



Department for Health and Social Care

Transitions Project

**Survey of parent carers' experiences and concerns
around the transition from children's to adult's
services**

A report from Contact, NDTi, Carers UK and NNPCF
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Contents

Executive summary	2
Introduction	8
Experiences of parent carers whose young person (18+) had already gone through transition to adulthood	8
Practices and processes	9
Practitioners involved	11
Reflections on what went well; challenges; and advice to other parent carers	13
Outcomes	17
Questions for all respondents (all young people ages 14+)	21
Top concerns around the transition to adulthood	21
Information needs	23
Annex: demographic information on respondents	25

Executive summary

The survey findings in this report form part of a project funded by the Department of Health and Social Care to support parent carers to navigate the transition from child to adult services. We surveyed parent carers of disabled young people aged 14+, in order to find out their experiences and concerns around transition and, if their son or daughter has already transitioned to adult life, what their advice to other parents would be.

We received 596 responses, of which 578 passed the screening question i.e. were based in England and are caring for / have cared for a young disabled person aged 14 or above. Responses came from 124 out of 151 local authorities. 89% of respondents were mothers; the rest were fathers and other carers.

88% were caring or had cared for 1 young disabled person; 10% for 2, and 2% for 3 young disabled people, which made a total of 607 young people listed by respondents. Of these, 53% were aged 14-17; 39% were aged 18-25 and 5% were over 25 (3% were under 14).

The respondents were asked for the disabilities or conditions of their son or daughter (or young person they were caring for). 56% reported caring for a young person with an Autistic Spectrum Disorder; 37% reported a learning disability including moderate, severe and Profound and Multiple Learning Difficulties. 25% reported a physical disability; 15% reported social, emotional or mental health issues.

Past experiences of transition to adulthood

Those who had a young person aged 18 or above (244) were taken to a longer set of questions around their past experiences of transition. Each of these questions typically had between 120 and 190 responses.

Of the young people who were 18 or older:

- 56% have a care and support plan;
- 33% had been assigned a personal budget;
- 49% of parent carers say the young person was involved, and their views considered, in the plans for their transition to adulthood; and
- 31% say the young person was supported in their transition to adulthood before they turned 18.
- 28% of parent carers have had a carer assessment or review in the last 12 months.

For some of the questions around whether a particular practice had taken place (e.g. whether a needs assessment had been carried out; whether a personal budget had been assigned), a relatively high proportion (up to 14%) were “not sure”, which may indicate recall issues (if the young person is older and the processes took place long ago), or perhaps a lack of communication from professionals or understanding of the processes.

The practitioners most frequently involved in the young person’s transition to adulthood were local authorities children’s services (51%); SENCO (35%); LA SEND team (34%); NHS professionals (33%) and other school staff (33%). We also asked parent carers which practitioners took their needs into account during the young person’s transition to adulthood. The most common response given was None (45%) followed by LA adult services (25%).

We also asked a series of questions to understand the behaviour of the practitioners involved in transition regarding coordination, provision of information, communication, co-production and listening to the views of families. For only 24% of respondents, there was somebody who coordinated the process; and 24% agreed that practitioners provided helpful information on the options available, while only 17% agreed that practitioners communicated with each other. In terms of involvement, only 48% of respondents did feel that they were included in planning and decisions; only 40% felt that their contribution as a parent carer was valued; and only 37% felt that practitioners were supportive of the young person and their wishes. These figures are worryingly low and are an indicator of why the overall experience of transition from children's to adult services for families of disabled children is predominantly poor.

Clearly some support was provided but we wanted to understand more about the quality of it by asking a free text question. The most common themes that were identified are outlined in Box 1. These are in order of frequency with which they were mentioned, but some themes have been grouped together for ease of exposition:

Box 1: Comments on the quality of support received

- Parents having to do things on their own and/or fighting battles, rather than support being provided when it is needed. Services are considered not to be proactive;
- Not getting any support;
- Support being of poor quality or not adequate;
- Delays; cliff edges; unreliable services; and high staff turnover;
- Issues in the provision of education including EHCPs;
- Coordination between services;
- Issues around other service provision including mental health; healthcare, and adult services;
- Good support from services are also mentioned, most frequently around education (many respondents' young people are still in education) but also health, social care, mental health, transitions team, social worker;
- Lack of information or guidance;
- Limited service provision.

Respondents were also asked about what was most helpful in meeting the parent carers' own needs; and about something that went well. The most common themes are summarised in Box 2 and Box 3:

Box 2: What was most helpful in meeting the parent carer's own needs

- Nothing (respondent cannot identify a helpful service or practice);
- Support groups and speaking to other parents;
- The young person's education provider;
- The parent's own skills, actions and determination;
- A charity or other local organisation;
- Other services.

Box 3. Something that went well during the young person's transition to adulthood

- Nothing (respondent cannot identify something that went well);
- The young person's education provider;
- Getting a good outcome for the young person, or the young person getting funding or Direct Payment for their needs;
- Specific practitioners, and specific behaviours from practitioners such as flexibility and good communication.

We also asked about something that could have been done better or something that was a challenge. The most common themes in the responses are summarised in Box 4:

Box 4. Something that could have been done better or that was a challenge

- Coordination between services, wanting someone to coordinate the process;
- Information and guidance;
- Everything;
- The process not starting early enough;
- Communication issues and other attitudes and behaviours from practitioners, in particular not being listened to;
- Issues around specific services such as adult services and education;
- Delays in services;
- Gaps in services, availability of services that are suitable to the young person; and being discharged from a service with nothing else in its place;
- More support for the parent carer;
- For the law, statutory guidance and best practice to be followed;
- Funding issues.

We asked respondents what advice they would give to other parent carers about how to look after their own needs as their young person transitions to adulthood. The most frequent themes are listed in Box 5:

Box 5: Advice to other parent carers on how to look after their own needs as the young person transitions to adult life

- Being well informed;
- Getting support from other parents in a similar situation, including joining support groups;
- Self care and the importance of looking after yourself;
- Attitude, such as being assertive and asking for what one wants, preparing for a battle, and not giving up;
- Being organised.

We also wanted to know about outcomes that were considered as part of the transition to adulthood process. We asked what outcomes were considered for parent carers as part of the transition planning, and what outcomes were considered for the young person.

The most frequent response on the outcomes considered for parent carers was *None* (67%) and the most frequent response on outcomes considered for the young person was *Education and employment* (51.4%) closely followed by *Health and wellbeing* (50.7%). As a free text follow-up question, we asked questions on what could have been done differently to improve outcomes for the parent carer, and for the young person. These are summarised in Boxes 6 and 7.

Box 6: What could be done differently to improve outcomes for parent carers

- Practitioner attitudes and communications;
- The system looking out for parents' needs, which includes carers assessments but also support around the whole family, support to work, support before there is a crisis;
- Information and guidance;
- Coordination between services;
- Some say they don't know what could have been done better – in some cases because their outcomes were supported, in other cases because there was no support and they don't know what good looks like;
- Availability of services including respite;
- Starting earlier, planning better;
- Being listened to and not having to fight for services;
- Resolving funding issues, not putting money over the young person's outcomes;
- Following the law and best practice.

