



*'giving a voice to parents & carers  
of children with additional needs'*

## **Report on Preparation For Adulthood February 2024.**

This document contains information from varying reports Wolverhampton's Parent Carer Forum, Voice4Parents, have written for and shared at SEND Partnership Board meetings throughout 2023 along with parent carer feedback gathered by the forum via social media, Voice4Parents' website, emails, coffee mornings and Voice4Parents' affiliated Community Group which have all been collated and anonymised before sharing with Wolverhampton's Local Authority and Health Services. The following Information is only pertinent to Preparation For Adulthood.

### **An Overview of Parent Carer Forums**

A Parent Carer Forum is made up of parent carers with a full range of experiences in Health, Education and Social Care as their children/young people have a wide range of conditions. They are a key strategic partner with their local authority, Health and voluntary sector to ensure local services and facilities better meet the needs of SEND children, young people and their families.

A Parent Carer Forum's core work is around strategic participation of families enabling their voices to be heard to shape service and policy design, influencing local policy and service design through strategic coproduction, as an equal and reciprocal partnership where everyone's experience, knowledge and skills are used to create better outcomes.

It develops a parent carer representatives' network (as steering group or pool of trained reps), which connect with communities to gather intelligence and evidence, to demonstrate success, to share key information, to promote participation and engagement with parent carers both strategically and individually.

As well as providing participation opportunities, developing and maintaining strategic relationships with its' LA (adults and children's services, including education, skills and learning, and social care teams), Health (again adults and children's services; acute care; community services), other key partners: IASS; support networks; condition specific groups, and providers for example schools & colleges

A forum will do this by gathering intelligence through social media presence, closed community groups, surveys, workshops, Focus groups and topic specific coffee and chat

sessions, community champions and through good relationships with other key organisations. From this the forum will feedback by producing reports on specific key topics, conferences, AGM's, presentations, newsletters, mailshots, updates, web content, community champions and now through interactive opportunities such as virtual meetings, videos and webinars.

Strategic work of forums include meeting with service leads to share Parent Carers collective experiences to improve service delivery for all families, forums working with commissioners, service providers and policy makers to develop and design services, pathways, and processes to improve outcomes for all children, young people and their families and by forums shaping and supporting improvement to practices to provide improved Parent Carer engagement across all services.

### **Who is Voice4Parents?**

Voice4Parents is Wolverhampton's parent carer forum whose representatives are parents and carers of children and young people (aged between 0-25) with special educational needs and disabilities, living in Wolverhampton. We work closely with families living in Wolverhampton and as a strategic partner, with the Local Authority and Clinical Commissioning Group, we work in coproduction to shape and improve services, by gathering feedback from parents and carers and listening to families' experiences. As parents ourselves of children and young people with SEND, we feel we have a genuine understanding of just how hard the struggle can be at times.

We are funded by the Department for Education; our participation contract lead partner is Contact and we are part of the National Network for Parent Carer Forum as well as the West Midlands Regional Parent Carer Forum.

In order to demonstrate that parent carer forums such as Voice4Parents work in co-production with local services, a senior officer of the local authority is requested by the DfE to sign a Memorandum of Understanding of working in co-production with the local parent carer forum. The MOU states the following,

***"We commit to uphold the principles of the SEND Code of Practice and to work in partnership with the DfE funded local parent carer forum to improve local services for children and young people with SEND. We recognise the independence of the DfE funded parent carer forum. We value the role of the DfE funded parent carer forum in representing the needs, experiences, and views of parent carers of children and young people with SEND including their role in raising issues, providing constructive feedback through open dialogue, and challenging partners when necessary. We agree to work together with respect and as equal partners."***

It is our aim is to make sure the services in Wolverhampton meet the needs of all SEND children, young people, and their families. Voice4Parents represents the family's views and experiences pan disability, and has a real in depth understanding of the issues families face on a day-to-day basis; from the challenges, to the joys our children bring.

We believe that parents, carers, and professionals are stronger and more resourceful when they work together, and when we do this, we achieve good outcomes for all our children and young people and their families. By working in co-production with the local authority, education settings, health providers and other providers, Voice4Parents can highlight where local services, processes and commissioners are working well, or challenge when changes or improvements need to be made.

We like the council for disabled children state, “want a society in which disabled children’s needs are met, aspirations supported and their rights respected.”.

### **KEY FINDINGS FROM ANNUAL SURVEY 2022/2023 Dec 2022 -March 2023**

**‘SEND support in Wolverhampton for parents and carers is hard to access. Services have long waiting lists and the criteria to receive support is too high. This results in children being let down and not supported as they should be. As a parent this is very upsetting and frustrating as it's hard to ask for help in the first place’.**

The Voice4Parents Annual Survey delivers a snapshot of life for children and young people with special educational needs and disabilities (SEND) and their families who live within Wolverhampton. It gathers feedback (both quantitative and qualitative) on the key issues affecting SEND families in the city and is a valuable tool for services across Wolverhampton to discover what families want, what improvements need to be made and where can lessons be learnt. There are a number of themes which dominate feedback across all service areas which are summarised in this brief summary – this will demonstrate what parent/carers want in order to make Wolverhampton an inclusive city and to improve the well-being and future chances for their child/young person. However, the overarching message from parents/carers is that they are experts in their child/young person and without placing families at the heart of the SEND process there will never be real changes:

**‘Professionals (need to) realise parents are the experts on their children regardless to what is put into place it will not work when parent/carers voices aren’t heard’.**

In December 2022 Voice4Parents sent our Annual Survey out to wider group members and also promoted the survey via social media, and Wolverhampton’s schools, inviting all parents and carers of SEND children and young people in Wolverhampton to complete it. The survey closed in March 2023 and received responses from **406** parents and carers compared to the 245 responses gathered in 2021

There are five topics which intersect with every service area throughout the feedback– inclusivity; the whole family approach; feeling heard; forward planning and autism. This summary will introduce each topic and indicate why these themes are at the heart of SEND families’ feedback – the positive change it can make to people’s lives when they are done well and the impact when things go wrong. This report introduces where parents believe there are areas of good practice from which we hope other services can learn – it is not just focused on what is poor for families in Wolverhampton but is designed to show the local authority, health and social care services what families want them to implement to create meaningful change for their families.

## 1) Inclusive services

**‘Wolverhampton is not an inclusive City and he is being excluded from an ordinary life’.**

The feedback from parent/carers indicates that many SEND families feel excluded from their local community and that the lack of adaptations mean that they do not feel part of society:

**‘There are no opportunities for my child to be included and supported in the community’.**

However, the feedback also indicates where services are adjusted for their families it has an impact on their family’s happiness. One explains the best thing for her child in the last six months has been:

**‘When she is listened to and adaptations have been made to meet her needs’.**

Parents have fed back overwhelmingly that some of the city’s specialist services are instrumental to their lives both in terms of well-being and belonging – one parent calls them a ‘lifeline’ for their family. Local community groups and charities are singled out for making a difference to the lives of SEND citizens – these include – Give Us a Break; Let Us Play; Include Me Too; Sassy Sensory and Voice4Parents. There are other service areas which are highlighted by multiple respondents – IASS, Outreach, The Way (SEND sessions) and special schools. These areas all include a common component – they are tailored to the needs of those with additional needs and their families – they are already inclusive – and this suggests that these services which have developed positive relationships with families – should be central to shaping the services for which the feedback is poorer. The feedback is unequivocal – SEND parents want their voices to be represented by those they trust and those relationships are already established.

Parents report that the whole family often feels isolated because they are unable to access activities as a family in line with non-SEND families – needing to look at the wider family picture is a thread which runs throughout all feedback. The charities and community groups mentioned by parents enable family members to access their activities whether on their own, with parents or with siblings.

**‘V4P represent our families voice, they have provided opportunities the local authority should be providing but aren’t to meet SEND family need’**

**‘IASS stands out with their quality of knowledge and dedication to support the SEN families.’**

These are positive examples of services that SEND families trust to meet the needs of their young person and the impact this has on the life of the whole household. Yet, this feedback is the minority, and parent carers feel that most services are not inclusive – mental health services are highlighted as a particular weakness because they fail to adapt their offer to the needs of families which means the help offered is either not appropriate or accessible. Another area where families feel excluded is being able to access leisure opportunities for their child and the whole family.

