



Evaluating Young People's Experiences Of Transitioning In Local Health Services in Leicester

Report

Young Advisors Leicester



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Summary

Between June and September 2017, Young Advisors Leicester (YAL) were asked to consult young people on their opinions and experiences of transitioning from children to adults local health services by Healthwatch Leicester. YAL then developed questionnaires for pre and post transition; as well as for parents and guardians on paper and online which were used to retrieve information from our partner organisations and young people in general. YAL also devised pre and post transition focus group plans which were undertaken with local young people's groups. The YAL consulted over 30 young people from the ages of 13-22 to gain an insight into their healthcare experiences.

Over the last four months, YAL spoke to young people's groups such as the Big Mouth Forum to gain a better understanding of young people's experiences. From all the data that was collected via focus groups and questionnaires, YAL were able to identify the following main themes:

1. Clarity of transitioning age
2. Transitional plans
3. Access to a transitional worker
4. User Involvement

Methodology

YAL were given a full mandate in the way in which they conducted their research. It was agreed that the best way forward would be to turn the paper questionnaire into an online version which is more accessible and can be used by a wider range of young people.

YAL also held a large consultation of young people mainly comprising of young people involved in the Young People's Council who represent all young people in the city and also the Big Mouth Forum, which is a support group for disabled young people and the Children in Care Council. This allowed the YAL to speak to frequent users of healthcare services and collect anecdotal information which is included later in the report.

Throughout the collection of data, our colleagues at Healthwatch were consulted to ensure YAL stayed on track and sought out the right type of data.

Summary of Findings

Clarity of transitioning age

Young People were asked whether they firstly understood the term ‘transitioning’ and at what age this actually happened for the health services that they use. From our focus groups, it was clear that 80% of young people did not understand the term transitioning, some got it confused with social care.

YAL tried to dig deeper to find out what the official transitioning age is within the NHS and various other health services; however there was no concrete age available for YAL to use as a benchmark. It seems that the majority of health services did transition at 18; with plans coming into place between 16 and 17 years old; however, some of the most important services such as Accidents & Emergencies, young people transition at 16 years old.

Transition plans

Young People were asked whether they firstly were aware of their own transition plan and if they knew what a transition plan was used for.

From both the focus groups and questionnaires, 85% of young people were very quick to state that they did not know what a transitional plan is, what it is used for or when they should start creating one.

A further 64% of young people who were consulted did not know what happens during the transitional stage and many did not even hazard a guess as to what it might entail. From the conversations and anecdotal data we collected, it can be concluded that young people were wary about transitioning and saw it as a very daunting task; another case of ‘fear of the unknown’.

Access to a transitioning worker

Much to YAL’s surprise, only 20% of young people consulted knew of a named worker that they were engaging with when they accessed their particular health services. The majority of young people did not know what a named worker/transitioning worker was what they were supposed to do and how they are useful. From the 20% of young people who had named workers, the majority scored their workers 2-3/5 on the scale provided, with some going as low as 0. This does seem to show that the named workers who are trying to help young people transition are not satisfying the needs of the young people fully.

User involvement

The final part of the questionnaire and focus groups focussed around young people's opinions of the health services they are currently getting and how they would improve them. From the data that was consulted, the biggest issue that stood out with an overwhelming 85% of young people mentioning a lack of user involvement in both children's and adult's health services.

Some of the comments that we collected included:

"I want to have more of a say in the process of my healthcare"

"I want the professionals to stop talking to my mum instead of me"

"I want to be regularly updated with information from my workers or professionals"

These comments show young people who are eager to be transitioning into adult services and searching for autonomy over their healthcare, however this is not the case everywhere as there were also many young people who felt safe and secure with their parents still being consulted and involved in the process of their healthcare. Clearly, the range of opinions and ideas within young people calls for a more active and flexible policy.

Recommendations

YAL asked for suggestions in ways to improve healthcare services in Leicester at the consultation event and these suggestions can be found below.

Transitional plan:

YAL consulted young people on what they wish to be in a transitional plan, as many did not what was included in one. Below are listed some of the suggestions that young people included in this activity. Appendix 4 shows the more detailed suggestions and recommendations.