Box 7: What could be done differently to improve outcomes for the young person

- A better focus on the young person's needs and outcomes, including person centred planning;
- Availability of services including independent living arrangements, and young people not being discharged from a service without another service to take its place (cliff edge);
- Everything;
- Starting earlier, planning better - including having defined pathways or timelines;
- Practitioners listening to parents and young people, and communicating better;
- Coordination between services;
- Support around specific outcomes such as socialising and being included in the community; independence; employment; health needs; education;
- Resolving funding issues, not putting money over the young person's outcomes;
- Information and guidance;
- Having a support worker or a mentor;
- A small number say nothing could have been done better;
- Attitudes and behaviours from professionals such as understanding of the young person's condition; being more proactive; following the law and best practice; less staff turnover.

We also asked whether services were available to meet the outcomes considered above.

- 55% said No,
- 30% said Partly and
- 11% answered Yes
- (4% did not answer the multiple choice question, but left a comment).

The question asked respondents to outline any gaps, and the most common response was "everything" or that no services were provided; followed by respite and day services or activities. Health and mental health services; and social care followed.

Questions about concerns around transition to adulthood

These questions were asked of all respondents, including parent carers of young people aged 14-17. Each of these questions was answered by between 400 and 410 respondents.

We asked the respondents to tick their top 3 concerns for themselves as their young person moves to adulthood. The responses are summarised in Table 1.

Table 1. Summary of responses to Question 24: What are your current concerns for YOURSELF as your young person moves to adulthood? Please tick the top 3.

Answer Choices	%
My own benefits and financial support	28%
Whether I'm able to work	32%
Whether I'm able to study	7%
Whether there is enough good quality care and support for me to care for other members of my family	33%
Whether there is enough support so that other members of my family don't have to pick up more care	39%
My ability to look after my own health and wellbeing	56%
My ability to have a good break	37%
My rights and responsibilities in caring for my child who will be an adult.	64%
My housing and where we'll be living	13%
How information will be shared and how I will be kept up to date.	34%
Other (please specify)	12%

We also asked respondents to tick their top 3 concerns for their young person as they move to adulthood. The responses are summarised in Table 2.

Table 2 Summary of responses to Question 25: What are your main concerns for your young person as they transition to adulthood? Please tick the top 3.

Answer Choices	%
Benefits and financial support	39%
Good quality care	52%
Personal assistance and employment of PAs	34%
Housing / supported living	38%
Health and wellbeing	61%
Employability and training	52%
Education options	41%
Personal and skills development e.g. independent living	58%
Making friends and maintaining personal relationships	58%
Legal aspects e.g. guardianship / power of attorney/deputyship	36%
Parent rights and responsibilities	29%
Other (please specify)	4%

We also asked respondents how well informed they feel about the above topics. The topics on which the highest proportion of respondents do not feel well informed are *Housing /supported living* (70%), and *Personal and skills development e.g. independent living* (64%). However it is important to note that for all the response options to this question, over 40% of respondents felt that they were not well informed.

We asked how parent carers would like to receive information relevant to their young person's transition to adulthood. The responses are summarised in Table 3.

Table 3. Summary of responses to Question 27: How would you like to receive information relevant to your young person's transition to adulthood? Please tick all that apply.

Answer Choices	%
Printed information	56%
Online information: web pages or downloads	68%
Online information: virtual events such as webinars, online Question & Answer	30%
Social media	27%
Information should be integrated into practice at schools, for example through annual reviews	60%
Workshops delivered by SENDIASS at the school	36%
The local authority's local offer web page	35%
Events held by the local authority	47%
Events held by the local parent carer forum	40%
Events held by independent organisations such as a voluntary organisation, charity or local group	42%
Other (please specify)	8%

Introduction

The survey findings in this report form part of a project funded by the Department of Health and Social Care to support parent carers to navigate the transition from child to adult services. We surveyed parent carers of disabled young people aged 14+, in order to find out their experiences and concerns around transition and, if their son or daughter has already transitioned to adult life, what their advice to other parents would be. The survey was open between 19 February and 6 March 2020.

Summary of responses

- There were 596 responses to the survey, of which 578 passed the screening question i.e. were based in England and are caring for / have cared for a young disabled person aged 14 or above.
- Responses came from 124 out of 151 local authorities (see Annex 1 for responses by LA).
- Respondents were asked to list the ages of their disabled young people aged 14+, up to 3 young people. 607 young people were listed by the respondents (88% listed 1 young person; 10% listed 2, and 2% listed 3 young disabled people). Of these, 53% were aged 14-17; 39% were aged 18-25 and 5% were over 25 (3% were under 14). 46% of respondents (244) were taken to questions 9-23 which were for those parent carers who had at least one young person aged 18+ and thus had been through the transition process with their young person.
- The respondents were asked for the disabilities or conditions of their son or daughter (or young person they were caring for), as a free text question. Respondents could report more than one condition, therefore the percentages add up to more than 100%. 56% reported caring for a young person with an Autistic Spectrum Disorder; 37% reported a learning disability including moderate, severe and Profound and Multiple Learning Difficulties. 25% reported a physical disability; 15% reported social, emotional or mental health issues.

See Annex 1 for charts on the demographic profile of respondents.

Experiences of parent carers whose young person (18+) had already gone through transition to adulthood

If the respondent had cared for one or more disabled young person who is now over 18, they were taken to Questions 9-23, which were for those respondents whose young person had already gone through the transition process. 244 respondents were taken to these questions based on their answer to Question 8 about their child's age.

Practices and processes

Question 9 (n=186) asks which practices or processes took place as the young person aged 18 or above was transitioning to adulthood. The respondents could tick *Yes*, *No*, *Not sure*. A glossary of terms was provided on this survey page. A summary of responses is provided below in Table 4.

Table 4. Percentage responding “Yes” to Question 9: Thinking of your young person aged 18 or above, did the following take place as they were transitioning to adulthood?

	% responding Yes (total excludes those responding not applicable)
The young person was involved, and their views considered, in the plans for their transition to adulthood.	49%
A needs assessment was carried out for the young person.	52%
The young person has a care and support plan.	56%
The young person was assigned a personal budget.	33%
The young person was supported in their transition to adulthood before they turned 18.	31%
When the young person turned 18, they were assessed and got support.	44%
You (as a parent carer) have had a carer assessment or review in the last 12 months.	28%
If the young person had a Statement or Education, Health and Care Plan (EHCP): preparation for adulthood started from the Year 9 review of the young person's Statement or EHCP.	45%

We can see that apart from the young person having a care and support plan (56%) and having had a needs assessment (52%), less than half of respondents said Yes to the other statements. For some of the questions around whether a particular practice had taken place (e.g. whether a needs assessment had been carried out; whether a personal budget had been assigned), a relatively high proportion (up to 14%) were “not sure”, which may indicate recall issues (if the young person is older and the processes took place long ago), or perhaps a lack of communication from professionals or understanding of the processes.