Parents also feedback the perception of a two-tier system in education – where special schools meet the needs of their pupils but that mainstream schools’ lack of necessary adaptations for their child/young person means that they are failing to meet the need – this leads to unhappy families – ‘Mainstream Schools are not equipped to manage SEN children even with EHCPs they are at full capacity and under staffed’. As mainstream is the most common destination for Wolverhampton families – this clearly needs to change and Outreach and Voice4Parents and staff from specialist schools must be involved in this process as these services have an established trust with families.

## 2) Whole family approach

**'I don't feel that people are listened to as family unit.'**

A golden thread which weaves through feedback on every service is the need for a focus on how SEND impacts not only the child/young person but their whole family including parents and siblings: 'Understand the whole family needs, not just the child who is diagnosed.' Parent/carers repeatedly ask for support for themselves and find that there is very little provision for this – one avenue is a carer's assessment but feedback shows that these are not being carried out consistently or in a timely manner – 'I've personally been waiting for a Carers Assessment for over a year'. Another common request is mental health support but this holistic approach to SEND does not exist in Wolverhampton,

– it is not just children and young people who are isolated but their families. As the primary caregivers, it is essential that parents are supported in this role: 'No one asks about our mental health, no one cares. And if you ask for help you get shamed or ignored' – when parent/carers are brave enough to ask for help – they should be heard and treated with compassion not judgement.

There needs to be more support and services for SEND families, especially to do with mental health and more SEND friendly leisure for all family members to help families to go out more often and to help their SEND child to explore the environment better.

Another area upon which parent carers report there needs to be a 'whole family' approach is accessing leisure in the community. Families want to experience things as a unit; 'there are many activities we cannot access in Wolverhampton. The ones we have been able to access is with Voice4Parents for the whole family and they meet the needs for my children'. Parent carers are communicating that they want accessible activities for their families and this could be developed under the universal and targeted Short Breaks offer.

## 3) Feeling heard

**'I feel like I'm banging my head up a brick wall constantly'.**

**'Everything is a fight. Everything'.**

Poor or inconsistent communication is something that is fed back constantly by SEND families – this report goes a step further and suggests that it is the importance of 'feeling heard' by services that is crucial – **'no one understands, no one really listens**. As the experts by experience in our children – parent/carers are a valuable and untapped resource in getting things right first time – **'no one listens and works with me'**. Our feedback shows that effective dialogue with professional services leads to families feeling happier: **'Having a SENCO that communicates with myself and my child. That does what she's says she will do and ensures I have the information I need to support my child. Also gives consistency'**.

Poor communication between services also results in a less than ideal experience for our families – the feedback on whether services communicate effectively is overwhelmingly negative: talking to families and talking to each other is a simple step to getting things right: 'A harmonious and consistent bond must be established amongst all the services involved in each individual case'

As it stands, the voluntary sector is providing an important network for parents' experiences to be heard by other parents: 'parents with SEND children offer peer support'.

Part of being heard is also family's needs being recognised – most parent/carers report frustration with having to repeat information about their child more than once and with for a 'Tell It Once' approach to be implemented: 'I hope that all services would come together and produce a document Tell it Once. This should a recognised document as this would save a lot of time and prevent families from getting upset by repeating their child/ren health/physical need.

The only way SEND families will feel truly heard is if their feedback is taken upon board and acted upon becoming the blueprint for changing lives.

#### 4) Forward planning and preparing for adulthood

**(My biggest fear for my child is) 'Adulthood. I won't always be here to stand between them and the world'.**

All professionals and parents agree that early planning for the future will lead to better outcomes for children and young people with SEND. One theme in the annual survey has been change and transitions – that when these are managed well it is better for the child. One parent's comments that the best thing in the last twelve months for their child was: **'being able to visit the new school and the teachers visiting his nursery setting prior to starting to build a relationship'**. Appropriate planning for the future at the right time is crucial but when this does not occur the impact can be widespread and long lasting: **'The challenge has been moving year groups into the next key stage. He took a lot longer to settle into school than in the previous year - his behaviour at home became very challenging and erratic'**.

When parents are asked what their biggest fear is there is one dominant response – what the future holds for their child/young person – most SEND children will become SEND adults and so there needs to be meaningful and targeted Preparation for Adulthood: **'acceptance and finding a career, relationship and being able to emotionally and financially mature.'** Therefore, planning needs to start early through a 'whole family' approach as parents report that they want to be fully involved in this process.

#### 5) Autism

Autism and other forms of neurodiversity affects the majority of families whom we represent in Wolverhampton and as such is a prominent theme in the annual survey. Autism intersects with every area in the detailed report.

The major factors with autism in Wolverhampton comes as no surprise as it has been prominent in our previous Annual Surveys since at least 2019 – access to a single and defined pathway for diagnosis, long waiting lists for diagnosis, confusion over which list/pathway a Child might be on and why there are huge disparities in waiting times for panels, lack of support pre and post diagnosis and poor education and health outcomes including but not isolated to the inaccessibility of mental health services for children and young people with autism ( and indeed many other SEND diagnosis). The importance of early intervention cannot be underestimated: **'Finally getting diagnosed has opened some doors'**. Families are finding the doors are being shut in their faces whilst waiting for a diagnosis with masking as a particular issue where parent/carers are not 'being heard' by services because their child/young person presents a different way at home to other settings or even not the same as another autistic child/young person: **'The problem is that my YP is a female with autism and she has masked her difficulties all her life. Some teachers have no understanding of autism, she was thought of as being 'thick'.**

## PREPARATION FOR ADULTHOOD

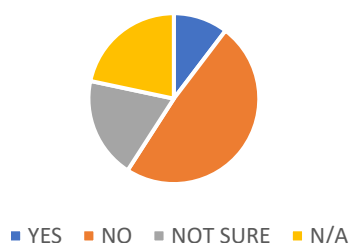
**'Work with the child to gain independence and explain more to the parent carers, I still don't understand what any of this means and I feel I am on my own with finding things out or I go to the parent carer groups for help, often what should be offered is not and it's a fight to get the help, it's all too stressful and complicated'**

When parents were asked in the annual survey what their biggest fear for the future was – adulthood was the overriding fear: **'daily life, she is scared and anxious herself about growing up and independence and what it means, there was no preparation for this at all.'** The importance of the preparation for adulthood process cannot be underestimated with all its branches including puberty, relationships and the importance of managing transitions.

How confident do you feel about your CYP's transition to adulthood has a baseline figure of **3.63** (scaled 1-10) – this is one the lowest average scores in the whole of the annual survey and is an indicator that many families are **confused by Wolverhampton's Preparation for Adulthood offer**. The rest of the questions and comments on Preparation for Adulthood show that parent carers and children and young people do not feel that conversations are happening early enough, if at all – **'Early introduction to parents so we can be prepared.'** There is considerable feedback on what parent carers want included in preparing their children for independence – which focuses on life skills including travel training; employment and training; budgeting as well as coping mechanisms for the 'outside world' – learning about social interaction, where to go for help and support and how to build relationships as important as finding a job or cooking and cleaning. **'Real life skills, self-management. Less focus on employability and more focus on knowing where to go for support & friendships as a SEND adult.'**

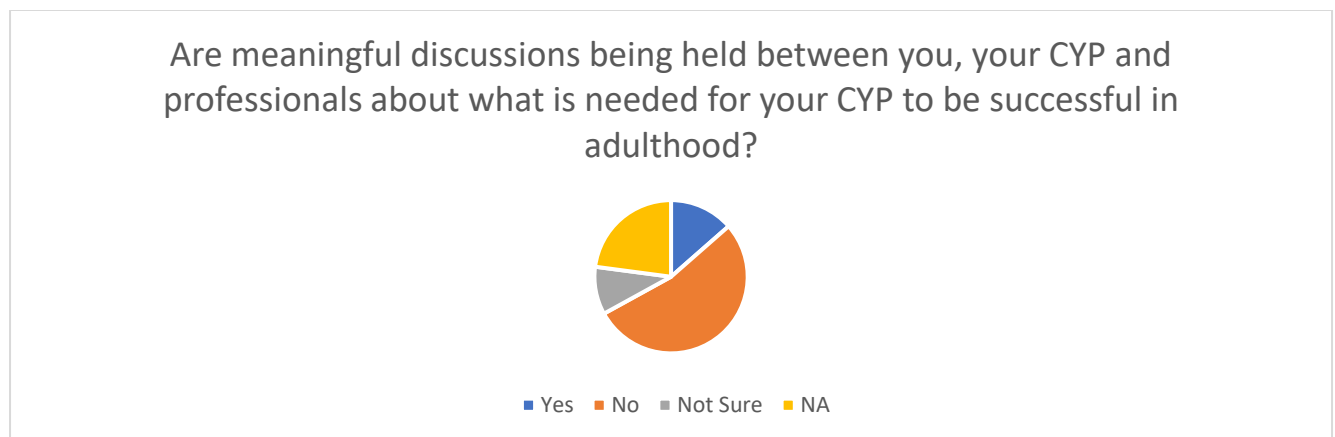
But there were some comments that services need to genuinely plan for young people's futures rather than assuming it would be left to their parents – **'I think the transition period should start earlier and be more about moving these children away from parents taking on all their future care...'** although there was an opposite view that the family should be involved holistically in the preparation for adulthood process to identify what they could supply and where there were gaps: **'holistic family sessions to see what support the YP needs and what the family are capable of doing themselves and where the gaps are with regular reviews to see how the transition is going'**. This perhaps shows preparation for adulthood needs to place individuals and their families at the heart of the planning for their future – **'Listen to the what the parents and YP are saying and actively move in that direction.'**

