



SNAP PARENT CARER FORUM
CENTRAL BEDFORDSHIRE

Preparing for Adulthood Report

Published October 2024

Introduction

SNAP Parent Carer Forum – our role.

SNAP (Special Needs Action Panel) is a proactive, independent forum of parent carers who all have children and young people with Special Educational Needs and/or Disabilities (SEND).

As members of the National Network of Parent Carer Forums (NNPCF), we support the development of parent carer participation, a process in which parents work together with professionals to make improvements to local services.

SNAP Parent Carer Forum (PCF) acts as a conduit for a wide variety of local professionals in their work with children and young people with Special Educational Needs and/or Disabilities (SEND). Our purpose is to improve the services provided for children and young people who are aged from 0-25 years.

Preparing young people with SEND for adulthood.

The Preparing for Adulthood programme designed by the National Development Team for Inclusion (NDTi) identified four key pathways for each young person that need to be addressed to ensure that they experience good outcomes as an adult:

- Paid employment
- Independent living
- Community inclusion, friends and relationships
- Good health

SNAP PCF conducted a survey between the 25th of June 2024 and the 4th of August 2024 to explore the extent to which a focus on these four pathways is being felt by young people as they engage with local services from the age of 14 and into early adulthood. The responses to this survey were provided by the parents and family carers of young people with SEND aged from 14 to 25 years.

83 parent carers of young people aged between 14 and 25 years completed the survey, with responses distributed across the following cohorts:

Young person's age	Young person has an EHCP No. of survey responses	Young person is on SEND Support No. of survey responses	Young person is not in education No. of survey responses	Total responses received
14 - 16	34	5	0	39
17 - 19	25	10	0	35
20 - 25	6	0	3	9
Total	65	15	3	83

The survey allowed us to analyse the responses separately for those young people with an Education, Health and Care Plan (EHCP) and for those with a SEND Support plan, to examine whether there were any collective differences in the experiences of these two groups.

Survey questions and responses.

The questions asked within the survey and responses collected provided below.

1. Preparing for Adulthood at the Annual Review of an EHCP or SEND Support plan.

We wanted to understand the degree of focus that the four key areas within the national NDTi Preparing for Adulthood programme¹ are currently receiving during the review of a young person's EHC plan or SEND Support plan. These four areas are:

- Employment
- Independent Living
- Community Inclusion
- Health

The figures below show the % of respondents who indicated that an area was discussed at their young person's last review. These results are shown across three age groups. Data for those with an EHCP and those on SEND Support are shown separately.

Figure 1

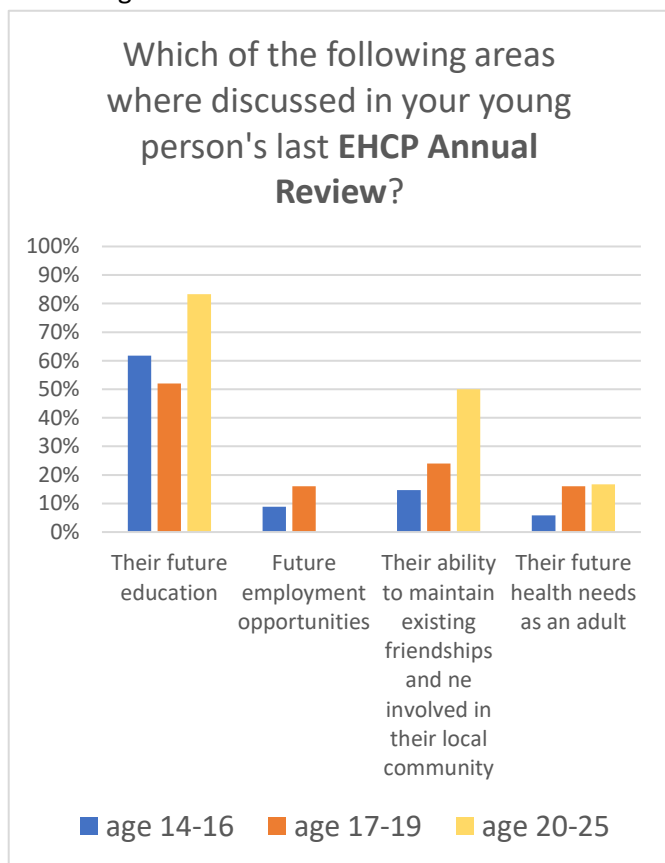
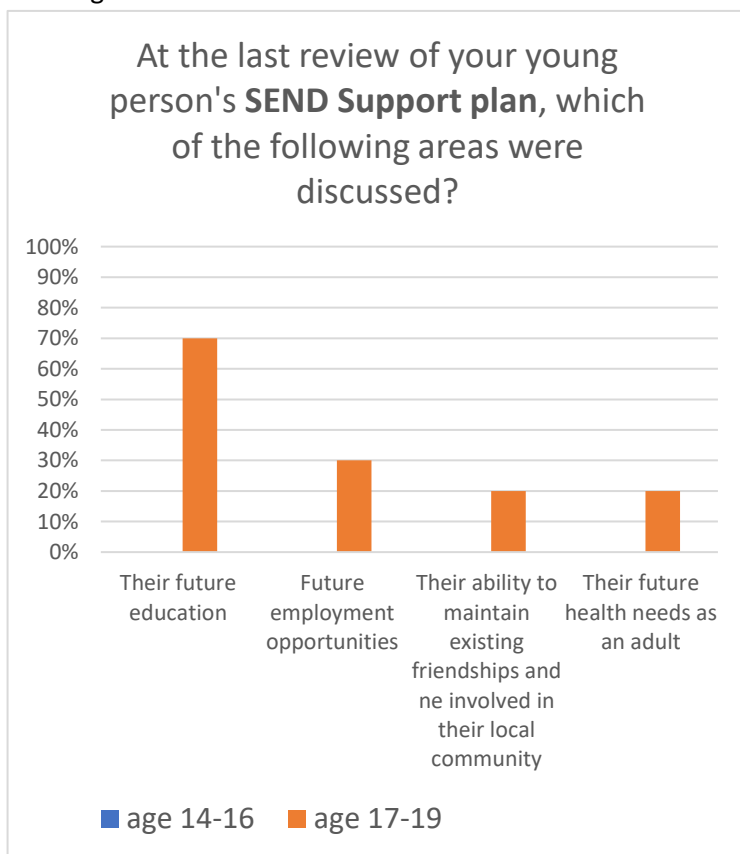


Figure 2



(age 20-25 N/A)

For young people with an EHCP, future educational options receive the most focus at annual reviews, with much less focus on employment opportunities, even for those in the older age groups. Future health needs are also infrequently discussed across all age groups. Community inclusion appears to receive a markedly greater focus once a young person has actually become an adult, with a much lower degree of focus before this time.

As the responses from those parents with young people on SEND Support were much fewer in number, results need to be viewed with greater caution. However, from the data we have collected, similar results to those with an EHCP are seen for the older age group, together with a marked absence of any focus on any of the four areas for those aged 14-16.

The parental comments given that were relevant to this question were as follows:

EHC Plan

- There was no focus on any area.
- No focus real focus on any of the above - set immediate targets at this meeting for the immediate future.
- We have only ever had one Annual Review since my son's EHCP was awarded in Jan 2023
- No-one really explained what the differences were and why the format was different (except that it was 'preparing for adulthood'), which was not helpful or clear.
- There was no decision about his future, just his current needs.
- No discussion on moving into adulthood at all.
- Did not cover any of this in the last AR.
- The review was 2 years old as still awaiting last years review.
- EHCP focus on getting education for now.
- we did talk about friendship and community but not received an updated plan/ minutes so don't know exactly what was recorded.
- We had an adult services person present who explained some of what is available.
- No, was purely about educational support at current placement.
- Conversations on our YP's future were initiated by us, the parents. No attendance by YAaIL, or anyone other than our YP's class teacher and the school's EHCP Manager.
- Never been discussed.
- We briefly discussed future education.
- No support given with regards to post 18
- Nope. None was mentioned.
- None of the above

SEND Support

- Review was so long ago cannot remember.
- Not had any info from school on this
- None of the above for either child (in different schools)
- my son's SEN support has not been reviewed for 16 months!
- None of the above

2. Curriculum content and focus on Preparing for Adulthood

This question investigates to what extent parent's felt that their young person's educational curriculum was preparing them to live independently of their family carers as an adult.

Results for young people with an EHCP and those on SEND Support are shown separately in figures 3 and 4 respectively.

