

# Moving from children's to Adult Services

Checking how well this was working for young people with high health needs.



This is an EasyRead of:  
"From the pond into the sea"  
Children's transition to adult health services



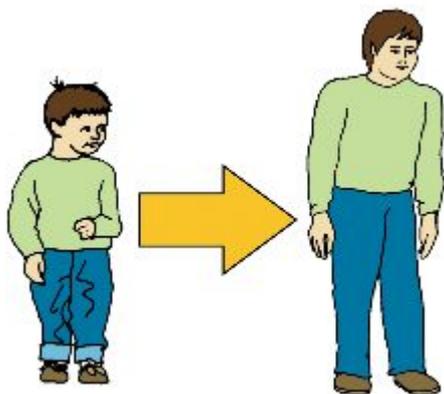
# What's in this paper?



This EasyRead paper is written by CQC, the Care Quality Commission.



We check health and social care services.

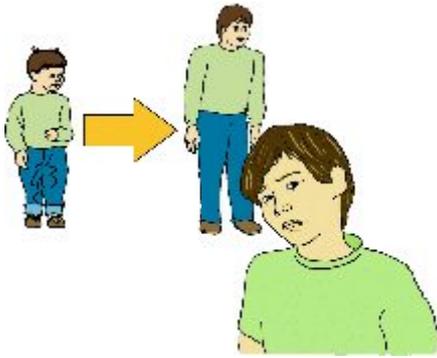


We wanted to look at how services were working for young people when they grew up and moved to Adult Services.

This is called **transition**.



In this paper we tell you about what we found out and what needs to be done to make transition better.



## The Issue

Growing up is difficult enough.



It's even more difficult when you have lots of health needs and you need to change services at a time when lots of other things are changing too.



To find out more about how transition was working for people and their families we asked 180 people how it was going for them.



There are lots of guides saying how to do it well.



But lots of people said they were not followed.



People had problems with:

- not enough information



- gaps in support



- services that just stopped or did not meet their needs.



We think it is simply not good enough to have services arguing about who should be giving a service when people are left with nothing!



One care worker said a service was working well, but that was only because the person's mother did the job for the professionals.

## Peter's Story



The story of what happened to Peter is the same for lots of people.



Peter has high needs, he is blind, he can't speak and has a physical disability.



His family organise their lives around meeting his needs.



Peter liked school and being with others, he talks in his own way.



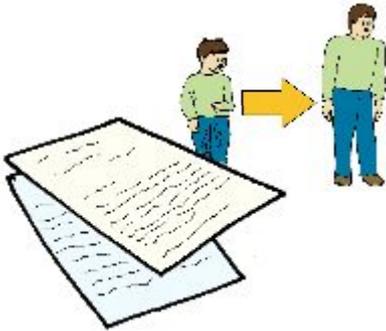
He needs health support with things like feeding.



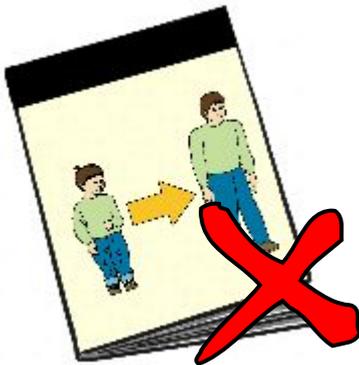
He sometimes needs emergency support with his breathing.



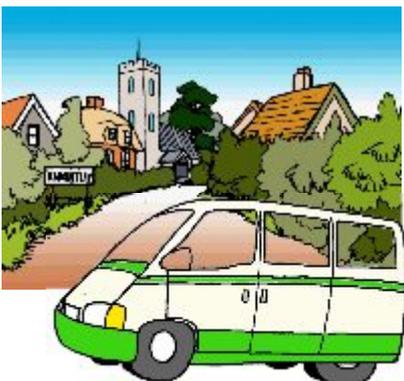
He used to have his services sorted out by a doctor who was a children's expert, which worked well.



When he was 14 his parents got a letter that said transition should be a part of his next review.



They did not get any more information about what that meant.



Peter was forgotten about because he went to a school outside his area.



His parents tried to organise meetings with professionals but things still went wrong.



He had to move his care to an adult hospital he didn't know, after he had an operation.



Peter had no one to organise his services and support properly.



His parents are trying to work with his doctor to find a local place he can go to now.



Peter's story shows all the things that should not be happening.

## What worked well?



We did hear about some good services and very good workers.

These were usually special health services that followed the guides about how to work well.



Some good things were:

- having the same staff who knew people and their problems



- having clinics for young people aged 10 – 19



- staff talking well with young people and their parents



- being given good information.

## What didn't work well?

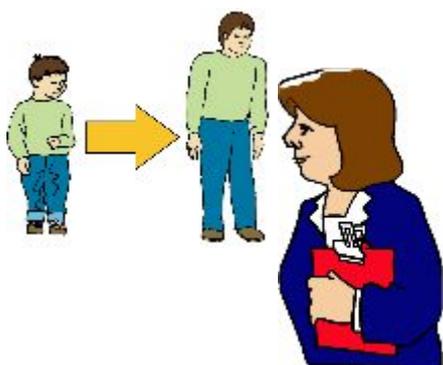


### 1. Planning was not good enough

Many people did not get good planning or information.



