

Will anyone listen to us?

What matters to young people with complex and exceptional health needs and their families during health transitions

Final Report

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Background

Times of transition of any kind for young people are highly significant but for young people with complex health needs, the transition from children's to adult health services is particularly challenging. This is due to 'an often complex health and social care landscape and a multitude of different concerns and issues that need to be resolved' (Scottish Transitions Forum, 2014).

Many more children with complex and chronic illness are now surviving into adulthood therefore requiring continuing healthcare. A report designed to raise awareness of the important issues facing young people as they move from paediatric to adult care, states that 'the change from paediatric to adult services should be a smooth one so that patients feel informed and in control of their health. (The Royal College of Physicians of Edinburgh, 2008) Scottish legislation states that it is obligatory to include the views of children and young people in decisions affecting them. 'Each child who can form a view on matters affecting him or her has the right to express those views if he or she so wishes' (The Scottish Government, 1995) and more recent legislation states that it is a requirement 'so far as reasonably practicable, to ascertain and have regard to the views of (i) the child and (ii) the child's parents. (The Scottish Government , 2014).

NHS England commissioned the Care Quality Commission to do a comprehensive review of transition arrangements in England. The report entitled "From the pond into the sea" (2014) made four key recommendations outlined here:

1. Commissioners must listen and learn from young people and their families.
2. Existing good practice must be followed to ensure young people are properly supported through transition.
3. GPs should be more involved at an earlier stage in planning for transition
4. Adolescence/ young adulthood should be recognised as an important developmental phase across the health service. (Care Quality Commission, 2014)

Therefore it is recognised both in Scotland and England that transition from paediatric to adult health services is an area requiring urgent examination. Our report, although small in scale, provides a unique snap shot of the experience of transition for some of the families in Scotland with children and young people with complex health needs.

CEN, the National Managed Clinical Network for Children with Exceptional Healthcare Needs, commissioned Talking Mats to find out the views of young people with complex needs and their parents about what matters to them at a time of transition in health services from children to adults. The literature suggests that we cannot assume that there will be consensus between parents and children or professionals and families about the needs of children. Listening to the perspectives of children and young people can be challenging since often the nature and complexity of their health condition includes significant communication impairment. The perspectives of the young people were considered to be vital to this study and we wanted to capture their experiences, record their voices and use the information to help us understand the reality of what matters to children and young people themselves.

Talking Mats is a social enterprise whose vision is to improve the lives of people with communication difficulties by increasing their capacity to communicate effectively about things that matter to them.

Aims

To ascertain the views of young people with complex needs and their parents about

1. Health services before transition
2. Health services during transition
3. Health services after transition
4. What could be improved

Methods

The Talking Mats team have developed an innovative visual tool which can support many (but not all) people with communication and/or cognitive difficulties to consider issues and express their views (Murphy & Cameron, 2008). Talking Mats is an interactive resource that uses three sets of picture communication symbols – topics (whatever you want to talk about), options (relating specifically to the topic), a visual scale (to allow participants to indicate their feelings about each option – and a space on which to display them. Once the topic is identified the participant is given the options one at a time and asked to think about what they feel about each one. They can then point or place the symbol under the appropriate visual scale symbol to indicate what they feel.

The Talking Mats team met with the CEN team to determine the symbol sets which would be the basis for the Talking Mats discussions. We agreed on 2 main topics relating to health care services i) at GP surgery and ii) at hospital and identified options which could be applied to both situations. As the GP is usually the first point of contact for the young people when they move to adult services we felt it was important to make this one of the key areas to investigate. The discussions around hospital could relate to the paediatric and/or the adult hospital experience, whichever was relevant.

See appendix 1.

It was agreed that we would interview both the young person and the parent/s using whichever symbols were relevant for them.

We also defined the criteria for the young people to be involved. These were:

1. Complex health needs
2. At or near time of transition
3. Living at home
4. Using health services
5. Sufficient vision to see symbols
6. Symbolic understanding for simple images
7. Reliable yes/no response

We prepared information sheets and consent forms and the CEN team agreed to contact families to explain the project and get consent. They then sent the contact details to the Talking Mats team who arranged the visits which were all conducted in the family home. We carried out a pilot interview with a young woman and her mother who had already gone through the transition from children's to adult health services and altered some of the symbols as a result. Talking about transition and future wishes can be difficult for us all. To do so you need language and cognitive skills to be able to conceptualise the future. In order to think about the issues around transition the primary focus needs to be on the present. We felt that if we could identify the aspects of their current lives and experiences that were going well, and not so well, we could extrapolate from this. Our pilot interview confirmed a practical focus was best and we made the topics and options as concrete as possible by relating them to actual situations.