Figure 3- EHCP

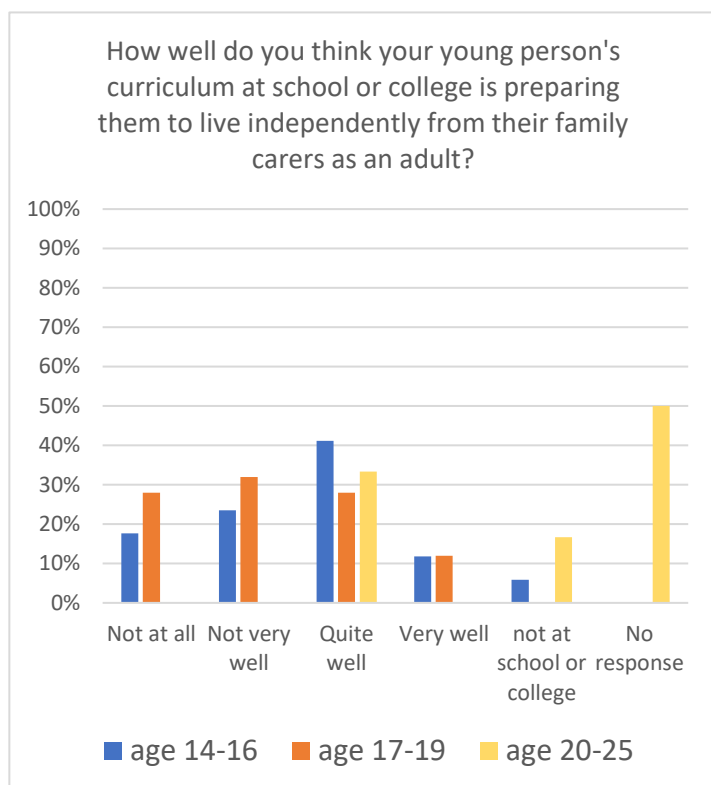
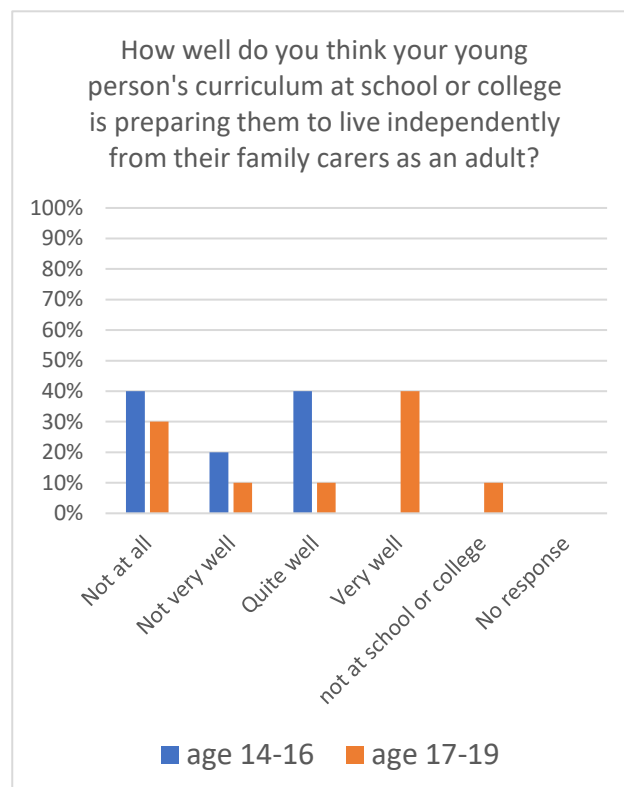


Figure 4 – SEND Support



The curriculum for those in the younger age group with an EHCP are viewed by parents as preparing their young person for adulthood slightly better than those in the older age groups, with just over half reporting at least a 'quite well' response. This was over 10% lower for the 17-19 age group and lower still for those aged 20+. Across all age groups at least half of the parents responding to this question did not feel that.

- Their young person's curriculum at school or college was preparing them well to live independently of their family carers.
- Parental views of their young person's curriculum are better overall for older young people on SEND Support, with half reaching the threshold of at least 'quite well'. However, results for the younger age group were worse than for those of this age with an EHCP.
- From the comments received, a significant number of parents appeared to misunderstand the concept of 'living independently' and appeared to assume this to mean living without support. As a consequence, some parents assumed that this question did not relate to their young person. The phrase 'living independently' is often used to describe non-disabled adults who move out of home, which could be causing the misconception of this phrase amongst some parents of young people with disabilities, who know that their child will require some level of care and support as adults. It is possible that this misconception of what is actually means to 'live independently' with a disability, may have affected the responses given to this question and influenced the resulting data to some extent.

Comments from parents relative to this question were as follows:

- Addressing needs to become more independent, like using money when going shopping.
- There is no support for promoting friendships or independence.

- Academic setting, not focused on life skills in this setting.
- The focus is purely academic. Any soft skills or social skills are not prioritised in the school timetable.
- Mainstream cannot accommodate this for our children too focused on academic abilities.
- No focus on say healthy eating, no opportunities to do any physical exercise or importance of this. No career guidance given as missed the year it was.
- School did not support my son to be independent. They took the toaster kettle out of the area so the students couldn't even make toast & tea?
- My young person's school is doing a brilliant job of teaching them life skills which will help.
- The school says all the right things (and the website backs this up), but in practice we see little preparation for when our YP leaves the current 6th form setting.... unless there's stuff happening that we don't know about (in which case school-parent comms need to be improved!).
- They can only do this during term time and between the hours of 9-3 and our daughter needs to develop and maintain these skills outside school hours.

3. Options for living independently.

The following question was designed to explore the degree to which parents understood what the different options for independent living are for adults with disabilities.

Results for young people with an EHCP and those on SEND Support are shown separately in figures 5 and 6 respectively.

Figure 5 – EHCP

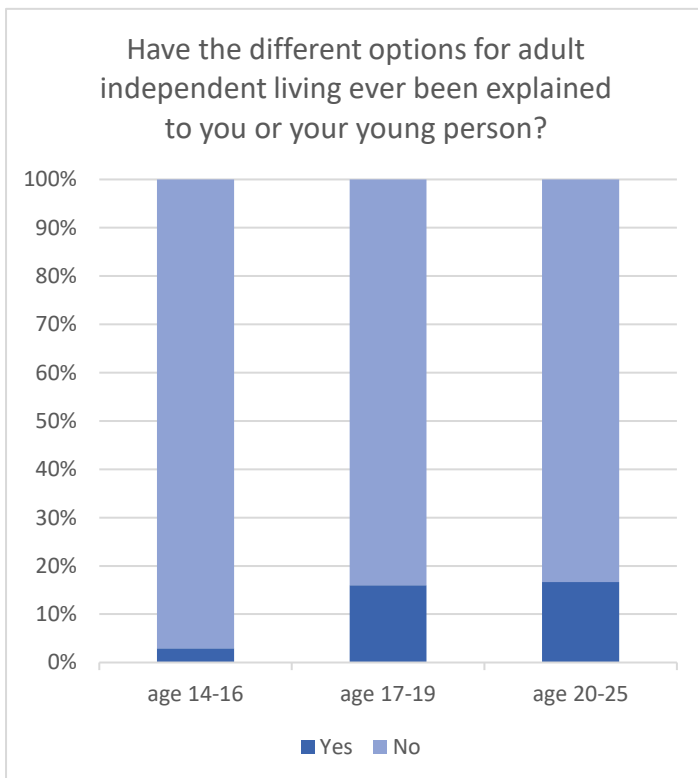
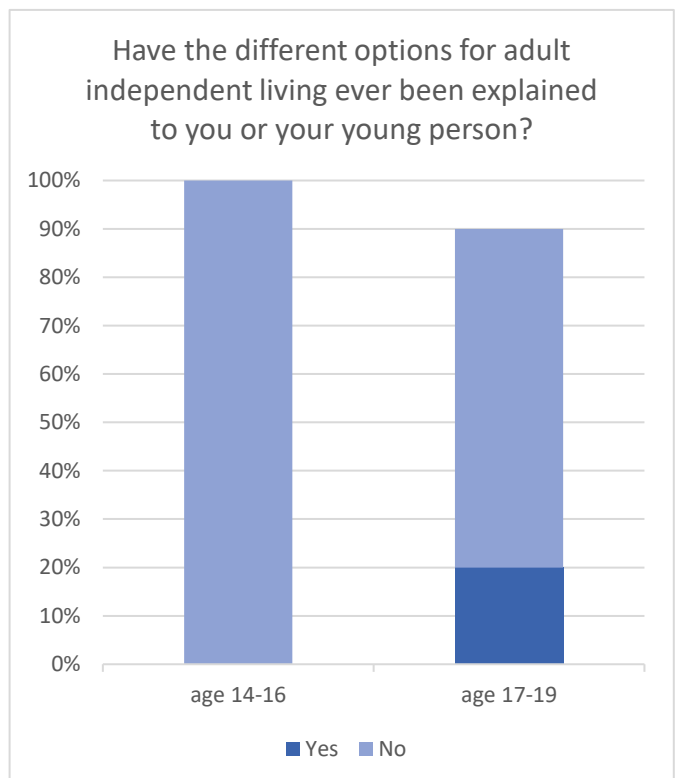


Figure 6 – SEND Support



The results clearly show that the vast majority of parents of young people of all ages are not aware of the different options for living independently for adult with disabilities. This lack of awareness and knowledge may well be contributing to parental misconceptions of what 'living independently' actually means, particularly for those parents of young people with more significant support needs. It is particularly concerning to see such low rates of understanding even amongst parents of those aged over 18.

