WellChild
the national charity for sick children

# Survey Results

Young People's experience of transition to adults services

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## Young People's experience of transition to adult services

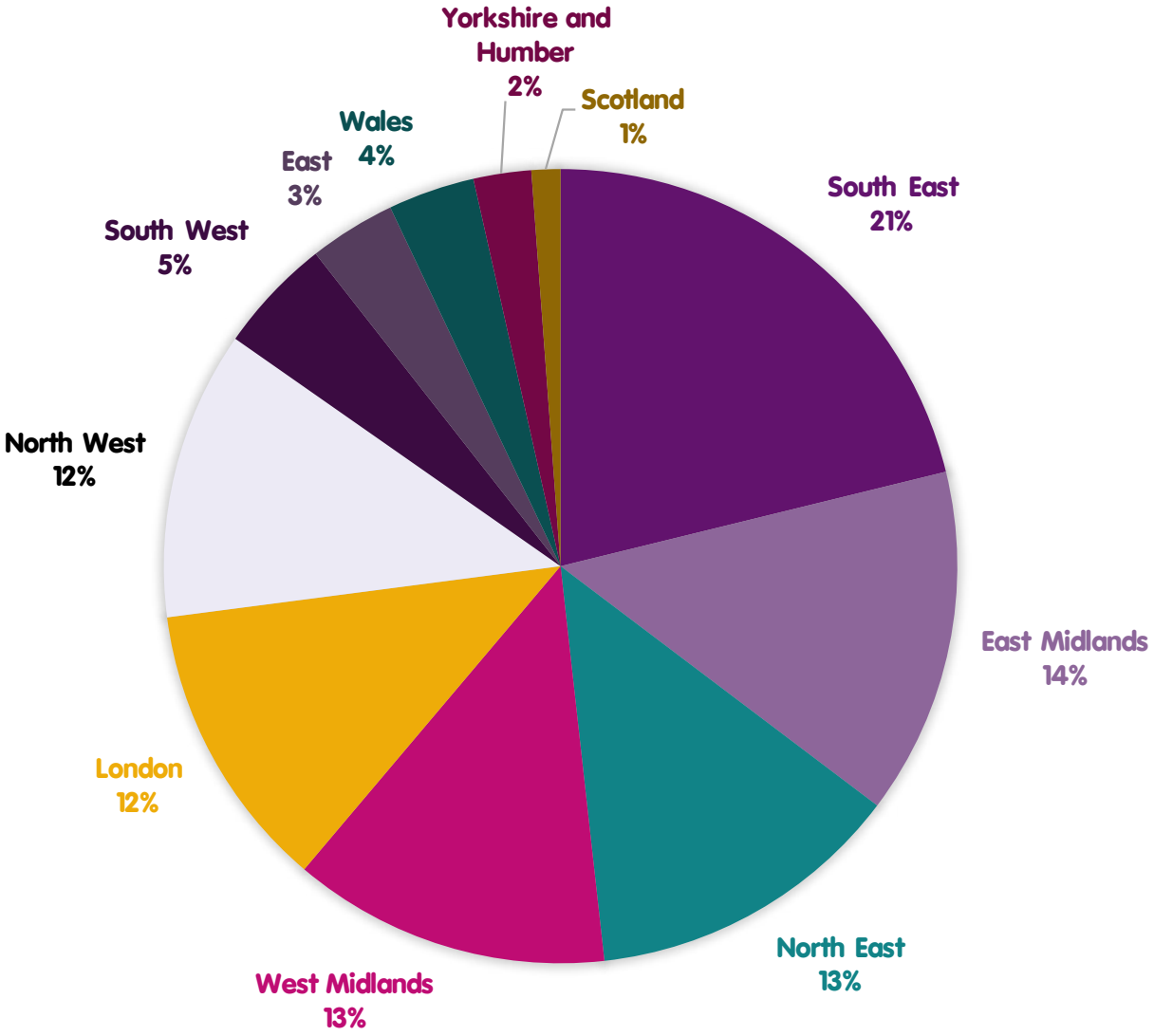
Preparing for adulthood is an important time in a young person's life when they should be planning for their future. In health services, this is called transition and includes the preparation, transfer and settling into adult services. WellChild were interested to hear more from young people and families who are either currently going through the transition process, or those who have already transferred to adult services. This survey was designed to be completed on behalf of the young person (YP) with support from a parent or carer if needed, or by the young person themselves if appropriate. As such, the questions were asked from the young person's perspective but could be answered by the parent/carer where required.

The survey is split into two sections. The first section asks questions about the transition process itself and what support was received by the young person. The second section had questions on experiences of transition including what worked well and what could be improved for others going through the process in future.