Question 9 asks if specific processes have taken place; however it does not ask about the quality of the support provided during those processes, and if they were adequate. Therefore Question 10 is a free text question that asks: **Please tell us more about the quality of the support you or the young person received as they were transitioning to adult life (n=163).**

The themes coming out of the free text comments are summarized in Box 8. Note that for all of the free text questions analysed in this survey, many of the responses included more than one theme. So for example in this question, the 163 responses included a total of 325 themes.

Box 8. Quality of support received (n=163)

Parents having to do things on their own and/or fighting battles, rather than support being provided when it is needed, is mentioned in 23% responses. Services are considered not to be proactive, so parents must be.

Support was very poor. Parents are left to battle through a minefield of funding battles, having to justify the needs of the young person.

I did all the work & educated the professionals around my daughter.

Around one fifth of parents (20%) respond that they **didn't actually get any support**.

*I have been told that my son is "not a safeguarding problem" so no help is available.
None given or offered.*

The next most frequent comment on the quality of support is that it was of **poor quality or not adequate** (15%). Some parents specify the reasons for this and this comes out in a number of themes.

Extremely poor. The support workers kept changing and their knowledge and understanding of the processes involved was very limited. There was no continuity. As parents we were very poorly advised and supported and the outcome was poor.

[...]. Relevant services were (and still are) very limited for young people with profound and complex needs.

Delays in getting support are mentioned by 13% of respondents, which could be due to a number of factors. **Cliff edges** (services stopping when the child turns a particular age, and not being replaced by anything) are mentioned in 10% of cases, and 4% of respondents simply highlight that services are **unreliable** (e.g. something is promised but not provided; or a practitioner does not get back to the family). 4% mention high **staff turnover**.

Still waiting for an assessment. PFA social worker has been appointed but there is a backlog of others needing assessments so nothing happening.

They had none. Were discharged from services aged 18 with no onward referral or support.

Very hit and miss. Allocated a social worker who never showed. Then another who we never met. [...]

Education issues are mentioned by 11% of respondents (including issues with EHCPs which may be issues with the education provider and/or with the local authority). Issues around **coordination between services** are mentioned by 9% of respondents. Issues around **social care** are mentioned by 7% of respondents; and issues around **mental health provision** are mentioned by 4% of respondents. Issues around **health care** are also mentioned by 4% of respondents. 4% specifically mention that the **transition to adult services** was poor.

It's all very confusing as some services continue until end of education others before. Parents are expected to take on far too much of the coordination of services.

College closed and my daughters statement ended no EHCP she spends 24/7 with me and has nowhere to go.

A good, helpful or adequate support from the education system and/or the school is mentioned by 10% of respondents. It is clear from the responses that many respondents still have young people in education (although this question is for parents of 18+ only), which probably accounts for education being mentioned as a service both with positive and with negative comments. 5% of respondents felt that **overall they got good support**. 2% had good support from **health or NHS**; 1% from **social care**; 1% from **CAMHS**; 1% mentioned getting good support from the **transition team**; 1% mentioned a particularly **helpful social worker**; 1% had a **good transition from children's services to the transition team** and 1% had a **good support to transition from children to adult services**; 1% had **support to apply** for direct payments; 1% mentioned a **helpful practitioner**; 1% had support from **charities**; 1% had support from **university**.

Support came from school, this was good but from other services and coordination of support poor.

Children's services were great but everything fell apart age 18.

Mostly ok. But it wasn't explained. The future was a huge unknown. We usually found out by accident from other parents.

School, social services, etc has been ok.

Lack of information or guidance was mentioned by 8% of respondents.

Y9 review initiated the transition to adulthood but nobody followed it up. I had to keep chasing them to get him to be assessed. I didn't know the process, I didn't know what I was asking for [...]

Limited service provision that is suitable to the young person is mentioned by 4% of respondents. **Support was only provided in a crisis** in 4% of responses.

Practitioners involved

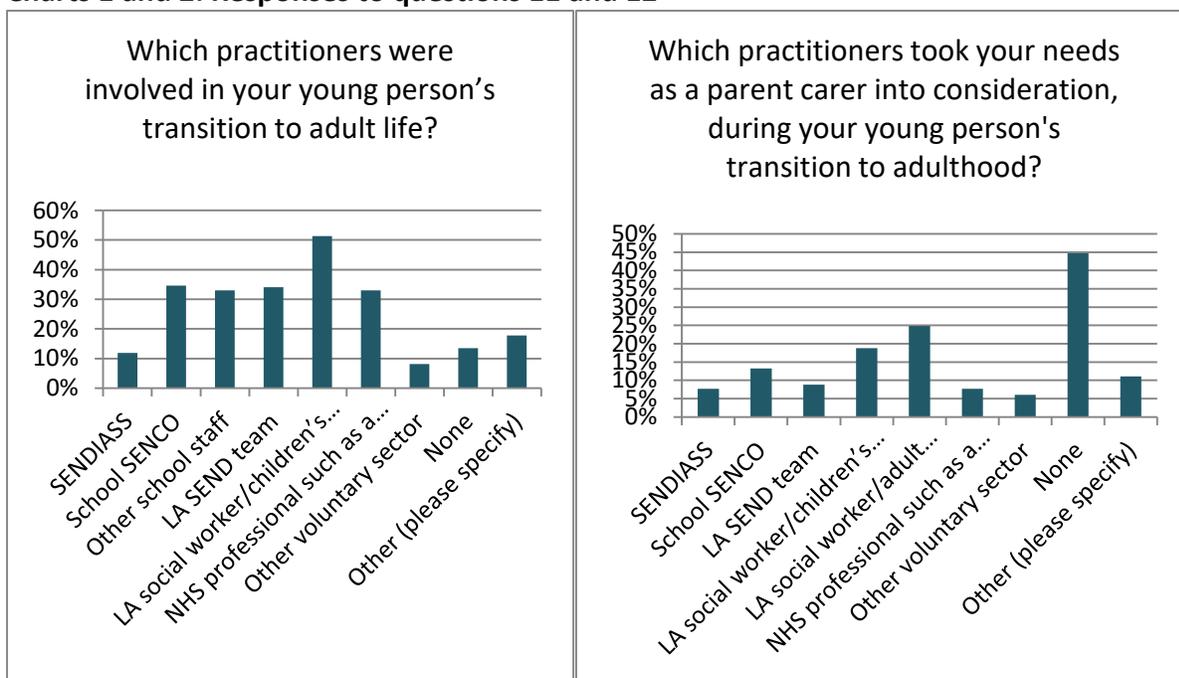
Questions 11-14 asked about the practitioners' involvement in the young person's transition to adulthood.

Question 11 asks which practitioners were involved in the young person's transition to adult life (n=185). Respondents could tick more than 1 option. The most frequent response was *LA social worker/children's services* (51%). The responses to Question 11 are summarized in Chart 1. Of those who ticked "Other" and added a comment, many of the responses are included in the question options such as NHS practitioners or a voluntary sector organization. However some practitioners/ teams are mentioned which were not included in the multiple choice responses, such as: a careers service; specific practitioners (either employed by the LA or NHS) such as support workers, care advisers, care coordinators; transition worker; specific teams such as autism outreach and continuing health care; adoption services; and the young person's college.