Comments from parents relative to this question were as follows:

- We have asked for guidance, and none has been provided.
- I would like better options for when my son turns 19 as there doesn't seem to be provision within CBC.
- He wouldn't understand and this conversation hasn't been had with us as his parents. Being honest I can't picture his life without us as parents fully supporting and caring for him as we do now. I'm not sure what happens when he finishes his college years.
- I am conscious that he might one day want his own space, but I've no idea what options might be available to him.
- My young person is in supported living, but options were not explained.
- Working with YAaIL at the moment and it is very over whelming and confusing.
- I have read a bit about it on the local offer which gives you some information, but it is not very detailed. My YP has not been provided with any information at all about living options. It seems to be assumed by social care that he will always be cared for by us at home. During assesment.my YP was asked by the assessor where he would like to live when he gets older. He said he would like to live independently with a friend, but Assessor made no comment about this or attempt to explain his options or how this could work for him.
- Never mentioned at all - no idea who or where to go for this advice/information
- We have found out about YAaIL for ourselves.... the usual situation of parent scrolling though the internet to try to find answers to support our YP. To be honest, we're still unsure what YAaIL is..... hoping to find out more form the CBC virtual training session later this month.

4. School or college curriculum preparing young people for paid or voluntary work.

We asked the following question to ascertain parental views on how well their young person's school or college curriculum was preparing them to engage in volunteer or paid work as an adult.

Results for those with an EHCP and those on SEND Support are shown separately in figures 7 and 8 respectively.

Figure 7 – EHCP

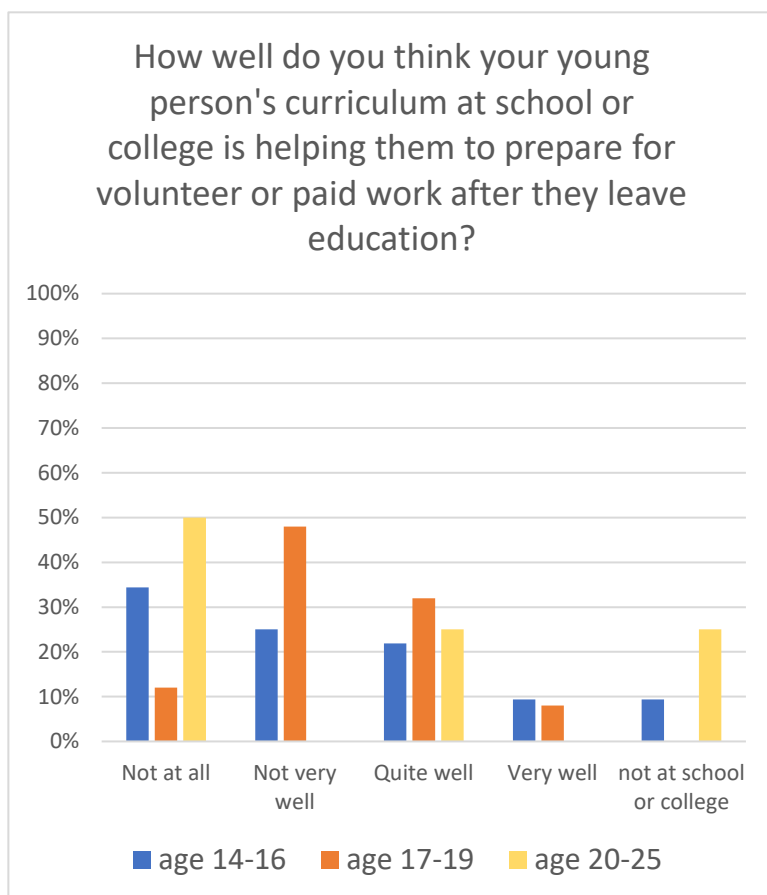
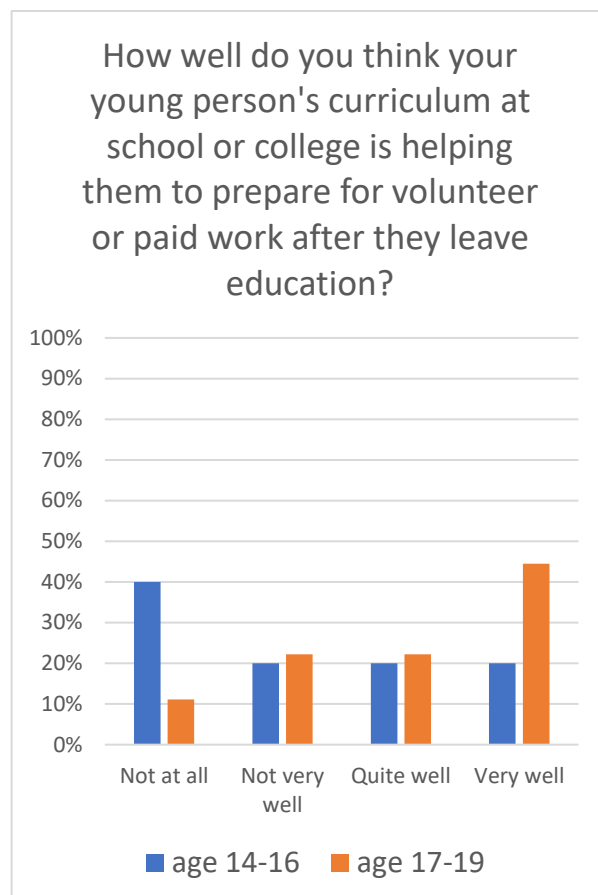


Figure 8 – SEND Support



For those young people with an EHCP, the majority of parents in all age groups felt that their child's school or college curriculum was not sufficiently focused on preparing them for work in adulthood. Although the best results were seen for 17–19-year-olds, only a third of those responding to this question thought their child's curriculum was preparing them for work at least 'quite well'. The results for those over the age of 19 were particularly low, although the sample size from which these results are drawn was much smaller.

Overall, the data shows better curriculum focus on preparing young people for work for those aged 17-19, particularly for those on SEND Support. However, even here there is still a significant minority of parents who feel that preparation for voluntary or paid work is lacking within their young person's educational curriculum.

There were a number of written responses from parents expressing their belief that their young person would never be capable of participating in any voluntary or paid work due to their particular needs. This could be indicative of a lack of awareness of available employment opportunities and support for adults with disabilities, or a genuine lack of local provision in this area.

Comments from parents relative to this question were as follows:

- they are at a specialist residential school and this forms part of the curriculum.
- the performance-based placement is arranging work experience opportunities.
- They only seemed to be interested in students moving onto further education. Any information given out was aimed at neurotypical children and not suitable for my son.

- A two-week unplanned job placement which is put on parents to arrange is wholly inadequate.
- I told school that my son (who would need 1-1 support) would be great helping in a food bank it took 2/3 years for them to put this in place & he loved it. Now college will support him in the future to volunteer.
- What are the choices for those with PMLD who are unable to be employed or volunteer?
- My young person has never had any work experience arranged through school or college despite requesting it and it being in EHCP. We have tried ourselves to try to find voluntary work locally without success... Unfortunately, although he enjoys his college course it has done very little in terms of teaching him realistic work-related skills. There seems to be no formal support to help them look for, apply for jobs or teach interview skills. Careers advice non-existent or completely impractical or unrealistic in terms of YP capabilities.
- Our YP is doing work experience one morning a week at Bedford College Cafe with other students from his setting.
- They are a post 16 AP and provide lots of opportunities for work experience. As a result of their support, we did successfully manage to get a part time job - but have not been able to maintain it due to mental health difficulties.

