

## **The impact of transition on adolescents and their parents**

Dr Jennifer MacDonald

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[Jennifer.macdonald4@nhs.net](mailto:Jennifer.macdonald4@nhs.net)

### **Background**

A working group was organised to investigate the possibility of standardising transitional care for West of Scotland Paediatric Gastroenterology, Hepatology and Nutrition (WoSPGHaN) in the Managed Clinical Network (MCN). It became immediately apparent that different areas throughout the West of Scotland were working to different policies and templates. The working group decided to pull together the current templates and to also consult service-users in order to plan transition optimally across the West of Scotland. This is in-line with a growing body of research which suggests that if transition is planned there are better outcomes for young people in health and disease management.

### **Research Aim**

This research focused on the service-users viewpoints regarding transitional care in the West of Scotland. Our primary aim was to investigate the views of both parents and adolescents both pre- and post- transition within the WoSPGHaN Managed Clinical Network (MCN).

### **Method**

#### **Recruitment and Participants**

Families were identified by the WoSPGHaN Transition Group members as to whether they met the inclusion criteria which required participants to be; fluent in English, age 13-16 years old for pre-transitioning group, age 16-19 years old for post-transition group, and a parent/guardian of young person for either parent group. In addition, the young people must be part of one of four speciality areas; inflammatory bowel disease, liver, nutrition and coeliac services within WoSPGHaN. We endeavoured to approach participants from diverse backgrounds and across the managed clinical network regions.

The WoSPGHaN Transition Group members asked potential participants to consider partaking in this research study either via telephone or in person. If verbal consent was obtained, all participants were sent a doodle poll to select days which were suitable. From this, two dates were chosen, based on the maximum number of participants who could attend.

Written consent forms were obtained from both the adolescents and their parents prior to taking part in the research. A copy of the consent forms can be seen in Appendix 1a and 1b.

Participants were assigned to one of four groups based on their age and stage in the transition process:

- 1) **Pre-transition adolescents (Age 13-16)**  
4 participants, White, 2 males: 2 females
- 2) **Post-transition adolescents (Age 16-19)**  
3 participants, White, 2 males: 1 female
- 3) **Pre-transition parents/guardians**  
6 participants, White, 3males: 3 females
- 4) **Post-transition parents/guardians**  
2 participants, White, 2 females

We were aiming for small focus groups of 4-6 people, but due to young person/family commitments our numbers were smaller than intended as revealed above.

## **Design**

Two focus groups were run in tandem on two separate occasions, i.e. adolescent and parent sessions. There were two facilitators and a scribe for each group. Prior to the focus group commencing, the WoSPGHaN working group had met and developed interview prompt sheets for use by each facilitator during the groups. These prompt sheets were not prescriptive in their nature, their main purpose was to guide the interviewer and provide prompts, without explicitly controlling the direction of the interview. A copy of the interview prompt sheets can be seen in Appendix 2a-d.

The focus groups were conducted at the Campanile Hotel, Glasgow in private conference rooms. The interviews lasted between 45 and 60 minutes, were hand scribed and anonymised for reference to person or place prior to analysis. Following the focus groups, there was a group dinner which was attended by all involved.

## **Data Analysis**

Thematic Analysis was employed to analyse this data. The six phase process as described by Braum and Clarke (2006) was followed (summarised in Table 1). This enabled the researcher to identify recurrent themes by gaining an insider's perspective of the participants' individual experiences.

Stage	Thematic Analysis: Description
1	Familiarising yourself with the data
2	Generating Initial Codes
3	Searching for themes
4	Reviewing themes
5	Defining and naming themes
6	Producing the report

Table 1: Six-stage analytical procedure

## **Results**

Throughout the interviews, the participants did not appear distressed by the content; in fact, many of them commented that they had enjoyed the experience. It seemed that partaking in this research study activated a process of reflection for most participants, where they seemed to be developing their own personal story about their experiences. This led to the emergence of a number of themes, many of which were recounted by multiple participants. The results have lent themselves to be divided into an overall super-ordinate theme, and then emergent themes within each group.

### **Super-ordinate theme**

Both participants and parents alike identified that there were common factors involved when considering if an adolescent is ready for transition to adult services. These were as follows:

- i. *'Maturity'*. This includes the adolescent having an understanding of their condition and actively engaging in hospital consultations.
- ii. A concept that the adolescent has moved on from children's services and *'outgrown'* them.
- iii. Adolescents *age*. This was stated as being age 14 years old minimum.
- iv. Individual basis – depends on *developmental* stage

### **Pre-Transition Adolescents: 'outgrown children's services'**

The majority of pre-transition adolescents identified that they felt they had 'outgrown children's services'. This gave rise to three sub-themes: (i) physically outgrown services, (ii) emotionally outgrown services and (iii) mentally outgrown services.