Question 12 asks which practitioners took the parent's needs into consideration (n=181). The most frequent response was "None" (45%) followed by *LA adult services* (25%). The responses to Question 12 are summarized in Chart 2. Of those who ticked "Other", again some teams were mentioned which were not included in the response options such as futures department; transitions team; continuing health care; care coordinator; autism team. Specific school staff, such as the school head, teacher or transition worker, were also mentioned.

Question 13 asked about which professionals were involved in the respondent's carers' assessment. We can see from Q9 that only 28% had had a carers' assessment or review in the past 12 months. Therefore fewer people answered this question (n=158) and among those who did, the most frequent response to Question 13 was *Not applicable – did not have a carers assessment* (53%). Of the ones that did have a carers assessment, 53% said that adult services were involved; 23% said that children's services was involved; 19% said other voluntary sector. Of those who ticked "Other", a few mentioned carers organisations or hubs, and the transitions team.

Charts 1 and 2: Responses to questions 11 and 12



Question 14 (n=181) asked the respondents to agree or disagree with a series of statements about the behaviour or practice of the practitioners who were involved in their young adult's transition to adulthood. Table 5 below gives the % of respondents who agreed or strongly agreed with each statement. We can see that less than 50% of respondents agreed with each of the statements, with the highest being 48% agreeing that practitioners included the parent carer in planning and decisions. The lowest was 17% who agreed that practitioners communicated with each other.

Table 5. % who agree or strongly agree to statements in Question 14

	% responding Strongly Agree + Agree
They provided helpful information on the options available	24%
They were supportive of my young person and their wishes	37%
They supported me as a parent carer	19%
They valued my contribution as a parent carer	40%
They included me as a parent carer in planning and decisions	48%
They communicated with each other	17%
There was somebody who co-ordinated the process	24%

As part of Question 14, we asked respondents for any additional feedback on the support provided by practitioners as the young person was transitioning to adult life. 108 provided additional comments,

with 186 themes logged against these. The most common theme in these comments (30% of comments) was around the **parent having to be proactive in finding and getting support**.

No proactive input. Parents left to get on with it and chase people up.

Other common themes were on issues with social care (9%) and the young person or parent getting no support (9%) or poor support (7%). Issues around information and guidance (7%) and communication (7%) were also themes, as well as lack of planning (6%); coordination issues (6%), issues in the education system (6%) but also getting good support from the education provider (6%). Delays (5%); lack of social workers (5%); service availability (5%) were also mentioned. Lack of support for parents; issues around healthcare provision; the young person not qualifying for support; funding issues; issues around employment; issues with the local authority; issues with the SEND team; good support from social services; issues around mental health provision; and no support provided once education has ended, were each mentioned by 3%.

This is difficult because some professionals did this and others did not - hence the answer in the middle. I was included in decision making etc but maybe because I forced myself into this - unsure if that would have happened had I not been so involved.

Reflections on what went well; challenges; and advice to other parent carers

In questions 15-18, parent carers of young people over the age of 18 were asked to reflect on what was most helpful in the transition process; what went well; challenges; and advice they would give to other parent carers. These were all free text questions.

Q15 What has been most helpful in meeting your needs as a parent carer as your young person moved to adulthood? (n=145)

Q16 Please give us an example of something that went well during your young person's transition to adulthood. (n=137)

Questions 15 and 16 aimed to glean feedback about what was helpful during the process, in general and in meeting the parent carer's needs.

For both these questions, the most frequent response was "Nothing" (30% for Q15, and 28% for Q16).

Nothing has been done in consideration of my needs.

I'm sorry I can't see that anything went particularly well, we had to fight for funding, support, social worker visits, diagnosis, college transport, and we still are unsupported and left to do everything ourselves, with the support and advice of voluntary agencies.

After "Nothing", the most common themes in Question 15 about what was helpful in meeting the parent carer's needs, and themes in Question 16 about something that went well, are summarized in Boxes 9 and 10. There are several themes in common between the answers to Question 15 (what was helpful in meeting your needs as a parent carer, analysed above), and Question 16 (an example of something that went well during your young person's transition to adulthood).

Although many comments in the free text questions are negative, these question highlighted that there is good practice out there and that some parents are pleasantly surprised when their and their young person's needs are met.

It all went much more smoothly than I had feared.

Box 9. What was most helpful in meeting your needs as a parent carer (n=145)

Support groups and speaking to other parents (15%). The local Parent Carer Forum was also mentioned (4%).
Online support groups, peer support.

The young person's college (8%). School (3%) and university (1%) were also mentioned.

Support usually from my sons support workers at college.

Her new, post 16 specialist college, us doing cooking and finance skills with her. Great assertiveness training from SLT at college. A good Ed Psych assessment.

The parent's own skills, actions and determination (7%).

Doing my own research and talking to other parent carers. Believing in being an advocate for my young person.

A charity or other local organisation (5%). Specific organisations include Contact, Preparing for Adulthood, AskJules, and local charities e.g. Lifeworks Newcastle Under Lyme.

Other services mentioned as helpful include Direct Payments (and other funding for specific services) (3%), respite (2%). Family, feeling heard and online resources were also mentioned (each 2%).

Our son has Direct Payments which helps us a lot

Understanding from education and social care that we need services to be 'present' and consistent so our son can learn to trust them so hopefully at some point we can get some respite...

To be heard and understood.

Box 10. An example of something that went well during transition to adulthood (n=137)

The young person's college (12%) and **school** (8%)

Transition to a local college with a very supportive SENCO who bent over backwards to ensure that my young person stayed and achieved.

Getting a good outcome for the young person (7%) and the young person being **involved** in the plans (6%).

"Intermediate" outcomes that were mentioned were the young person getting an EHCP (3%), getting free transport (2%), getting specific training that was helpful to them e.g. travel training (2%).

The day when she finally moved in- a few days previously we had no carers appointed and I thought it would never happen.

In the end the court awarded my son all that we had been fighting for for over a year, so the LA had to accept the decision.

When my son expressed a specific wish to study then a college place was funded.

Specific practitioner providing a good service: from the NHS (5%) or Social worker (5%). Other practitioners mentioned were educational psychologist; keyworker; team around the family; SENCO; support worker; Personal Assistant; CAMHS; OT.

Paediatrician helping to co ordinate transition for health issues.

Being allocated an intelligent, reasonable and emphatic Social Worker who knew her job and who I liked very much.

Some responses mentioned behaviour from professionals which was helpful such as instances when professionals showed flexibility (4%) and when they communicated well with each other (4%). Other examples mentioned include having a named professional; having the professionals' direct contact details; professionals getting involved early.

We had a team around the family at the time so this helped as social care and education were already talking [...].

Able to stay at special school till 19 where staff were supportive and instrumental in finding a college [...]

Leaflet of consultant with their photos and contact details.