5. Careers advice provided to young people.

We wanted to find out whether young people are receiving careers advice, and if so from whom.

Results for those with an EHCP and those on SEND Support are shown separately in figures 9 and 10 respectively.

Figure 9 – EHCP

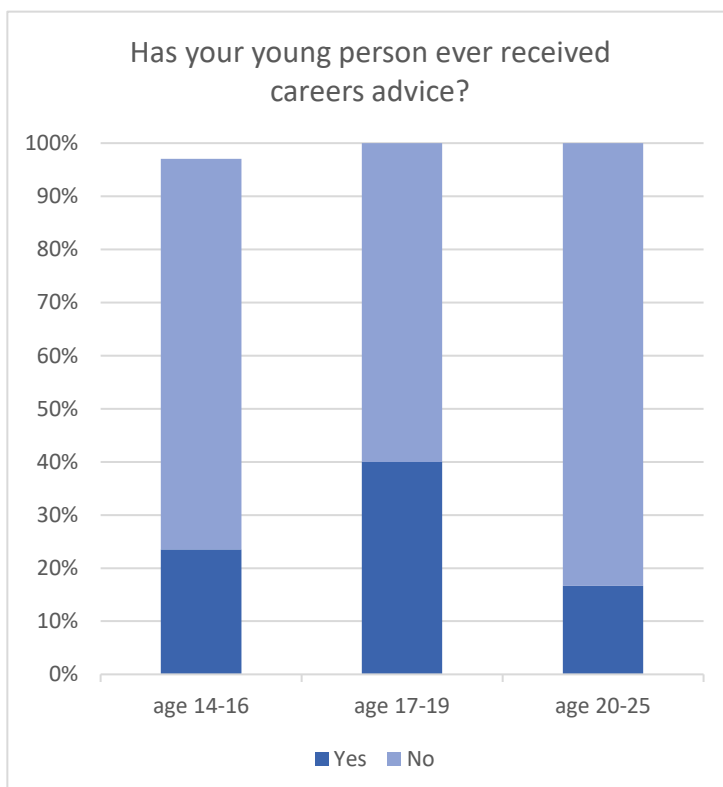
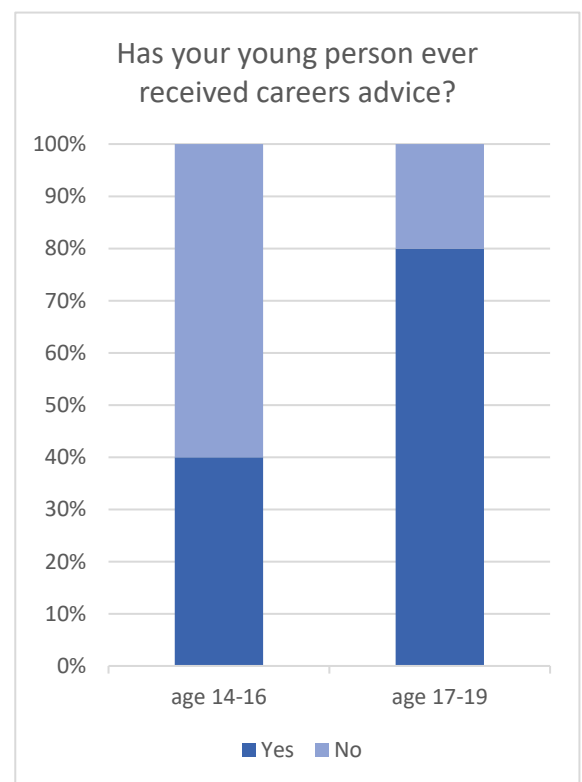


Figure 10 – SEND Support



Results show that significantly more young people on SEND Support are receiving careers advice when compared to those with an EHCP. This could be due to young people with an EHCP having higher support needs and so having fewer services available to facilitate their participation in some form of work. A greater perception that the higher needs of those with an EHCP precludes them from participating in some form of voluntary or paid work could also be a reason for the lack of careers advice given to this cohort.

The organisations identified by parents as the source of their young person’s careers advice are as follows:

- School 67%
- College 19%
- Youth support service 15%
- Other 4%

6. Awareness of employment support

We asked parents about their awareness of the services available to their young person for accessing supported employment as an adult.

Results for those with an EHCP and those on SEND Support are shown separately in figures 11 and 12 respectively.

Figure 11 – EHCP

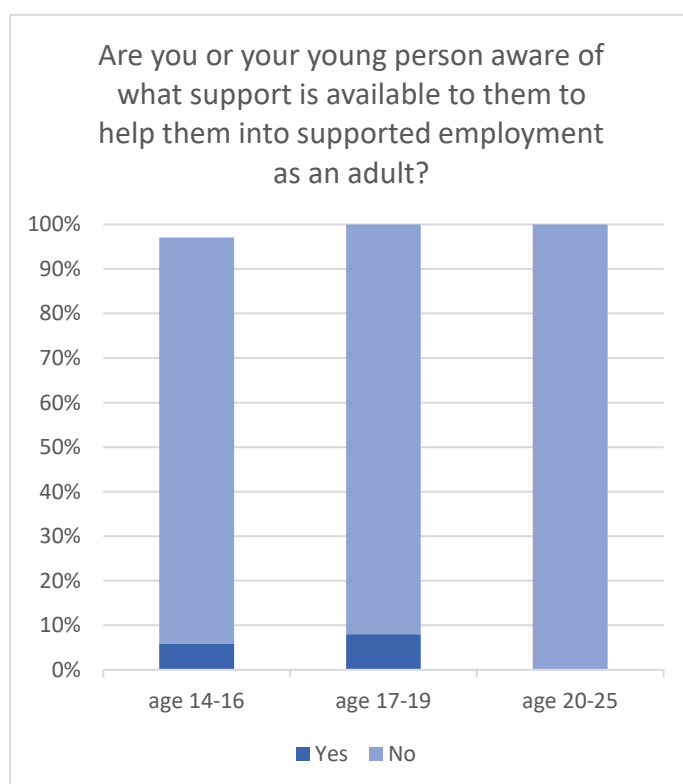
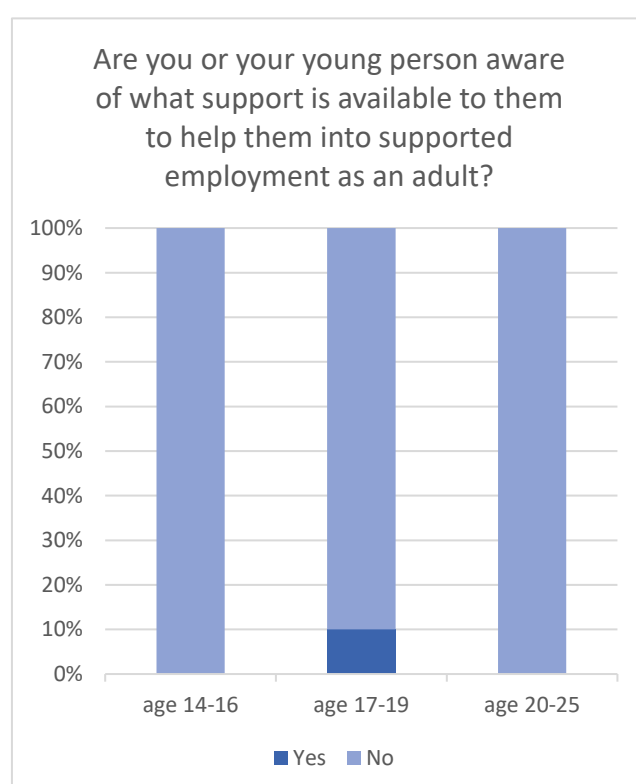


Figure 12 – SEND Support



Knowledge of supported employment services was minimal amongst parents of young people on both SEND Support and an EHCP, across all age groups.

It is plausible to suggest that this is one reason why some parents' may believe that their young person will not be capable of engaging in any kind of voluntary or paid work as an adult, if they are unaware of the services that may be available to support and facilitate this for their young person. The data could also indicate a lack of local services that can support young people with SEND to find and stay in regular work-related activities.

Comments from parents relative to this question were as follows:

- N/A for them - they won't be going into employment.
- She has not received any help.
- If there is any, we haven't heard of it.
- Only from the information SNAP PCF have given.
- There is very little information about what day services are available. All adult services seem to be 18-65 yrs old he doesn't want to be socializing with people old enough to be his grandparents.
- I believe the job centre are supposed to help people into work but not had any detailed information.
- It's a very scary thought - and support and advice seems very limited. We're doing our best to find out.

