Family Voice Norfolk Consultation on
Preparing for Adult Life

Consultation
Parent carers of children and young people with special educational needs and/or disability (SEND) were consulted via an online survey from 27 May to 27 June 2022 about Preparing for Adult Life (PfAL).

Background
Family Voice Norfolk (FVN) is a collective of parent carers from over 1,370 families across Norfolk and represents nearly 1,800 children and young people with SEND. FVN has been the strategic voice of parent carers working in partnership with Norfolk County Council (NCC) and the NHS Norfolk and Waveney Integrated Care Board (ICB), formerly the Norfolk and Waveney Clinical Commissioning Group (CCG) since 2006. It is funded through a direct DfE grant (administered through Contact), by NCC and by the CCG.

Preparing for Adult Life was identified at being one the three serious weaknesses by Ofsted/CQC inspectors when they visited Norfolk in 2020.

Parent carers were invited to complete a questionnaire online and had the opportunity to include comments on their experiences about PfAL. The survey ran for a month. FVN received 61 responses

Key messages

- Only 28% of parent carers had “starting to plan for adult life” as part of the Year 9 annual review. 35% did not have this in their plan.
- 25% of parent carers did not have an annual review before a transition.
- Of those that had an annual review, teachers and tutors attended 59% and EHCP coordinator attending 39%. Parent carers were not always involved (78% attended) nor was the young person (41%.).
- On average, three people were present at the annual review. The number of attendees range from 1 to 6.
- 44% of parent carers did not know if the EHCP has been shared with and used by everyone working with the young person.
- 42% of parent carers whose CYP has an EHCP and is 19+, feel that they have been supported to continue education if this is what is needed.
- 48% of parent carers did not feel that they had a real choice for what their CYP could do post 16. 35% felt that they did have this choice.
- 35% of parent carers felt that they had enough information to make an informed decision, 40% did not. 25% of parent carers felt they only partly had enough information.
- 36% of parent carers only found out that many college courses only provided three-day provision when they were applying for college. Some children require 1:1 support and parent

carers have to find alternative provision or reduce their working hours. Some children can only manage a three-day provision.

- 27% of parent carers have never heard about the Preparing for Adult Life team, with a further 36% having no involvement with the team.
- Only 23% of parent carers and their young person have ideas about how they may live more independently.
- 67% of parent carers are not aware of organisations that can help their young person move forward into adult life.
- Parent carers hope that their young person will be happy, healthy and have the support and care that meets their needs.
- Parent carers greatest fears are not having care and support for their young person when they are no longer around.

A few quotes from parent carers:

> Only because I continually push. Each year there is a threat his education will be removed - but he continues to make progress and attain qualifications and work/ life experience so it's maintained

> Money is put first. They don't employ the correct number of staff or staff that are suitable for the environment they will be working in

> My main fear is that lack of provision, and that access to provision is becoming even more limited due to funding cuts and red tape

> My child needs are complex and it is becoming clear that adult social care is not well provisioned for someone like him.

> I feel the local mainstream college was pushed on us - even though I knew it was unsuitable - I feel my son had to fail first in order to get a more suitable college placement

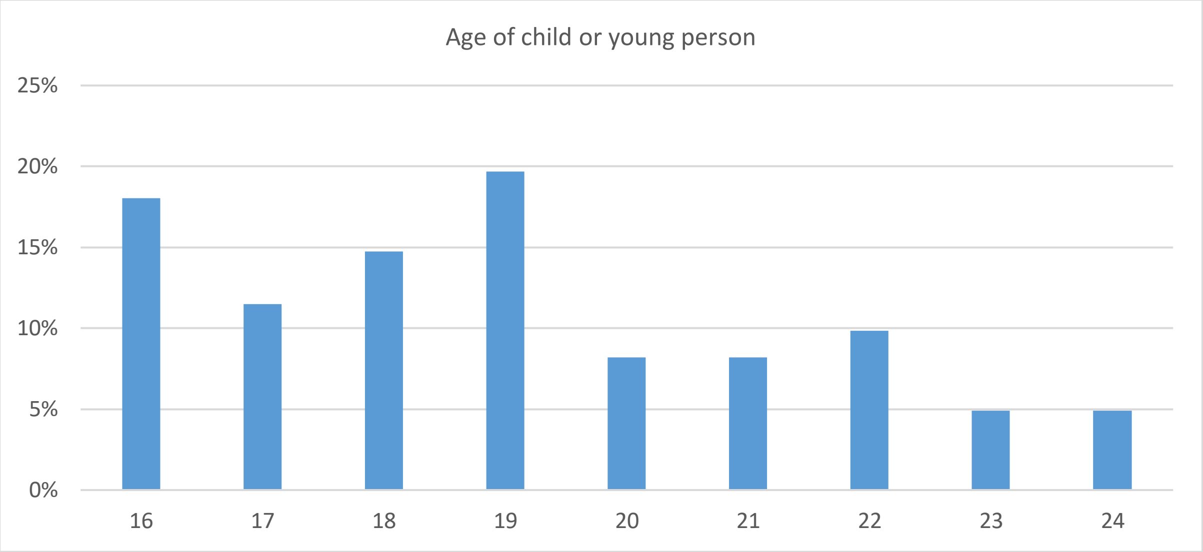
> When we, as parents, die, what will happen - who will advocate for him, help him continue in 'work' if he is ever lucky enough to secure that, ensure he is healthy, happy and safe? That is my biggest fear. I know that as long as we are alive and 'there' for him, we will do the best we possibly can to ensure he is/has those things. But without us around, what then?

> It was an utter battle to get the referral [for PfAL] accepted despite my child having all the criteria stated. It was only after I stated that I would appeal the decision was the referral accepted.

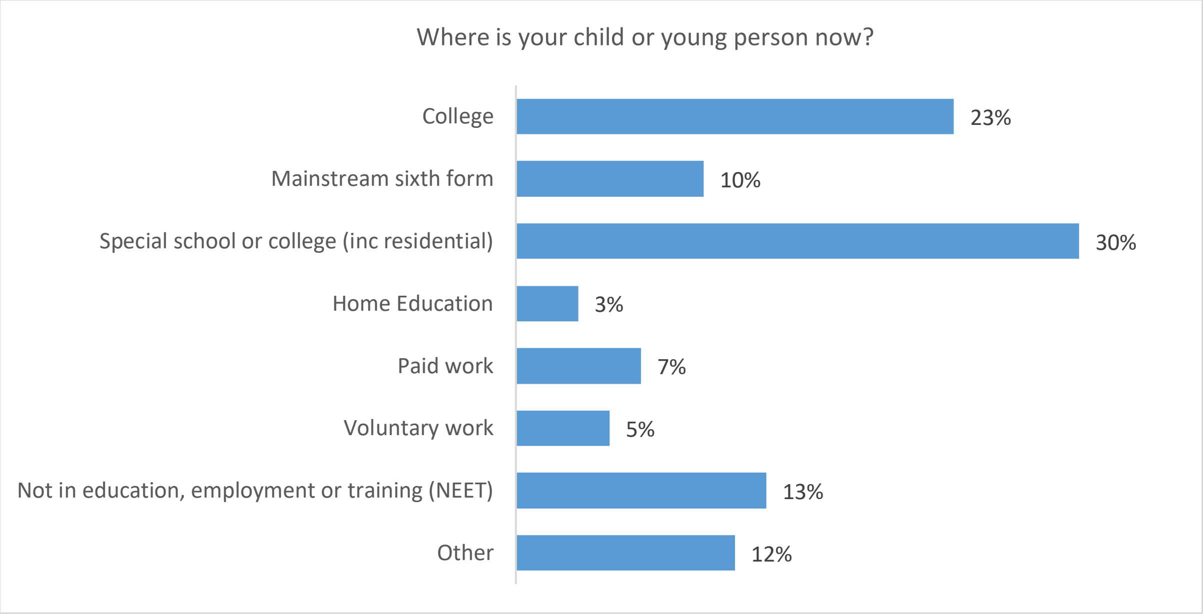
Main findings

Before looking at questions about preparing for adult life, the first two questions set the scene with ages of children and young people with SEND and where they are now.

1. *What is the age of your child with SEND?*

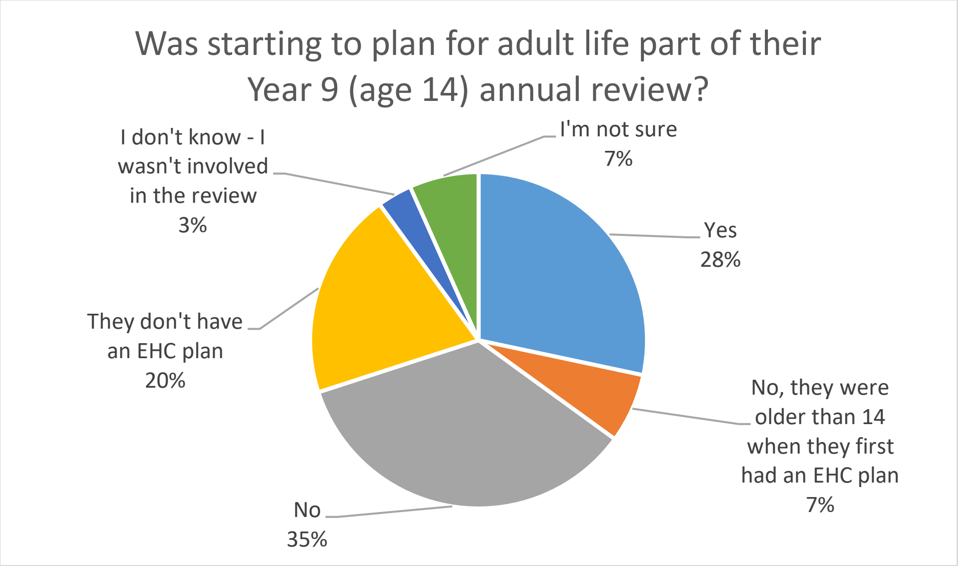


2. *Where is your child or young person now?*



The other category includes young people in day care and residential care centres, wating on a college placement or in supported living.

3. *Was starting to plan for adult life part of your child or young person’s Year 9 (age 14) annual review?*



> I have had to chase and find out stuff myself with regard to post 16 and annual review in Y11 – CYP aged 16

> It was discussed but post 16 options were not – CYP aged 16

> Planning was started but did not contain any detail about how this would be done – CYP aged 19

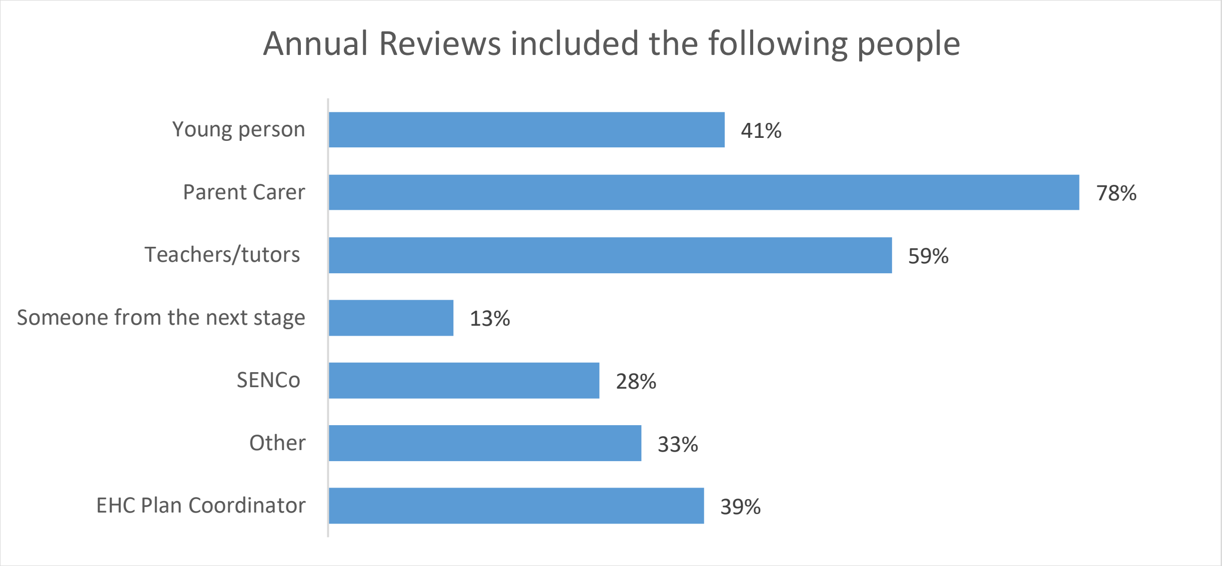
Please refer to Appendix A on pages 15 16 for all comments.