Having a joint clinic with both paediatric and adult clinicians present, along with school nurse and parents [...]

The young person receiving a Direct Payment or other funding (4%); having the opportunity for **the young person to get used to their new setting** (4%); the parent getting **respite** (2%) and **feeling heard** (2%).

Discussions with us all, direct payments for her needs

Q17 Please give us an example of something that could have been done better or a challenge that you faced as your young person transitioned to adulthood. (n=150)

Question 17 aimed to identify something that had not gone well in the transition to adulthood process. There were some parallels between the themes coming out of Q17, and those coming out of Q9 on quality of support. In the responses to Question 17, the most common themes are summarized in Box 11. The 150 responses included 231 themes.

Box 11. An example of something that could have been done better or a challenge (n=150)

Coordination between services (13%)

Each service worked independently and no coordination. Process took a very long time to complete. No allocation of SW who knew us as a family so hindered the process and made things more difficult.

All problems could have been avoided with earlier involvement with the 18-25s team, communication between departments & a clear path of who is responsible for what rather than all claiming everything is someone else's job.

Information and guidance (12%)

Timely advice and guidance in later childhood available in printed form and from a coordinator for the process with actual knowledge of the system, the chain of events and what is available.

Everything (could have been done better) (10%)

The whole process was flawed.

The process did **not start early enough (9%)**

*Should have started discussion in year 9more info
Everything is left to the last minute unless you are proactive all the time*

Communication issues (8%). 3% also mention they would have liked more **politeness** from practitioners; 2% mention issues around **reliability** and 1% mention they would have liked them to be more **professional**.

Communication with all the agencies involved with young persons care. A list of contacts. Polite conversation. [...] Pro active in looking for opportunities rather than leaving it to me every time. Following up on promises.

Not being listened to (8%)

Understanding, listening and help.

Issues around **specific services** such as issues around **adult services (7%)**; around **education (6%)**; **college** not meeting needs (5%); lack or poor **careers advice (3%)**; issues with **mental health** provision (3%).

We moved to a college which after 1 term decided it could not meet need. We have been without provision for 3 months[...] Transitioning from CAMHS to adult mental health was a nightmare [...].

The biggest issue is Social Care. They don't want to assess because they don't want to find a reason to have to support.

Delays in services (7%)

*Not knowing what was happening, long periods before County SEN team got back to us.
Local Authority taking months to return EHCP after review meeting - 4 months and not returned.*

5% would have liked a **coordinator** or someone taking responsibility for the whole process

*Communication, co ordinator to support parents and chase professionals.
The process should have been coordinated by a key person. The onus should not be put on the parents [...]*

5% mentioned **gaps in services** – either as a result of a cliff edge or other reason. 3% were unhappy that the young person was simply **discharged** from a service with no plan or substitute service available. 4% would have liked more **support for themselves**. 4% say they would have liked for the **law and statutory guidance to be followed**. 3% mention limited **service availability** for their young person. 3% mention **funding** issues. 2% would have liked more **support for the young person** to become more independent; and 2% would have liked the young person to be more **involved** with plans for their future.

Q18: Advice to other parent carers about how to look after their own needs as their young person transitions to adulthood (n=145)

Question 18 asked those parent carers whose young person had already gone through transition to adulthood, to give advice to other parents, specifically on how to look after their own needs. The most common themes are summarized in Box 12 (231 themes across 145 responses).

Box 12. Advice to other parent carers about how to look after their own needs (n=145)

Being well informed: staying on top of the relevant information (rights, legislation, doing one own research) – 31% of responses.

Gain as much information as you can, via other parents, the internet, transition groups, anywhere.

Educate yourself on the SEN code of practice. Know your rights. Join support groups. Reach out and talk to others. Know that you are strong enough to fight if you have to. If your child is passionate about something don't let the authorities try and pigeon hole them as it doesn't suit 'their' needs!

Other parents: Getting support from other parents in a similar situation, including joining support groups – 16% of responses;

Seek out voluntary agencies and meet other parents, because they are the only people who know what you are going through and might be able to give advice.

Join support groups - our local FB group is great now, as lots of us are going through transition now and are helping each other out. I've learned far more from other parents than from most of the professionals involved.

Self care: the importance of looking after yourself – 12% of responses

If you can, share the load. Agree who takes on what. Make sure you have at least one day that this process is not discussed.

Don't get angry and lose tempers [...]. Remain calm but firm.

Look after yourself no matter how hard life gets. You can only support your children if you appear cheerful. Be positive with your children but always honest.

Look after yourself first. Look for financial support from charities as much as you can. Don't trust what you are told by the professionals about entitlement to services, check everything you are told via research online or independent charitable organisations.

Attitude: in particular being assertive and asking for what one wants (10% of respondents), preparing for a battle (10% of respondents), and not giving up (8% of respondents).

Do not give up fighting for your young persons basic rights to an education, for a reasonable transition to adult services and to the relevant support that is needed for them to be happy and taken seriously into adult life with the same opportunities and 'normal' child or young person should be able to expect.

Start early, go and visit the hospital, keep notes of questions you want to ask, don't be afraid of speaking your mind, make sure you have open communication with adult service.

Keep every piece of communication, follow up conversations with an email to confirm discussions. Read up on the law & let them know what should be done. Prepare for the never ending fight you are going to face, & don't give up!!

Being organised: with 8% highlighting the importance of starting early; 6% the importance of planning, and 4% urging parents to be proactive as it won't be done for them.

Don't leave everything to the last minute. Make sure you look at least two years ahead for your young person's next part of their life. ie college and what happens after college.

Please make sure the transition to adulthood work starts as early as possible. Your child only had one go at being an adult.

Other themes: 8% don't feel that they have any advice to give; 6% urge parents to ask for help and to make it clear what their and their children's needs are; 5% of responses were around communication with professionals and keeping in the loop; 3% suggest getting help from voluntary organisations (with 1% urging parents to join their local parent carer forum); 3% urge parents to prepare for difficulties ahead and 3% say they are on their own; 3% tell parents to get a carers assessment; and 3% remind parents to accept and listen to their children and to pursue their goals and dreams.

Outcomes

Questions 19-23 ask what outcomes for the parent carer and the young person were considered as part of the transition to adulthood process; what could be done differently to improve those outcomes; and whether the services were available to meet the plan and outcomes for the parent and young person.

Question 19 (n=165) asked what outcomes for the parent carer were considered as part of the transition planning. Question 21 (n=142) asks what outcomes for the young person were considered. Questions 20 and 22 are free text questions and ask what could have been done differently to improve outcomes for the parent carer and young person respectively.

Chart 3 and Chart 4 summarise the responses to questions 19 and 21. The most frequent response to Q19 on the outcomes considered for parent carers was *None* (67%) and all other responses were given by less than 20% of respondents. Among the small number who ticked "Other", no additional outcomes for the parent were mentioned but a few mentioned outcomes for them (including happiness) as a result of the child getting the right provision or outcome.