Do you feel that your CYP is being well prepared for Adulthood



Out of 406 responses, the question on preparation for adulthood was not relevant for 88 parents. For the remaining 318 responses, 42 parents stated that they felt their CYP were being prepared well for adulthood and 78 felt they did not know.

However, the overwhelming majority of parent carers did not feel that their CYP were being prepared for adulthood. Moreover, many families did not feel that these conversations were happening early enough – ‘**an early introduction to parents so that we can be prepared**’. The number of respondents (78) who did not know whether their children were being prepared for adulthood is also concerning because it suggests a lack of awareness of this essential part of preparing those with additional needs for adulthood. Feedback suggested that it was mainly parents leading on preparation for adulthood with little support from outside services including health and social care – ‘**ultimately it starts with parental support but if outside support doesn't continue into adulthood, I feel this is why so many young people and adults with disabilities lose so much faith and hope when it comes to having opportunities and independence.**’



This question was not applicable to 93 respondents which is concerning because this should be taking place from the very early years and is therefore a useful process for all SEND CYP. Only 55 parents said that there were meaningful conversations and a further 41 were not sure suggesting unfamiliarity with the process – one parent commented that preparation for adulthood was currently ‘**a tick box exercise**’.

217 parents said that these conversations were not happening in a meaningful way which is 69% of parent/carers who filled in the survey.

If your child / YP has an EHCP and is in Year 9, have plans been made within their annual review to start preparing for adulthood? was only relevant to 128 respondents – one parent commented they were not given the option to be involved in the planning for their young person from yr9. Only 19 parent/carers said that preparation for adulthood was being planned for in their annual review. 49 parents said this was not happening and 20 were not sure. There were several comments that those young people without an EHCP were being forgotten in preparation for adulthood.

**‘Not just those with an EHCP need support. What happens if he fails all his GCSEs because he wasn’t given enough support in school. What then? What are his options how will he get a job. Unless a person has an EHCP they are ignored by the local authority and given minimal support by school’**

**‘Support for my child on SEN support she is overlooked and no opportunities to prepare’**

There were also comments that young people who are educated out of city are unable to access help with preparation for adulthood. **‘Again - Educated out of City so nothing for our son is offered - health forget him, social care forgets him - services certainly don’t work together’**

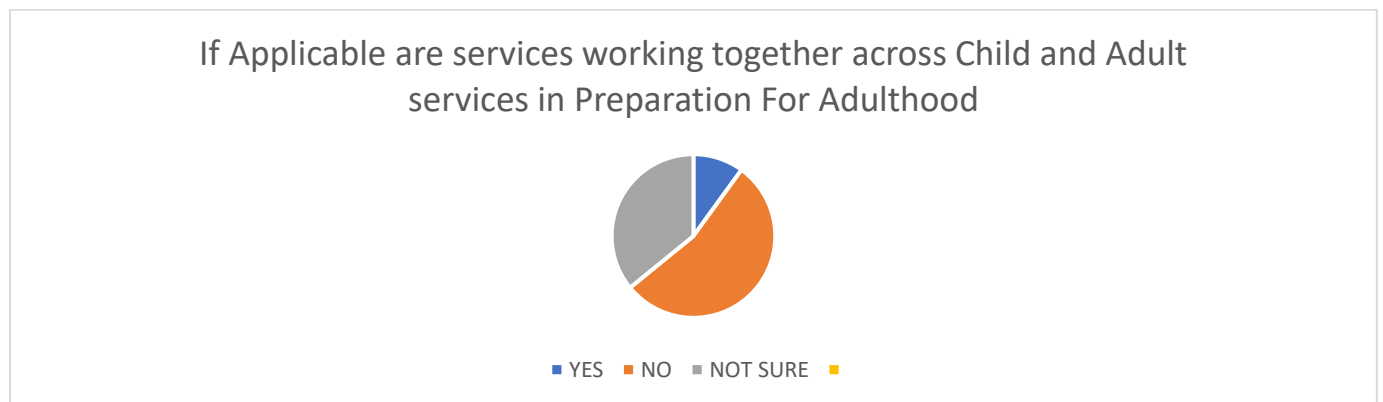


Question 58 asks whether a CYP aged 16+ whether plans have been made in their annual reviews for preparation for adulthood. 19 stated yes but 39 said no and 15 were unsure. However, many parents thought that this involvement was happening too late – **‘everything needs to start earlier rather than 16 and 18’**. This was echoed in several comments where parents did not feel either they or their young person was being prepared for adulthood early enough or effectively enough – **‘should start whilst young so that correct needs are identified’**

Connexions Wolverhampton work with young people and with schools across the city to ensure that all local young people have access to the opportunities available and can acquire all the knowledge and skills needed to begin the career of their choice.

A question asked regarding Connexions and whether families had had any involvement from them shows that 175 parents replied with 39 saying they had had Connexions involvement but 70 respondents said they were not involved and 66 parents did not know who Connexions were. This is reflected in the feedback where some parents were very supportive of the service that they received from Connexions although it was difficult where the young person refused to engage – but this could be patchy and sometimes did not feel personalised enough – the phrase tick box exercise was used on more than one occasion’ – **‘I had a connexion advisor ring me to ask questions about my child and they wrote a report for his ehcp, no advice or support was offered it was more like a tick box exercise they had to do’**. The comments show that that the involvement of Connexions and the support received was inconsistent for families. Information for eligible children should be sent from SENSTART to Connexions for follow up support/conversations.

#### ANNEX A BELOW SHOWS THE COLLATED RESPONSES



The final question in this section asks whether services are all working together across children and adult services to prepare for adulthood but the majority of parents did not know this was happening – **‘A transition team or board of multi-agency professionals who sit over health, education and social care from both children and adult services so that families are not thrown off a cliff edge at 17/18.’** Other parents commented that services do not have effective communication – **‘co-ordinated working between all services’**

17 people responded positively but 92 parents said no and 61 parents were unsure. One comment said that Social Care should be involved in annual reviews from the age of 14 so that the care needs of the young person are known in advance rather than leaving it until it is too late. Another commented that **‘young people with special needs to just get better overnight’** suggesting that the transition from children to adult services was not smooth enough. **Further comments on what Parent Carers**

feel is required to support their Child and Young Person into Adulthood are in ANNEX B BELOW SHOWS THE COLLATED RESPONSES.