See Appendix 2

Participants

The aim was to involve ten families but it proved problematic to find families known to CEN who fulfilled the inclusion criteria. When we visited some families it became apparent that some of the young people were not able to express their views using Talking Mats but their parent/s were keen to be part of the study. The following table summarises those who were involved. We include the participants in the pilot interview as their views were relevant and helpful for the main student.

Participant ID	Age	Disability	Young person Interviewed	Parent interviewed
Pilot	30	Quadriplegic Cerebral Palsy Epilepsy Visual impairment Learning disability	✓	✓
1	18	Quadriplegic Cerebral Palsy	✓	✓
2	14	Quadriplegic Cerebral Palsy Epilepsy	✓	✓
3	19	Withdrew		
4	13	Withdrew		
5	17	Multiple complex disabilities	-	✓
6	18	Cerebral Palsy Learning disability Visual impairment	-	✓
7	19	Genetic abnormality Tracheostomy Enteral feeding Visual impairment	-	✓
8	20	Dystonic quadriplegic cerebral palsy Microcephaly Hypothermia	✓	✓
9	10	Chromosomal abnormality Learning disability Epilepsy	Transition too far ahead.	-

Analysis

With the consent of each participant we video recorded the interviews in order to capture all their views and nonverbal comments. We transferred the comments onto spreadsheets and then analysed them thematically using mind mapping. All the participants' comments were anonymised and their data was stored using a coded numbering system. All confidential data will be destroyed at the end of the project.

This resulted in two large mind maps, one of the young persons' views and one of the parents' views. Each mind map focused on three health services - paediatric, GP and adult. In addition we gathered additional comments from the parents who had not yet experienced the adult services but who had many concerns and fears. We also asked the parents to tell us what they thought should happen to make transition better.

Findings

Young persons' views

Because of the complexity of their health needs and cognitive difficulties, only four of the young people were able to express their views.

Paediatric Services:

Their experience of paediatric services at the children's hospital was generally seen as good and the reasons for attending were either for planned admissions or for outpatient appointments. The journey to the children's hospital was fine although having to wait for appointments as outpatients was mentioned as a problem. All the young people were clear that they needed to have their Mum with them and they wanted to have their own things for comfort. They felt the staff were generally good although they mentioned that some didn't listen to them and some used difficult words.

Adult Services:

All but one young person had not yet experienced an adult hospital but all said if they had to go they wanted their Mum to be with them.

The following case study highlights the issues surrounding an unplanned admission to an adult acute hospital. The young person's name has been changed to protect confidentiality.

Rosie has quadriplegic cerebral palsy. She has to be fully supported in her wheelchair. She is unable to care for herself and relies on her family and carers for all her day to day needs. She has a full and active life and goes to college 3 days a week. She enjoys meeting people, has an interest in beauty and trips out. She can speak in a quiet voice and is a competent communicator.

When she was 16, she had a planned admission for a surgical procedure in the children's hospital. The operation was successful and she was sent home for 6 weeks in a spica cast. Whilst at home she suffered complications from the surgery and had to be readmitted to hospital. She had just had her 17th birthday. The journey to hospital in the ambulance was "horrendous" as there were no adaptations and she had to be transported on the bed. On arriving at the hospital she was informed of the hospital's rule: as she was now aged 17 she could not go to the children's ward and needed to go into an adult ward. Rosie and her mum were left in A&E for **14hrs** as the hospital tried to decide where to put her. This proved distressing for Rosie as she was frightened by the shouting and swearing around her. She did not understand why she couldn't go to the children's ward (although she had officially reached the age to access adult services, her Mum felt that developmentally she was still requiring the level of care suited to a child)