The most frequent response to Q21 on outcomes considered for the young person was *Education and employment* (51.4%) closely followed by *Health and wellbeing* (50.7%). Note that the option "None" was not included in this question but 18% of respondents did give this response in the free text box under the "Other" option, and the lower number of respondents to this question suggests that some of those who would have answered "None" did not answer the question. Of the comments under "Other", some mention a specific service or provision but not specifically linked to an outcome (e.g. place in a specific residential home; specialist activities; respite; taking care of their own finances); and others say that the outcomes were mentioned but not addressed by services or actioned.

Chart 3 Summary of responses to question 19

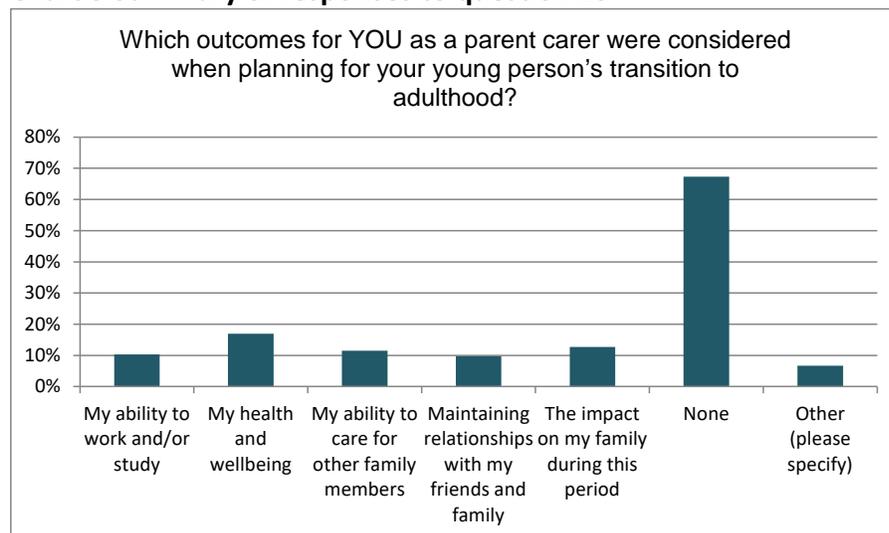
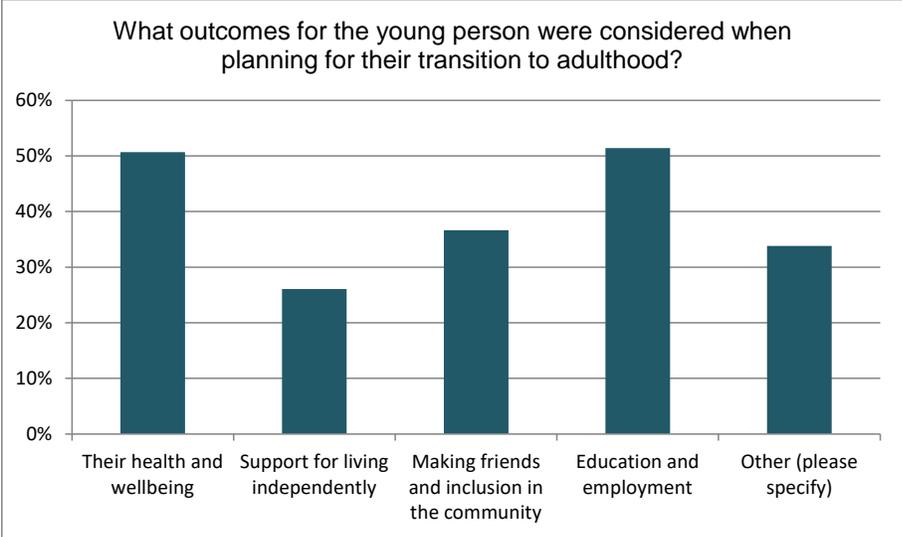


Chart 4 Summary of responses to question 21



Questions 20 and 22 asked, respectively, **Q20 What could be done differently to improve outcomes for you?** (n=132) and **Q22 What could be done differently to improve outcomes for your young person?** (n=127).

The main themes coming out of Question 20 are summarized in Box 13. A total of 158 themes were logged across 132 responses.

Box 13. What could have been done differently to improve outcomes for parent carers (n=132)

Practitioners' attitude (12%). Additionally 6% also mention **communication** with and from practitioners; 2% mention the ability to have a **one-to-one meeting** with a practitioner, and 1% mention **staff turnover**.

Politeness. Understanding...awareness....be an advocate.

Ask me how I am. Receive support. To be listened. Communication between departments x myself sadly lacking if any at all.

Practitioners or the system **looking out for parents' own needs** (10%). 5% also mention wanting **support around the whole family**; 5% mention having a **carers assessment** or a better version of the carers assessment that they did have. 3% mention getting **support to work**. 2% say they should have got **support before there was a crisis**. 1% would like a **personal budget for the parent's own needs**.

It would have been beneficial if I had someone to look out for my needs in the process, nobody did.

Having a carers assessment, even if nothing came of it. Nobody was the slightest bit interested.

The fact that I have to be struggling before help is offered. I struggle privately, have given up careers [...]. If he's not at school he is with me, he is lovely but the constant care wears you down.

Looking at us all as a family most just looked at one person's needs at a time [...]

Information and guidance (8%)

Make us aware of what we could ask for such as needs assessment - had no idea we could have one.

To know what support is available.

Coordination between services (6%)

My daughter's provision to be organised, structured, monitored by the agencies who are supposed to do that. This would mean that I didn't have to be constantly badgering for support and could get on with my own life.

Joint working school, health, family and all LA departments.

Some parents **don't know** what could have been done differently (6%), which could be because things have gone well or badly – 5% say **"everything"** and 2% say **"nothing"**.

I don't know. It's quite a muddle. It's all so hidden, so you don't know what's out there until it's almost upon you.

Availability of services (5%). Also 3% mention **respite**.

Services available so I am not the person who has to complete and coordinate my son's care. I went from being totally supported while he was a child to feeling very isolated post transition.

Many adults with learning problems just sit in their room alone. They can be rude and abusive [...] That is not their fault [...]. Having a break from caring is the only solution to my problems.

Starting earlier and planning better (4%). Also 3% felt a lack of a **transition plan**, and 1% mention **delays**.

Better preparation, earlier intervention.

Actually having a transition plan.

Being able to make a plan with the LA, to share responsibility in a way, as when I am gone the LA will be fully responsible for the wellbeing of both my children. [...]

Not having to **fight** for things (4%) , and for the **parent's ideas to be listened to** (2%)

Someone other than me being proactive, support that enables me to work, sleep, see friends and have a relationship with my husband.

Letting us have the post 18 provision we have picked with careful consideration which will future proof our son and hopefully aid him to be less of a drain on LA resources in the future!

Not putting **funding over the young person's health and wellbeing** (3%), and in general, **funding** issues (1%).

To not put cost of services as priority over a persons health and well-being

For professionals to be working with you instead of against you to protect their budgets.

Practitioners **following the law** (2%) and/or **following best practice** (2%).

Learn and emulate the superior and accessible services which are available in Northampton & Bedford LA's.