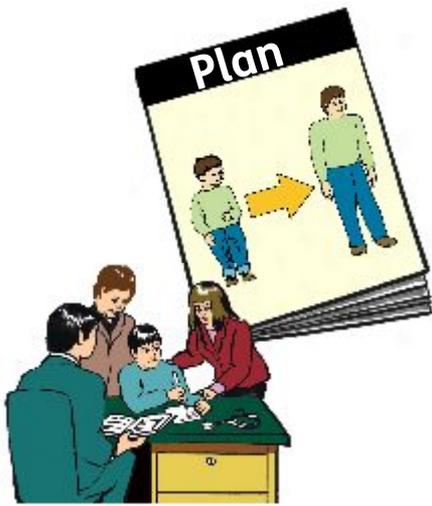
People did not know about the changes that would be happening.



Some professionals said they did not know how to do transition planning properly.



Sometimes an important service just stopped completely at 16.



## 2. Plans were not made at all

8 out of 10 young people we talked to did not have their health needs included in their transition plan.

It is clear in the guide that people should have a plan that includes their health needs.

We were told they were not done because:



- health and social care working together didn't always work well and the planning was left too late



- there just was not an adult service doing the same job as the children's service



- professionals did not always know who should do what



- adult and children's services did not talk to each other enough.

### 3. Health Passports were not used



Health Passports are a way of people keeping their own health information together.

That way it can be shown to anyone who needs to see it.



Some people did have Health Passports, but lots did not.



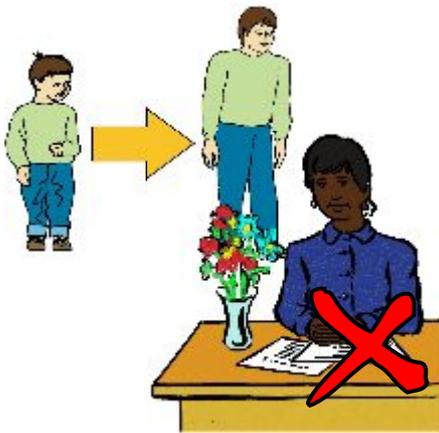
People said it was very annoying having to tell lots of new professionals the same things about health needs.



Everyone liked Health Passports but they were still not used.

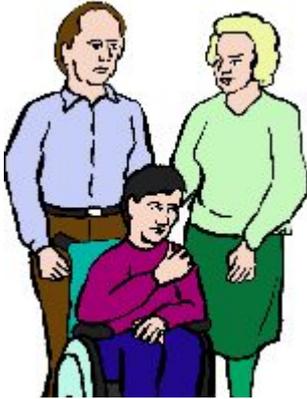


Everyone said that health information needed to go onto computers so everyone could see it when they needed to.



#### 4. There was no one professional in charge of supporting a person through to adult services

Half of the families we spoke to said they did not have a person in charge of their move to adult services.



7 out of 10 professionals agreed. People said the job was left to parents.



This was because:

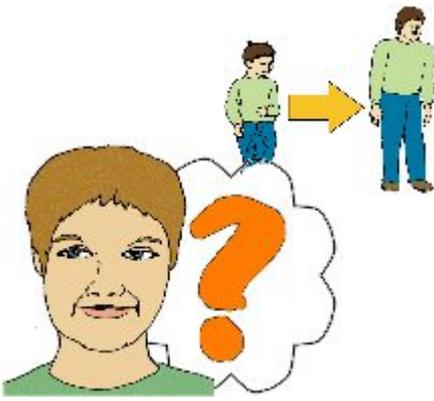
- professionals were not sure who should do it



- adult services are not paid to get involved with people under 18

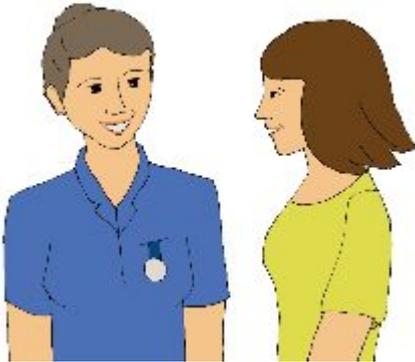


- GPs (local doctors) are not involved in the care of children with high health needs, but they are expected to when they are 18.



## 5. Adult services were not right for young people

Some adult services said they did not know how to support some young people when they moved from children's services.



Some community nurses who look after adults could not do the same jobs as children's nurses.



Some parents had seen children's and adult services arguing in A&E about the best place for the young person to go to.



## 6. Carers needs were not checked

Health staff did not look enough at the needs of parents as carers.



Some children's nurses said they had not had training on the needs of carers or the money and time to do it.

## 7. Services did not agree who should pay for what people needed

Because sometimes services could not agree who was paying, some young people were left without:



- equipment



- services



- respite care



- the other things they needed.

?