4. *At your latest annual review directly before a transition (for example, from school to college, or when leaving education) who was present?*

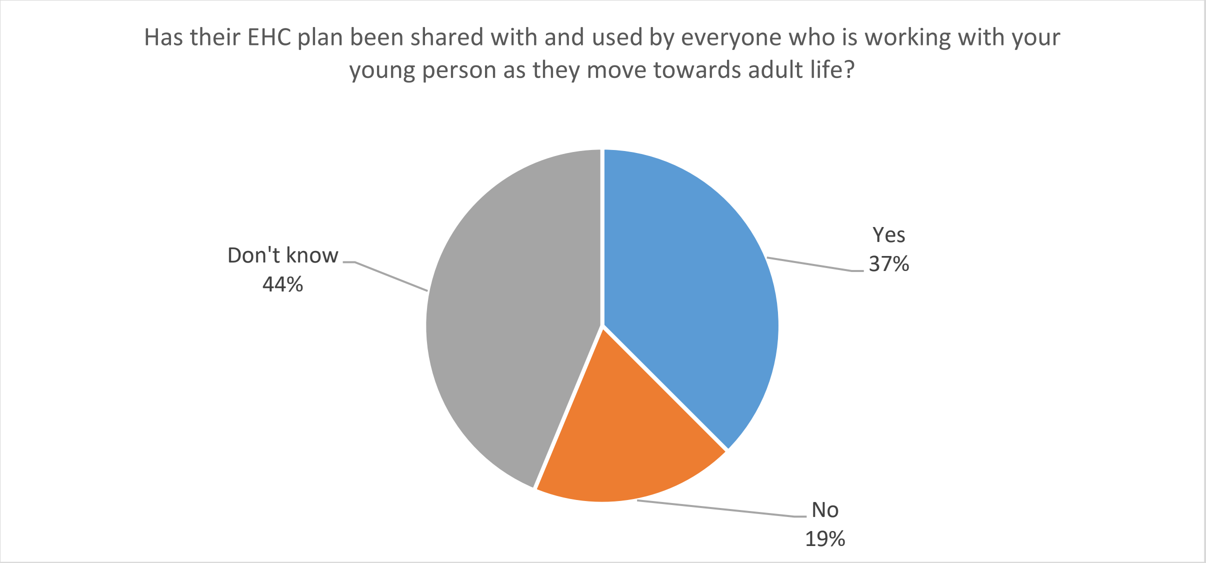
Parent carers were able to pick more than one, so the total adds up to more than 100%. On average, 3 people attended the review.

Parent carers who chose “other” stated that the review was completed online without a meeting, mainly due to Covid. In addition to this, a quarter of parent carers (25%) said that they did not have an annual review.

The chart below refers only to those that had annual reviews.



5. *Has their EHC plan been shared with and used by everyone who is working with your young person as they move towards adult life?*



We have a social worker who is supporting us well but in 9 months she will go and we will be on our own, we are very worried about this lack of support post 18 – CYP aged 17

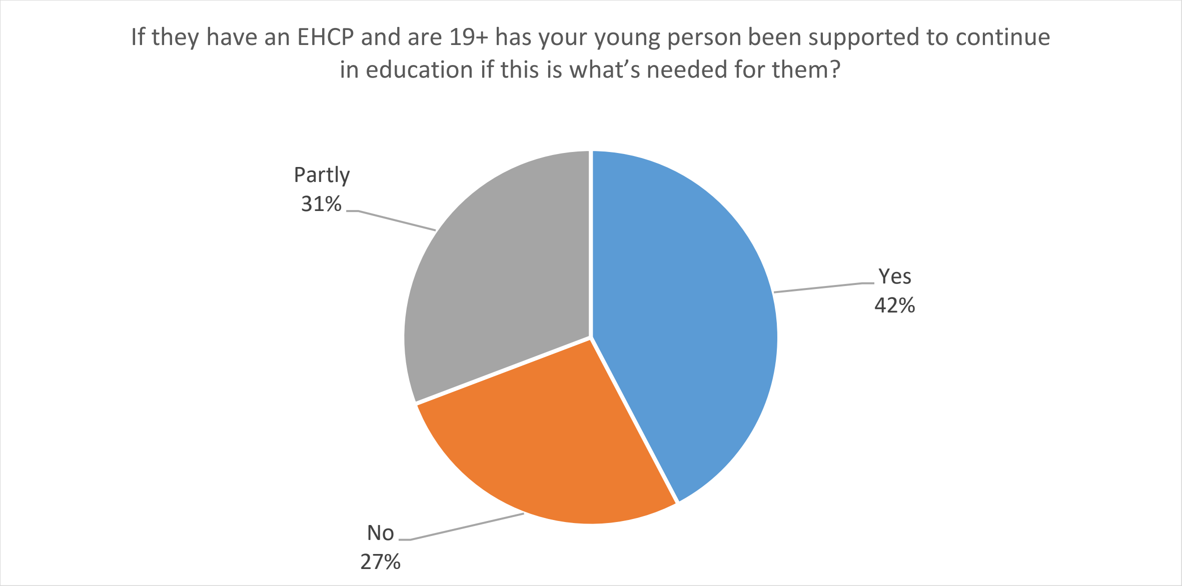
EHCP's seem only for education - no one else even really knows what they are - health - no idea and never looked at it – CYP aged 19

No idea if the PfAL team has seen it; they didn't attend latest EHCP and are poor at communicating – CYP aged 17

Please refer to Appendix B on page 16 for all comments.

6. *If they have an EHCP and are 19+ has your young person been supported to continue in education if this is what's needed for them?*

Only 43% of the parent carers had a young person who was 19 or older and had an EHC plan. Their views are reflected in the graph below.



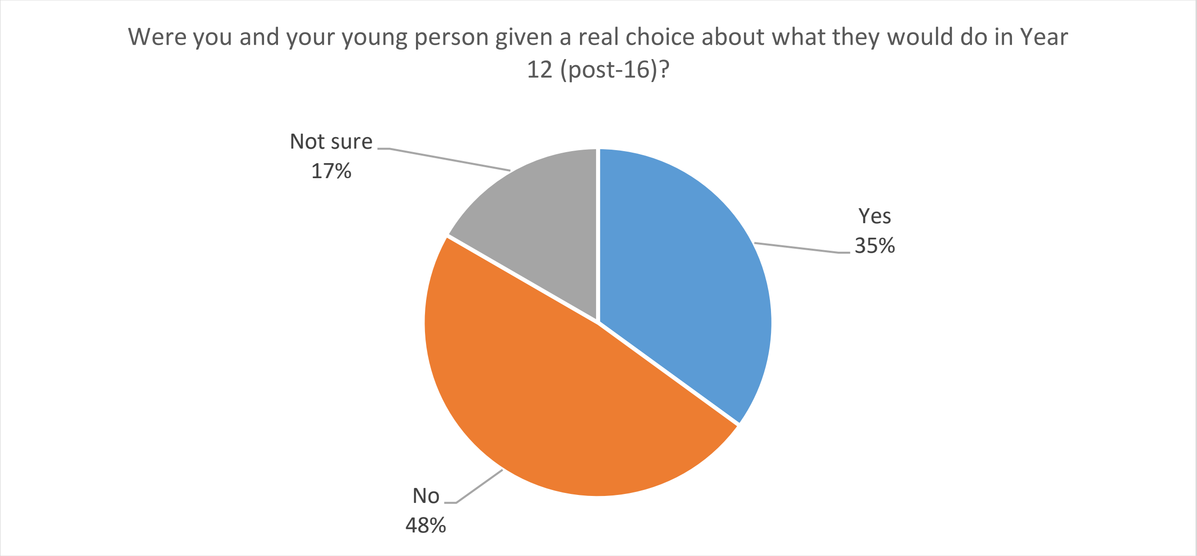
Only because I continually push for this, each year there is a threat his education will be removed – CYP aged 24

I don't feel support or guidance is given based on need it is always around funding – CYP aged 21

Requested PfAL support a year ago, never heard back – CYP aged 19

Please refer to Appendix C on page 17 for all comments.

7. *Were you and your young person given a real choice about what they would do in Year 12 (post-16)?*



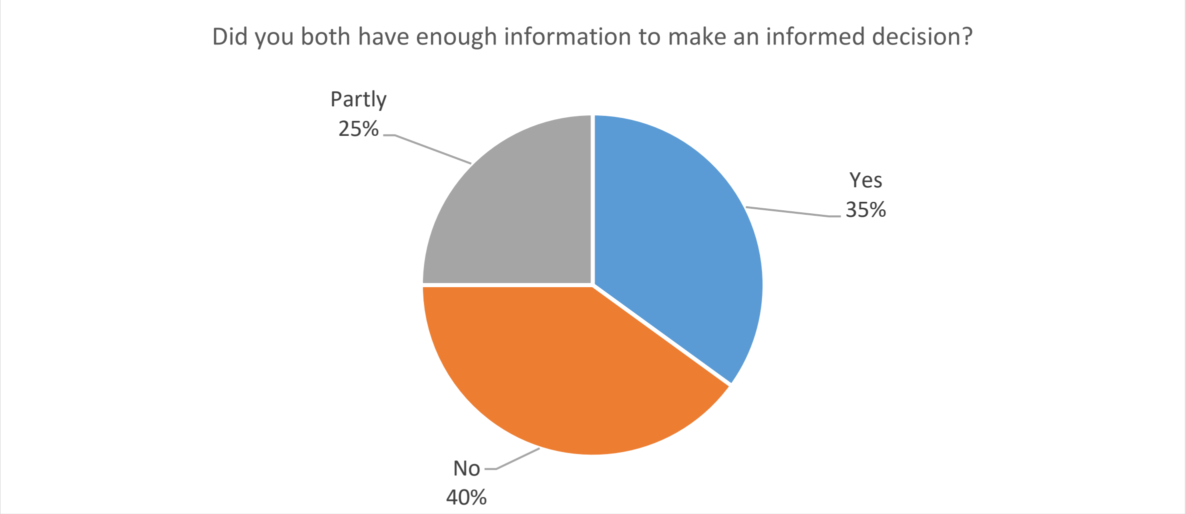
Although the choice was limited there was a choice – CYP aged 17

I've had no guidance. It's been horrible. No one ever contacted me from the council either. It's all been left to me to investigate and find suitable post 16 education – CYP aged 16

The careers adviser steered towards college as the standard choice. We were told the college would have to reject him as not being able to meet his needs for us to secure funding elsewhere – CYP aged 17

Please refer to Appendix D on pages 18 19 for all comments.