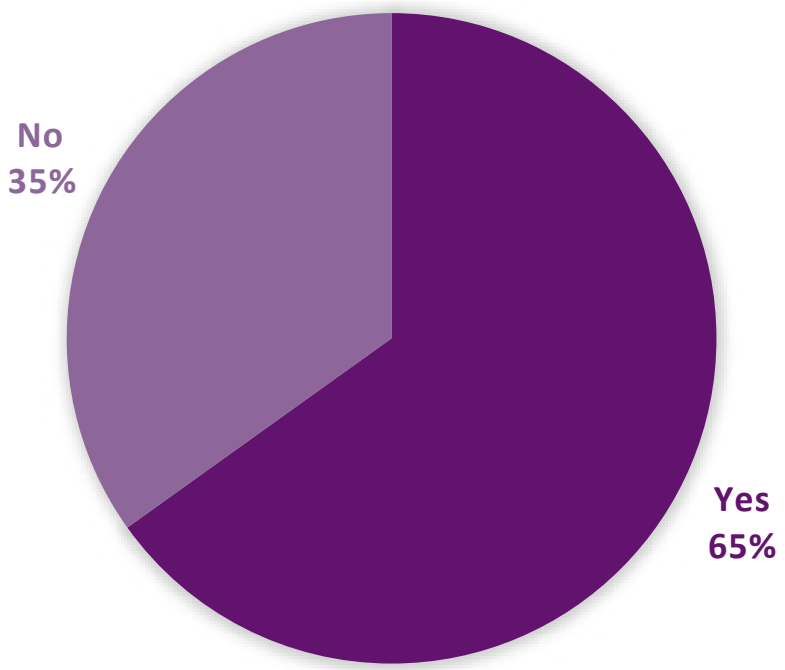
### Respondent details:

We had 86 relevant responses.

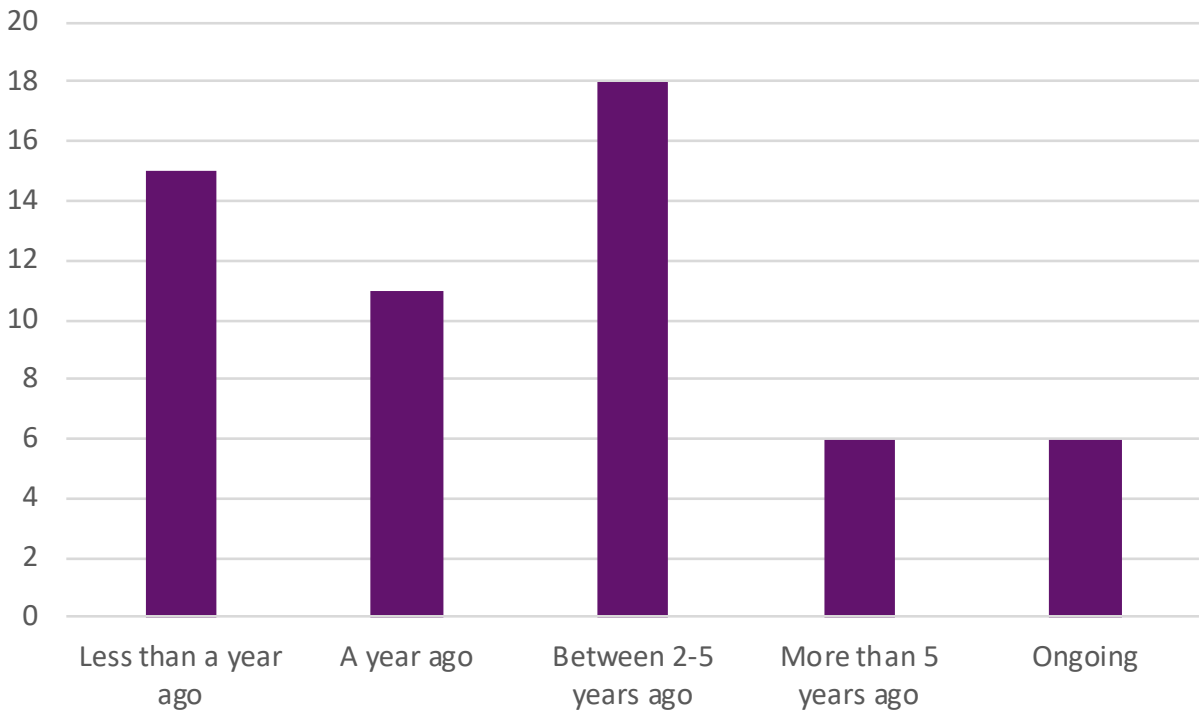
### Responses by region:



## Has the young person already transferred to Adult services?

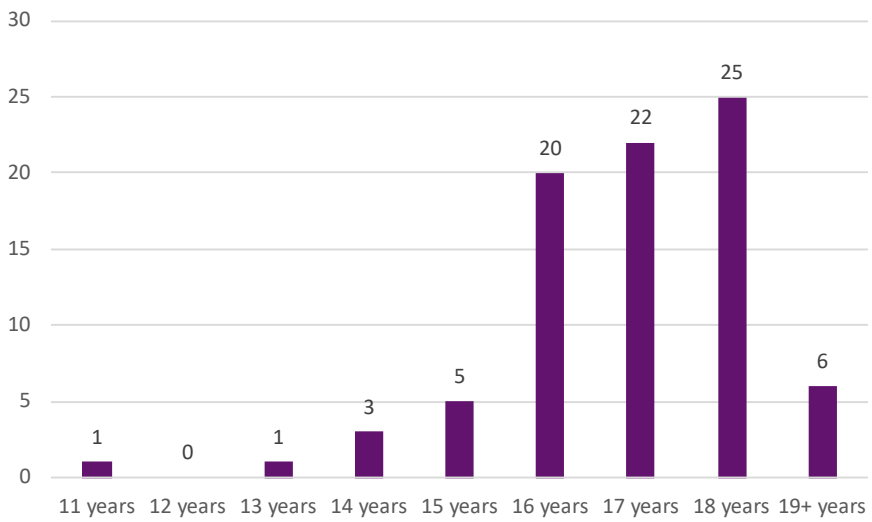



## If yes, how long ago did the young person transfer to Adult services?

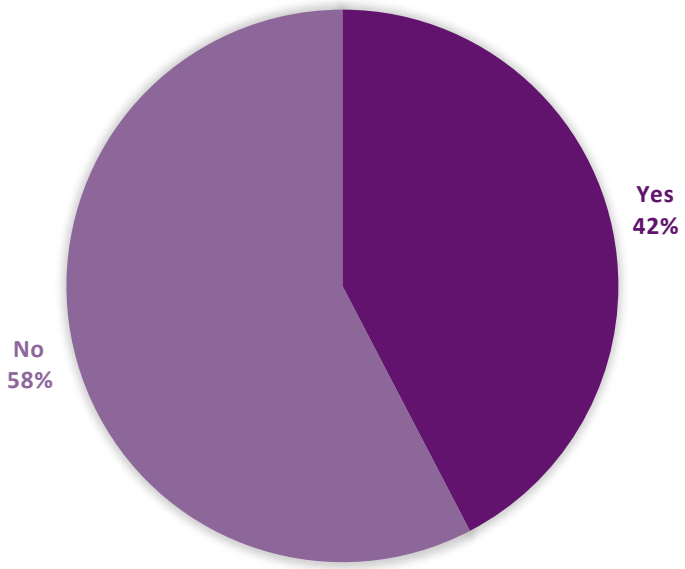


# Section 1 – The Transition Process

## Q1- What age did transition planning start?




## Q2- In your opinion, did the transition planning start at the right/appropriate time for the young person?



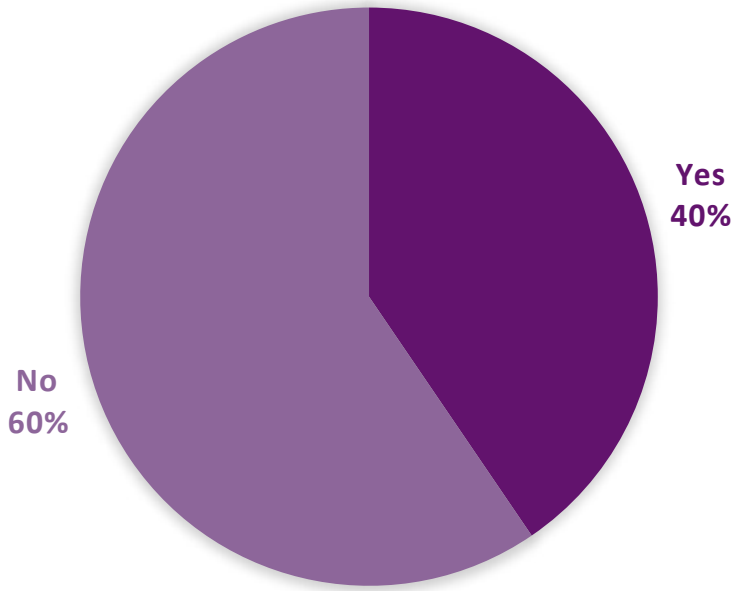

## Q2A- Comments

| Key Themes | Number of Responses |
|---|---|
| Starts too late leaving YP and parents unprepared for adult services which has a negative impact on YP. | 19 |
| Lack of awareness and engagement from professionals. Differences between health and social care, and between specialities. | 13 |
| Transition planning not happening - being dumped into adult services for which they are not prepared. | 13 |
| No pathway for some. Specific gap between aged 16-18 e.g. new diagnosis, and also for those with undiagnosed conditions. | 6 |
| Lack of or inadequate communication and information available. | 6 |

## Q2A- Quotes:

- "It should have started much earlier, which I believe it now does to help families get used the idea over a few years"
- "Lack of communication between different trusts and areas of care lead to breakdown in care"
- "Transitioning should start younger and they should start to treat you the same as they will in adults so it isn't a BIG shock"
- "Health transition planning started at 14. Social care however is trailing far far behind. It hasn't really started and we are 17 now"
- "We really had no planning just thrown into a jungle where everything conflicts and doubles"

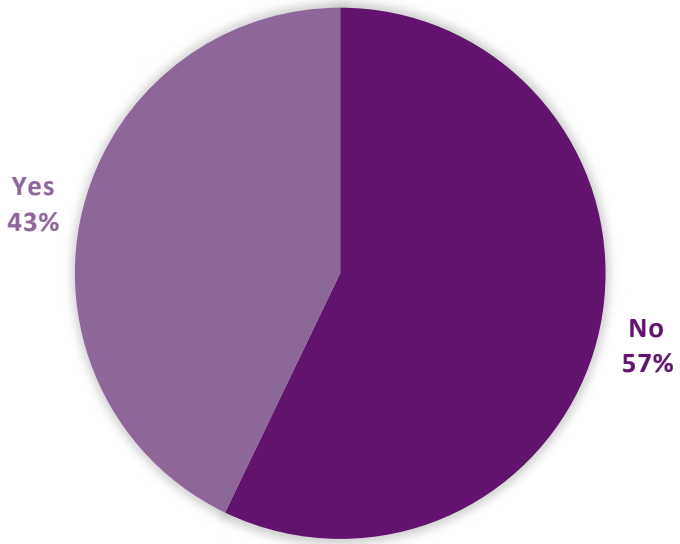
## Q3- Did someone coordinate the young person's transition to Adult Services?