7. Access to leisure activities and community inclusion

The following question explored a young person's access to community groups or activities.

Results for those with an EHCP and those on SEND Support/not in education are shown separately in figures 13 and 14 respectively.

Figure 13 - EHCP

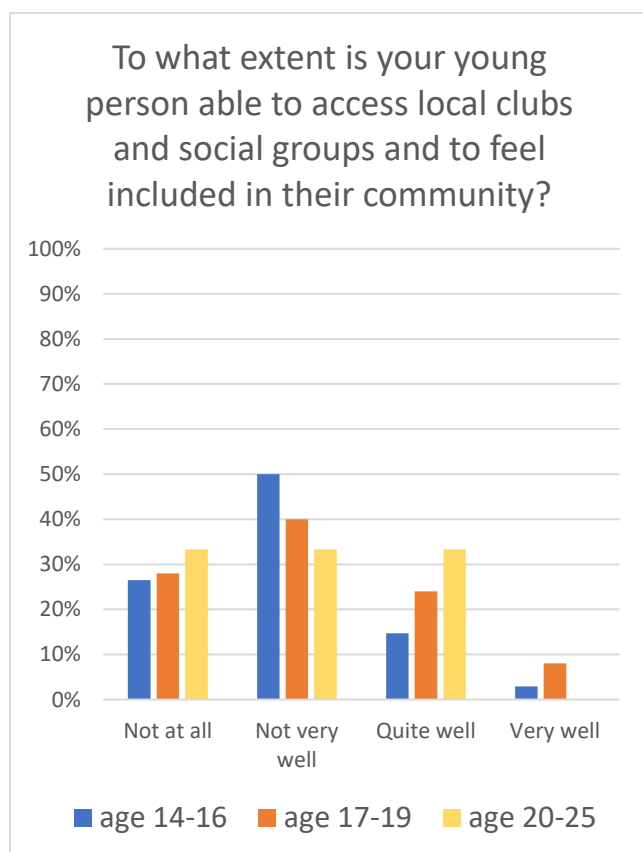
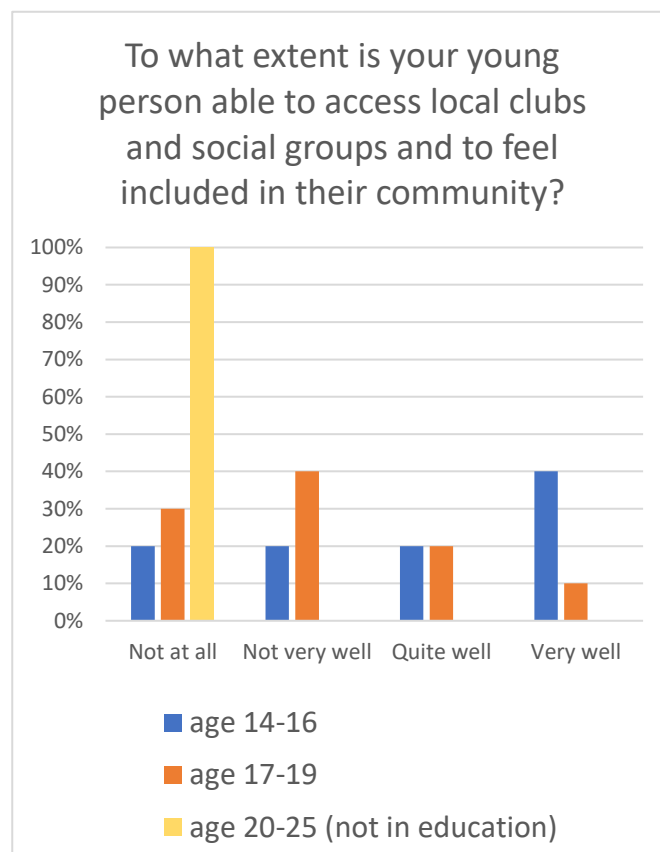


Figure 14 - SEND Support/not in education.



Community inclusion for those young people on SEND Support who are aged 14-16 is better than for those with an EHCP. However, this difference drops off after the age of 16. A significant majority of parents in all but one cohort report that their young person is not well included within local community groups and activities.

Whilst acknowledging the small sample size for those aged 20-25, there is a marked absence of community activity for those no longer in education after the age of 18, and two thirds of those with an EHCP have young people who are not well engaged with their local communities.

Comments from parents relative to this question were as follows:

- All involvement in the community is with parents or the school if during the school day.
- There is nothing locally that meets their needs or suits their interests.
- They all seem to be based in South Bedfordshire, and we are North Beds
- He has social difficulties but there are options available.
- The only issue is transport to the clubs.
- He is part of scouting, but that involvement will end when he reaches 18 then I don't know how he will access these.
- Experiences bullying was enjoying football at quite a high level but had to stop due to pressure and bullying.
- Used to attend a group but since stopped as can't cope with other peers.
- He plays Rugby for our local team. Very excepting with his additional needs & also make him feel welcome & encouraging him to be confident.
- As a parent we also have to attend
- Not enough is done with schools to include them in their community.
- Nothing locally is suitable. Lots of clubs stop at 18 and there is no similar adult service.
- Up until 18 he had an active social life but now that he is turning 18, many of them are ending and we are struggling to keep him as engaged in social activities and his community.
- Transport is such a big barrier to accessing your community especially if you live in rural villages and need to be accompanied on public transport.
- My young person attends a few groups which are aimed for young people with special needs, but these groups only run to the age of 18 and have no idea what is available for an adult with special needs.
- Autism Beds offer a youth club, but this finishes when he's 18.
- Attends one group monthly that she loves and is amazing BIGG - hoping to Police cadets as have heard this is very inclusive.
- Clubs for young people (particularly 18+) are almost non-existent or not suitable.
- Managed inclusive activities such as Autism Beds and Yes, we Can inclusive sports until end of yr 11 when everything fell apart.
- There isn't much available locally.
- Lacking in the local offer - we have managed some but that's been because of our work as parents working with organisations and sourcing them - we've never had any support in this area.
- No info given, have to go searching for things.

8. Support provided to make and maintain friendships (outside of family carers)

The survey explored the extent to which parents felt their young person was being supported to make and maintain friendships by services external to their own family.

Results for those with an EHCP and those on SEND Support/not in education are shown separately in figures 15 and 16 respectively.

Figure 15 – EHCP

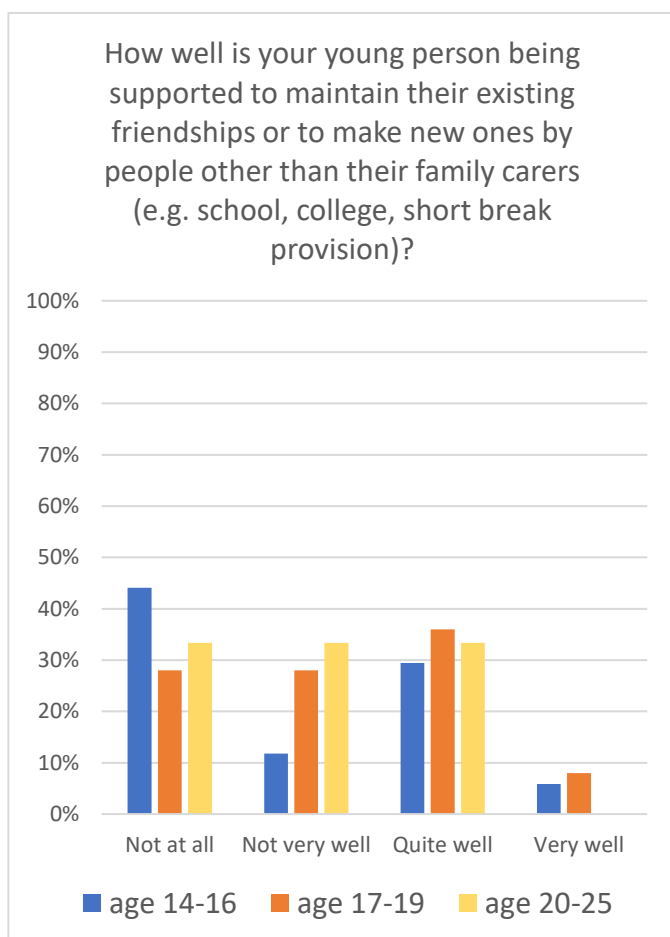
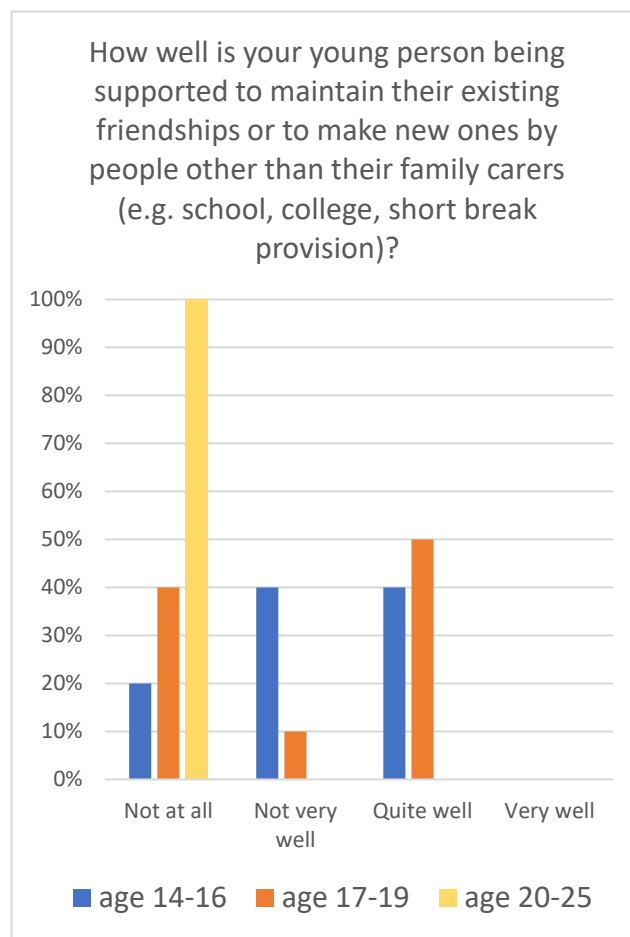


