

# Transition from Children's to Adult Specialist Health Care Services for Young People with Neurodevelopmental Conditions: A Qualitative Study Exploring Personal Experiences

## INTRODUCTION

- As health care professionals providing adult neurodevelopmental services, we noticed recurrent problems young people transitioning from children's to adult health care services.
- Transition can be extremely stressful for young people with neurodevelopmental conditions.
- Poor transition can lead to negative health, social and educational outcomes.
- Previous research has attributed negative transition experiences to: lack of information about adult services, lack of specialist services, inconsistent transition protocols and lack of a holistic approach.
- Our research includes qualitative evidence from young people and their families who have experienced transition – this is lacking in previous research.

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## METHOD

- 10 semi-structured interviews with young people with ADHD, Autism or Intellectual Disability (ID).
- 6 young people and 11 family members were interviewed.
- Parents were interviewed on behalf of young people if they were unable to communicate effectively with the researchers themselves.
- Data analysed using Interpretative Phenomenological Analysis (IPA).

Table 1. Participant characteristics

ID	Age	Gender	ADHD?	Autism?	ID?	Severity of ID
1	23	F			•	Moderate
2	19	M	•	•		N/A
3	21	M		•	•	Severe
4	20	F			•	Moderate
5	18	M		•	•	Moderate
6	18	M			•	Moderate
7	18	F	•			N/A
8	20	F			•	Moderate
9	24	M		•	•	Severe
10	18	M	•	•	•	Mild

## RESULTS

Theme	Sub-Theme
<b>1. Parents as advocates</b>	1a. Parent's taking responsibility for young person's care
	1b. Young person's awareness of transition
<b>2. Availability of adult's health and social care services</b>	2a. Eligibility criteria and availability of services
	2b. Opportunities for young people to socialise
	2c. Seeking private health care support as a result of lack of availability
<b>3. Lack of information sharing</b>	3a. Don't know where to get help and what support is on offer
	3b. Help doesn't come to you, you have to search for it
<b>4. Transition as a binary, abrupt change</b>	4a. Second transitions when education ends

1a

"My experience is, if you as a parent aren't pro-actor, in planning for the next step, the next step just ends up being a train crash because the statutory agencies don't wake up to it"

1b

"I think they did tell us [about transition] but I wasn't really aware. They probably told mum and dad"

2a

"She [children's services] didn't think that I would qualify for them because the requirements are quite sort of stringent to get into adult mental health services"

2b

"The main problem is they're too isolated"

2c

"I've had to go privately and I am going to maintain seeing somebody there now. Only because I have concerns"

3a

"I don't even know where they [adult's services] are. I haven't got a clue, I don't know where they are based, I dunno what, you know, I don't know what disciplines there are in that team, I have no idea"

3b

"We have to find where to go and who to come and talk to and how to organise all this stuff"

4

"Very much, right you are going to be an adult now and yeah, that was it. There was no sort of, how can I say, smoothing. No sort of, no value added to what that transition meant"

4a

"My fear would be what happens to him when he comes out of college and where does he go and who looks after him"

## DISCUSSION AND CONCLUSIONS

- Parents play an important coordination role in transition and take a lot of responsibility in organising their children's care.
- Commissioners should consider a 'transition period' in which young adult's with neurodevelopmental conditions can access health care services from either children's or adult services (e.g. 16 to 20yrs).
- NICE guidance and appropriated policies should be reviewed as health inequalities have been highlighted.
- Future research:
  - Service evaluation of implementing a 'transition period' including perspectives of health care professionals perceived barriers and facilitators for change.
  - Research to understand the service provision gap for those young people who are unable to rely on their parents for support during transition.