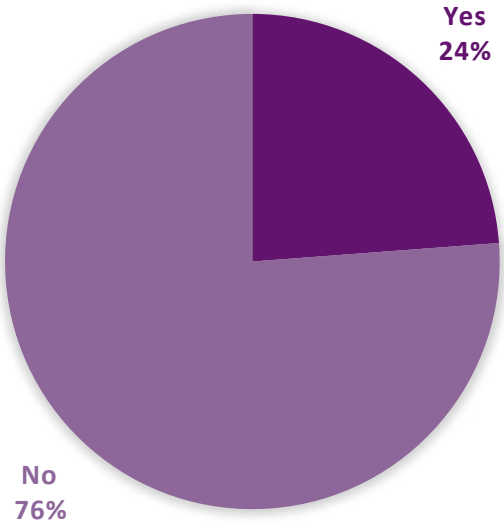

## Q3A- If yes, who?

| Who | Number of Responses |
|---|---|
| Social Worker - some specifically transition focussed | 12 |
| Specialist nurse | 6 |
| School - SENCO, EHCP, Head of Sixth form | 6 |
| Consultant | 3 |
| Paediatrician | 3 |
| Parent | 2 |

## Q4- At the beginning of the young person's transition planning, were they made aware of what was going to happen?




## Q5- Was the young person made aware of how long transition was expected to take?



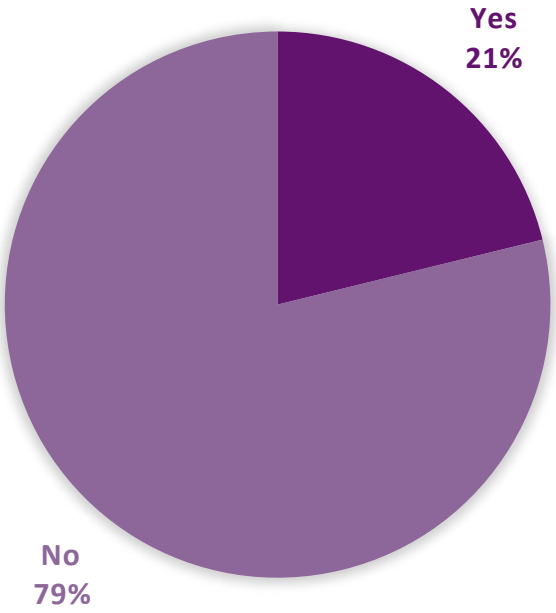

## Q5A- Comments

| Key Themes | Number of Responses |
|---|---|
| Young person not cognitively able | 11 |
| No planning or communication yet - despite some age 16+ | 10 |
| Fell to parent to either keep young person updated or seek information for themselves | 6 |
| Parents made aware | 4 |
| Different services cut off at different ages/have different approaches - lack of consistency causing issues. | 4 |
| Felt very sudden | 4 |
| No corresponding service in adults | 2 |

## Q5A- Quotes:

- "No one knows! One department suddenly moved to adults without warning. Another said adults but then came back with childrens. Some cannot touch her until 18. Currently in limbo as childrens ward reluctant to take her but adults can't cope with her disabilities without support from LD team who won't touch until 18. Etc. some will stay children to 19. And two services have no adult replacement so we will just have to manage without but no idea how."
- "Would take about 12 months as starting point, was not rushed or driven by age, but by our daughters care and treatment needs"
- "It was all very sudden, that I went from a social worker to have a care leaver personal advisor."
- "We got told in an appointment that it was the last appointment in paediatrics and he would now be under adults"

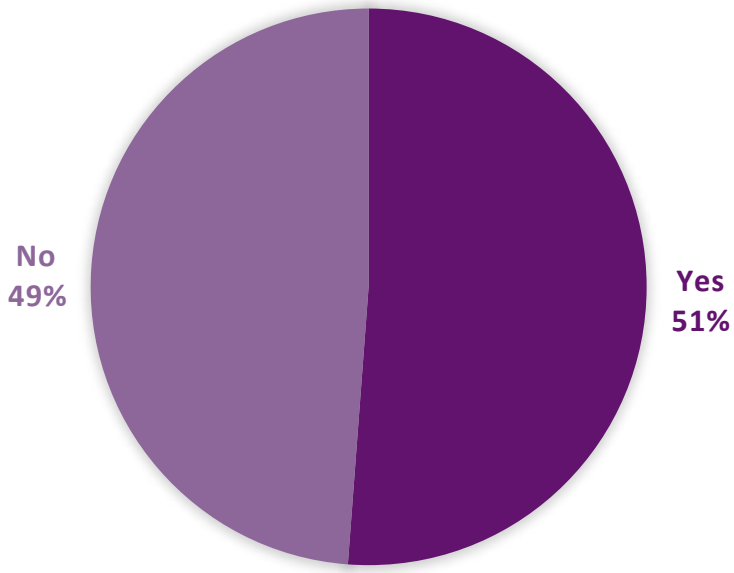
## Q6- Did the young person receive regular updates during the transition process?




