for people with learning disabilities. The programme is called 'Improving Lives'.



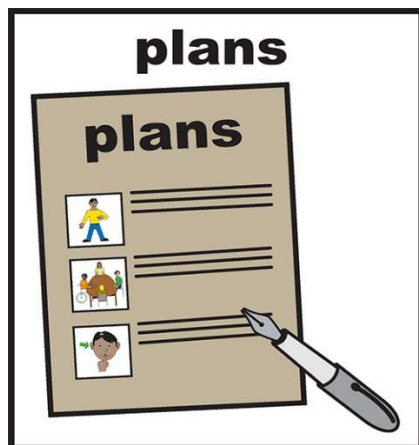
I will review the annual reports of the Regional Partnership Boards. These are local council organisations that are in charge of making sure services work together.

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I will ask you about your experience. I will listen to young people and their families to see if their experiences improve.



I will ask Welsh Government to improve planning for young people who are becoming an adult. I will ask for transition to be included in the 'Improving Lives' programme.