In A&E Mum asked for her daughter's regular medication for her bowels but it was refused and was told that this was because they didn't have enough staff on duty to clean her up. Her mum had to fight to reverse this decision and eventually an auxiliary was sent from the children's ward to help them. On admission to the ward, Mum had to explain the situation in detail to the nurses and doctors as they had no access to her previous medical history. A specialist learning disability nurse had been due to visit to make a 'Health Passport' for Rosie but this had not yet been completed. This document should contain information about care needs, history and requirements. It is possible that if that had been in place it would have helped to reduce some distress and anxiety. Whilst children's hospitals have facilities to enable parents to stay with them this is not the case on an adult ward and after sitting up all night in a chair, Mum decided she must go home to get some things for Rosie. On her return at 2pm she found her daughter in distress and Rosie's breakfast and drink still lying on the table in front of her. Rosie had been put in the single room furthest from the nurse's station and she could not get help as she cannot shout or use the buzzer. No-one on the ward seemed to know anything about her and she had received no personal care. Even the doctors did not know how to treat her and clearly felt out of their depth. Rosie had nothing to do which was such a contrast from the children's ward where she was visited regularly by play leaders.

Mum managed to get her discharged after three days. At the end of third day, a nurse on the ward came and apologised to Rosie and her mum for the level of care they had received and said "I have lost all faith in my job". On returning home, Rosie needed someone to pass a naso-gastric tube but, as she was now 17 years old, the children's community nurse could no longer come round to do it. She was told that there was no one in the community trained to do this but that if she returned to the hospital someone in the renal ward may be able to do it within 24hrs.

Rosie's experience of transitioning to adult services left her feeling frightened and confused. Her mum explained that it was like going from one end of the scale to the other.

- *She went from being a child to an adult within days. We were cushioned from reality - we expected the best because we were used to the best.*

Mum and Rosie have been allowed to return to the children's hospital for the time being.

One parent said that there was a distinct change in attitude once their daughter reached transition age.

- *We felt when we went recently there wasn't the same relationship because now she's 18 she shouldn't really be here. The relationship changed. The consultants were like she should be transitioned over. We don't know who we're going to see - it's all a bit vague. (Participant 6)*
- *I got this letter saying 'L is now de-registered from the system' - very cold – it's a cut off that happens overnight (Participant 6)*

Parents felt that their children need more time to recover from the trauma of an operation because their bodies need longer to heal. One mother felt that her son had been discharged too soon and there was not enough aftercare provided on returning home. Many of these young people go through a multitude of operations and there need to be good teams in the background.

- *You don't see anyone to follow you up. We were feeling physically sick at having to move him and he was shaking and distressed. (Participant 2)*

General Practitioner:

Few of them had had to contact their GP while their son/daughter was still with children's services as the level of general health was remarkably good. They had been told that was mainly because the parents cared for their children so well.

Several parents expressed anxiety about having to start using their GP as the main point of contact once their son/daughter reached transition age in order to access specialist services. However they were pleasantly surprised and all but one family had had an overall good experience. They generally had good relationships with receptionists which helped in getting prompt appointments. Only one had any problems and they hope this would be resolved with online bookings. Several said that they felt the GP took the lead from Mums and acknowledged that the parents knew their son/daughter best.

- *They don't have the experience of such a complex young adult and they say 'you know best'. They do listen – they take my lead because they know that we know what she needs. I can book a double appointment – they are very good at getting me an appointment – they know I'm not wasting an appointment. (Participant 6)*

- *Our GP retired and I was apprehensive that we would lose continuity - but whatever work was done behind the scenes – it was fabulous. (Participant 5)*

Adult Services:

Few parents had yet to experience adult hospital services but they were all extremely anxious as will be seen below.

One family's experience is described in the case study already outlined. They all said they could not contemplate anyone else being with their son/daughter and even when they were asked what would happen if they were not available, they could simply not contemplate it.

- *I always do her personal care- that's my biggest fear if she does take ill – someone has to be with her all the time. (Participant 6)*
- *We stay and do all the personal care – all the staff do is the medication – we are supporting the staff but we are the ones needing support because its even more stressful than at home because our son is so unwell. (Participant 5)*

Some said that they wished there could be someone there to support **them** and help explain things.

- *They have a team but I'm on my own – I've got his life in my hands. (Participant 5)*
- *Sometimes I feel it would be quite nice for someone to be there for me. It's hard to take everything in ...it can be quite daunting ...you miss things...important things. It would be good to have some support someone there that knows me and D. (Participant 8)*

Several talked about Communication Passports/Anticipatory Care Plans but commented that they would only be of use if they were actually read – otherwise they were a waste of time.