### **SOCIAL CARE AND ROLE IN PREPARATION FOR ADULTHOOD**

Question 70 asks if their child/young person has an EHCP has a social care assessment been carried out for their plan – this was relevant to 225 families – 51 answered yes and 174 answered no (77%) – this is a worrying statistic as the Preparation for Adulthood process is supposed to begin from the earliest stages of young person’s life in order to plan effectively for the future – the lack of social care awareness in the majority of EHC plans means that social care could be missing a significant amount of young people with whom they could be making plans for independent living – early enough – **‘Hard to keep track of joining up what the carer should be doing with child’s EHCP targets.**

Q71 asks whether families have applied for Short Breaks – 74 responded yes; 260 said no and 55 said it was not applicable. The data shows that only a small proportion of families are aware of that they might be eligible for Short Breaks and although they would not be suitable for some families – the small number of people applying could mean that opportunities for early help could be being missed – **‘families end up in crisis and needing even more help because it took so long to get extra support’.**

**‘Near impossible to access. We had an assessment nearly a year ago and yet to see any outcomes from it. Had to complete informal complaint. Still waiting’.**

**‘Moved to Wolverhampton April 2021 and still not even the process in action even after a number of calls. Feel like I’m banging my head on a wall’.**

Families are being left in limbo after social care assessments or requests for help and there needs to be a clear policy in Wolverhampton which explains eligibility and the timescales for when parent/carers should receive a response from social care. The ease of accessing Short Breaks had a baseline score 4.21 although the majority of scores either fall in 1(lowest) and 5-9 (highest) which suggests a two-tier level of satisfaction – it is unclear whether this is related to families who have not met the criteria for Short Breaks but it is clear that the criteria for the Disabled Young People and Children’s Team should be more explicit.

**‘When my daughter did have an EHCP nothing was offered even though I asked, I was told my a support worker who I got in touch with for help with my own mental health we didn’t meet the criteria for help but again not clear what that was for, guidance reads as though we should have been eligible for a parents assessment and a social needs assessment but I was told not’.**

However, the criteria and eligibility process are not just misunderstood by parents – professionals also seem to be giving families incorrect information – this is clearly an opportunity to use Send Champions so that families are being given the correct advice and guidance by professionals.

There was feedback on the current Short Breaks provision which showed an uncertain and inconsistent picture. There was widespread dissatisfaction with the Direct Payments system – **‘finding a consistent PA with suitable experience and commitment.’** – where families were eligible for respite hours but due to being unable to source a personal assistant, they could not access these hours – the money for this was taken back by the Local Authority without any benefit for the child/young person. The intricacies of the Direct Payments system were also fed back on by families

who believed that the system place too much pressure on parents and carers especially with the financial details.

**'When we used direct payments, we found it impossible to recruit a personal assistant despite looking for over a year. This meant that my child's money was taken back and so not only could he could not access respite, he was also unable to access his money. The direct payments system places too much responsibility on parents e.g., pension contributions and maternity leave and we were left without any support when the service provided by the council to help with this admin was inadequately withdrawn.'**

As post-Covid the market for Short Breaks has changed, the social care team may need to diversify their offer as parents report being unable to access respite both through Direct Payments and commissioned services. Parents request that there is a level of flexibility in the Short Breaks offer so that services are suitable for their family's needs – **'direct payments could be more flexible to meet changing needs'**. But it cannot be underestimated how important developing a young person's independence using Short Breaks will be to their preparing to adulthood journey and well as helping them feel part of the local community: **'He enjoys spending time with his carer which allows him to access the community.'** Parents are obviously frustrated that their child/young person is eligible for help but they are unable to source a personal assistant.

**'I was offered this, 4 hrs a week in the holidays, no one wants to take care of a child with extremely complex needs for 4 hrs a week it amounts to £30 odd pounds. Also looking for someone, being their employer, paying them, doing taxes for them. It's another job, on top of being a single mom. Absolutely pointless! Makes me feel like they do it on purpose so we just cancel altogether and save them money.'**

**'We now use a commissioned service which is much better but due to there being more young people than workers, we can only access half of the hours that our child has been assessed as needing.'**

The appropriateness of the Short Breaks which people have been offered is an even split (45% yes; 55% no) which supports the earlier suggestion that Short Breaks either get it very right for some families – **'not accessed for a few years now but when I did it was very helpful. So, we could afford a holiday that was better suited to our children's needs'** – and very wrong for others – **'disastrous. Terrible service'**. Services need to understand what lessons can be learnt from these two cohorts.

From parental feedback a clear theme develops around Short Breaks and Direct Payments – paired with parent carer feedback mentioned above, that they are inappropriate for a large number of local families.

**Not enough carers. Pay for carers poor so can't attract or keep decent ones. Social workers remove hours at the drop of a hat when it suits them**

The cross-referencing with the feedback from the Local Offer demonstrates that the Short Breaks offer across Wolverhampton is unsuitable for many families who do not require high levels of intervention (such as overnight respite) – **'We don't need respite maybe something local during school holidays something active'**

However, families do not feel that all universal services are suitable for their children and that there is clear gap in provision for those young people/children and their families to access leisure. This builds a clear message that families want activities which are both accessible and suitable – this does not necessarily mean expensive subsidised activities but opportunities to be involved in the local

community – **‘they don’t recommend good services because they don’t exist’**. The feedback on how involved SEND families feel in their local community is has a low rating by parents (4.85) and with Wolverhampton billing itself as an inclusive city – the annual survey shows what steps parents/carers think need to happen to make this reality for their families.

## **HEALTH – ROLE IN PREPARATION FOR ADULTHOOD**

Out of 394 responses (where Health services are appropriate for Children and Young People), 146 families are currently on a Health Service waiting List. Detailed responses given have been difficult to analyse properly and we recognise that in future surveys we will ask the question in regards to waiting times for specific services in a different way to give better quantitative data.

In the main, findings here are no surprises and partially touched on in other parts of this report (as also reported in V4P reports since at least 2020) is that waiting lists for CAMHS, ASD and ADHD diagnosis and Therapy Services (mainly OT and SALT) are a major concern for families. Although all vary in period of waiting times, on average parent’s report that waiting times for CAMHS and Psychiatrist appointments, ASD diagnosis, ADHD Diagnosis, OT and Salt can be anywhere up to 3 years and currently waiting.

**“Asd pathway- been on and off it since age 4! Now nearly 11”**

**“Waiting on an ASD assessment had the initial assessment on video August 2021 and was told it would go to a panel, recently rang them up they couldn't give me any update other than there is a long waiting list”.**

**“We pay for our own OT as we had no help with our daughter, we have paid for 6 years!”**

**“Occupational therapy - since February 2020 Base 25 - since January 2021 Outreach - since February 2023”**

Community Paediatrics, Dieticians, Dermatology and Neurology have also been reported as also having longer waiting lists with parents reporting a wait time up to 18 months for these services.

**“We wait for up to 18 months at a time to see community consultant paediatrician - and audiology which should be regular (3-6 months) but we haven’t been seen for at least a year.”**

**“Splints been made , awaiting to see consultant regarding the fitting, was put through as urgent and changed for no reason to routine still waiting 2 months on since his first big fit to see a doctor and put as urgent is missing out on school activities in meantime out of routine upset” .**

As reflected in many comments, most families are waiting on more than 1 service and this leads to frustration within the Health Service generally as the situation for Children and Young People seems never-ending and constant waiting. From comments, it appears that if a child Young Person is seen under paediatric services, then there is at least some collective responsibility/oversight of entire needs but otherwise families receive a very disjointed service.

**“Speech and Language was seen in school setting at the start of last year. No one has been out to see or assess him again he is still not talking. Been calling them every few weeks. Not heard from dietician in over year or so, or from feeding services nearly 2 years ago”**

This does lead to the question of whether Children and Young People are actually on waiting lists that they families believe they are on. Work maybe needs to be done on the whole referral process

– to include timelines for families to make contact with relevant service if they have not had any responses from services. Further feedback from coffee mornings suggest that some families believe they are on waiting lists that under further investigation they are not on. Families should be given information at the point of referral that could stop this ambiguity.

It feels as though there is a need for Parent Carers, Families and also professionals to have a really clear understanding of what a Child Young Person needs, how to obtain what is needed and how to ensure provision is correct and timely. Pathways for ALL services seem to be required and shared with ALL health professionals for clear guidance.

Comments were consistently made on discharges from services without further support or explanation, what seems apparent is that inappropriate discharges lead to Children and Young People being re-referred back into teams. Again, clear guidance on pathways would help with this issue.

**“Waiting lists for any of these are into years not months, and that's if you can get in at all. Years for help and constant chasing and phone calls”.**

**“We received 1 appointment from CAHMS a few years ago which was not helpful at all and then he was discharged. My child was also under a Paediatrician and as soon as he got his ECHP she discharged us and said that school would pick up on anything he needed”.**

**“My son is 4 and doesn't talk but speech and language said they are discharging him!?”**

Taking all comments into account a register of a Child Young Person needs, highlighted on all Health records could also help with the issues above. Parent Carers feel that full needs aren't understood/known about and is therefore not catered for.