Many of the themes listed above around support for the young person come out more strongly in Question 22 on “**What could be done differently to improve outcomes for your young person?**”. The themes coming out of Q22 are summarized in Box 14 (176 themes were logged across 127 responses).

Box 14. What could have been done differently to improve outcomes for the young person (n=127)

A better focus on the young person’s needs and outcomes (13%) – this includes person centred planning.

I insisted on using the Pfa guidelines for my son’s EHCP review so it was done well. These should be compulsory for all students.

Looking at her as a whole person. The forms are all about need and risk and countering that, not about what makes up a full and satisfying life and how to work towards it.

Availability of services (8%); also options, support and quality of **independent living** arrangements (3%); and young people **not being discharged** from existing service (2%).

Proper assessment, proper investment in provision - the only in- borough college course for children with LD was closed down.

More communal living and sheltered workplaces to provide purpose and companionship.

“**Everything**” could have been done differently (8%)

Everything the systems in place are inadequate

Practitioners to **start planning earlier** (8%) – this also includes having longer term goals and planning. In general having a **plan** or a better plan (3%); and some mention a better defined **pathway** or timeline (2%), or a **coordinator** (1%).

Better preparation, earlier intervention, more suitable providers

That there is a timeline and timetable of events. Felt like we were navigating system for the first time when must have happened before.

Listening to parents and the young person (7%) and better **communication** (7%)

Listening to my daughter and her parents

Regular communication and more provision

Coordination between services (6%)

A more holistic approach. Health, mental well-being. Living independently. We had to address a lot by ourselves.

Various different types of support for the young person for a range of services and outcomes: support with **socialising and being included in the community** (6%); support with **independence** (5%); support with the young person’s **employment** (3%); support around the young person’s **health needs** (3%); support with **education** (2%); getting an **EHCP/a better EHCP** (2%); support from **social care** (2%); support from **mental health** services (2%); support **after education ends** (2%); having **more suitable courses** (2%); **travel training** (2%); help when the young person does not have an ECHP (2%); support into adult services (1%); support with careers for young people educated out of county (1%).

Look at wider picture to include health and social care factors, especially around relationships and socialisation.

Robust mental health support throughout the transition process [...].

Genuine practical and flexible support for young people moving from education and living at home to be independent individuals working and participating in the community. [...]

Other themes included issues around **funding** (4%) and putting funds before the young person’s outcomes and needs (2%). **Information and guidance** (4%). Having a **support worker** (3%) or a **mentor** (1%).

Some say that “**nothing**” could have been done better (3%) *I sorted everything to my satisfaction..*

Attitudes that would be more helpful from professionals include a better **understanding** of the young person and their condition (2%); being more **proactive** (2%); **following the law/best practice** (2%); less **staff turnover** (2%); some would like a change in the **LA’s management** (2%); and the parent **not having to fight** for everything (2%).

Question 23 (n=161) asked whether services were available to meet the outcomes considered above.

- 55% said *No*,
- 30% said *Partly* and
- 11% answered *Yes*
- (4% did not answer the multiple choice question, but left a comment).

The question asked respondents to outline any gaps, and 81 responses were provided. The most common response was “**everything**” or that no services were provided (12%); followed by **respite** (10%) and **day services or activities** (9%). **Health** and **mental health** services (both 6%); and **social care** (4%) followed. **Information**; services for **complex needs**; **employment**; **support workers**; and **independent living** were all mentioned by 4% of respondents, as well as **delays** in receiving the services that did exist. Other services mentioned were services for less disabled; service quality; EHCP or provision therein; transport; choices; support for independence; social inclusion; residential college; key worker; social workers; coordination; college; transition to independent living; benefits; a plan; and nothing.

No practical alternative for living outside family home. No paediatric follow on in adult acute hospital care - even though those skills are required. Always more person-centred specialist activities within a group are needed - very costly to provide and personal budgets do not always include payment for activities rather than paid support.

Questions for all respondents (all young people ages 14+)

All respondents, regardless of the young person’s age, were taken to survey questions about their concerns for themselves and the young person during transition to adulthood; how well informed they feel; and how they like to receive information.

Top concerns around the transition to adulthood

Question 24 and 25 ask about respondents’ concerns for self and the young person. Question 24 (n=404) asks the respondents to tick their top 3 concerns for themselves as their young person moves to adulthood. The most frequently cited concerns are *My rights and responsibilities in caring for my child who will be an adult* (64%), and *My ability to look after my own health and wellbeing* (56%). Table 6 summarises the % responses for each option given. Out of those who ticked “Other”, the most common responses were around concerns for their child’s service provision, outcomes and continuity of service (as those who answer this question include parents of younger adults who have not yet gone through the transition to adulthood). Some mention concerns about what will happen to their young person after they are no longer able to care for them; others mention concerns about how they can best support their child as they transition to adulthood.

Table 6 Summary of responses to Question 24: What are your current concerns for YOURSELF as your young person moves to adulthood? Please tick the top 3.

Answer Choices	%
My own benefits and financial support	28%
Whether I'm able to work	32%
Whether I'm able to study	7%
Whether there is enough good quality care and support for me to care for other members of my family	33%
Whether there is enough support so that other members of my family don't have to pick up more care	39%
My ability to look after my own health and wellbeing	56%
My ability to have a good break	37%
My rights and responsibilities in caring for my child who will be an adult.	64%
My housing and where we'll be living	13%
How information will be shared and how I will be kept up to date.	34%
Other (please specify)	12%

Question 25 (n=406) asks the respondents to tick their top 3 concerns for their young person as they move to adulthood. Table 7 summarises the % responses for each option given. The most frequently ticked answer is *Health and wellbeing* (61%) followed by *Personal and skills development e.g. independent living* (58%) and *Making friends and maintaining personal relationships* (58%). We asked respondents to tick their top 3 concerns as we knew that for many respondents, many or all of the items listed would cause some level of concern, but we wanted to understand which were at the forefront of respondents' minds. Nonetheless a few people who ticked the "Other" box said that they are concerned about "everything" or all of the items listed. As in the previous question, a few comment that they are concerned about what will happen to their young person when they are no longer able to care for them.

Table 7 Summary of responses to Question 25: What are your main concerns for your young person as they transition to adulthood? Please tick the top 3.

Answer Choices	%
Benefits and financial support	39%
Good quality care	52%
Personal assistance and employment of PAs	34%
Housing / supported living	38%
Health and wellbeing	61%
Employability and training	52%
Education options	41%
Personal and skills development e.g. independent living	58%
Making friends and maintaining personal relationships	58%
Legal aspects e.g. guardianship / power of attorney/deputyship	36%
Parent rights and responsibilities	29%
Other (please specify)	4%

Information needs

Question 26 (n=407) asks respondents how well informed they feel about a range of topics. The topics on which the highest proportion of respondents do not feel well informed are *Housing /supported living* (70%), and *Personal and skills development e.g. independent living* (64%).

Table 8 summarises the responses.