- *They are going to do a medical passport which is important but in practice people will not read it. It's one of the first things they should read, it's only good if it's used. (Participant 6)*
- *He also has his forms - his anticipated care form - these are our issues- these are the things that might be wrong with him and the checklist of medication so I don't have to go through everything again. It is 3 pages...you allow the doctors to read it first - I let them know it is there. The ambulance can have it. The ACP was done with a nurse and the parents don't have to do much. We have enough to do. (Participant 8)*

One participant told us of an electronic record which can be immediately accessed by an acute setting if their daughter required a hospital admission. This had been put in place by her GP and provided some reassurance.

- *If L needed to be admitted the Key Information Support (KIS) would be activated ...so by the time we got to A&E they should be ready to receive us. We should be seen right away given a side room/electronic bed and medication required.*

The Transition process:

They all had high praise for the transition nurse from the paediatric hospital who had supported, explained things, advised on guardianship, attended meetings with them and helped coordinate things. However, during the discussions about transition meetings there were mixed views as some had found them helpful while others felt that few people from the adult services attended and that they had to find out a lot of information for themselves.

- *Last time I had a transition care nurse and that was so helpful. She stopped everyone and said 'speak one at a time, write it down. How do you feel about that K.? Would that work in your home environment?' It was just awesome - someone outwith the family that knows us both. (Participant 8)*
- *They go on about this big transition meeting but there were not many people from the adult service – I just came away and I don't think the right people were there. (Participant 6)*

In some places there is a lack of clarity over roles and responsibilities regarding transition with parents having to take a lead role in managing the process.

- *You have to organise everything. I have been dealing with the NHS for 16 years*
- *It's taken a whole year. We've had meetings but still have to find out a lot ourselves. We don't get a lot of information. It's a lot of pressure and you're back to square 1. It's a minefield. (Participant 6)*
- *We started 9 months before his birthday but it wasn't long enough – lots of reports to coordinate. (Participant 7)*
- *She was transferred from child to adult services in the space of a week and it is hard to express the contrast in experience. (Participant 1)*

For one of the participants there was a gap between children's and adult services which meant that at 16 years the children's hospital stopped supplying essential equipment with

the community team taking over. They then had to negotiate to get vital supplies needed to care for their son.

- *There was a real problem getting the right equipment. There was a fundamental lack of understanding about what we actually do at home. They offered us things that are not appropriate and it took a couple of years to get 2 stats monitors. Once he turned 18 years the vent team took it on and that has made a huge difference. (Participant 7)*



Figure 4. The views of one parent about the transition to adult services and a hospital admission

Fears

There was palpable anxiety and fear among the parents when talking about transition. The following are some of the things that these parents said:

- *Why does it have to change? (Participant 7)*
- *We don't know who we will see (Participant 2)*
- *There's is a lack of understanding and training about these young people(Participant 7)*
- *I need to be there all the time (Participant 5)*
- *Services get cut overnight (Participant 6)*
- *Transition- I can't put into words what I feel – I find it extremely upsetting to go there in my mind – it's too upsetting Come next year I know it's all going to change so I don't know (Participant 5)*

- *It's a huge concern if he needs to be admitted now – I don't know where they will put him- we don't know the answers yet. (Participant 7)*
- *She could go into a hospital ward and be lying beside someone with dementia and it doesn't sit comfortably with me. I do have a fear- I feel I've already got my guard up. (Participant 6)*
- *Up until he was 16 we were happy with the whole package – rolling along nicely – but suddenly it all changes. The terminology is that the transition from children to adult services is different but what they really mean is it's worse and it's going to be hard! (Participant 7)*
- *Someone somewhere decided we need that level of support [respite when he was a child] but now we don't have it (Participant 7)*

One parent felt that they were seen as demanding and problematic and put it succinctly:

- *We are not problem parents – we are parents with problems (Participant 8)*

What should happen?