8. *Did both the parent carer and young person have enough information to make an informed decision?*



Only because I find out the information – CYP aged 24

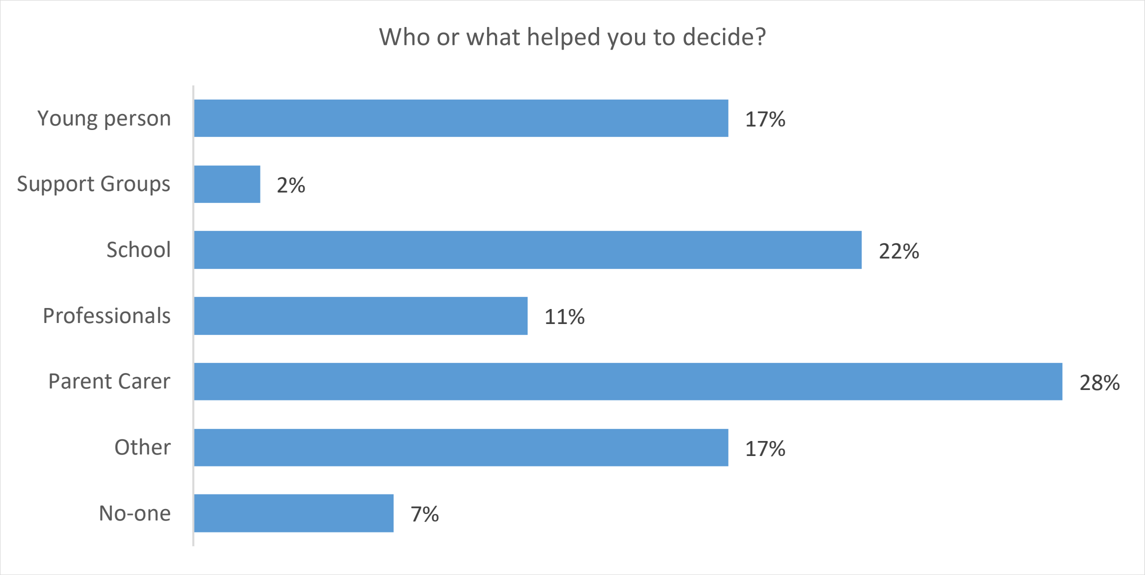
We had lots of online information but nothing that he didn't feel relevant to his needs – CYP aged 18

There is no list...it's a large rural area....facilities are spread too thin – CYP aged 22

Please refer to Appendix E on pages 20 -21 for all comments.

9. *Who or what helped you to decide?*

Parent carers were able to choose from a list. Some chose more than one option.



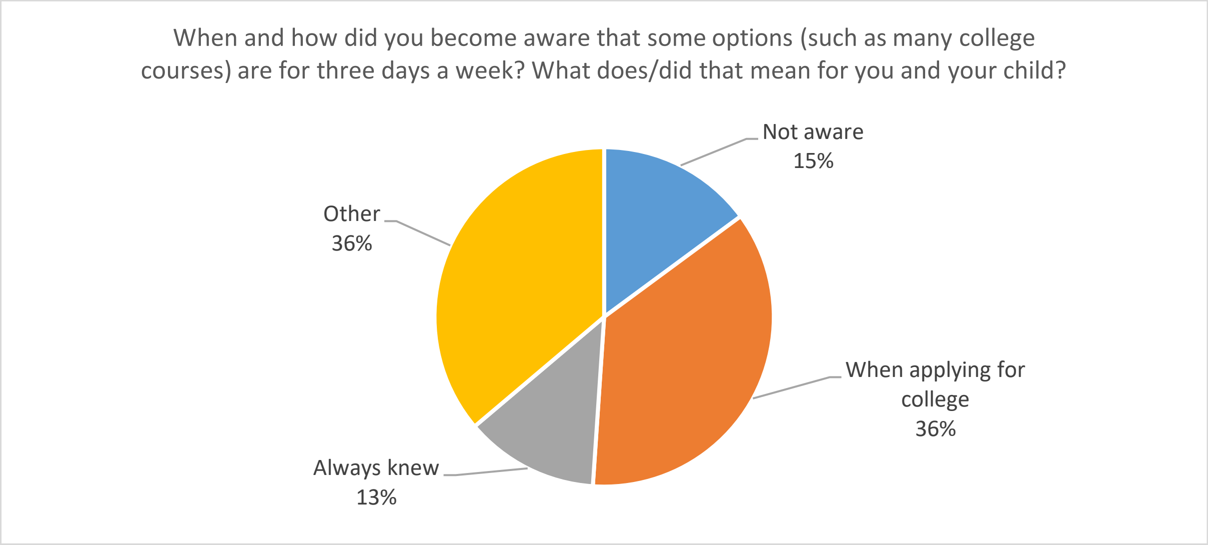
Key worker within school who really knew our young person and family – CYP aged 19

Just me – CYP aged 18

CAMHS team mainly who identified that this setting could meet needs failed by previous setting – CYP aged 18

Please refer to Appendix F on pages 21 - 22 for all comments.

10. When and how did you become aware that some options (such as many college courses) are for three days a week? What does/did that mean for you and your child?



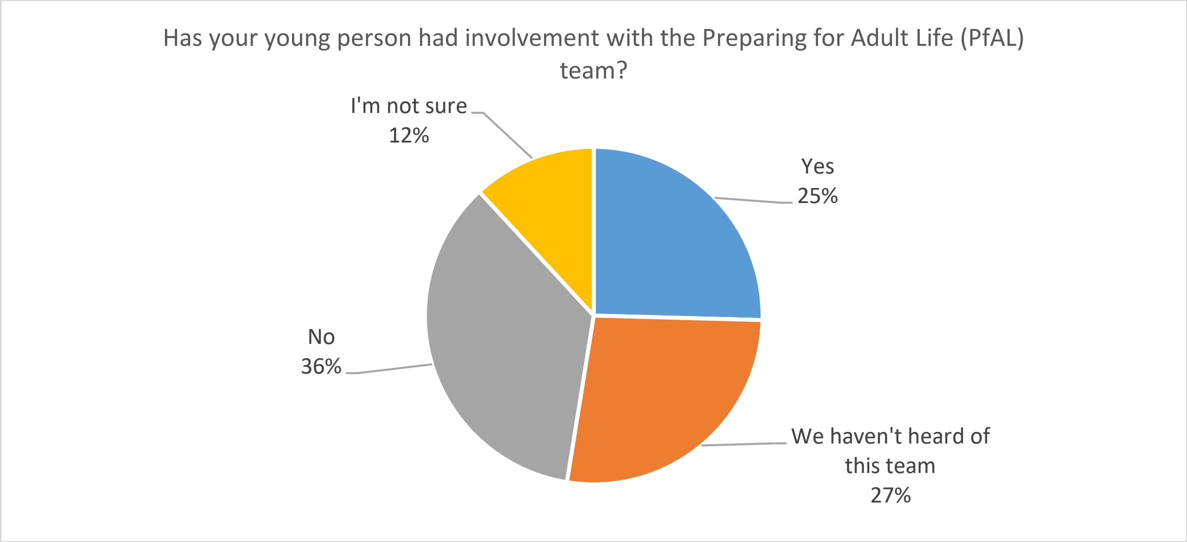
My son's course was 4 days a week. It was stressful that he was alone while I was working for that one day. He did encounter some peer pressure to engage in alcohol and drug taking – CYP aged 17

It would also have been helpful to have known at the point of being allocated/ choosing a special school for our child that some schools only take young people to 16 whereas many others take young people to 18 or 19 – CYP aged 21

That wasn't an issue for us because he can't cope with full time – CYP aged 19

Please refer to Appendix G on pages 23 – 24 for all comments.

11. Has your young person had involvement with the Preparing for Adult Life (PfAL) team?



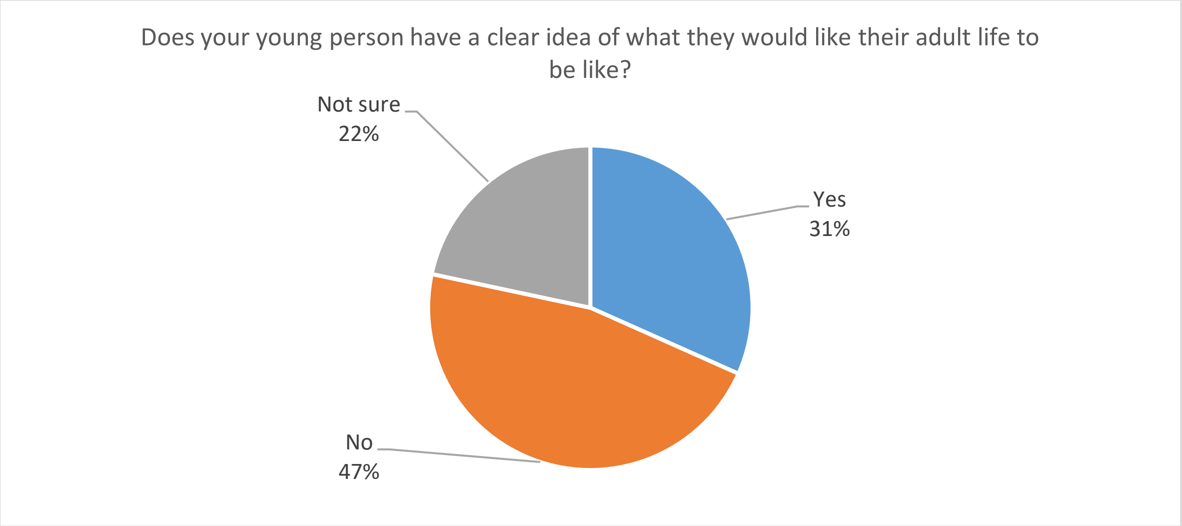
Absolute Godsend in the transition to adult services for our young person and he/we had a practitioner who truly listened to need and instigated referrals which actually will positively transform life moving forward and enable true help and support to be accessed – CYP aged 19

Absolutely no idea what this is – CYP aged 21

It is awful, very upset as PfAL has our son at panel Tuesday we think but she has this week cancelled her visit to us, not sent the report and ignored emails from us and the social worker too. We are very upset and feel ghosted – CYP aged 17

Please refer to Appendix H on pages 25 - 26 for all comments.

12. *Does your young person have a clear idea of what they would like their adult life to be like?*



He has hopes, but does not know how to get there, and nobody has helped us as a family, or my son choose a direction or tell us about any support he might be able to access – CYP aged 16

He wants to become his own boss – CYP aged 18

Young person does not have the capacity to recognise the reality of what independent adult life would be like for them – CYP aged 19

Please refer to Appendix I on pages 26 - 27 for all comments.

13. *Please tell us about the hopes and/or concerns you and your young person have about employment and what stage you are at as far as this is concerned.*

All parent carers have hopes and concerns for their young person around employment. Below are a few examples. Please read appendix J on pages 28 - 30 for all the comments.