Figure 16 – SEND Support/not in education.



Nearly two thirds of all parents of young people aged 14-16 felt that services external to the family were not supporting their children to make and maintain friendships. Results were marginally better for 17–19-year-olds across both cohorts, but worse for those in the oldest age group who were not in education. Young adults aged 20-25 with an EHCP fared better than those without, but still only a third of this cohort achieved at least ‘quite well’.

Comments from parents relative to this question were as follows:

- My son doesn't have relationships/friendships with peers.
- Being autistic means that a person is highly likely to be very lonely all of their lives. I wish society knew how to be kinder and more inclusive. I am constantly on the lookout for ways to get him to connect with others.
- Their school is incredibly supportive.
- School is very supportive but as it's a specialist school options for friends are limited.

- Friendships are well maintained in the performance-based foundation course, but not elsewhere. We have a big concern this option will stop when the EHCP expires, and she will lose her friendship group.
- Mainstream not specialised to support this.
- School do give him the time to make sure he is with friends in class.
- School have been really supportive and being with other similar YP has really helped build friendships alongside close adult support with this.
- Not accessing anything outside family. unsure what she can do where to make friends.
- YP becoming more isolated as they can't keep up with existing mainstream friends who are fully independent, driving, going off to university. College mainly centred around work and social activities very limited for YP to make new friends or meet other YP after college or on days off.
- Only in school though
- School is supportive of this, as well as Autism Beds
- Alternative provision has helped with this.
- Has no friends at school?

9. A focus on life skills for independent living within short break provision

In order to understand whether current short break provision is helping young people to prepare for independent living as an adult, we asked the following question.

Results for those with an EHCP and those on SEND Support/not in education are shown separately in figures 17 and 18 respectively.

Figure 17 - EHCP

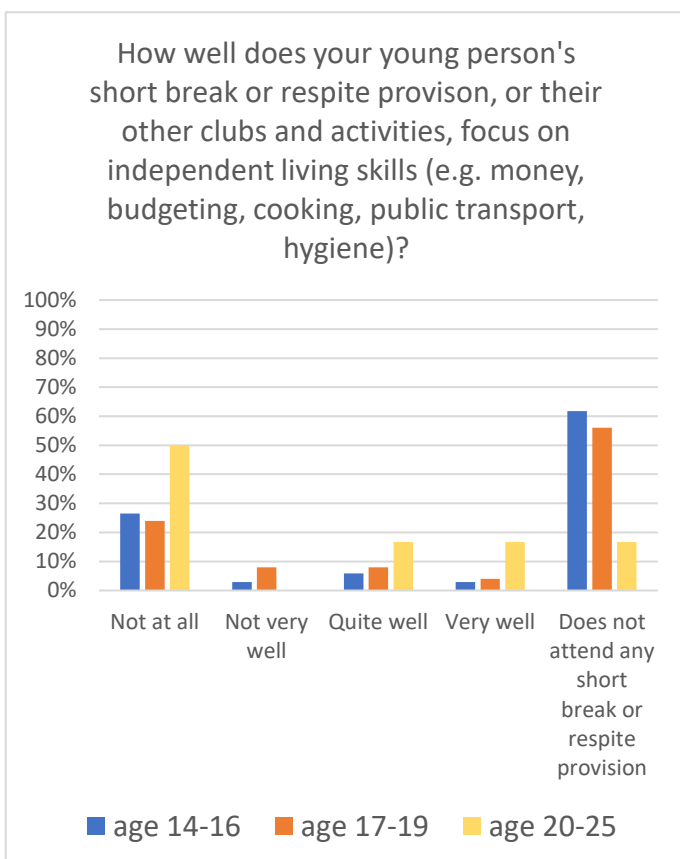
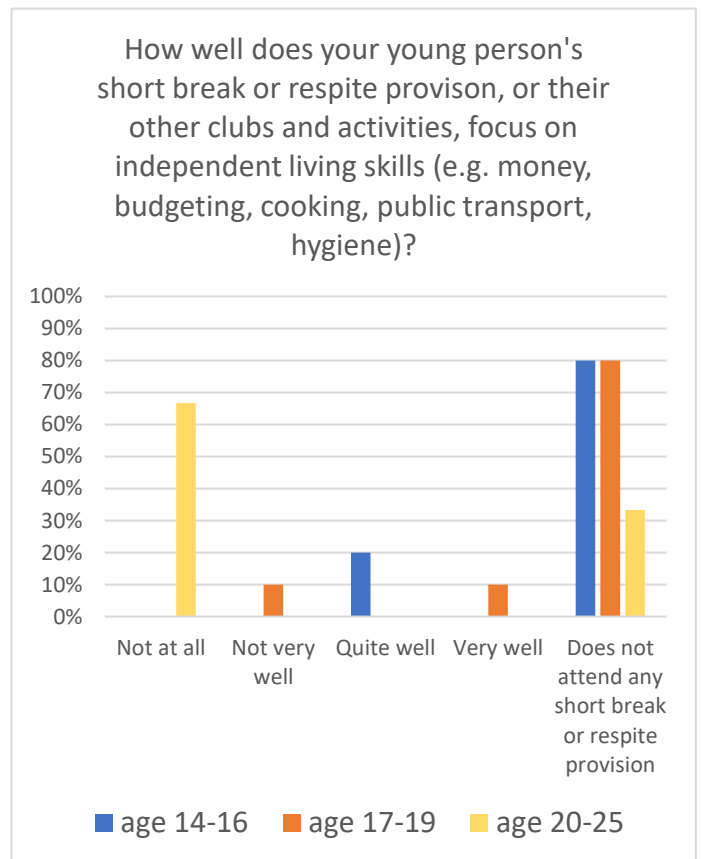


Figure 18 – SEND Support/not in education.



Parental responses demonstrate that whilst some short break providers do address this area, the majority of those accessed by young people within all cohorts are lacking a specific focus on skills for adulthood and independent living. It is also concerning to see so many young people not accessing any kind of short break provision at all, particularly those with an EHCP.

Comments from parents relative to this question were as follows:

- Scouting teaches him cooking and independence skills.
- BIGG are brilliant! Cover life skills, cooking, planning etc.
- No service I know of helps towards their independence.
- Not set up for him or young people like him.
- The out of school groups that are available are dance and performing arts - nothing to do with independent living skills.
- We are unable to manage clubs consistently (PDA profile) cadets have been good for Uni forms/ironing etc - but skills in budgeting/living independently we have had to push for assessments.
- Some of this is covered in school as PHSE but not sure how well tailored it is to meet my child's needs and understanding.
- It is not for the want of trying to access respite/short breaks - CBC threshold criteria are impossibly difficult to meet.

10. Annual health checks

Everyone over the age of 14 who has a learning disability should be on their GP's learning disability register and be offered an annual health check. We asked the following question to explore whether young people were accessing this annual check.