## Q6A- Quotes:

- "Every 4 months, so lucky as not the experience of other parents at other treatment centres. Should be consistent nationally and meet the needs of the young person, siblings, and family."
- "The paediatrician updated a transition document at every 6-month review"
- "All services just abandoned him"

## Q7- Was the young person and the parent/carer involved with transition planning?



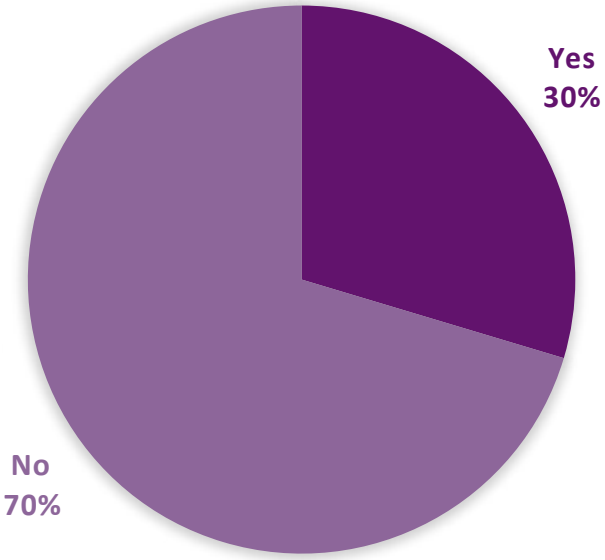

## Q7A- If so, was their wishes taken into account by professionals?

| Key Themes | Number of Responses |
|---|---|
| Yes | 16 |
| To an extent but still some limitations | 7 |
| No | 4 |
| Some professionals not aware of how they could help | 4 |
| Only after persistence/escalation | 2 |
| Still in early stages of info gathering | 2 |
| Restricted by what support was available rather than YP needs | 2 |

## Q7A- Quotes:

- "Yes it was a smooth transition that involved us"
- "Close and open partnership with clinical team."
- "No, all therapists were going to discharge our son from their services even though he was still in full time education"
- "Had to explain why son needed night care. The first thing adult services wanted to do was cut the package of care."

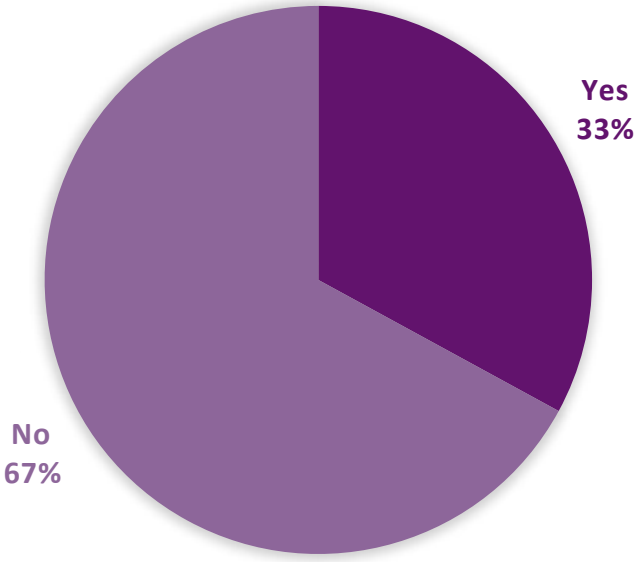
## Q8- Did the young person have the opportunity to ask questions about the process at the start and throughout?




## Q8A- Comments:

- "Inadequate diagnosis of SEND & ASD with no relevant diagnostic pathway now classed as an adult. So records do not accurately reflect our young persons' needs."
- "No control at any point -literally told we couldn't access Childrens ward anymore when I called to go in-had to go to A&E and wait whilst very vulnerable"
- "The opportunity would have been there had she been capable of understanding"

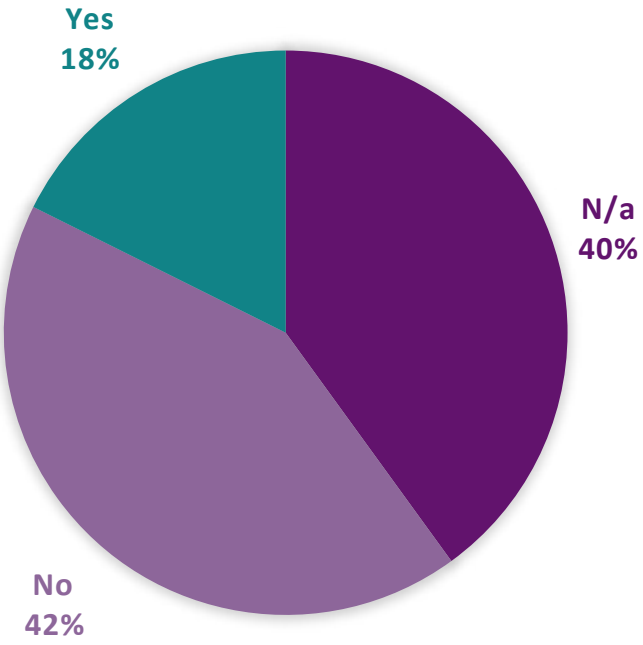
## Q9- Did the young person have the opportunity to attend multi-disciplinary team meeting where social care and education were present?