We asked all the parents what they thought should happen and this is what they said:

- *If there could be something for 18 – 25 year olds– a ward or something they could move on to. (Participant 6)*
- *Ideally for me health transition should happen at a different time from the transition from school. (Participant 5)*
- *Up until he was 16 we were happy with the whole package – rolling along nicely – but suddenly it all changes. The terminology is that the transition from children to adult services is different but what they really mean is it's worse and it's going to be hard! (Participant 7)*
- *Is it too much to ask for the same provision in adult services as in children's services? (Participant 7)*
- *Doctors need more training about complex needs, there's a lack of knowledge (Participant 6)*
- *We need more respite and emotional support, not less. One team leader suggested that our son go into a home – we had the stuffing kicked out of us. (Participant 5)*
- *Our life is extremely stressful – we really need a hotline to the GP (Participant 5)*

The following is the account of one parent who had decided to take control and manage transition for her son herself. This could be helpful for other parents although it must be acknowledged that not all parents have the energy or resources to do this.

Sheila's story: Participant 8

"We started transition when our son was in school - at 15 - we had 3 meetings for different purposes -hospital to adult services (specialist teams).

I found it daunting so I set up one large meeting so everything is interlinked. We met every 4 months at different places.

I had help from a lovely community nurse at sick kids. We worked together as a team and she helped to coordinate things. She came to the house and spoke to us and she facilitated the meetings. We had 6 meetings in total over 2 years.

It is important to plan what you want to discuss - break it into doable short term and long term aims. The social worker asked us what we wanted for our son; I said go to college, university and a day service where he doesn't sit around and watch TV. Services need to catch up.

Don't give up. Don't be scared. You could have a good service.

A good transition is doable but I might not see everything in my lifetime."

Challenges of project

There were several challenges, the first one being recruitment of young people and parents for this study which delayed the timescale. We were very careful not to put any pressure on families to take part.

Some of the young people suggested for the study did not meet the initial criteria. Some families initially agreed to take part in the study but then had to withdraw for personal reasons. Some felt badly let down by the system and did not have the capacity to relive the experience.

Another challenge was that some of the young people had such severe cognitive impairment that they were not able to use Talking Mats. However, as described above, their parents were particularly keen to be included in the study and for their son/daughter to attempt to use Talking Mats. Wherever possible we modified the use of Talking Mats by using fewer

symbols and only focusing on concrete concepts. At all times we recorded and took note of the nonverbal reactions of the participants.

A third challenge was that some parents were very emotional about the issues involved in transition and were in the midst of dealing with a great deal of complexity. However, they were still determined to give us their time and thoughts as they really wanted their views to be heard.

Discussion

This study captures the complexity and variation of transition services for young people with complex health needs from the perspective of both the young person and their parents. Despite the problems and fears we also saw evidence of good practice and suggestions from families which give hope for the way ahead.

The parents in this study all want to be active participants in the process of transition. Many give up their own employment to facilitate a smooth transition for their children. They are dealing with numerous professionals and some feel that, with the transition to adult services, it is like putting the clock back to the early years when countless agencies were involved. Parents bring a great deal of knowledge and expertise to the process and many had devised their own solutions. There is a great deal of resilience and determination to get the best outcomes for their child. The actual detail of these outcomes are highly individualised and linked to unique environmental and personal factors. However this takes time and energy and there is very little recognition for the work that they do.

Children's hospitals are used to dealing with the significant health care needs of children with complex needs, but most adult units do not have the specialist training or specialist equipment to manage complex mobility needs or healthcare procedures. The staff appear not to be trained to deal with the physical needs of these young people such as involuntary movements, feeding or moving and handling. The general feeling is that parents need to be listened to more as they know their children best. Parents want staff to use their skills and knowledge but to also recognise that parents need support at times of particular crisis, not just off-loading the weight of the personal care onto parents who are already exhausted. The overall feeling was that the paediatric services had, on the whole, worked well but that for those that had experienced the transition to adult services, it had been dramatically worse.

For those who had not yet experienced adult services there was a lot of anxiety and fear that adult services would not be able to provide developmentally appropriate care and indeed lacked the resources and trained staff to maintain and support a smooth transition. Rosie's story illustrates dramatically what can go wrong and highlights the gaps in the process whereas Sheila's story shows that transition can be a more positive experience.