Results for those with an EHCP and those on SEND Support/not in education are shown separately in figures 19 and 20 respectively.

Figure 19 – EHCP

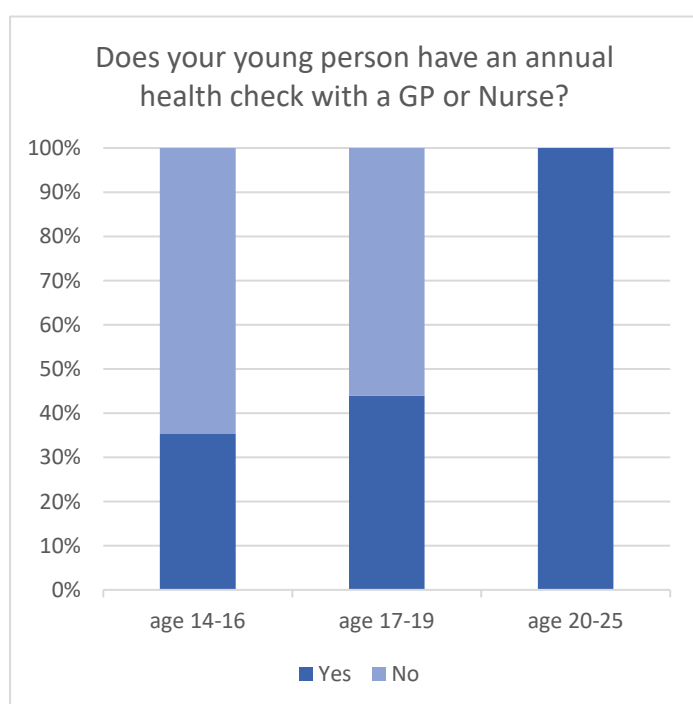
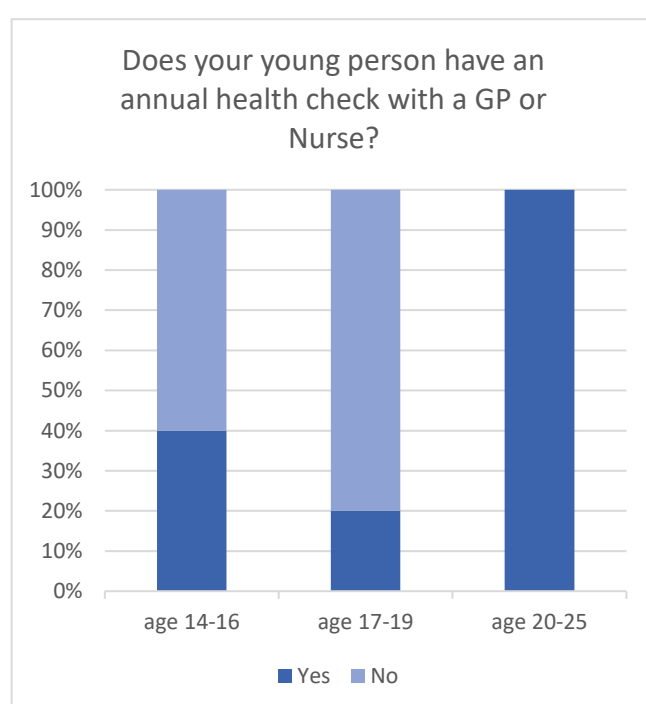


Figure 20 – SEND Support/not in education.



Whilst the sample size for ages 20-25 was small, results showed that these young adults were all accessing their annual health check.

Results for the younger age groups were less encouraging, with most young people still not accessing their annual health check.

Comments from parents relative to this question were as follows:

- CAMHs nurse checks meds regularly but no general health check. This would be nice.
- He should but they're always running behind with yearly reviews.
- I've only just discovered that he is entitled to this so have booked him an appointment with a GP.
- She has no input from health.
- He has only had it once and he is 15 years and 8 months.
- Had a first one this year, doctors' surgery didn't know anything about it.
- We have a CDC specialist nurse. Regular appointments are in place.
- Didn't know this was a thing.
- It took ages for him to have his first check up, it was 18months between appointments.
- Initially this was declined as he does not have a diagnosed learning disability but after writing a letter to the GP, they agreed YP can have one.
- GP every year
- I arrange this independently myself for our YP. I am registered as a carer at our surgery, but they have never contacted me about arranging an annual health check for our YP.

11. Understanding of health services after the age of 18

We wanted to explore the extent to which parents feel that they understand the transitional arrangements for their young person's healthcare as they approach and turn 18.

The results below show the responses from parents who indicated that their young person is under the care of a health professional. Data for those with an EHCP and those on SEND Support/not in education are shown separately in figures 21 and 22 respectively.

Figure 21 – EHCP education.

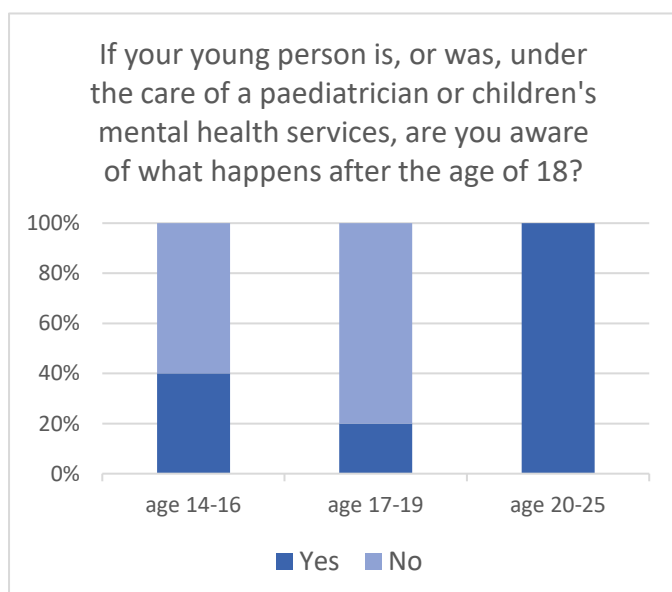
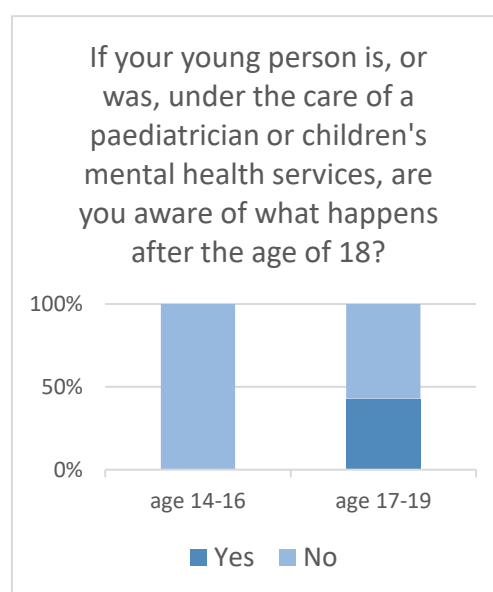


Figure 22 – SEND Support/not in education.



The data shows that the majority of parents of young people who are approaching adulthood are not aware of the process of transitioning their young person from children to adult health services. This is particularly true for those aged 17-19 who have an EHCP and who are therefore more likely to have more complex conditions.

Comments from parents relative to this question were as follows:

- I would be keen to know when/how the transfer happens...who replaces a paediatrician? I haven't a clue
- She was discharged from paediatric care and CFS as soon as she was 16. She has had no input from health since then. She has medical needs, is housebound and is vulnerable and isolated.
- Paediatrician just basically said at his last visit I doubt I'll see you again.
- Discharged from VI consultant, transferring to adult services for health issues (hopefully)
- My youngest was suicidal and self-harming with CAMHS for more than 2 y. I have no idea about what happens after 18 y.
- CAMHS have arranged a transition worker to help transition to other services.
- Only because I navigated the system myself and have learnt along the way about hospital passport, Mental Capacity Act forms for procedures etc. I had no help at all.
- Just about to go for the final annual paediatric appt...hopefully we will be informed then as to what happens next.
- Sadly, like most, our paediatrician discharged our YP a long time before age 18.
- Currently navigating transition has been a slow process and has often felt like falling off a cliff, scary for both parents and young person.
- But it was awful - only because it was on the local offer, and I gave it to the locum psychiatrist and asked what was happening did anything start to happen. Completely switched off engagement with the service as the transition was appalling - done 3 weeks before 18th birthday, 1 year of work done in 3 weeks
- Need to transition to adult services, nothing else known. CAMHS stopped whilst still self-harming.
- Attends CDC at Kempston and they have advised us.