I'm frightened he'll be alone and vulnerable. Want him to be doing the things that make him happy and are productive and rewarding – CYP aged 24

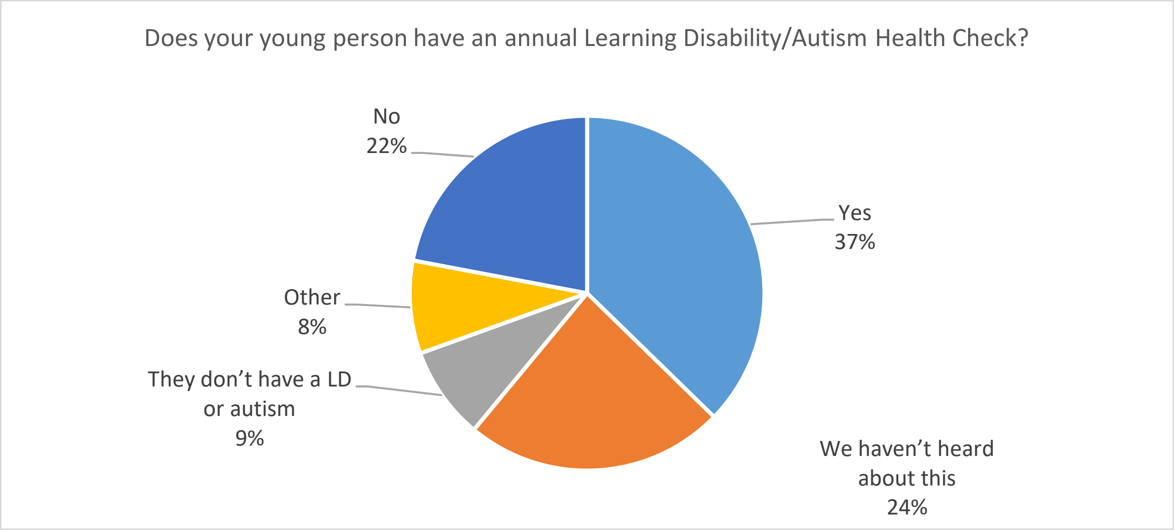
My main fear is disability discrimination, as it is many employers won't even take her on for work experience - CYP aged 19

My son is oblivious, thankfully. My hopes are that he will have good friends, nice experiences and a safe and happy life – CYP aged 19

Getting his first job in the field he wishes to be in. Getting past interviewers who don't understand reasonable adjustments, tics, neurodivergence and see his ability – CYP aged 18

I don't know if T will have these kinds of opportunities as he needs are so high and he's continually been failed until this point – CYP aged 18

14. Does your young person have an annual Learning Disability/Autism Health Check?

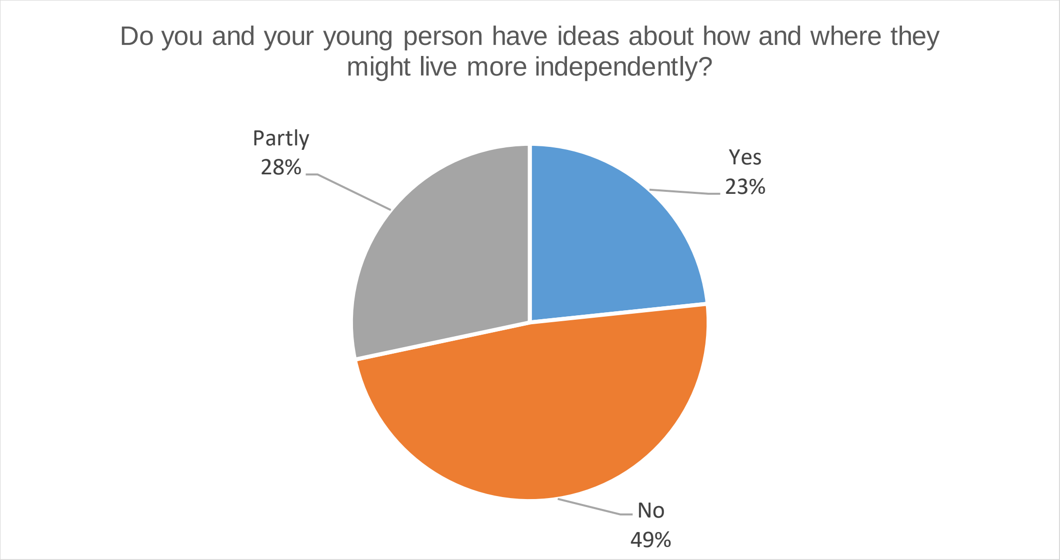


But was recently told by the nurse that ASD isn't covered by the LD Annual Health Check unless they have a LD Diagnosis as well – CYP aged 20

It's patchy. We got one this year but not the year before – CYP aged 17

Please refer to Appendix K on page 30 for all comments.

15. *Do you and your young person have ideas about how and where they might live more independently?*



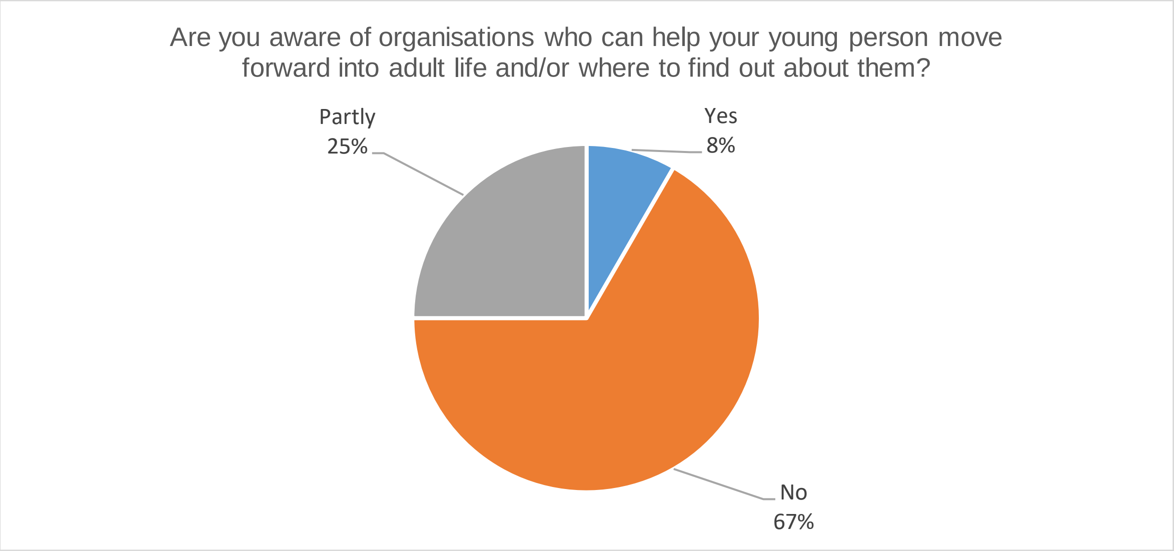
Not in supported LA care that's for sure - even the overnight respite here in west Norfolk is in a terrible state – CYP aged 24

I'd like him to settle in supported living – CYP aged 19

No, we don't. This is despite asking via the EHCP every year for the past 5 years – CYP aged 21

Please refer to Appendix L on pages 31 – 32 for all comments.

16. *Are you aware of organisations who can help your young person move forward into adult life and/or where to find out about them?*



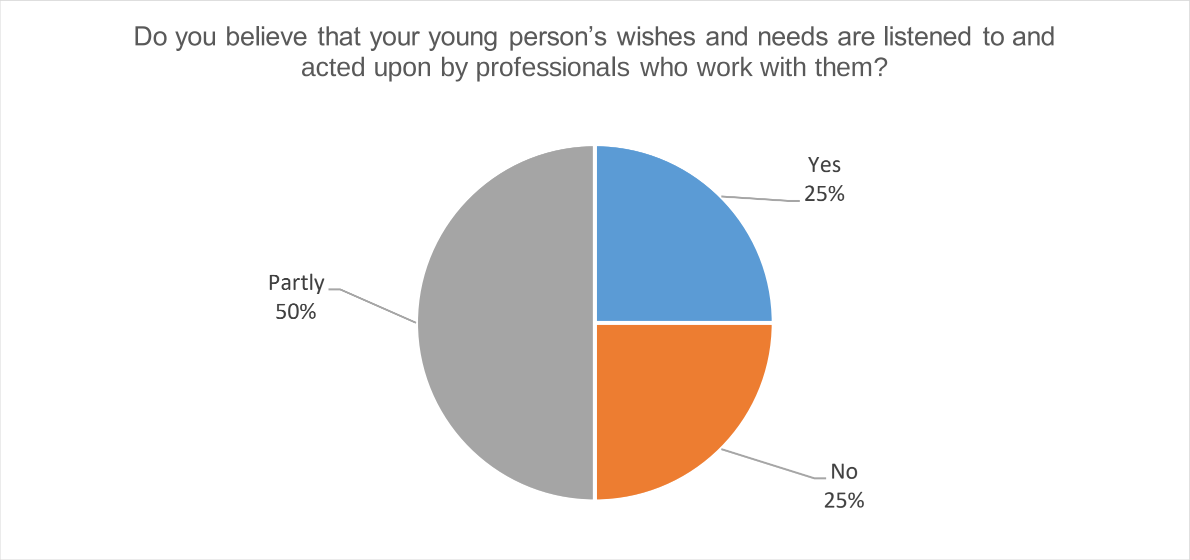
No, never had information or talks about this. Apparently from other parents going through it now, you drop of a cliff at 18 – CYP aged 16

What we do know is mostly down to my research and support as daughter's carer than support or intervention from professionals – CYP aged 21

Are there such things? How do we find out about them? – CYP aged 16

Please refer to Appendix M on page 32 for all comments.

17. *Do you believe that your young person's wishes and needs are listened to and acted upon by professionals who work with them?*



Preparing for adult life team have been fantastic – CYP aged 19

No, because meetings are a disaster because they haven't listened and done what they said they were going to, so what is the point? – CYP aged 23

Some do listen but mostly it feels like a tick box list – CYP aged 16

Please refer to Appendix N on page 33 for all comments.

18. *When you think about your young person's future, what is the main hope or fear that comes to your mind?*

All parent carers have hopes and fears for their young person regarding their future. Many of their hopes are around their young person being happy and leading an independent life and many of their fears are around what happens to their young person when they can no longer care for them. Below are a few examples. Please read all the comments in Appendix O on pages 34 - 36 for a full appreciation of our parent carers views.

We want an active, happy life for our child. One where he feels valued and loved and needed – CYP aged 18

My main fear is that lack of provision, and access to provision is becoming even more limited due to funding cuts and red tape. There is no doubt this will impact on his future and his career. He has worked so, so hard and overcome so many obstacles to get to this point and it's so disappointing to think that the crux of his success or failure rests on adequate provision being in place – CYP aged 17

I hope he can get a job and live independently with support. My fear is when I am dead he will be alone – CYP aged 19

Equal opportunities and the same ambitions as someone without the disabilities or the correct support of others to achieve their aims and wishes – CYP aged 20

Appendix A - Was starting to plan for adult life part of your child or young person’s Year 9 (age 14) annual review?