#### **i. Physically outgrown services**

Adolescents indicated that they felt physically too old for children's services, commenting on the bed size and atmosphere of the wards as examples.

*"There was a lot of screaming from young children and I found the beds too uncomfortable – outgrown them".*

## ii. Emotionally outgrown services

Adolescents reported that emotionally they felt the children's service was not geared for them, citing examples such as the constant repetition of young cartoon television programs and the expectation that their parent would stay the night.

*"The only thing that was on tv in the ward for six days was Peppa Pig"*

## iii. Mentally outgrown services

Adolescents stated that they felt mentally undermined by children's services.

*"They still give you children's plasters in clinic".*

*"If you are at an appointment at clinic waiting for important results or getting an important test, but is hard to keep yourself calm when there are lots of young children running around laughing".*

However, some adolescents did report **worries/fears about moving** to Adult Services.

*"Adult services will be a lot quieter and calmer, although you will need to wait longer for an appointment".*

*"They would treat you like an adult and you might not know what they are talking about"*

*"they will not care in adult services"*

## Post-Transition Adolescents

### Theme 1: Outgrown Children's Services

The theme portrayed by the pre-transition adolescents of having 'outgrown children's services' was similarly replicated by most of those in the post-transition adolescent group. They reported similar issues as indicated by the following quotes:

*"ready to go"*

*"I felt mollycoddled in Yorkhill"*

In fact they appeared to have formed an overall positive reaction to adult services and when asked what they would tell those adolescents who are yet to transition, they all said similar ideas such as:

*"don't worry"*

*"You will adapt quickly. Don't freak out! It seems a big deal but it really isn't".*

However, they noted an interesting additional theme over and above their own feelings, that of parental reluctance.

## **Theme 2: Parental Reluctance**

It seemed that the adolescents felt that their parents were often not ready for the change in responsibility which came with moving to adult services.

*"I was ready to move on but my parent's weren't"*

*"Its easier for parents to come into the consultation at Yorkhill and they feel its difficult to come into a consultation in adult services as they want to lead the consultation".*

### **Pre-Transition Parents**

#### **Theme 1: Loss**

A common theme replicated throughout the testimonials of the pre-transition parents, was that of a feeling of 'loss'. This gave rise to two sub-themes: (i) loss of support and (ii) loss of trust in services.

##### **i. Loss of support**

Parents reported that they worried that when their child moved to adult services, they would receive a lot less support and advice to the detriment of their health.

*"If we have any problems we can contact Yorkhill for advice and I feel access to advice and support may suddenly stop when transition is complete"*

*"Mental health support is not available in adult services"*

##### **ii. Loss of trust in services**

Secondly, parents reported that they were worried that they would not be able to trust the adult services to care for their child optimally.

*"getting lost in the system due to staffing issues"*

*"Adult services may not go that extra length into researching other drugs that may be beneficial for my child".*

### **Theme 2: Anxiety**

The second theme to arise from the pre-transition parents reports was that of underlying anxiety regarding moving to adult services. Two sub-themes emerged from the data; (i) anxiety regarding increased independence of their child and (ii) anxiety regarding expectations of adult services.

##### **i. Anxiety regarding increased independence of their child**

The majority of parents reported that they were worried about 'letting go' and allowing for increased independence.

*"Its hard for parents to let go and let their child take charge of their condition"*

*They may "miss something during the consultation".*

## ii. **Anxiety regarding expectations of adult services**

In addition, parents were worried about their low expectations of adult services and their negative perspective of the adult services was voiced by many.

*"Adult services are brutal compared to children's services".*

*"We are preparing for adult services but adult services are not preparing for us".*

*"Nerve-wracking"*

## **Post-Transition Parents: Parental Concern**

Within the post-transition parents, there was a coherent reporting of parental concern regarding adult services. This was displayed in worries regarding the increased reliance on the child's ability to be independent within adult services and also through experiences where they have perceived a lack of adequate support. The overarching message was that they were struggling within adult services and would return to children's services if they had the opportunity.

### i. **Lack of confidence in adolescent's ability**

*"when child goes into the consultation and gets all the questions asked she just zones out"*

*"when you ask your child how appointment went, they reply all is well and to keep taking their medication".*

### ii. **Less support**

*I "called nurse [in Adult Hospital] three days in a row and left messages. There was no response... went to A&E and did not have a good experience - was told to sit in the room but not to say anything".*

*"When you phone they don't always get back to you. In RHSC you always got a response".*

## **Conclusion**

This study is an exploration of the impact that transitioning to adult services within WoSPGHaN can have on young people and their parents. The results convey an overarching message that adolescents report feeling ready and more prepared for transition, however their parents are struggling before, during and after the transition process is completed.