12. Finally, we asked parents if there was anything else that they would like to tell us about either education, health or social care.

Below are all of the responses received:

- CBC spend the entire process making up excuses because they cannot assist. Excuses why they cannot invest any money and excuse why their service is abysmal.
- Need better provision post 19 within CBC for non-verbal young people with profound disabilities.
- Just that this has been and still is a very lonely process for my son. He deserves to have a space in society, just like everyone else, yet it seems that he is isolated from pretty much everything and as he doesn't have behavioural challenges, can't play sport, doesn't do gaming, isn't into social media or drinking or partying or vaping he simply doesn't seem to have a space in society. I will never give up hope though and will continue to advocate for him and others like him, to have a decent quality of life.

- It has been an incredibly difficult fight to get and maintain receiving the support that we do. Our family unit is broken, and so is parental mental health and wellbeing.
- Very limited information about any of this. Any workshops etc run do not accommodate working parents.
- Not enough support available
- She has had no support from Central Bedfordshire Council despite having a disability and having education and health needs since she was diagnosed with CFS in 2018. I have been requesting help since then. That is 6 years ago! Central Bedfordshire Council are only interested in gatekeeping, not meeting the needs of young people.
- There are not enough clubs/social activities outside of school/college hours.

Discussion and recommendations

The results of this survey suggest that more work needs to be done to ensure that all aspects of a young person's life from age 14 are focusing on their upcoming transition into adulthood.

This work begins with ensuring that there is a clear and specific focus being given to each of the four areas outlined within the NDTi PfA programme within every annual review of an EHCP or a SEND Support plan from age 14. Providing a distinct and structured focus around these four areas will help ensure that each pathway is explicitly considered and discussed at each annual review; providing important opportunities to share information and support young people and their families to consider future options for education, work and independent living. Dialogue with young people and their families at each annual review must move beyond just discussions about future educational options and include conversations about independent living, supported employment, community inclusion and health transitions. The young person's aspirations in all of these areas need to be explored and reflected within their EHCP or SEND Support plan. This will then allow the local authority and health services to aggregate this information to inform plans for the provision of future services to meet the collective needs of young people with SEND in the county.

The concept of what 'independent living' means for young people with SEND needs to be better explained. Many parents appear to either have a complete misunderstanding of what this term means for their young person with SEND, or they don't have any vision of what 'independent living' might actually look like for them in practice. An almost universal lack of knowledge about what the different options for independent living are for adults with disabilities is likely bolstering misconceptions about its meaning and preventing young people and their families from understanding and considering future options early and in good time before their young person reaches 18. Without a clear vision of the options available to their young person and clear pathways of how to get there, families are being left in the dark trying to figure this out for themselves.

Curriculum content offered by schools and colleges needs to better address each of the four NDTi preparing for adulthood areas. Many parents feel that their young person's curriculum is not preparing them well enough for life beyond 18, after their education has ended, and that an emphasis on teaching the skills needed for finding and maintaining voluntary or paid work is lacking within their child's curriculum. A lack of knowledge about what supported employment

options are available to their young person or how and when these could be accessed, is leading some parents to assume that their young person will never be able to engage in any kind of work, particularly where they have higher support needs. Careers advice, particularly for those young people with an EHCP, needs to better reflect and explain the supported employment options that are available and the pathway towards accessing these.

Ensuring community inclusion in adulthood begins with strong inclusion before that age. Many parents reported that their young person's access to community groups and activities was very limited, for both those with an EHCP and those on SEND Support. Younger teenagers on SEND Support reported better community engagement than those with an EHCP, although much of this difference dropped off after the age of 16. Some parents reported difficulties for their young person because of a lack of appropriate transport and a lack of provision local to where they live. For all age groups, a majority of parents reported poor community inclusion after the age of 19, with a number of parents highlighting the cessation of their young person's club or activity once they became an adult.

Some parents were very complimentary about the support offered with their young person's school to help them with building friendships, whilst others felt the opposite. In their comments, no parents mentioned friendships outside of school; suggesting that school is often the only place where most young people with SEND interact with friends if they have them. The results of this survey suggest that most families are still the main supporting factor in facilitating their young person's access to friendships with their peers outside of school. This issue echoes parent responses about the lack of their young person's community engagement overall, which further confines their friendships to the time they spend at school. As a consequence, any friendships that they have made are at risk of being lost once a young person moves onto a new educational placement or leaves education entirely. Increased access to out-of-school clubs and activities with providers who offer both children's and adult provision, allowing young people to move up from one to the other, would help support them to maintain their childhood friendships into adulthood. Such a provider would likely be better equipped to provide an earlier and more long-term focus on teaching skills for adulthood and independent living as part of its offer. This might also help to address the lack of focus on such skills by short break providers that parents have expressed within this survey, particularly for those young people with higher support needs.

These results demonstrate that there are still a high number of young people with SEND who are not accessing their annual health check. Annual health checks break down barriers to health services for people with learning disabilities and allow any health issues that they develop to be picked up early and treated, thereby reducing the health inequalities that young people with SEND often face. It allows young people and their families to be more fully and proactively involved in their healthcare and provides young people with a vehicle for becoming more familiar with the surroundings at their local GP surgery. It also gives young people and their families a way to build trusting relationships with particular health professionals at their GP surgery and to be given the extra time and adjustments that they need to access the services at the surgery successfully. It is evident from the results of this survey that more needs to be done to inform parents of their young person's right to an annual health check, as many families are still unaware of this service. More importantly however, is the need to ensure that every GP is consistently maintaining their own practice's learning disability register, so that every person with a diagnosed learning disability

on their records is being proactively contacted to make arrangements for their annual health check.

The parents responding to this survey also report a lack of knowledge and understanding about how their young person's healthcare in childhood will change when they become an adult. Many families still have no idea when or how this change will happen. They often lack a basic understanding of which adult services, professionals or consultants their child will move onto when they are 18, where these are located and how the move is actually made. More work is needed to ensure that pathways into adult health services are clearly explained to families well ahead of their young person's 18th birthday. As is currently the case with educational transfers, transitional plans and arrangements need to be put in place to make the move into each new adult health service as smooth and stress free as possible for the young person and their family carers.

Due to the challenges, we see parents face SNAP PCF have created a PfA Padlet, this is written by parents for parents using our lived experience to provide information to support parents through the complicated journey of navigating their young person successfully into adulthood [Moving towards and into adulthood \(padlet.com\)](#) We hope we will be supported by Central Bedfordshire Council, the BMLK ICB and local health providers to promote this resource across Central Bedfordshire to ensure as many parents as possible have the opportunity to access this resource.

The work that has started with Central Bedfordshire Council commissioning the NDTI is an important step in ensuring the area is clear where their strength is and the gaps in services are, with a plan to improve this. We hope CBC will continue to put a strong emphasis on Preparing for Adulthood to ensure our young people have every opportunity to be successful in their adult lives.

In summary SNAP PCF recommendations are:

- To review the EHC Teams processes during Annual Review to ensure they are person centred and includes a specific focus on the four pathways: employment, independent living, good health, and friends, family and community.
- To ensure the young person's aspirations are explored and reflected in their EHCP or SEN Support Plan.
- To review how schools review their SEND Support plan, and advice aged 14 plus with a focus on Preparing for Adulthood four pathways.
- A review of the offer for young people for independent living, with clear and concise information being provided.
- A review of how education settings promote the NDTi pathway with clear examples of how young people can access these services. A particular focus on work experience and finding voluntary and paid employment.
- To review and communicate better how young people can access activities and be a valued member in their community.
- To review how Central Bedfordshire Council and the BMLK ICB children and adult commission services to reduce the cliff-edge of young people being prevented from accessing clubs from the age of 18 years.
- To review how the young persons annual health check is being promoted with a view of better communicating the offer to ensure more young people access this.

- To continue with the work already undertaken with the NDTi.
- Central Bedfordshire Council, the BMLK ICB and local health providers work with SNAP PCF to promote their new Preparing for Adulthood Padlet [Moving towards and into adulthood \(padlet.com\)](https://padlet.com), to ensure that parent carers receive information about this at every opportunity when their young persons is transitioning into adulthood.

Thank you.

Thank you to the parent carers who gave their time to complete our Preparing for Adulthood survey, your time is appreciated, we cannot do this work without your support.

Contact SNAP Parent Carer Forum

E: admin@snappcf.org.uk

F: <https://www.facebook.com/snappcf.org.uk/>

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Link to our membership form

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