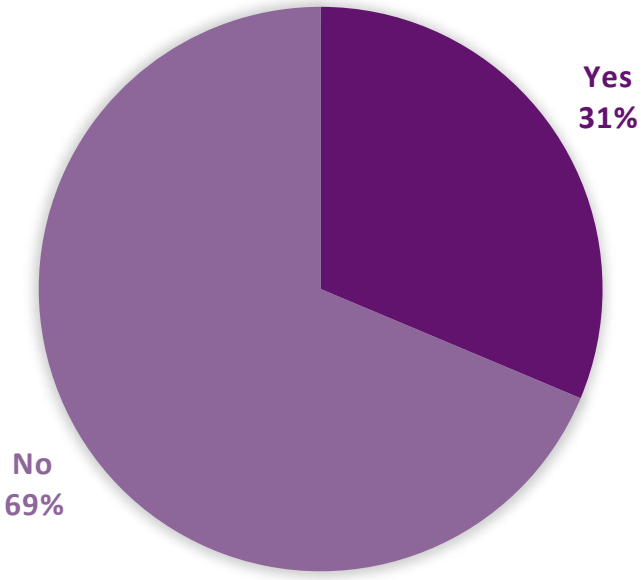
## Q9A- Quotes:

- "I attended MDT meeting when he was 15 but there were things on his plan which never materialised"
- "Forget hospital. I wasn't even invited to meetings between social and education as there were NONE. Even now aged 21, ehcp, education and chc and social care are not working together"
- "These MDT meetings with social care and education have been non existent. Feel totally forgotten about by these two services"
- "They don't attend any meetings the only thing is an Annual Review that no one attends except a SEN officer"

## Q10- Were long term plans like university or supported living considered where appropriate?



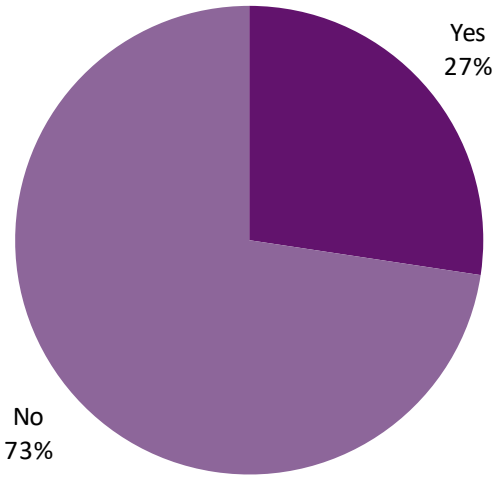

## Q11- Did the young person get the opportunity to meet the adults team that were taking over their care in advance?



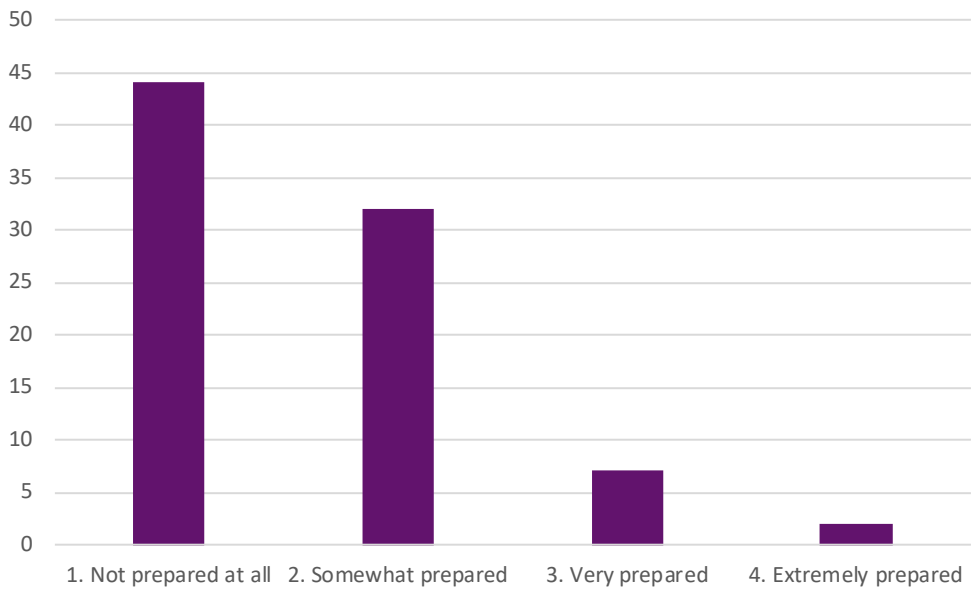
## Q11A- Quotes:

- "We only found the learning disability nursing team as our daughter was admitted to an adult ward in 2021 ... 6 months after we should have transferred. The first I heard of ready steady go was when I was asked to attend a feedback meeting about how it was going for us!"
- "The endocrinology clinic was closed before COVID-19 and not re opening. According to the Brittle Bone society Scotland have no adult brittle bone services/clinic"
- "Supported living- I'm currently sorting this now but wish it had been discussed much earlier than now at nearly age 24. No teams were introduced as all that was available was not appropriate, however the offer she got was a new offering at where she had already been attending for the last 3-4 years! Great result, fortunately."
- "He met the Adult Social Care team at the time that his adult needs assessment was conducted."
- "Health care yes, other services ... nothing has happened"

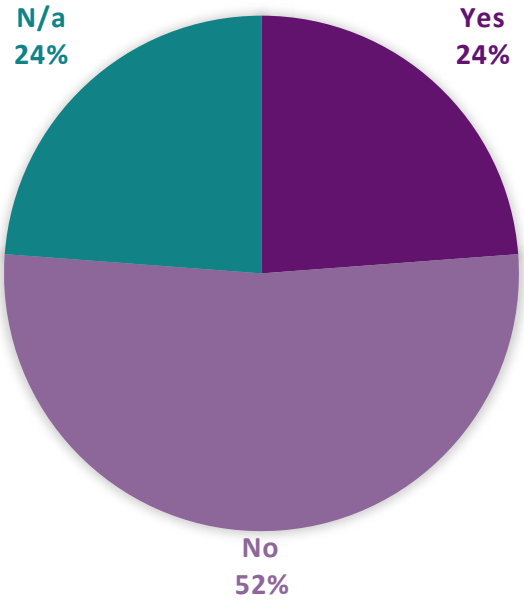
## Q12- Was the young person aware of the differences between children's and adults' services?




## Q13- On a scale of 1 to 4, how prepared does/did the young person feel for the final transfer to adults services?



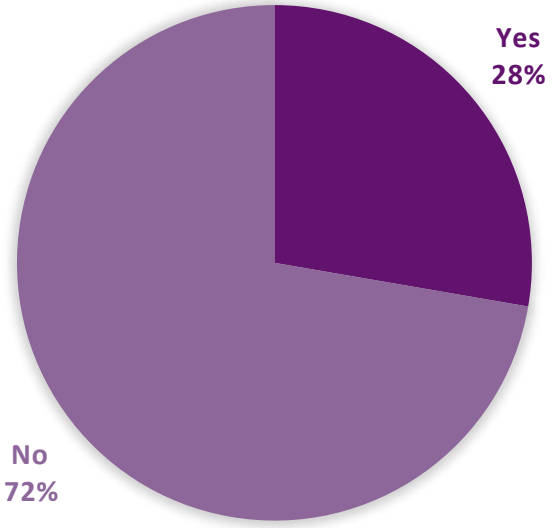
## Q14- Has the young person received any follow up contact since the transfer to adults services?




## Q14A- If yes, Who from? Please give their job title

| Key Themes | Number of Responses |
|---|---|
| Social worker/care support worker | 7 |
| Adult consultant | 3 |
| Various | 3 |
| Nurse | 3 |
| Named key worker | 3 |
| Left to parent | 1 |

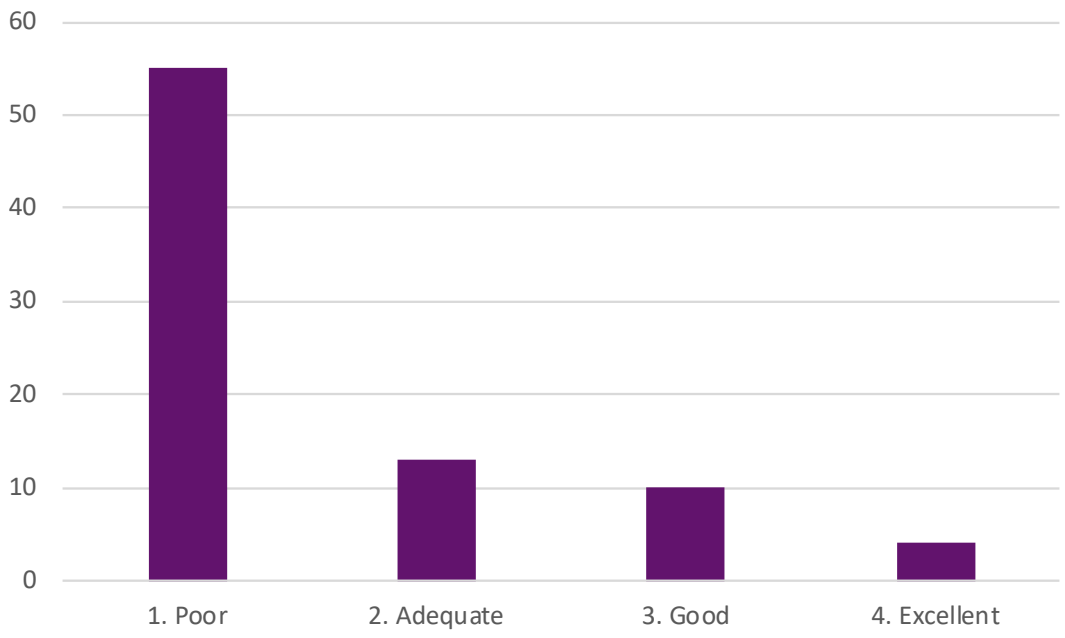
## Q15- Does the young person have a key worker or know who to contact regarding their health after they have transferred to adults services?