Services told us that:

- it was not clear who should pay



- professionals, who did not know the young person, did the check to see what they needed and left important things out



- other important information was left out



- making decisions took longer



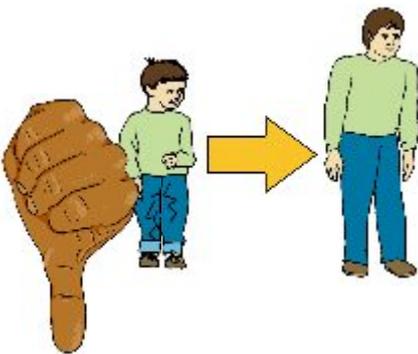
- having a personal budget left some people feeling they were just left to get on with it themselves



- even if you did have the money it was no use if there were no services to buy with it.



It was expected that staff in children's and adult services should work together.



Lots of staff did do a good job, but not when it came to transition.



If transition is not done properly people can get very worried about who is going to help them and give them the care they need.



Sometimes important care just stops or they can't get equipment they need until the money is sorted out.

## What needs to be done?



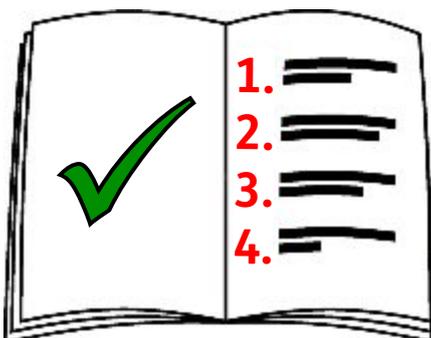
We did think about whether there should be a special service just for people between 14 and 25.



This does work well in some areas, but other services work well if they are able to change to meet people's needs.



We decided that what matters most is having services that work together to give the care young people need.

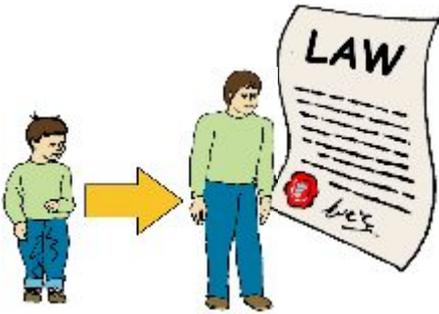


We think there are 4 main things that need to change.



**1. The people who buy services (commissioners) must listen and learn from young people and their families.**

Families know what works well and when things go wrong, they need to be listened to.



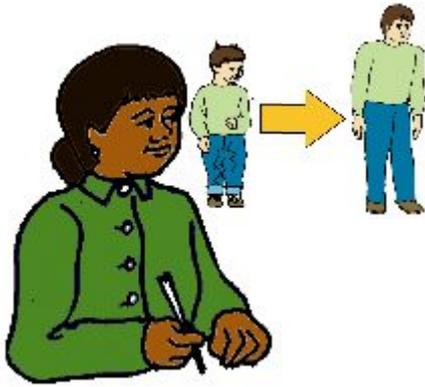
With new laws on care coming out the time is right to do the things they say about moving to adult services.



**2. There are lots of examples and guides on how to do transition well. These need to be followed.**



There is no excuse for not following these guides.



Every person over 14 with high health needs should have:

- a named professional in charge of helping move to adult services



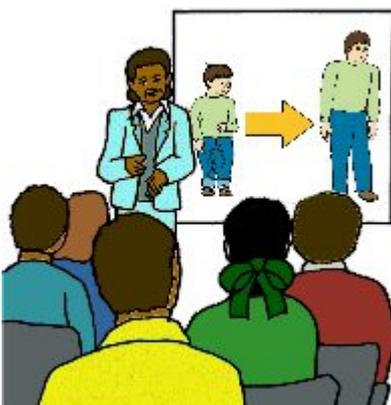
- a good plan



- a Health Passport



- good services with no gaps



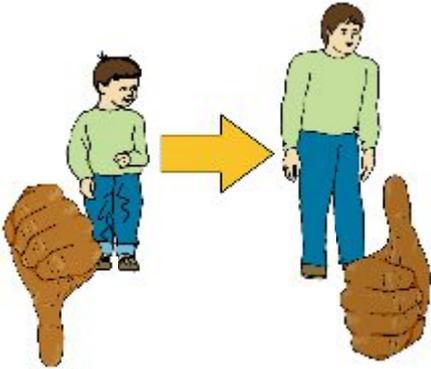
- training and advice about transition



- advocates if needed



- respite or short breaks that meet people's needs.



When we check services we will look at how well they are helping young people move to adult services.



If they are doing it well we might give them a better score.

If they are not doing it well we might give them a lower score.



If they are very bad we might take action to make them change.



### 3. GPs must be involved earlier to help planning

A GP service is the only service that does not change in transition.



Over the next year GPs will be starting a new, better service to look after older people with high health needs.



They should be thinking about doing this for younger people as well.



When we check GPs we will check to see if they are doing this.



#### 4. Growing up should be seen as an important time by services

The people in charge of health services should be making sure services work well for young people.



They need to make sure:

- staff have the proper training



- services work together to plan what to do



- there is a manager whose job it is to make sure services work well together.



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