Table 8 Question 26: How well informed do you feel about the following topics? % replying *No, I do not feel well informed.*

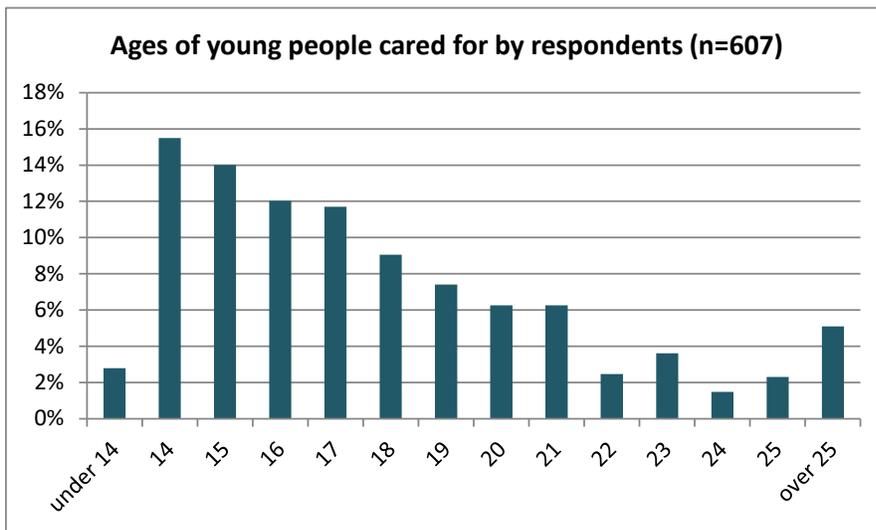
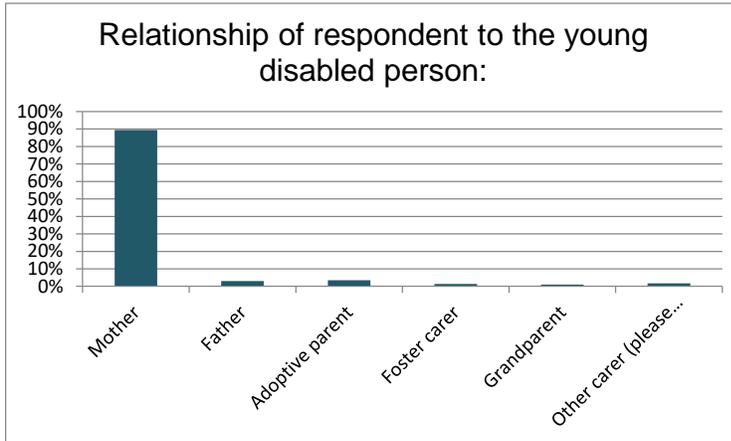
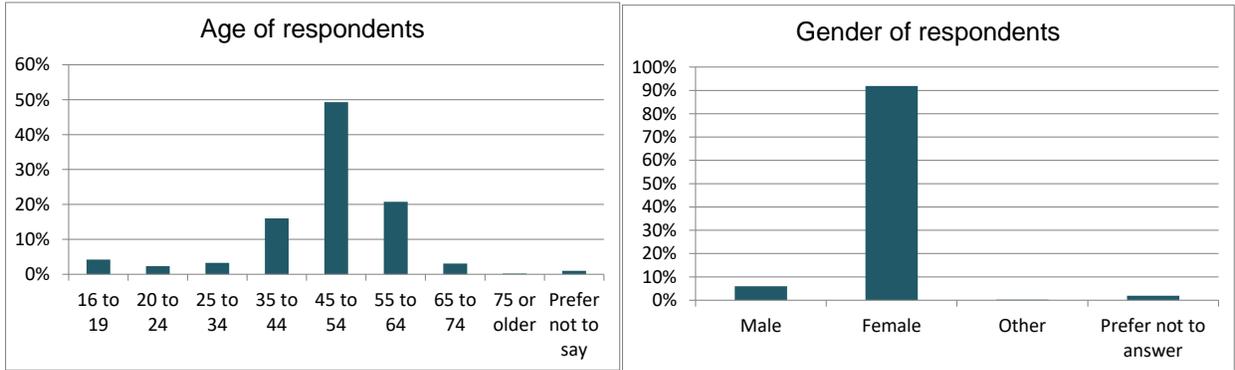
Answer choices	% answering No, I do not feel well informed
Benefits and financial support	48%
Good quality care	61%
Personal assistance and employment of PAs	60%
Housing / supported living	70%
Health and wellbeing	46%
Employability and training	58%
Education options	45%
Personal and skills development e.g. independent living	64%
Making friends and maintaining personal relationships	55%
Legal aspects e.g. guardianship / power of attorney/deputyship	61%
Parent rights and responsibilities	57%

Question 27 (n=404) asks how parent carers would like to receive information relevant to their young person’s transition to adulthood. The most common response is *Online information: web pages or downloads* (68%), followed by *Information should be integrated into practice at schools, for example through annual reviews* (60%). Notably the 3rd most frequent response is *Printed information* (56%) while there is little appetite for information through *social media* (27%). Table 9 summarises the responses. In the comments left by those who ticked “Other”, the most frequent response is that they would like information from a named person such as a keyworker, social worker, mentor or central person to deal with.

Table 9. Summary of responses to Question 27: How would you like to receive information relevant to your young person's transition to adulthood? Please tick all that apply.

Answer Choices	%
Printed information	56%
Online information: web pages or downloads	68%
Online information: virtual events such as webinars, online Question & Answer	30%
Social media	27%
Information should be integrated into practice at schools, for example through annual reviews	60%
Workshops delivered by SENDIASS at the school	36%
The local authority's local offer web page	35%
Events held by the local authority	47%
Events held by the local parent carer forum	40%
Events held by independent organisations such as a voluntary organisation, charity or local group	42%
Other (please specify)	8%

Annex: Demographic information on respondents



Note: respondents were asked to list young disabled people aged 14+ but some included younger children. We do not know if some included non-disabled children in their response.

Number of responses by LA, for those LAs from which 5 or more responses were received

Answer Choices	Responses %	Responses number
Birmingham	5.86%	30
Hillingdon	4.10%	21
Lancashire	3.32%	17
Staffordshire	3.13%	16
Surrey	2.73%	14
Hampshire	2.54%	13
Shropshire	2.34%	12
Southampton	2.15%	11
Derbyshire	1.95%	10
Devon	1.95%	10
Leicestershire	1.95%	10
Lincolnshire	1.95%	10
Northamptonshire	1.95%	10
Reading	1.95%	10
Kent	1.76%	9
Buckinghamshire	1.56%	8
Milton Keynes	1.37%	7
Norfolk	1.37%	7
Nottinghamshire	1.37%	7
Sefton	1.37%	7
Suffolk	1.37%	7
Bolton	1.17%	6
Isle of Wight	1.17%	6
Liverpool	1.17%	6
Redcar and Cleveland	1.17%	6
Somerset	1.17%	6
South Tyneside	1.17%	6
Cambridgeshire	0.98%	5
Dorset	0.98%	5
Sheffield	0.98%	5
Southwark	0.98%	5

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