## Q15A- If yes, who?

| Job Title | Number of Responses |
|---|---|
| Learning disability nurse | 3 |
| Social worker | 4 |
| Support Worker | 3 |
| Specialist Nurses/District Nursing Team | 3 |
| GP/care coordinator at GP surgery | 2 |
| Consultant/community paediatrician | 4 |
| Transition Nurse/social worker | 2 |

## Q16- Overall, how would you rate the quality of the young person's transition experience?



# Section 2 – Experience of Transition

## Please tell us what went well with the young person's transition experience

| Response Theme | Number of Responses |
|---|---|
| Positive experiences | 25 |
| Negative experiences | 27 |
| Mixed experiences | 10 |

### Positive experiences:

- CHC case management proactive and finally put in place
- Health transition managed really well across all services
- Adult services have been fantastic
- Some services are better in adults than paediatrics
- Good communication

"CHC case management seem proactive and keen to avoid a gap in provision. Excellent."
"So far, the adult doctors have mostly been brilliant and there are more specialities to access for my son's complex needs. There is a transition nurse and LD nurse who have been supportive too. We now have access to carers via an agency who specialise in complex care and have a much better care package and our social worker is good."

### Negative experiences:

A common response to this question was that nothing had gone well with the young person's transition experience. In addition to this other negative experiences related to:

- Poor communication with services involved in transition
- The process being exhausting and disappointing
- Transition simply not happening for some YP meaning some are without specialist support in adults

"My son slipped though the net and his neurologist never got transferred over. This means he hasn't seen anyone for over 3 years despite being on anti convulsants"
"Nothing went well, we have found since turning 18 a lot of support stops, the professionals looking after young adults don't seem on the ball like the paediatric professionals."

### Mixed experiences:

Another common theme was that some multi agency services had provided great support during transition, but others were lacking, leading to a mixed experience. Within health services, it was also mentioned that some services were better than others.

"Education was OK but health and social care was terrible"
"My social workers are on side as they know and want health to pay. Struggling to get health to the table. We need information and consent now and they are delaying any way they can"
"Only thing that went well was the transition from paed physio to adult neurology physio who happens to fight for him when needed"
"Our sleep specialist has kept her longer until she is stable but has said they will joint visit before she moves over to adults. That's it"
"Some services were really helpful and kind and understanding and others have been utterly rubbish"

## Please tell us about anything that could have improved their experience of transition

| Response Theme | Number of Responses |
|---|---|
| Better coordinating, planning and delivery of transition | 33 |
| Communication and information provision | 28 |
| Services working together - joined up working | 17 |
| Better service provision to enable transfer of care and YP's needs to be met | 9 |

### Better coordinating, planning, and delivery of transition:

Answers under this theme included:

- Having one person to coordinate everything and oversee the transition process taking the stress away from the parent/carer
- Having a set transition plan, timeline, and pathway for all aspects of care including equipment, medication, and access to specialist services
- Starting the process earlier to give the YP more time to prepare
- Ensuring the transfer of care is completed before discharging YP so they do not go without the services they need

### Communication and information provision:

Suggestions for improvements in this area focussed on:

- Ensuring better and more regular communication with the YP/Parent/Carer before, during and after the transition process
- Provision of more information, guidance, and support for all aspects of the process
- Have opportunities for families to feedback their concerns and to be respected and listened to
- Provide follow-up contact once in adults' services to check everything is ok

### Services working together - joined up working:

The main recommendations for this theme were as follows:

- All services should work together – health, education, and social care
- Collaboration between paediatric and adult services before transfer of care including blended clinics where the YP can meet both services together
- Having MDT meetings for all involved

### Better service provision to enable transfer of care and YP's needs to be met

Answers under this are included:

- Ensuring consistency and continuity of services, having the same age of transition for all services, ensuring all are transferred
- Providing person-centred care rather than focussing on budgets and processes
- There is a specific gap between the ages of 16-18

## Quotes:

"It surprises me that there isn't a set plan for all transitions as it happens every year for many young people, and no one seems to know how to go about it. I now understand why parents who have previously transitioned had told me it's the most horrendous time of their lives. It would have also been great if someone even bothered to check that we were settled and ok after transition but we just got letters telling us our cases with everyone was closed."

"A hand over with the paediatric doctors and adult at the same time. For you to be able to discuss your concerns with the adult team before you transition. For community care to stay the same I.e supplies ,medical needs don't change they just turn 18 so shouldn't have to fight for all equipment that is needed for them. Maybe a support worker for each young adult going through transition to help support the families it's a big thing for parents to go through."

"Joined up working together and all services aiming for same age instead of all having different transition ages"

"A guide for us as parents to know what to expect, when, and how to challenge when absolutely none of it happens"

"Keyworker with health to support transition to adult services for those with complex health needs"

"Start younger and make children clinic as you get older more like adults so the shock isn't as big"

"There needs to be somewhere for children to go between 16 and 18 when they have a new issue. At the moment no one wants them at all."

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