I'm not sure

- There was a folder and leaflet.
- Long time ago can’t remember but very much doubt it

No

- I have had to chase and find out stuff myself with regard to post 16 and annual review in Y11 addressed it (although not the Ed psych in time and still waiting yet due to leave soon!).
- I think it needs to be as mine is 16 and I still have no clue on anything adult related. Money or no staff is normally the issue. It’s not good enough
- Nothing was done about preparing for post 16 until March year 11.
- There hasn’t really been much planning until recently when my child is about to leave high school
- Didn't get one till last year, they then left final, got one in Jan. Son is 18 in Sept!
- This was not started until half way through year 10.
- We kept asking and were told that would happen later
- This was just ignored as it was an emergency review, despite us asking about it
- I think that the EHCP are a complete waste of time, I am constantly chasing up the educational setting, as she is not getting what is on the plan, despite the college receiving over £6000,as stated on the EHCP
- This was not something made known to us during annual reviews at years 9 and 10. Only in year 11 did it become a 'thing' with school.
- It never really happened. Due to severe behaviour issues, my son moved quickly into Child care sector out of county
- No one was looking more than a year ahead at a time
- No, they were older than 14 when they first had an EHC plan
- No, because he missed out on the year 9 transition this has never been addressed especially through lockdown reviews he’s now 20 and no idea what being an adult means and what it entails.
- Due to Covid, transition went to pot. Plus lack of places to go to. 2 have now closed
- They don't have an EHC plan
- Failed when they were called Statement as primary school have been doing more for him

Yes

- It was discussed but post 16 options were not
- very light touch, going through information on review paperwork and discussing plans we were considering for post 16 (initiated by us)
- It was just mentioned but not really gone into detail
- Very woolly and glossed over.
- Planning was started but did not contain any detail about how this would be done.
- School have a bullying, mercenary approach to all important issues. This means that it is very likely that my son will remain under the care of people with little or no understanding about his true capacity. They are ready to lie at any opportunity to make us dependent on them because their jobs are at stake. For example, the school teach independent travel, however, my son has always refused to participate in the lessons, but has been brought up to be and think of himself as independent since birth. I gave him small errands to do as soon as possible, then discreetly following, was able to gauge how capable he was of independence. Recently he showed instantly outside of the dark, repressed school environment that he can travel long distances alone. When school became involved at the annual review meeting, a senior corrupt member of staff said his independent travel was coming on, as though school should take credit, and implying that they enjoyed good relations with the family. The reality was that they had nothing to do with it!

I was recently horrified after hearing from my son that each time he has returned from a family funeral and has had to travel 800 miles round trip, as soon as he arrives in school (usually the morning after), he is made to do an important piece of assessed work or an exam which could be done on another day.

My son asked me to request Special Consideration for him this year, as he recently lost his Grandfather. The Exams Officer's only reply was that many other people could benefit from that, as though he resented the advantage! He has a ruthless bullying problem. I rang Ofqual, who said it was malpractice, and that I should report him to his bosses at the school , and Ofsted. However, they have power over my son, and they abuse it. Reprisals form part of their approach, which they disguise as behaviour management. Thus, formal complaints are difficult.

Under these conditions, it is clear that the Government and schools are unsupervised and unaccountable which means children and adults with SEN are unlikely to reach their true potential.

Appendix B - Has their EHC plan been shared with and used by everyone who is working with your young person as they move towards adult life?

Yes, EHCP has been shared

- Phoenix Purple at City College have a copy
- We have a social worker who is supporting us well but in 9 months she will go and we will be on our own, we are very worried about this lack of support post 18. At our request we have met with the schools careers adviser (a year earlier than normal) to get his advice.
- difficult. As some kids need more support. Getting staff is a problem
- Not many people involved

No, EHCP has NOT been shared

- All I know is school and possibly some council departments. Not sure anyone else does.
- Teachers clearly not aware of it all, unsure about TAs
- The sixth form that our young person moved to did not even have the latest EHCP when I went to the first annual review there. I am in no doubt that with the exception of one teacher, no-one else has ever looked or worked from the EHCP.
- EHCP's seem only for education - no one else even really knows what they are - health - no idea and never looked at it.
- Had problems in Essex for two years the college never knew he had an EHCP. Hence we moved away from the crap we had to do with the college.
- Plan was shared but has not strategies stated in plan have not been implemented.
- The plan was completed by staff at City College but not updated on their system so when he joined MINT (based at City College) they didn't have it and we were never sent a final draft after the last review.

I don't know if the EHCP was shared

- I know college have it but not sure about PfAL team and Titan.
- It’s available but hadn’t been followed causing issues.
- No idea if the PfAL team has seen it; they didn't attend latest EHCP and are poor at communicating
- No one has ever said
- Do not get told enough information just presume that it should!
- My son with leave college in July and starting an apprenticeship in September .

Appendix C - If your child or young person has an EHCP and are 19+ has your young person been supported to continue in education if this is what's needed for them?

Yes, our young person was supported

- By the SENCO and LSA supporting him to pass his course, when his teacher said he would fail and lacked motivation. Even though it was due to the fact that he couldn't access the learning the way they wanted him to or when he needed the support more individualised to meet his own needs.
- Education package is provided by residential care setting
- Only because I continually push for this, each year there is a threat his education will be removed - but he continues to make progress and attain qualifications and work/ life experience so it's maintained . If I didn't do this at home here in West Norfolk there would be absolutely NOTHING in terms of appropriate specialist autism specific educational input . The mainstream college is useless and totally inappropriate to meet his needs
- Supported to apply for the next steps, has applied for and been accepted to specialist department within City College Norwich.

Our young person was partly supported

- Again back in Essex I had meetings but they removed my son from college which put his mental health in serious state. We then moved to Norfolk and he turned 19. Now he is in limbo to find out if he is going to college here as he has had two wasted years in Essex college. Hopefully he will be going in September 2022. He needs to have a sense of purpose. He is lost and needs that asap.
- Covid and lack of care in adult services e.g. respite has caused us lots of grief
- I feel I'm very much left on my own to find suitable alternatives, I don't feel support or guidance is given based on need it is always around funding - however once I made the decision on the suitable college my EHCP co-ordinator was very helpful
- She certainly doesn't get the support that she is supposed to get
- Specialist home education
- Young person has not been given sufficient support to choose appropriate courses. It is a constant battle to get college to directly support the young person rather than just giving on-line information which he does not read or process.

No, our young person was NOT supported

- He was supposed to go the hummingbird programme at Kings Lynn college but it never worked out, they didn't seem to have a programme available for him even though he has enrolled he has only had visits so has just been sat at home for a year.
- No support provided to remain in education or to consider wider learning opportunities
- Not really given as an option
- Requested PfAL support a year ago, never heard back. EHCP not amended in a long time.
- was not offered

Appendix D - Were you and your young person given a real choice about what they would do in Year 12 (post-16)?

Yes, we were given a real choice

- Although the choice was limited there was a choice.
- But lack of suitable places. Lack of transport...more needs to be done
- Child stayed on at special school in 6th form.
- He wanted to do A levels and City College were very good with flexible entry for him as his education was disrupted due to illness. Plus they were also very accommodating to him only doing 2 A levels.
- He was taken to a couple of colleges to look round
- My daughter was fortunate to attend a special school and transition in the post 16 class there until she is 19
- School SENCO helped us both
- She was able to make informed decisions.
- There were choices but my son was very focussed on working on a farm
- We made our views quite clear as to the preferred route for our YP.
- We were informed about college or 6th form

No, we were NOT given a real choice

- Guidance was limited due to lockdown. First course selected he changed his mind at the 11th hour. Quite a stressful transition and he struggled to engage in written assignments and required timescales.
- I feel the local mainstream college was pushed on us - even though I knew it was unsuitable - I feel my son had to fail first in order to get a more suitable college placement
- I had to thoroughly research. No advice given.
- I have long expressed a wish for my son to leave his abusive special school and come to school locally. I wanted him to be schooled near his home and integrate into the community. We have been kept under a rock by the school system for many years. We went to an open day at the local community college. The college was very nice, but the lady who was our contact met with the school without ourselves and began to verbally abuse me in a meeting soon after. I had to ask her if she had been told to annoy me, she said she hadn't. Currently, we do not have a place for this September, and are not yet able to apply for an interview, but have been verbally assured by the SEN co-ordinator that she and her boss have the power to insist on the subject teacher taking my son on the course. Basically, we must depend on her for everything, which I personally think is fishy!
- I've had no guidance. It's been horrible. No one ever contacted me from the council either. It's all been left to me to investigate and find suitable post 16 education
- It was left completely to me.
- My child wanted to do an apprenticeship in Hairdressing & had a place with an employer but the college wouldn't let her do it due to her maths ability.
- No choice as school decided class post 16 but T had just moved to this new setting due to failure of previous one to meet needs. New setting very good.

  Planning for post 19 feels very daunting. It seems that one college can’t meet needs and the other appears too big for him despite possibly having a suitable course. Also concerned that the vibes from some social care settings are that his needs are too high. He’s been failed throughout the system until starting in Sheringham at 15. I wish he could stay there!

- No considered at all
- No he just went into year 12 and was doing what they had planned and at the moment it’s football and DVD. Apparently not enough confident staff to deal with his anxiety and aggression so I’ve lost all faith in education. I was promised a place for him in 6th form and now it might not be happening I find out this week, bit late
- Only given one option of college
- Phoenix Purple was the only option
- School didn’t support us with any information. We made enquiries ourselves. The school couldn’t really inform me much about year 12
- There are little or no choices here in west Norfolk
- We didn't want to change settings so no choice needed
- We had no careers guidance and no help whatsoever - nothing
- We were only made aware of the 'formal' style education for year 12 onwards, so college or sixth form within special schools. Nothing further was discussed with us and only now am I aware that other options do exist if 'out of the box' thinking is applied.
- We've had no advice or support at all from anyone

I'm not sure if we had a choice

- Choice post 16 was not recognised by school, was told by school course did not exist, school would not do transition to the course moving onto. Professionals from health supported transition instead.
- His apprenticeship will be one day at college
- Not sure what is available really - doesn't seem to be much that would suit my son. We were told of different colleges.
- Options were limited.
- The careers adviser steered towards college as the standard choice. We were told the college would have to reject him as not being able to meet his needs for us to secure funding elsewhere.
- The natural progression was to move to 6th form within school which was excellent
- We applied for Phoenix Purple at City College, finally offered a place in April after interview in December. It was made clear they were oversubscribed and we were unlikely to get a place. There is very little in place for academically able young people who have high support needs.

Appendix E - Did you both have enough information to make an informed decision?

Yes, we did have enough information

- Because I find out the information
- For what we did choose, there was information available and also real people to talk to, both within the then current school and the special school sixth form to which young person was transitioning.
- He wanted to stay in education
- I had put in EHCP from the age of 12 where I wanted her to go!
- She has chosen to stay where she is.
- There is very limited choice so there wasn't really a choice
- When T started at the new setting aged 15 he went straight into the college class rather than having to transition again after one year. School discussed with us the class they thought could meet his needs. We trusted them as they were recommended by CAMHS team. There wasn't really a choice more we were being finally offered a setting which could actually meet needs. We had lots of info and contact with the new school and the transition planning was thorough.
- We had a meeting with the head of sixth form who was very helpful.

Partly

- From what we thought available to us then yes, we chose where to go though we felt there wasn't really much of a choice.
- I was very happy to continue within the school setting
- The course details were all online and tutors were available to support.
- we had lots of online information but nothing that he didn't feel relevant to his needs I spoke to a lady at city college who runs Purple Phoenix but my son point blank refused to entertain the idea
- What options there may be available seem extremely hard to find . It's word of mouth no central point and no-one seems responsible

No, we did NOT have enough information

- Have asked continually for meetings about support available for Sixth Form, keep being told funding is different etc. Have decided to trust the school because EHCP is pretty detailed, Sensory Support are helpful and school have been good up to now but it feels like a massive leap of faith.
- I believe our young person has had conversations at school but he has not been able to share them with us and there has been no information coming from the school.
- I feel there is very limited local education for children/young adults with autism
- I was given no help until she became in danger of becoming NEET
- Just asked if he could do apprenticeship where his dad worked as he knew the people and had an in interest, but wouldn't admit he needed support even though it was put on the application form, that mysteriously went missing, and was talked out of requesting, a new support form as he's over 18 and didn't need parents' consent to fill it in so was persuaded by assessor that he didn't need it and went along with it and then college pulled the plug on him near the end with 18mths of being furloughed and unable to work on course due to lockdowns, saying he wouldn't finish in time, as he was behind on one part of the course filling in college 'one-file' system daily diary part, through lack of support and help to know how to use it, four years wasted, no qualification and now won't leave his room or do anything for himself. Denied the support he really needed and felt he wasn't able to speak up and be listened to! If he had a EHC plan they wouldn't have been able to treat him like that! The failure is also within colleges and apprenticeship as only one person from the class actually passed and the rest were all pulled the plug on too, without having his disability needs.
- No, had to search for information, other parents and support groups passed on word of mouth advice.
- there is no list...it's a large rural area....facilities are spread too thin

- There we'll be a better place for my son post 16 but no one helped me with options.
- Very limited info out there - you just have to find out about stuff from other parents - care farms/volunteering opportunities etc.
- We have not been given any information regarding how my son's therapy needs will be met by the local community college. They are only offering a two-to-one Teaching Assistant. However, it is very likely that his occupational therapy needs weren't met by his special school either, and this was hidden. I believe that this is caused by the Government policy of the schools doing 'anything it takes' to stop behaviour. They have taken advantage of this and are using it abusively to stop me from complaining or objecting to malpractice. I have seen much unacceptable, newsworthy stuff hidden at the school in which the Government is complicit.
- We were only given one option
- Young person made decisions based on subject courses. College did not involve parents enough in talking about what additional support was needed.