## **Suggestions to improve the transition process**

It is apparent that adolescents feel well prepared for transition, and they suggested the following considerations to improve upon the process. It should be noted that some of these suggestions already occur in certain regions throughout the West of Scotland.

- Treating you more 'adult-like' – encouraging individual attendance to 'get used to it'
- Patient appointment cards

- Encouraging adolescent to take own notes when with the Doctor
- Not drawing too much attention to transition (e.g. family day not focusing on transition)
- Time to discuss the language they might encounter in adult services (e.g. results and terminology)

Furthermore, parents both pre- and post- transition suggested the following considerations:

- Peer support network for parents
- Parents remaining involved in adult services – flexibility?
- Family day focusing on transition
- Trip to visit adult hospital/wards and meet key members of staff
- Leaflets with contact information details for adult services

**Finally, there were some themes that both the adolescents and parents suggested: -**

- Joint clinic meetings: Adult clinicians attending child appointments
- Gradual introduction of transition with multiple transition appointments
- Professionals having more specific knowledge of adult services (e.g. visiting times, appointment gaps, what to expect)

### **Implications for clinical practice**

The findings from this study provide some unique insights into the personal experiences of young people and their parents who are in the transition process. It is from this that we can extrapolate and consider both the clinical implications and recommendations for healthcare professionals involved in their care.

Firstly, we should consider incorporating some of the adolescent and parent suggestions into the guidelines which are being developed by the WoSPGHaN working group. In particular, it would be prudent to explore possibilities to increase adolescent independence skills, to not only support the adolescent but to also allay parental fears. For example, the use of 'voice training' for the young people to become more articulate and to learn some of the medical terminology. Secondly, it would be helpful to have more joined up communication with our adult colleagues, and look to develop a standardised leaflets on the specifics regarding the hospital the young person is transitioning too.

It should be noted that adolescents and parents reported wanting different things from family days and this should be taken into account when devising future agendas. For example, parents should have a focus on transition but adolescents should not.

## **Limitations**

This study could have been improved by a larger sample size in each group, incorporating a more equal distribution of age, ethnicity and gender. Further, participants who were not fluent in English were excluded from this study which may impact the generalisability of the results. Finally, the use of a hand-scribe throughout the focus groups was required due to time pressures; however this has its limitations and may have subjectively influenced the results. Any future research should look to employ audio/video recording and verbatim transcription.

**Appendix 1a: Participant Consent Form**

**Transition Focus Group**

**Participant Consent Form**

**Please initial the BOX**

I confirm that I have been informed about this focus group and have had the opportunity to ask questions

I understand that I do not have to take part in this study. It is my choice and I can stop at any time, without giving a reason and that this will not affect any part of my care.

I am aware that the summary points from the focus group will be recorded by a member of the group in written format, and only used for the purposes of the study, to support transition guidelines.

I understand that all names, places and anything that could identify me will be removed and nothing that identifies me will appear for others to see.

I agree to take part in the study

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Name of Participant

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Date

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Signature

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Name of Clinician

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Date

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Signature

**Appendix 1b: Parent Consent Form**

**Transition Focus Group**

**Parent/Guardian Consent Form**

**Please initial the BOX**

**Please initial box**

I confirm that I have been informed about this focus group and have had the opportunity to ask questions

I understand that this is voluntary and my child or I can withdraw at any time, without giving a reason and that this will not affect any aspect of their care.

I am aware that the summary points from the focus group will be recorded by a member of the group in written format, and only used for the purposes of the study, to support transition guidelines.

I understand that all names, places and anything that could identify my child or me will be removed and nothing that identifies my child will appear for others to see.

I agree to my child and myself taking part in the above study

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Name of Participant

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Date

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Signature

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Name of Clinician

-----  
Date

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Signature

## **Appendix 2a: Pre-transition adolescents Interview Prompt Sheet**

- 1) Do you know what transition is?
- 2) How do you feel about coming to Yorkhill children's hospital? e.g. Is it ok being surrounded by younger children? Is it age appropriate?
- 3) How do you feel about being in the clinic waiting room and/or ward with other younger children?
- 4) What do you think is different between child and adult hospitals? e.g. Clientele, Expectations, Support
- 5) What are your worries/concerns about moving to an adult service? e.g. Not knowing anyone, getting lost, less support.
- 6) What would you like to know before moving to adult services? e.g. Where hospital is, who is named consultant/nurse, any differences?
- 7) How do you feel about talking to Health Professionals on your own? (e.g Doctors Nurses, Dieticians) Have you done this?
- 8) Has transition been mentioned and/or discussed yet? If so, how? Was information provided?
- 9) How do you think teams decide that you are ready to be transitioned to adult services? e.g. Age? Maturity?
- 10) How do you feel about your parents/guardians not coming into your appointments with you? e.g. worried, happy, relieved, scared
- 11) What would make it easier to transition to adult services? e.g. length of time, meeting new team earlier or more frequently, attending a clinic with only others who are transitioning?
- 12) Do you think there are things you would like to talk more about in child services? e.g. sex, alcohol, condition, meeting others, support?