**“Something is needed to show the child's additional needs”**

Feedback shows that out of 391 family responses that only 30 families reported they have a Health Passport and an average rating of 5 was given on how helpful these were. V4P feel that if awareness and take up of the Health Passport can be increased then this might help with a Child Young person's need being met and understood without the constant need for re-telling a family journey.

**“Health passports are only useful if the hospital reading them actually listens to them parents aren't listened too and they don't listen to a piece of paper either”.**

127 Families stated that their Child Young Person would be eligible for an LDA 14yr Health Check. Only 25 of these families received the check. V4P feel that this is something we need to collate more data on, although we are aware that regionally this piece of work was done some time ago via Dudley Voices4Choices. However, we do feel that there is some confusion over eligibility and potentially understanding via GP surgeries (reception and not GPs).

**“No annual health check - although I've asked for one every year since he was 14 - was told by the receptionist that they don't exist?”**

**“Annual health check doesn't happen. can't even get a regular appointment when I'll let alone a health check. GPs are so out of touch and don't even read notes from Gem or hospital. I have to update them on everything”.**

There seems to be a real lack of communication generally. Teams seem to be working in isolation and do not talk to each other and there is little consistency to care received. Families are evidently

frustrated and asking for help – GP Services aren't aware of what is happening within a Child Young Persons general health and general reports/ updates aren't shared sufficiently.

This impacts throughout ALL services not only within Health Services but also between Health, Education and Social Care.

### **EDUCATION – ROLE IN PREPARATION FOR ADULTHOOD**

Parent carers feel that schools are not offering a rounded approach to educating their SEND child/young person with an over-focus on academic progress

**'It is disappointing that mainstream secondary do not have enough provisions for additional needs students and its very geared towards GCSE attainment'** – rather the other areas of need (SEMH, sensory, social skills) – **'as my child has got older her sensory needs are not being dealt with at school, they haven't got time'** and that where young people are flourishing academically, their emotional needs are being overlooked particularly where they are neurodivergent. To add to this there is substantial feedback about children/young people with additional needs not having reasonable adjustments made so that their child is not included in school – **'last school year for sports day my son was sat on a bench whilst other children participated!'**

The lack of reasonable adjustment can result in some form of exclusion. Another thread that runs through the section on education is the transition to senior schools and post 16 provision and the difficulties this can cause for SEND young people and their families – **'it took a year before my daughter settled into college and found the transition from school to college very challenging, especially to her mental health.'**

There is a set of baseline questions on transitions in Wolverhampton – between lessons, key stages and schools – and at the beginning and end of school. The majority of these scores are high within the survey (5/6) especially with transitions within schools – the scores are lower for when young people are moving between settings with lowest score of 5.08.

**'School worked very hard with him but it wasn't a good setting for him - his transition to college has been difficult without support but he's now really well settled and fitting in well and now progressing well.'**

**'No help with the transition to high school or help knowing which school would best meet her needs'.**

**He is now happy at school but we were left to just deal with the transitions between schools with no support.**

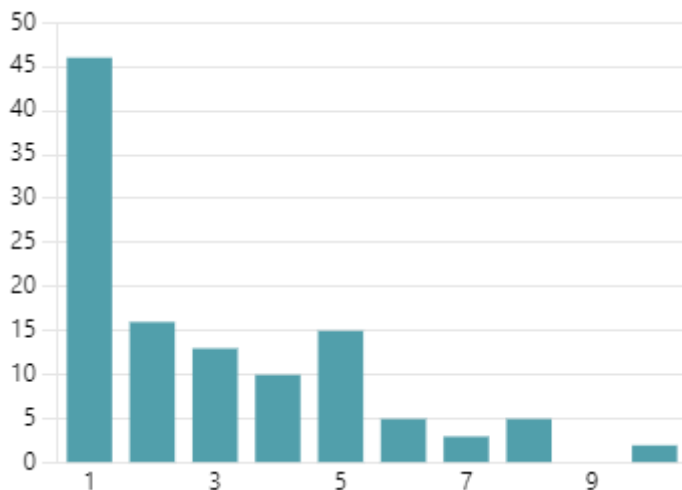
**'We have had help in high school but it is such a huge transition our daughter is really struggling. Some staff & SENCO really supportive, other staff unhelpful'.**

Three of these quotes demonstrate the difficulties for families when transferring at standard transition point (primary to senior and senior to 16 plus) and during an in-year transition. The fourth quote suggests that an inconsistent transition can be detrimental to a SEN child/young person's mental health and the local authority's message that all teachers are teachers of SEND is not filtering through to schools especially at secondary level. This demonstrates that families feel they lack knowledge and support in this area and this is echoed in the Preparation for Adulthood section's feedback.

**Recent survey results from Autism Survey Launched 31.01.24 in regards to Preparation For Adulthood - Still currently open**

Currently 184 responses – PFA is not appropriate for all respondents.

- 1) Please rate how confident you are in your child/young person readiness for adulthood? (1 being not confident at all and 10 being extremely confident) **Average rating is 2.98**



**NB/ This is a decrease in Average Rating from 2023 Annual Survey where average was 3.63.**

- 2) What could help prepare your child/young person for adulthood?

Findings are very similar to those reported in our 2022/23 Annual Survey.

Families main responses are that Children and Young People need much more training in Life Skills that needs to include practical help not only for the CYP but also for family members/ Parent Carers in how to help facilitate practical help. Skills that are needed include: **Confidence Building, Independent Travel/Transport, Communication Skills, Independent Living to include Financial management, Cooking, Cleaning and Self Care. Workshops are being requested by Parent Carers.**

**“Confidence building sessions. Help learning to access the city via public transport, easy access to information.”**

**“Life skills lessons, cooking, day to day activities”**

**“Workshops for family Ranging from sex education life skills further education getting ready for the workplace etc”**

Families feel that better transitions are required between Child and Adult Services and this could be best placed by starting in schools at an earlier point than it currently does. Many feel that support would be invaluable and a key worker to help navigate information and the systems would be beneficial. Many families are unaware of what is available and unsure how to access support or feel so out of their depth that they don't even know what could help their young person to help prepare for adulthood.

**“More support and a system that actually works for the yp rather them being left out”**

**“Better transition services in schools to support this”**

**“Anything !!! We were offered a DNACPR at our GP appointment”**

**“Better services transitions from child services. We were literally discharged from New Cross Paediatricians and left”.**

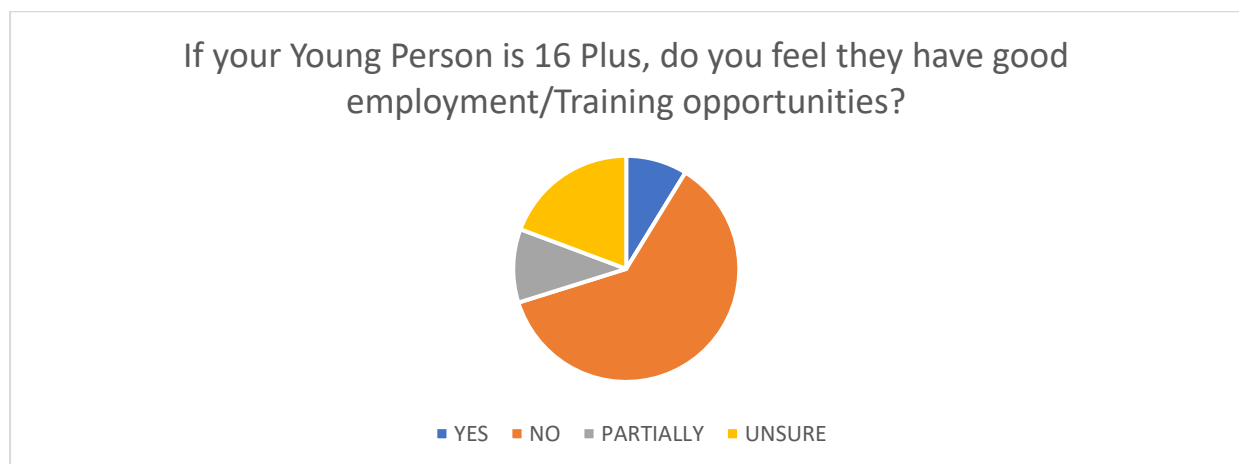
Overwhelmingly in all feedback is that Social Interaction is a major need for Children and Young People to be best able to prepare for Adulthood and this is lacking for CYP with SEND in Wolverhampton. There is mention to appropriate leisure and Youth Clubs etc – these challenges for CYP are better highlighted in our separate reports on HAF/Leisure and Short Breaks in Wolverhampton. It is felt that without Social Inclusion and Interaction that CYP with SEND are not fully realising potential within the community and are already isolated before they start.