- **Detailed explanation of the difference between child and adult services**
- **Contact information for their workers and other useful services in their transitional plans**
- **Information on how to look for a doctor/GP or other professional in their service**
- **Information about their workers within their plan**
- **To be assigned to the same worker despite any geographical changes**
- **Direct involvement in their plan and treatment**
- **Having medical terms defined and explained to them**
- **Direct say and involvement in actually generating their care/transitional plan**

Transitional workers:

From our research, it has become clear that the majority of young people do not have or know about transitional workers. YAL recommend that Healthwatch, Leicester City Council & the NHS work together to provide more information for young people who are coming up to 16 years old about transitioning, the allocation of workers and a full plan. It would be ideal for these organisations to provide young people with roadmaps that explain the full process of transitioning in a clear and concise manner as well as making it accessible online and physically.

Transitioning age:

The uncertainty around the official age of transitioning is a problem that will continue to disrupt transitioning and health services for the foreseeable future. However, to remedy this, YAL suggest that individual health services clearly state and circulate their specific transitioning age and start the transitioning process with appropriate time.

User Involvement:

User involvement is a key aspect to any service, especially health services. As young people transition to adult services, they are expected to have more autonomy over their conditions

and experience. Due to this, involving young people in every part of their treatment and experience and from the research undertaken by YAL, it can be suggested that through improvements regarding workers and plans, user involvement will automatically become part of the transitioning process.

Action Points

YAL would recommend the following action points.

- **Improve, circulate and use transition plans for young people**
- **Clarify transitioning age between health services**
- **Consult young people on how best to increase user involvement**
- **Clarify the role of workers and how they are allocated**

YAL would recommend further discussion on these points and how to act upon them.

Appendices

Appendix 1: Questionnaire (Pre-Transition)

Age:

Gender:

Postcode (First 3 letters):

Type of service(s):

1. Do you have a named worker?

Yes

No

Don't Know

2. On a scale of 1 to 5 (1 being very inconsistent and 5 being very consistent), how effective do you think your worker has been?

1

2

3

4

5

3. Do you know what a transitional plan is?

Yes

No

Don't Know

4. Do you know what happens during the transitional stage? / What do you think happens?

5. Do you have any expectations for the transition? If so, what are they?

6. What do you currently like about the service you are getting?

7. What things would you change about the service you are getting?

8. Do you have any additional comments?

Appendix 2: Questionnaire (Post-Transition)

Age:

Gender:

Postcode (First 3 letters):

Type of service(s):

1. Do you have a named worker?

Yes

No

Don't Know

2. On a scale of 1 to 5 (1 being very inconsistent and 5 being very consistent), how consistent do you think your worker has been?

1

2

3

4

5

3. Are you aware of your transitional plan?

Yes

No

Don't Know

4. If yes, on a scale of 1 to 5 (1 being very unhelpful and 5 being very helpful), how helpful do you think your transitional plan has been?

1

2

3

4

5

5. Why have you given the above rating?

6. On a scale of 1 to 5 (1 being the worst and 5 being the best), how would you rate your current service?

1 2 3 4 5

7. What is working well with your current service?

8. What changes would you make to your current service?

9. Which service do you prefer overall, your current service or your previous service? Why do you feel this way?

10. Is there anything you would have changed about your previous service?

11. Which service do you think caters better to your needs?

12. What advice would you give to anyone experiencing the transition process?

13. Do you have any additional comments?

Appendix 3: Questionnaire (Parents/Carers)

Age of child:

Gender of child:

Postcode (First 3 letters):

Type of service(s):

1. Does your child have a named worker?

Yes

No

Don't Know

2. On a scale of 1 to 5 (1 being very ineffective and 5 being very effective), how effective do you believe your child's named worker has been in supporting both you and your child through the transition process?

1

2

3

4

5

3. Are you aware of your child's transitional plan?

Yes

No

Don't Know

4. On a scale of 1 to 5 (1 being very unhelpful and 5 being very helpful), how helpful has this been or how helpful do you expect it will be for your child's transition process?

1

2

3

4

5

5. On a scale of 1 to 5 (1 being not involved at all and 5 being very involved), how involved do you think you have been in your child's transition process?

1

2

3

4

5

6. How has your involvement changed or how do you expect it will change after the transition process?

7. Do you think your child's needs and feelings have been taken into consideration during the transition process?

8. Do you feel that you have been fully informed about what the transition process entails?

9. What do you feel worked well with the transition process?

10. What would you change about the transition process?

11. Do you have any additional comments?

Appendix 4: Transitional Plan Activity

Appendix 5: Hopes & Fears Activity

Hopes	Fears
Gives enough support	Not being given enough understanding about their condition and treatment
Given enough understanding and knowledge to deal with their treatment themselves as well (e.g. taking medicine)	Having unhelpful staff, making the procedure frightening
Friendly and open workers who have a direct dialogue with the child	Fears of losing the care of their parents once they become independent adults
Being treated seriously by staff	