Appendix F

- No choice really. About with Friends. Closed down in Cromer...other places are 20 plus miles away. Logistically difficult with family life. Impossible to travel further. You would spend one third of the day driving
- No one, no informed social workers
- Nobody.
- A friend who works at Phoenix Purple told me about the course. I looked online and the made contact with the college. I felt it was a good step from an SEN school to college because of the separation from the part main campus and availability of a safe space.
- My child needs are complex and it is becoming clear that adult social care is not well provisioned for someone like him.
- The only answer was for special needs 6th form as close supervision one on one needed
- The only option was to do a full time college course.
- We don't believe it is healthy to encourage the idea of 'helping us decide ' as in the past this has led to coercion.
- We had to go with the only course with space that would take her.
- We had to go with the provision that agreed they could meet need, as they were the only one LA would fund.
- We work in education
- I found the college myself it was NEVER recommended - I found it online
- Just have to do all of your own research!
- Just me
- Looking around the care farm ourselves
- Me
- My Knowledge of my son and obtaining the right reports
- Ourselves
- The fact he was only comfortable with younger people rather than people of all ages, he decided sixth form college would be a better choice and safer environment for him, now he’s one of the oldest there.
- Us going for an open evening and speaking with tutors
- We felt remaining at the school, but in their sixth form, where he'd been since 11 would help him transition well rather than him move to another location/education stream.
- We found out ourselves about Phoenix Purple course at City College Norwich and went to an open evening to find out more about it. We then self-referred and asked school to assist.

- We just had to do the best to choose, but I have no idea as a parent how things will work out come September
- Advice from support groups and professionals in health, and college transitioning to.
- CAMHS team mainly who identified that this setting could meet needs failed by previous setting
- Key worker within school who really knew our young person and family. Visits to the SS sixth form, very well prolonged period of transition visits.
- PfAL team. Social worker. School and health teams
- Transition lady in school
- City College
- My son and his teacher of the deaf
- My son felt uncomfortable at City College interview and they seemed unwilling to accommodate his V.I., Sixth Form open evening- everyone seemed very positive about having my son there and his academic potential.
- School
- School SENCO was brilliant, I wish we still had her.
- School, ourselves, open days and conversation with college and our son had an input too.
- Teacher
- The College
- The excellence if the setting
- Tutor
- Advice from support groups and professionals in health, and college transitioning to.
- He decided himself he tried college but felt the same feelings he felt at school and hated it
- He decided what he wanted to do but never got the full help in Essex. He was let down by the system and wasted two years and is behind in his peers.
- He did
- My daughter wanted to go to college and she has achieved that.
- My son and his teacher of the deaf
- My son is strong minded and made his own choices. I agreed as I want him to learn through his own decision making process. Even though he has struggled he has managed 91% attendance and was able to think about plan B! Progress!!
- She chose herself.
- Young person chose college based on the course that they wanted to do.

Appendix G - When and how did you become aware that some options (such as many college courses) are for three days a week? What does/did that mean for you and your child?

Not aware of this

- Had no idea
- I did not already know
- I did not know this until I read it in the questionnaire! I'm not sure how we will manage this
- Never knew may have made a difference will never know now
- Not aware of this
- We are not aware. Trying to do our own research
- We were not aware. My child does a 5 day week - 4 on site, 1 work experience.

When applying for college

- At college interview. Added huge pressure as I have to be home more during the week.
- At Easton college Interview.. I was happy that my son would be at home for the other 2 days & so was he.
- At the point of beginning the course. The next question should be 'And what additional provision was put in place to ensure a full week of challenging and developmental input?'. To which the answer would be 'none' ....
  It would also have been helpful to have known at the point of being allocated/ choosing a special school for our child that some schools (Parkside for example) only takes young people to 16 whereas many others take young people to 18 or 19. We had a nasty shock at 16.
  This has meant that mum has become the main carer and social worker ATTEMPTING to ensure that a full week of provision for our daughter is possible.
- I was told by a friend - not a professional - when child aged 16. This is a massive problem. My child has autism and needs to have consistency of provision 5 days a week, he become very unsettled (which can lead to lashing out) if he is not in a consistent placement every day.
- in year 11 when we had to choose new setting for post 16. Rather concerning and part of the reason a 5 day sixth form place was chosen.
- Late in my investigation. It's made things difficult as I'm not sure where my son will go on the 5th, no college, day. I work 5 days a week and have been unable to find care or help for that 5th day when he will not be in college.
- Never new until he attend college and got his timetable.
- On enrolment day!!!
- On the interview day. That is a concern as our son needs structure and struggles at home. He needs more than has been offered.
- Only once he had applied for college. Nightmare for me trying to work and trying to find suitable activities for his days off. He had one day in day-care which was not really suited to his needs, but as he was under 18 at the time, the options were really limited. He did volunteering with Volunteering Matters but we ended up paying for him to be supervised. It was very expensive but at least got him out the house for a couple of hours.
- Told by another parent, Sixth Form is full time with 2 blocks of home study a week so is much more suitable
- Upon leaving school, it made me anxious about how I would cope with the extra caring responsibilities
- Was told when arranging college visit. Hoping for funding for local Helping Hands placement for further 2 days weekly.
- we became aware about the college courses being 3 days a week at a school meeting.
- When college explained course or given timetable.
- When we applied
- When we went for the open evening and spoke with course leaders

Always knew

- Few years ago
- Have always known. It’s unacceptable for our people and education post 19-25 should be 5 days a week
- Have known for years but it’s totally inappropriate should be 5
- I work at City College so knew this
- Very early on and not suitable. Needs 24/7 support.
- Very hard only having 3 days - not able to hold down a job full time and lack of further study at an age when they could still be developing and learning new skills, not great at all.

Other

- A while back and it was something I was concerned about and made a note to check up on, however, post 19, we have been offered either 3 days education with 2 days social care or all social care funded by health.
- He can work independently anyway so it's fine
- he tried the three days but the whole environment felt like being back at school even the English tutor was overwhelming once she knew how bright he was she expected more effort which he then despised going which put us back to square one with refusal and fighting and arguing.
- I did not find it a problem . I knew it would be 3 days a week because my eldest son had previously attended college
- I'm not looking forward to cutting my work hours if I don't find 5 days a week!
- My son’s course was 4 days a week. It was stressful that he was alone while I was working for that one day. He did encounter some peer pressure to engage in alcohol and drug taking. This was in part due to the fact they had so many free periods and boredom led to reckless/impulsive behaviours (ADHD).
- Not appropriate, she needs to be in full time school.
- Not relevant to A levels
- Our 6th form place was 5 days per week
- She made her own choice, my husband and I supported her all the way
- That a placement needed to be found and funded for the other 2 days in the week
- That wasn’t an issue for us because he can’t cope with full time
- This option was fine for all of us
- We believe that this time will be used in work experience, studying and taking the opportunity to work on other things.
- We had to make sure that contingency plans were in place as both parents work full time.
- When we looked around the college. A lot more expense as wasn't always in full days.
- Young person really struggles with 5 day week but no other options were given.

Appendix H - Has your young person had involvement with the Preparing for Adult Life (PfAL) team?

Yes, we have had contact with the PfAL team

- Child was 18 in January 2022. Am still waiting for assessment to be completed am without respite and personal care services at present. Child services dropped us on child’s 18th birthday. Am self-funding Helping Hands in holidays.
- Contact just after 17th birthday and follow up to agree post 18 respite contract with NCC
- Excellent practitioner who’s been involved since T was 15
- It is awful, very upset as PfAL has our son at panel Tuesday we think but she has this week cancelled her visit to us, not sent the report and ignored emails from us and the social worker too. We are very upset and feel ghosted.
- It takes months, 3 months post 18 and nothing's been finalized equalling. No respite for last 3 months!!
- It was an utter battle to get the referral accepted despite my child having all the criteria stated. It was only after I stated that I would appeal the decision was the referral accepted.
- It was very unsatisfactory, with lots of chasing from us which caused much frustration
- Not really sure what they do to be honest...
- Picked up by the PfAL team at about 17.5 years of age, rather late but a new team overwhelmed by need I believe. Absolute Godsend in the transition to adult services for our young person and he/we had a practitioner who truly listened to need and instigated referrals which actually will positively transform life moving forward and enable true help and support to be accessed. Care plan put in place and signed off from service after its first review. Unsure where we turn now we don't have that practitioner assigned to us but I am sure I can find that out. Only things not really explained to us were the massive differences between having Short Breaks as a child and accessing adult services where only the cost if the PA is accounted for. DRE were not explained to us and I am still flummoxed by those and there wasn't much information about a carers assessment for me but in all other areas, the PfAL Team experience was very good and helpful indeed.
- Really good then the lady left, a man took over who was really awful and now we have another lady who’s yet to do anything
- Very good team
- We have had a 1 hour zoom call from the team. They are going to arrange a visit to school this half term

We haven't heard of this team

- Absolutely no idea what this is
- No idea what this is.
- No one has mentioned it
- Not aware of them
- This would have been very helpful as he’s in his twenties now, with no future!
- Who are they? No one has told us about them
- Would be very helpful to us if we did know!
- Would like further information

No, we have NOT had contact with the PfAL team

- He has been on the wait list since the middle of year 11 when TITAN was mentioned. He will be 18 in 4 months and is still on the wait list - this was supposed to be a priority list as well.
- Never heard of them!
- Never heard of this
- Never offered.

- Our social worker referred us 15 months ago. She has been chasing up every 3 months. Last month we had a video call with someone from PfAL where we outlined why we felt we needed to be allocated prior to age 17.5 which is their current plan. they told us we would get someone allocated in May. The end of the month is next week and we have not heard anything.
- Referral was accepted at age of 14, have heard nothing since school also referring him recently and him being almost 17, Short Breaks have suggested I chase it up
- This wasn't offered or discussed.
- We are apparently on a waiting list so I have been told
- Who? What ?

I'm not sure

- I think this may be the case
- We know a referral has been made by school (with our consent) and we have been accepted but the communication was via school and not with ourselves until I phoned them and asked for an answer. Not heard since.

Appendix I - Does your young person have a clear idea of what they would like their adult life to be like?