**“More SEN schools, key workers for homeschooled kids also would be great having youth clubs for kids with disabilities with cooking lessons how to spend money, etc I think this would give them confidence”.**

**“Support from social services, to allow carer support in the way of direct payment, so my child can gain some independence for the future without it being a parent. We as parents are not always going to be around.”.**

Full comments received are in ANNEX C.

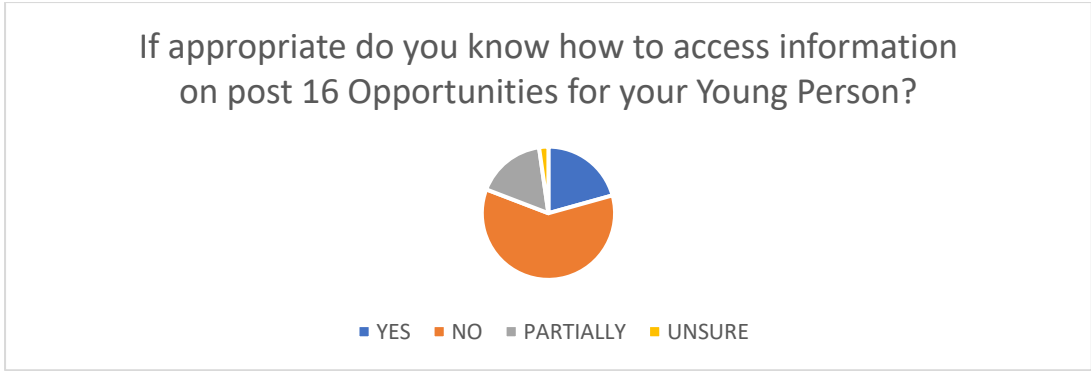
3) If your young person is 16 plus, do you feel they have good employment/training opportunities?



Yes	5
No	35
Partially	6
Unsure	11

4) If appropriate, do you know how to access information on post-16 opportunities for your young person?





Yes 11  
 No 32  
 Partially 9  
 Unsure 8

5) What would support and help your young person in accessing work or training? have you come across any barriers? or any positive experiences?

As through most feedback, Information and Access to Resources and knowing what is available seems to be a key barrier and would help CYP in accessing Work and Training. Families feel that there need to be more job opportunities with accessible employment made available across the City and several comments were made on how employers don't understand SEND with examples of how reasonable adjustments are not being made. Families whose CYP are supported in school and colleges in terms of work placements feel that this works well in preparing CYP for work and Training in Adult life.

**“Information and options need to be shared with parents not just young person so that we can support better with decision making and being prepared”.**

**“My child is going to need a lot of help and support if she we're to get a job & I don't feel like that help or support is there for her at all. I don't know of any organisations locally that support or help young people with autism to find work or training. That's the main barrier”.**

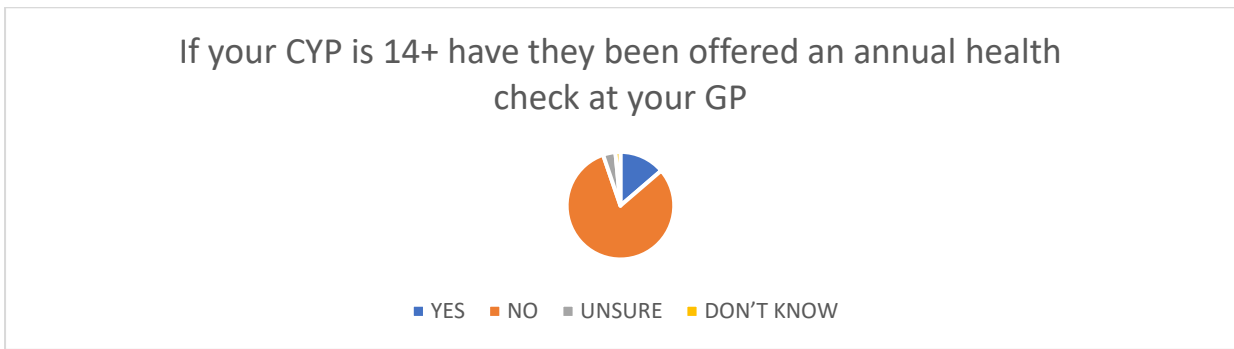
**“Lack of understanding of the issues faced”**

**“Just no information from school and not being involved or invited to get advice for career development”**

**“Her college has provided her with work placements in a nursery - 0 to 5 years of age. She is liking this very much. This type of work is accessible with job opportunities”.**

Full comments received are in ANNEX D.

6. If your child/ young person is 14 and above have they been offered an annual health check at your GP?

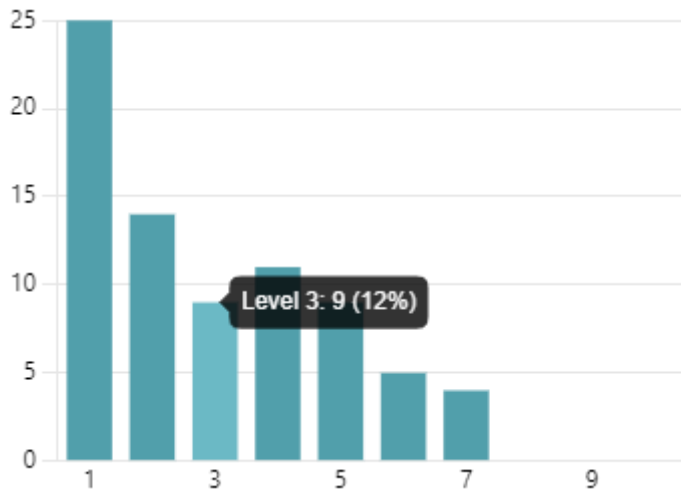


Yes 11

No	65
Unsure	3
Don't know what this is	12

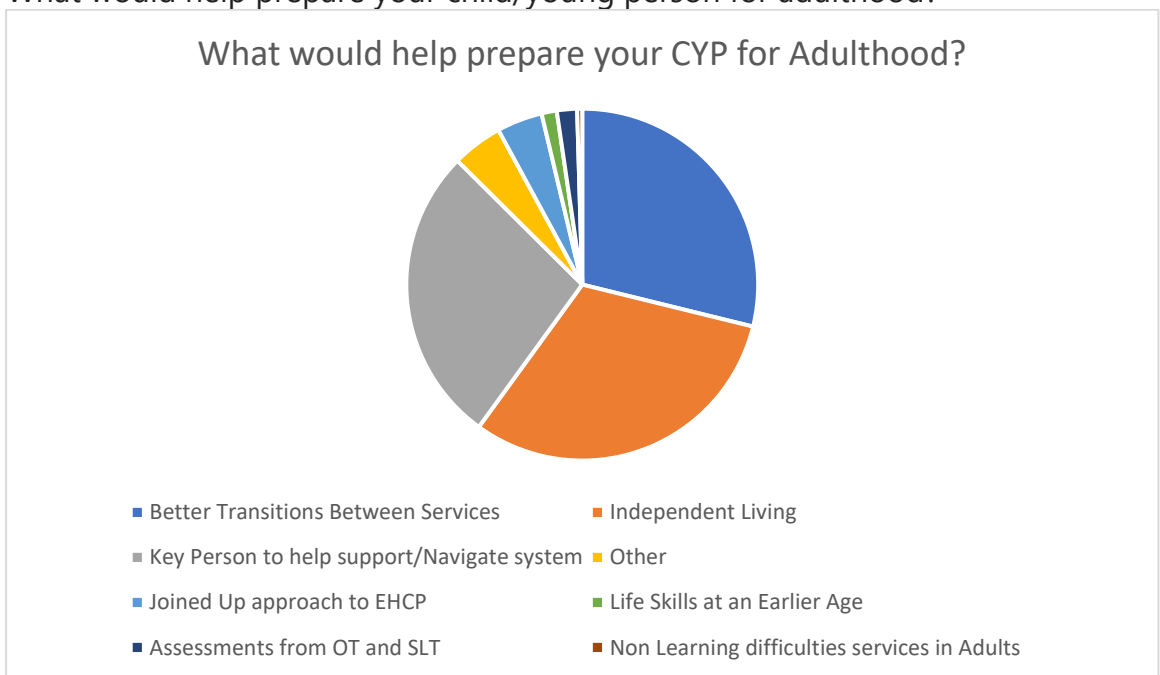
**Recent survey results PFA Questions Launched 21.02.24 in regards to Preparation For Adulthood – Closed 22.02.24 (24 hours) 77 Responses. A further 15 Parent Carers completed the same questions in a POLL held on our Closed Facebook Page.**

1) Please rate how confident you are in your child's/young persons readiness for adulthood?  
1 being not confident and 10 being very confident



Average score is 2.95 which is similar to the average score given in the Autism Survey listed above.