## **Appendix 2b:**

### **Pre-transition parent Interview Prompt Sheet**

- 1) What does transition mean to you?
- 2) Has your child started / or been through the transition process?
- 3) How do you and your child feel about coming to Yorkhill children's hospital? e.g. Is it ok being surrounded by younger children? Is it age appropriate?
- 4) How do you and your child feel about being in the clinic waiting room and/or ward with other younger children?
- 5) What do you think is different between child and adult hospitals? e.g. clientele, expectations, support
- 6) Have you or your child any worries or concerns about moving to an adult service? e.g. Not knowing anyone, getting lost, less support
- 7) What would have been helpful to know before moving to adult services? e.g. Where hospital is, who is named consultant/nurse, any differences?
- 8) How do you feel about your child talking to Doctors and Nurses on their own?
- 9) What has been helpful/unhelpful about discussions about transition? e.g. Was information provided?
- 10) How do you think teams decide that your child is ready to be transitioned to adult services? e.g. Age? Maturity?
- 11) What would make it easier to transition to adult services? e.g. length of time, meeting new team earlier or more frequently, attending a clinic with only others who are transitioning?
- 12) Do you think there are things you would like to talk more about in child services? e.g. sex, alcohol, condition, meeting others, support?
- 13) Did you access any other supports during transition? e.g. meeting other parents with children/YP with same condition, attending a support group?
- 14) Do you feel you are/you were included in the transition process?

## **Appendix 2c:**

### **Post-transition Adolescent Interview Prompt Sheet**

- 1) Do you know what transition is?
- 2) Have you gone through the transition process?
- 3) How did you feel about coming to Yorkhill children's hospital? e.g. Was it ok being surrounded by younger children? Was it age appropriate?
- 4) How did you feel about being in the clinic waiting room and/or ward with other younger children?
- 5) What do you think is different between child and adult hospitals? e.g. clientele, expectations, support
- 6) Have you or did you have any worries/concerns about moving to an adult service? e.g. Not knowing anyone, getting lost, less support
- 7) What would have been helpful to know before moving to adult services? e.g. Where hospital is, who is named consultant/nurse, any differences?
- 8) How do you now feel about talking to Health Professionals on your own? (e.g. Doctors Nurses, Dieticians)
- 9) Do you do this?
- 10) Did anyone talk to you about transition? e.g. parents, health professional
- 11) What did you find helpful/unhelpful regarding transition? e.g. Was information provided?
- 12) From someone who has been through the process, of moving to adult services, how do you think we can tell when someone is ready to transition to adult services? e.g. Age? Maturity?
- 13) How do you feel about your parents/guardians not coming into your appointments with you? e.g. worried, happy, relieved, scared
- 14) What would make it easier to transition to adult services? e.g. length of time, meeting new team earlier or more frequently, attending a clinic with only others who are transitioning?
- 15) Do you think there are things you would have liked the opportunity to talk about in child services? e.g. sex, alcohol, condition, meeting others, support?
- 16) Did/do you access any other supports when you were moving to adult services? e.g. Meeting an older person who has your condition, attending a support group, talking to support networks on the phone/internet?

## **Appendix 2d:**

### **Post-transition Parent Interview Prompt Sheet**

- 1) What does transition mean to you?
- 2) Has your child started / or been through the transition process?
- 3) How do you and your child feel about coming to Yorkhill children's hospital? e.g. Is it ok being surrounded by younger children? Is it age appropriate?
- 4) How do you and your child feel about being in the clinic waiting room and/or ward with other younger children?
- 5) What do you think is different between child and adult hospitals? e.g. clientele, expectations, support
- 6) Have you or your child any worries or concerns about moving to an adult service? e.g. Not knowing anyone, getting lost, less support
- 7) What would have been helpful to know before moving to adult services? e.g. Where hospital is, who is named consultant/nurse, any differences?
- 8) How do you feel about your child talking to Doctors and Nurses on their own?
- 9) What has been helpful/unhelpful about discussions about transition? e.g. Was information provided?
- 10) How do you think teams decide that your child is ready to be transitioned to adult services? e.g. Age? Maturity?
- 11) What would make it easier to transition to adult services? e.g. length of time, meeting new team earlier or more frequently, attending a clinic with only others who are transitioning?
- 12) Do you think there are things you would like to talk more about in child services? e.g. sex, alcohol, condition, meeting others, support?
- 13) Did you access any other supports during transition? e.g. Meeting other parents with children/YP with same condition, attending a support group?
- 14) Do you feel you are/you were included in the transition process?