Yes, my young person has a clear idea of what they would like their adult life to be like

- A professional boxer or footballer
- Currently wants to be a mechanic
- He doesn't want to go to university. He hopes to get into video/ film/ editing work.
- He has some ideas, but they are ever changing depending on his peer group.
- He wants to be a zookeeper specialising in Herpetology.
- He wants to be accepted into college to continue his plan.
- He wants to become his own boss in barbering
- Partly, within her understanding and experience.
- They need services to help them to do this, but SW and employment services don't seem to be able to adapt to helping people with HF Autism
- Want to become mainline train driver and earn money doing so. Regrettably has researched and discovered unlikely due to medications, no GCSE's and LD. Already disappointed that not been successful accessing volunteering there due to high support needs and further disappointment that sixth form has continuously failed to provide/enable meaningful work experience. NONE at all and son told directly by school (as have I) that they cannot afford the staff to support him to do work experience at a heritage railway, or anywhere else it would seem.
- Wants to be a midwife and live with her friends, it won't happen but that's what she would like
- Zoology

No, my young person does NOT have a clear idea of what they would like their adult life to be like

- Being an adult just means being over 18 in his eyes?
- Child has Down Syndrome, functioning age 3-4 years.
- Cognitive ability and understanding of a 2-year-old
- Doesn't have the mental capacity
- He doesn't really understand the options and can't think very far ahead.
- He has hopes, but does not know how to get there, and nobody has helped us as a family, or my son choose a direction or tell us about any support he might be able to access.

- He needs total care and to be safe...recent horrors at local places included deaths of children with Downs syndrome. It hit BBC news. Gives one real fears for the future!
  The new Downs law, which will help. But it needs action as well as words.
- He's terrified about moving from his special school and about becoming an adult. It's affecting his mental health.
- Severe mental health issues are affecting her decisions.
- She has severe LD and Autism, life is confusing for her. She just wants to be happy.
- She lives for the day!
- Some ideas
- They have no ideas really and it makes them anxious
- Young person does not have the capacity to recognise the reality of what independent adult life would be like for them.

I'm not sure

- ASD
- Does not think past one day at a time.
- He cannot communicate verbally any idea about what he wants to do beyond today. He struggles with the concept of time or future.
- He doesn't know yet is trying lots of different things to see where his best fit is
- He has a rough idea
- I don't think this is something he thinks about
- I know that my son would like to live independently and to work. He doesn't like to be referred to as autistic, he wants to be called by his name. The system is limiting his opportunities in many ways.
- My daughter would be unable to express her opinion on this
- My son wants to be a famous author, but he lives mainly in a fantasy, and it is concerning about how we can get him to develop life skills and other skills in case being an author is not successful.
- T is non-verbal, he likes certain things but I still very very overwhelmed having to decide the wider framework for him.
- They are just confused and anxious about where and how they fit into society

Appendix J **-** Please tell us about the hopes and/or concerns you and your young person have about employment and what stage you are at as far as this is concerned.

- I just hope that he is able to get a job of some description
- Hoping that if they learn a trade, it will give them a better chance of employment as only has one GCSE.
- Getting his first job in the field he wishes to be in. Getting past interviewers who don't understand reasonable adjustments, tics, neurodivergence and see his ability. Then it will be to earn enough money regularly to manage his life independently.
- My son is not very motivated to look for work. He is hoping that he can work with family members. IN some ways this is good because he will be supported. However, I would like him to become more independent with job seeking skills and preparing a CV. I could help him as have experience, but teens don't always want their parents' input.
- We are concerned that he will be unable to work in that kind of environment unless he is part of a buddy system.
- He is in limbo as he has no college to go to and his mental state is suffering
- He works part time and found the job by himself so I really have no issues there but he won't tell anyone he's neurodivergent so they don't understand why he has no filter. He also wants a certain fit for the barbering and he doesn't seem to understand that he needs a qualification and won't entertain it, even an apprenticeship he refused to entertain.
- Where is the 'laughing but crying' emoji option when you need it??
  I cannot answer this question in a few words or without extreme frustration and emotion. The system is shocking, and support for families is unbelievably poor.
- Had a meeting with a new worker from NES Norfolk employment services, after rudely being told my YP didn't qualify for a service, well she did before Covid? They are not trained enough about how to work with people with Asperger's and I am sick of organising meetings where the incompetence of those people causes such stress to my family and really is not helpful.
- Both of us (son and I) feel this is a pipe dream. It shouldn't be but high-level support needs, LD, ADHD and autism are not conducive to finding success in a job. Or finding a job that he wants to do at all. Not driven by money, not interested in just having 'a' job, he wants to do what he truly loves because all through his life it has been about hopes and dreams and not actually about realities. I think this is a massive mistake really and with hindsight, and what we do now, is try to talk about the real likelihoods and how these might lead to being able to be within a railway environment rather that the ultimate goal, a much less likely outcome. I feel very sad to write this really but our life/his life is 'real' life and we have to work with what we can to give him a good life as an adult.
- I can't see her being employed due to continence issues she cannot deal with herself
- None at the moment
- My main fear is disability discrimination, as it is many employers won't even take her on for work experience.
- We are concerned about our son's vulnerability. He has no desire to be independent.
- My son has positive thoughts about his apprenticeship at the moment with the college that he attends. My concerns are the people who he will be working, money and being taken advantage of because his sensitive/kind nature.
- I hope he can have employment in whatever area he chooses that he wishes to have,
- Hope for ongoing placements for learning life skills and social interaction with peers.
- My son is oblivious, thankfully. My hopes are that he will have good friends, nice experiences and a safe and happy life. My concerns are that he is very articulate yet there is so very little understanding there so he can talk the talk but has the abilities of a young toddler. He is extremely vulnerable

- Sadly, he will never work
- Employment seems unlikely given his needs. He loves the day care farm, but don't know if this is an option long term, I guess depends on funding.
- I'm not sure how employers will approach him having ASD whether to hide it from them so he is not discriminated against, how he will cope in the workplace. Also he is in receipt of PIP and I don't know if this will get taken away when he starts work, which will have a huge impact on choices.
- will never work
- No Support, being it 1:1 of sat on the side watching. I've not had any discussions about work or experience with work from any one for my son.
- Currently self-harming, suicidal and anorexic. Unable to make any decisions for the future.
- Many concerns about the future and ensuring she has a meaningful life
- It's hard to know how independent he will be, the charity LOOK has been very helpful informing us about support for V.I. young people and Access to work scheme. My son has continually been in the void between specialist provision and mainstream so it's hard to know where he will find his niche.
- I feel that it is so hard to get a job and with a disability that makes it 10x harder
- Young person has not been supported to do any work placements and I do not know what career guidance has been given by college as they do not communicate this to parents.
- There is nowhere to go or ask - I find work experience placements myself
- To be happy and involved
- He is now realising he has to do something but is willing to explore his options
- I have extreme concerns about every part of independent living and his vulnerability
- I really don’t know
- Not having the academic ability due to her educational needs. She has struggled to get a job she enjoys. Had to give up her college course due to lack of help & understanding at college and due to a health condition.
- I very much doubt she will ever be able to cope with working full time
- I think he will need supported employment at first but will be able to thrive when he is comfortable with it. Finding something that suits his high ability with computers, but his low social skills will be tricky
- Will never be employable
- Finding employment and being independent.
- Having to be denied jobs due to his diagnoses and being discriminated against and they are still being discriminated as they just won’t get the job even if they achieve an interview the diagnosis will still be a barrier to learning and having their desired career
- He will likely never be employed. He needs 1:1 support in a secure environment and 2:1 in the community.
- I’m frightened he’ll be alone and vulnerable. Want him to be doing the things that make him happy and are productive and rewarding for him and his community and society not NEET like so many
- He can only do part time due to medical conditions which is proving very difficult
- He is in his first year at college, I’m not sure this is something he will be able to achieve
- I am concerned that the press, schools and other parents have an unhealthy idea about people who have SEN finding employment. If possible, I would prefer to be treated like anyone else and so would my son. The government has been very busy intruding and sabotages too much.
- I don’t think employment is an option
- I am actually quite concerned about what my son may do and how he will cope in life.
- I don’t know if T will have these kinds of opportunities as he needs are so high and he’s continually been failed until this point.

- He would like to be in paid employment commensurate with his potential skills. He would like to live independently with support.
- Leaving education soon. Young person worried about what is next.
- We have tried various options that are apparently designed for young people with barriers, to help them access opportunities for those not able to follow conventional routes into independence/training/employment. These have included Kickstart (when it was running), The Princes Trust, and Apprenticeships. But with all of these (and others) it appears that only certain barriers are being considered and that only some people can access these schemes, they're not as inclusive as they try to make out. It's appalling! I understand that MENCAP are beginning a journey of lobbying the government to remove or amend the apprenticeship bottom line of GCSE maths and English (reasonable adjustments not actually that reasonable) to allow those capable of the completion of an Apprenticeship syllabus but not capable of conventional maths and English to be included. It would be great to see wider lobbying and attention being brought to this inequality.

Appendix K - Does your young person have an annual Learning Disability/Autism Health Check?

- But not because any professional told us about it, NCC, teacher, Social Services, Health....it has only happened over the last three years because mum heard about it via a parent conference.
- But was recently told by the nurse that ASD isn’t covered by the LD Annual Health Check unless they have a LD Diagnosis as well
- ADHD review which I believe is annually. He is about to transition to adult services and I understand that this can be challenging.
- He doesn't technically have a learning disability (so I have been told when trying to access services) but he had one LD health check once at old GP surgery (I was surprised he was offered that but they said no to my daughter who also has autism and ADHD and that was it.
- Wasn't aware it referred to those with Autism without a LD. Have mentioned this to GP but heard nothing else.
- We only found out about this in April 2022
- We see his Paediatrician, around once a year.
- I have so many other things to deal with that this is not something that I remember to do. If sent an appointment this is something we would attend.
- I think he needs one of these, didn’t know anything about it
- It’s patchy. We got one this year but not the year before.

Appendix L - Do you and your young person have ideas about how and where they might live more independently?

Yes, we have ideas about independent living

- Already sorted
- At home for near future, possibly move on when older??
- He would likely need to go into supported living
- I know supported living will not meet need; complex need therapeutic residential is the only way
- I will move out leaving my son in his home to live here in his own house with a.n. Other young person/ a friend of his with support coming into them. That's the plan anyway
- Looking at Assisted living options
- Not in supported LA care that's for sure - even the overnight respite here in west Norfolk is in a terrible state
- They are desperate to move out, PfAL and Social Services are painfully slow with information
- They want to move out and get a place with their partner
- We have made future plans to move to bigger property with my daughter and family to ensure child is safely living with extended family and is encouraged to be as independent as possible.

Partly

- He can be independent when he wants but his dad refuses to let him be independent, he will override anything especially teaching son that bills need paying his dad won't let him pay board to teach him the values etc.
- He feels he could manage by himself if he lived close to family support. He is not aware of any other support available.
- He may remain under our household, possibly a garden home.
- He needs a lot more work with independence skills and social development, but I think it is more likely to be some kind of supported living. I don't think he will manage on own with in/out support.
- He wants to go away and work in specialist reptile zoo in Oxford. He is unable to live alone, and he is not on any lists for supported housing in Norfolk, let alone in Oxford. So, it is difficult to see how this could happen.
- I am embarking on a project to convince either social services or health to adapt a property whereby my daughter and three of her girlfriends who have near identical needs could live together with full support,
- I'd like him to settle in supported living
- PfAL made a referral for supported housing approx. 5 months ago but we are still waiting for the assessment for this.
- They don't exist or I don't know about them. Social workers also don't share information. I feel they only look at what will be funded, not what best fits the individual and they seem to have little knowledge of out of county placements
- We are talking often with the CHC nurse about what the longer-term future might look like. Feel positive we have got CHC funding
- We have discussed options and I guess this will depend on life events. Taking each step as it comes, or he gets too stressed.
- We have talked about it a little but not yet in earnest as causes mental health escalation.