2) What would help prepare your child/young person for adulthood?



Better transitions between services i.e. child to adult services, primary to secondary school or further education 62

Independent living in confidence building, financial responsibility training accessing the community and leisure activities 67

Key person to help support/navigate system 59

Other 10

Joined Up approach to EHCP 9

Life Skills at an earlier Age 9

Assessment from OT and SLT – 4

Non Learning Difficulties services in Adults 1

Other comments alluded to the need for a much more consistent and joined up approach with EHCPS and Annual reviews and the need for Health and Social Care to also be part of these conversations within PFA. Schools are needed to play a pivotal role in teaching Life Skills from an earlier point.

“Planning and prep from within school to help with lifestyles and help to access places in wolves such as library or community shops. Something like a buddy to help independent living”.

“I would like my sons aspirations for when he gets older to be the focus in his Annual reviews and steps put in place for him to reach those as most at such things like learning to drive, learning to cook, learning to be independent financially, hopes to find a job, make a difference in his community, to be active and lead a healthy life”.

Parent Carers have also commented that support for themselves to help their CYP navigate systems in preparation For Adulthood is required and that if they struggle to access the correct/needed services now then how can they possibly know what is available in adulthood.

“If there was a place where parents and carers could go for support to find the corrects techniques to help our children/young person with SEND.”

“Services actually existing for complex needs Adults. Cant transition into provisions that don’t exist.”

Full responses from Parent Carers on this can be found in Annex E.

3.If your child/young person is 11 or older and has an EHCP, are plans /discussions taking place with professionals regarding Preparation for Adulthood in annual reviews

If your child/young person is 11 or older and has an EHCP, are plans /discussions taking place with professionals regarding Preparation for Adulthood in annual reviews



■ YES ■ NO ■ UNSURE ■ N/A ■ OTHER

More Details

Yes	6
No	40
Unsure	11
Not Applicable	34
Other	1

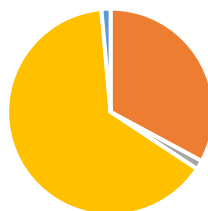
It is clear from the above data that it is felt that CYP have been left out of discussions that might be happening within EHCP Process. 2 Parents left the following comments

“Sen start don't add information discussed in school and when I asked for help with independence for son was told to contact social care myself. Who I turn haven't done anything. I asked for a personal budget at ehcp.to help access health activities and for independent living and again got ignored by Sen start and not included in review documentation.. they just remove what they don't want to deal with.”

“son is 16 was skimmed over as in a mainstream school in year 11 age 16”

4)If your child or young person is 11 years or older and DOES NOT have an EHCP, but receives SEN Support, are plans/discussions taking place with professionals to support Preparation for Adulthood

If your child or young person is 11 years or older and DOES NOT have an EHCP, but receives SEN Support, are plans/discussions taking place with professionals to support

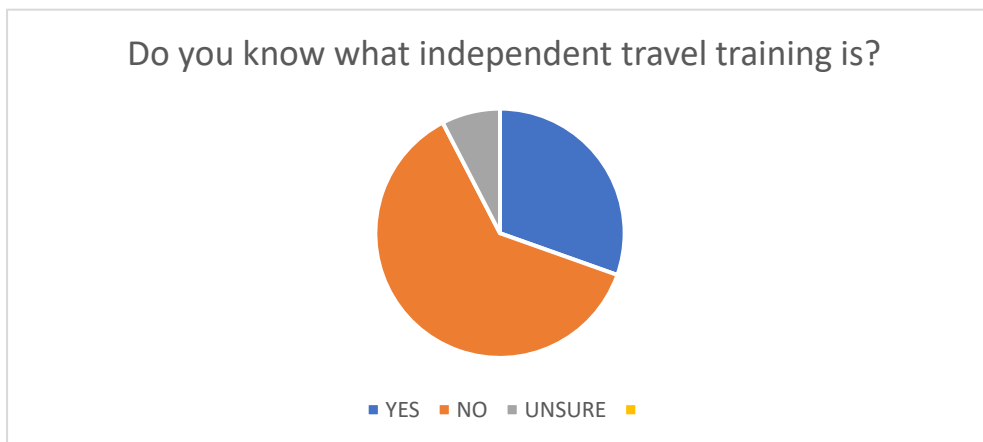


■ YES ■ NO ■ UNSURE ■ NOT APPLICABLE ■ OTHER

More Details

Yes	0
No	23
Unsure	1
Not Applicable	45
Other	1

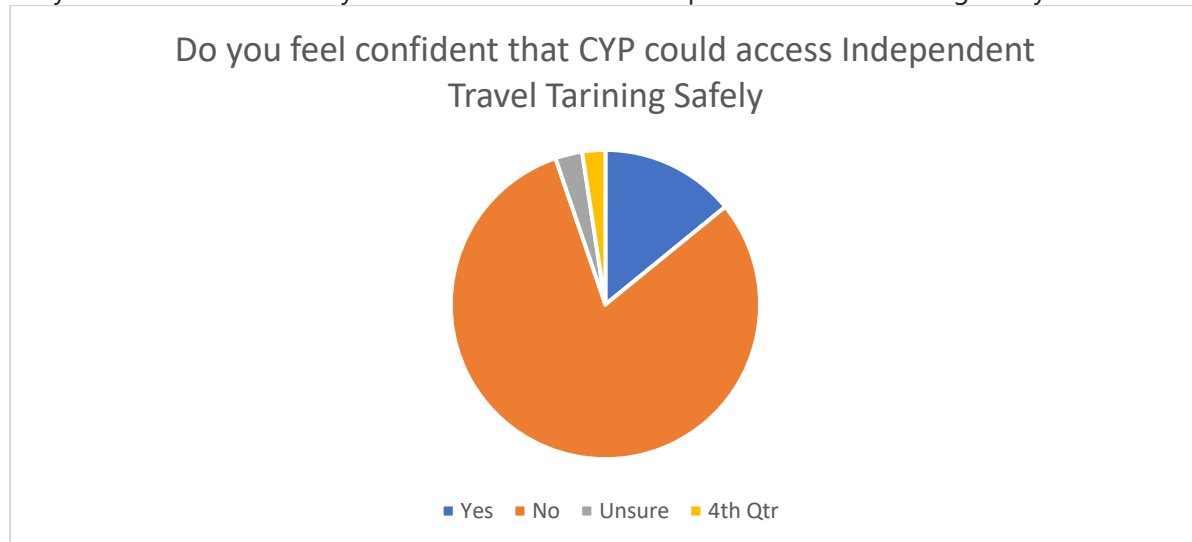
This recent data shows that Parent Carers are currently feeling that there is no PFA discussions being held if their CYP access SEN Support only. This does reflect the data from our 2022/23 Annual Survey in that it is felt the system is 2 tiered for those with EHCP and those without and also predominantly more favourable for those in Special School.



More Details

Yes	28
No	57
Unsure	7

Do you feel confident that your child could access Independent travel training safely?