There is still a great deal that needs to be changed and improved. The families in this project have given us clear views about the problems and some thoughtful suggestions for what could be made better. It is often in making small changes that significant improvement can occur. These include:

- Courses for parents on transition
- More specialist nurses e.g. transition nurses, acute liaison learning disability nurses
- Start preparing early – at least 2 years
- Transition wards for young people
- Training for doctors and nurses about complex needs
- More respite, not less
- Emotional support for parents
- Longer appointment times
- A hotline to GPs

Conclusion

The transition from children's to adult services for young people with exceptional needs and their families is complex, multifaceted and fraught with concerns and fears. This study collected the views of a small number of young people and their families who are experiencing this transition in Scotland. For the families that we spoke to, the hope of the Royal College of Physicians of Edinburgh in 2008 that 'the change from paediatric to adult services should be a smooth one so that patients feel informed and in control of their health' has not yet been realised.

Because of the distress experienced by so many of these families we feel a great responsibility to produce a report that will be listened to, that will result in a change to services and that will have a positive outcome, if not for the families in the study, at least for others who will face the same hurdles.

Professor Steve Field, Chief Inspector of Primary Medical Services and Integrated Care) in the Foreword to the Care Quality Commission report said:

“A system-wide change is needed to achieve a joined-up approach....each part of the system at every level, needs to work together ...we have put the interests of a system that is no longer fit for purpose above the interests of the people it is supposed to serve”

We need to be courageous and determined to see change occur. It is easy to make excuses about not having the time, the resources or the skills. Caring for the most vulnerable has to be made a priority and we hope that this small project will go some way in answering the question posed by a father – “*Will anyone listen to us?*”

Acknowledgements

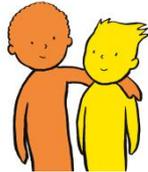
We are extremely grateful to the young people and especially to the parents who gave their time and personal thoughts to us on a subject that was emotional and demanding for them.

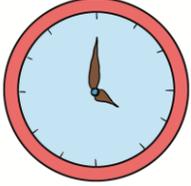
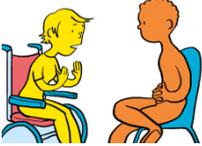
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Appendix 1. Symbol set for CEN

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LABEL	Symbol		
Transitions (overall topic)		Someone with you	
Health Centre/ GP(topic)		Mum	
Hospital (topic)		Dad	
Journey		Brother	
Explanations		Sister	
Phone		Friend	
Communication aid		Carer	

iPad		Dressing	
Time given		Being helped to eat	
Staff		Toilet	
Own things		Brushing hair	
Doctor /GP		Brushing teeth	
Doctor / Hospital		Bathing	
Being listened to		Showering	

Appendix 2. Feedback from Pilot interview conducted 9/12/14

Joan and Margo conducted a pilot interview with Helen (a young woman with complex health care needs now in late 20s) and her mum, Margaret.

We completed 2 Talking Mats with Helen. In the first Talking Mat we asked her how she felt about attending her local Health centre.



Helen was happy about her journey in the car as it is very close to where she stays. She is happy for her carer to come with her to see the GP. She feels she is listened to and the doctor explains things to her. She likes to have her mobile phone with her so she can call her mum.

She put the GP and the staff at the Health centre in the middle of the mat.

Helen was not happy about the length of time she was given for her appointment and would like more time. She was not happy about being undressed and felt “affronted” and had a bit of a “meltdown”

In the 2nd Talking Mat we asked her to think about an experience she had in hospital and tell us how she felt. Helen was a little agitated and anxious as she is going to be going into hospital soon for a procedure. Her mum was reassuring her as we were discussing the issues on the mat.

Helen is very happy to have her mum staying over with her in hospital and likes her dad to visit. She feels happy with the doctors in hospital; they are friendly and nicer than the Health Centre. She wants to have her own things with her especially her phone and her iPad. She feels happy about having a “communication passport” or “All about me” profile with her in hospital.



Helen is anxious about staff assisting her in hospital if she doesn't know them as she is worried they may hurt her. She is unsure about having a bath if assisted by the nurses. Although she feels that things are quite well explained to her, staff don't use pictures to help. She put "being listened to" in the middle of the mat as she needs her mum to be with her.

Helen is unhappy about most aspects of personal care in hospital and wants her mum to do it. This includes: doing her hair; cleaning her teeth; being fed and going to the toilet. She did not like the long journey into hospital. She feels that she is not given enough time.

Margaret commented that transitions can be a time of particular stress and uncertainty for families and emphasised the need to be aware of the distress talking about this may cause.

"There is a danger of meltdown for parents if we ask about transition especially if they are going through or have gone through transition"

Margaret highlighted the challenges of going from a holistic paediatric service to a more fragmented adult service.