No, we do NOT have ideas about independent living

- At the moment my son wishes to carry on with me and I am happy with this and do not have a problem with him living at home.
- Concerned that she cannot be left alone.
- Haven't a clue or never been spoken to about this
- He wants to stay with us

- Hopefully some sort of supported living but no idea where to start.
- I wish I would know if there were options.
- Need information on options in our area
- No idea. Nobody has spoken about this, and I have no idea what or if there are options.
- Not sure if he will manage and help available
- She is hugely dependent on us and doesn't want to ever leave home
- She would love to live independently but have no help or guidance with this.
- Still only 16. Life will evolve
- This is despite asking via the EHCP every year for the past 5 years.
- Would dearly like someone to support him like I have over the many years and live a life just like their peers but with guidance and support when needed until one day he may be able to do more

Appendix M - Are you aware of organisations who can help your young person move forward into adult life and/or where to find out about them?

Partly aware

- Aware of organisations and charities that help find work or volunteering opportunities
- But what we do know is mostly down to my research and support as daughter's carer than support or intervention from professionals.
- He has been engaged with Mint service, but his time there ended during the pandemic, and he did not have any contact, discharge or further referral. He just stopped hearing from them.
- I am aware of PfAL but that’s about it.
- I believe there is a shared house in Norwich for deaf people
- I’ve seen some on Instagram
- Only know of PfAL, not been given any information about who else can help.
- Social workers just lead us round in circles and am sick of them leaving, and I am tired of engaging with services as it causes more stress.
- There is no focus point for information - we all have to find this out for ourselves. No one at LA responsible for 19-25 SEND
- There is nowhere central to refer to or look

Not aware of organisations that can help

- Are there such things? How do we find out about them?
- I would like information about this
- No, as there is not enough support out their just advice given that you can Google anyway, more direct phone numbers that can access the help and support needed rather than main numbers and being put on hold and never get through to a person especially adult social care in Norfolk, unless you are at risk then you don’t get that support.
- No, never had information or talks about this. Apparently from other parents going through it now, you drop of a cliff at 18 and there is not a lot of places at all
- Not really looked into this yet but hopeful that 'someone' will be able to talk to us about who/what is out there to assist this.
- Not really sure about this at the moment. I am trying to take one step at a time and tackle post 16 first and maybe learn more there. When settled in, I plan to start exploring more that.
- some help would be good
- Very little information available.
- Would like to know more about this support and if my son is eligible.

Appendix N - Do you believe that your young person's wishes and needs are listened to and acted upon by professionals who work with them?

Yes, I believe my young person wishes and needs are listened to

- Child is almost non-verbal and has limited understanding.
- Council is cutting back, withdrawing support on some larger units. One of 25 has sold. Council is not wanting units of such, which I can see is right, in lieu of recent horrors. But then what?
- I make sure of it
- Only because I make sure of it
- The college course is helpful.

I partly believe my young person wishes and needs are listened to

- College knows about the bullies but do not act on bullies' behaviour tutors say keep away. As most people are aware bullies find every opportunity to follow, name call etc and involve other students to bully the innocent person.
- Depends on the professional
- Funding constraints / acknowledgement of the severe nature of the disability affect the agenda/outcome
- Hard to get him to answer due to mental capacity
- He doesn't have the understanding of what he says, so too much notice is taken of what he says
- His school do, but not necessarily supporting him in that but do things about his interests at school.
- I have to make them very aware of how his anxiety affects him, e.g., he can learn how to walk to school on his own but is far too overwhelmed and anxious to do so at present
- My son is extremely manipulative I've watched him play a lead psychology consultant unfortunately once he's worked his magic they will listen and work with him.
- Or maybe the 'Partly' option is more 'Occasionally'
- Preparing for adult life team have been fantastic
- Some ask the young person but sometimes what they are asking isn't clear enough for them to understand the content of what they are being told and May give the wrong impression
- Some do listen but mostly it feels like a tick box list.
- The trouble is, once you leave children's services you no longer have any continuation of therapists to develop any relationship with your child
- There are no professionals working with him.
- Young person has difficulty in recognising and expressing his needs.

No, I do NOT believe my young person wishes and needs are listened to

- No, because meetings are a disaster because they haven't listened and done what they said they were going to, so what is the point?
- Certainly not within the current special school sixth form. Work experience has been dismissed as not possible and not 'affordable'. Both son and I have been told they cannot afford this - too many staff needed to support.
- Definitely not when they were attending college.
- He finds talking about adulthood causes great anxiety. We do not have anyone to help us.
- No again money is put first. They don't employ the correct number of staff or staff that are suitable for the environment they will be working in
- The issues have been ongoing for 2 years and she keeps being discharged without any improvement.

Appendix O When you think about your young person’s future, what is the main hope or fear that comes to your mind?

Main hope for the future

- Access to reliable care and independent living
- Being able to find work and live independently
- Equal opportunities and the same ambitions as someone without the disabilities or the correct support of others to achieve their aims and wishes
- Fulfilling, happy, purposeful, engaged great work/ life balance
- Happy, as independent as possible and part of the community
- He’s happy and well cared for.
- Hope he will be happy and fulfilled and able to make his own decisions
- I hope my son can develop enough independence skills to function, I would hope he could be in supported living (with minimal support if able to cope), I would hope he is not isolated as he is now, I would hope he is happy and that he manages financially. I am concerned about his vulnerability to abuse, and I am concerned that he if he struggles, his wishes may not be accommodated and a fear is that he would be controlled by medicine, admitted to inpatient stay and that he may harm self or others.
- I hope she has a happy life with purpose, and I hope she will be safeguarded
- I hope they are happy and not being taken advantage of
- I just hope he achieves these dreams and hopes he has of becoming his own boss and is successful.
- I just want him to have a lucky break!! He has ability and skill but will need support with working in the normal world!
- Independence and fulfillment.
- Stays healthy and happy whatever happens!
- That he can manage his own medical health adequately. We are keen for him to have opportunities to enjoy a fulfilling adulthood.
- That he gets enough confidence to move forward
- That he is happy and that he has an understanding of how life works
- That her mental health improves to enable her to make better life choices.
- Their happiness
- They will work independently
- We want an active, happy life for our child. One where he feels valued and loved and needed.
- Whether he will be happy!

Main hope and fear for the future

- Being alone and unsupported/ wrongly supported / vulnerable and open to abuse, being lonely, bored and disengaged. Hope he is happy, has love and friends and a busy fulfilling and productive life.
- Hope they are healthy, happy and feel fulfilled with their life, feel safe and supported in way that is appropriate for their individual needs. Worry that this will be left for us as parents to do and what will happen when we can no longer do this. Who and how will this happen, that they will be left to own devices and won't be able to care for themself or will be put into inappropriate care and not be safe, healthy or happy.
- I hope he can get a job and live independently with support. My fear is when I am dead, he will be alone.
- I want my YP to leave home and get a part time job, but to do that they need more help than I can give them, but the help offered isn't a service that goes above and beyond, they need to do more than read out job adverts they need to find out the finer details of these jobs. They do not get they are dealing with very vulnerable people.

- My fear is the day that we are no longer alive. My hope is that we get him what he needs without a fight, but we will fight to do so all his life. I also hope that disabled adults get better treatment by the LA.
- My main fear is that lack of provision, and access to provision is becoming even more limited due to funding cuts and red tape. There is no doubt this will impact on his future and his career. He has worked so so hard and overcome so many obstacles to get to this point and it's so disappointing to think that the crux of his success or failure rests on adequate provision being in place.

  My hope is that he can go on and have a fulfilled and happy career and work/life balance. He has known since he was a young boy what he has wanted to do with his life, and I will move heaven and earth to make it happen for him.
- My main hope is that he can learn resilience and not be so easily led by peers. My fears are substance or drug abuse. Due to the impulsive side of his character, he can be talked into doing things to impress friends. I have tried to manage this but am stepping back to give him room to make mistakes and learn.
- That the appropriate provision cannot be found, and he will either be warehoused in an unsuitable placement which would lead to risk to my young person or risk to staff, or we will have to both quit work to look after him at home leaving us in financial hardship.
- They can manage to look after themselves. Manage money, paying bills, things that go wrong with water leaks, maintenance, electricity care of the home, Cooking, cleaning, and my biggest fear is people taking advantage of them and their finances. their health problems as they are scared of hospitals and doctors and explaining what the health problems are.

Main fear for the future

- After I not here anytime
- Although she thinks she is a normal 16-year-old her actually mental age is a lot younger and with a weakness on one side she is unable to perform all everyday tasks the same as someone without this weakness. We do not think that she will be able to live without lots of adult support.
- Biggest fear is him being looked after by people who have his best interests at heart like we do
- Fear is lack of responsible care in the area of Kings Lynn. Not knowing how we will cope in our old age. We have no trust in the respite system in the area
- Fear is that now 19 will just be forgotten about.
- He is and will continue to be misunderstood.
- He is willing to be employed but I fear a way forward may not be identified within the next few months
- He won't be able to cope with it all.
- How he will cope with independent life
- I fear the new Harvard University in vitro scan for Autistic brain types will lead to high levels of abortion for these people in the name of humanity, which will be a great tragedy, as it is hugely discriminatory. Plus, the cost of living might have an impact on their perceived viability. I think my boy is a wonderful person with a lot to offer. Fear is an agent saboteur of life.
- I have a terror of their being placed somewhere that isn't for them and that they wouldn't be understood or be happy
- I sink into a deep depression when I think about his future
- If I'm not around, who will support him. He has no one!
- It's all fear. He will be lonely and abused in some way cause the government and the council do not care enough for our children and do not supply enough to meet their needs as they don't care
- Lack of academic ability. That an employer won't offer her a job due to this even though she has a willingness to learn is hard working and wants to do well. I hope that employers do not see a disability as a negative but as a positive.
- Lack of fulfilment of her potential, however apparently limited that looks to certain parts of the world.

- Loneliness.
- My husband and I dying before our daughter is settled in adult life.
- My son has always been bullied & that is my biggest fear if he moves out.
- My Young person has so much potential and could live a very fulfilling and independent adult life. But because he struggles to identify and express his needs, I worry that he will not get the on-going support that he needs. I fear that he will struggle with self-care and gaining and maintaining employment. Because of his vulnerabilities, I have deep concerns that he will come to physical and/or emotional harm and that he could easily get into criminal troubles because of his social/emotional difficulties.

- That something bad will happen to them or they will just give up all hope without necessary support given and he's willing to seek it now!
- The future is grim. You cannot rely on the family/cares to battle on...the care system need is growing. The demand is high, but who pays, who loves the job? We need to change people's attitude to disabled folk.

  Who monitors the places, more surprise checks, smaller unique units are needed. It is cause for real concern to all. We as a nation are not doing enough. It's not all about money; it's a person's life and right to be safe and secure
- They won't have a fulfilled life, safeguarding concerns, no suitable near families,
- We worry that he will never find an employer with the patience and understanding to train him. We feel he would be a good worker once he has learned his role. He would like to have a job so he can earn his own living and live independently. unfortunately, whilst achieving these things is much more difficult for him, he has fallen through the net as his difficulties are not 'bad' enough to trigger any kind of further services.

- What on earth will happen to her when she doesn't have us anymore - a terrifying thought
- When we, as parents, die, what will happen - who will advocate for him, help him continue in 'work' if he is ever lucky enough to secure that, ensure he is healthy, happy and safe? That is my biggest fear. I know that as long as we are alive and 'there' for him, we will do the best we possibly can to ensure he is/has those things. But without us around, what then?

- Who will care for him when we are no longer here