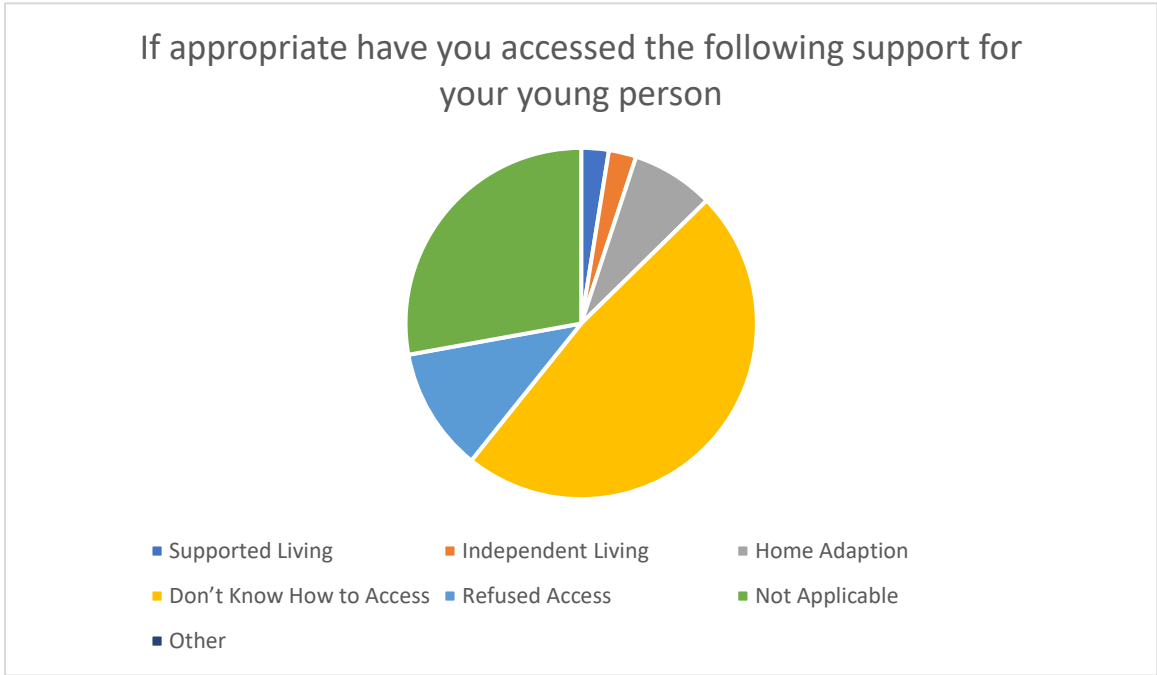
More Details

Yes 7  
No 40  
Unsure 28

31 Comments were made and can be found in Annex F but in general those that answered No or Unsure to the above question are that Parent Carers and Families feel that Independent Travel might not be appropriate for their CYP due to extreme vulnerability. Alternatively, many have expressed that they are wither unaware of the service or simply don't know enough about the offer and how it is delivered to ensure safety. Eligibility and Criteria need to be much more widely publicised.

"Don't know enough about it or how staff are trained for send"

"I've never been told what this is, he has never been offered any preparation for adulthood support what so ever so how can I say he could or couldn't do it".



More Details

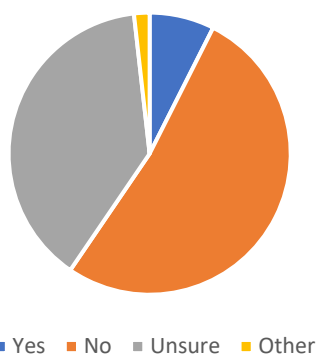
Supported living	2
Independent living	2
Home adoptions	6
Don't know how to access	34
Refused access	7
Not Applicable	22
Other	1

6 further comments were made on the survey in regards to this question that generally highlight accessing correct information and support can be problematic and that knowing where to ask for relevant help needs better signposting.

"Have asked and haven't been refused buy not given information on application either for independent living skills. Who is responsible for this? Is it social care? Dcyp don't think so and carers assessment team said they would but me I touch with social care tram by referral and haven't done that either. They did send me a list with 2 voluntary organisations though that they figured would help but actually don't."

Do you feel Preparation for Adulthood is being discussed early enough? If no please additionally put what age you feel it should begin under other.

### Do you feel Preparation for Adulthood is being discussed early enough?



#### More Details

Yes	5
No	35
Unsure	26
Other	5

ANNEX G shows the 24 further comments made that generally highlight a range of Ages that Parent Carers feel PFA should be considered from. The consensus is around 11. Comments also reflect that there needs to be clarification on what Preparation For Adulthood is and that many Parent Carers feel that PFA isn't happening for their CYP and can be dismissed when they raise concerns and that if services aren't currently accessible or appropriate then they cant have proper transitional services.

"There should be clear options available to all children who have disabilities, regardless of needs. This would stop the parental worry about what the future holds and allow mental preparation for the future .I've asked what options are available to different services, and seem to always get "Their too young to worry about this now, it's a long way off" etc"

"As soon as possible. Under aspirations for the future. Then should be made aware of how and when to access support. Appears to depend on who you see as to whether or not you get the information"

When asked if they would like to add anything further regarding Preparation For Adulthood 23 responses (FOUND IN ANNEX H) were received that highlight families need more help and support as well as being able to access support. Parent Carers feel that they don't know enough about PFA . Parent Carers are aware that their CYP need better Preparation For Adulthood and this in turn makes them feel as though they are failing.

"Preparation for adulthood should start early so steps can be put in place from a young age to prepare for adulthood...it may require years of support to be able to manage money, cook independently, live independently, hygiene, cleaning, managing a home, making meaningful



friendships and being part of a community. So starting at 11, 14, 16 or 18 is leaving it too late. I will not have my son on the fringes of society. He wants to be a active and healthy person. My son wants a job and become independent but the opportunities are just not out there and neither is the support to get him there within his EHCP."

"No one professionally seems to know exactly what happens or how things are found/accessed. No appropriate college provision for complex needs (or access to appointments etc for that same group of people) transitions are so important to the success of moving services/placements yet when there is no service identifiable or waits for funding and approvals then this important show transition cannot happen"

14 comments made on our Closed Facebook Page shows 14 families felt that Services simply don't work together to Prepare their CYP for adulthood. Similar comments were also made in in our survey.

"Services working together sooner to prepare families for the options available. Parent workshops more available to aid transitions. Parents involved in panel meetings/ decisions"

Voice4Parents have been granted funding over the last few years to help SEND families living in Wolverhampton to purchase food, fuel and essential items.

As part of the application process, we ask families on what would help support them and their CYP as well as asking for information that could be helpful for commissioners when making commissioning decisions.

Since January 2021 we have received over 1400 responses to these questions and whilst responses are not narrowed down to the age of family members or CYP, themes certainly run throughout the feedback that impact Preparation For Adulthood and need don't really appear to have changed in this time. The most recent responses have been collected since January 2024.

### **Leisure / HAF – Community Inclusion / Social Inclusion**

Families have frequently explained to us how Isolating it is having family members with a disability and many with complex needs and the Impact of this isolation on their mental health and the mental health of their children and young people and further family members.

Families speak of an "ordinary life" doing "normal things" together as a family, but this isn't always possible, this impacts families and their wellbeing.

Families are frustrated by the lack of inclusive and accessible leisure facilities, causing separation and resentment within families when siblings may freely access leisure or are unable to because their sibling with SEND would be left out causing massive isolation.

It's important that families feel included/have social interaction, many parents feel that their children and young people don't get this opportunity.

On from this, the lack of available Social Care Help, Personal Budgets, Support Plans within EHCPs/SEN Support, Accessible Leisure provision and SEND Information means that Children and Young People are simply not prepared for Adulthood and the challenges that arise with social interaction in Adulthood.

HAF is meant to cater for those post 16 in receipt of an EHCP but a couple of 16 + and their families have commented that the post 16 offer was non-existent and even those activities that they could previously access (cinema showing) were not appropriate for their age.

**"More support groups & opportunities for SEN child to make friends, he struggles with this a lot."**

**"Place for young people to go a meet others like there self"**

**"Half term activities for those with SEN specifically. This provides some family activities aswell as meeting others in similar circumstances as we all feel isolated/judged at times when with general public who do not experience the impact of having a child with SEN."**

**“A buddy to spend time with our son and accompany him on his outings so I can have a break. Youth workers and small young people support groups to deliver interesting and fun activities.”**

Full Report for HAF/LEISURE FROM SUMMER 2023 CAN BE FOUND IN Annex I

Help requested for CYP in Preparation For Adulthood doesn't appear to be unrealistic or demanding but simple requests that could easily help individuals as well as specific training/ workshops/ skill training that will allow CYP to lead a much more independent life, including (but not limited to)

- help towards SEND Friendly driving lessons
- Counselling or Money Management Courses
- Help with funding free passes for local leisure centre, animal therapy,
- information about community shops and how to access
- A link up with local bus / train networks for travel cards/ tickets to get out of the house
- Support– from Services/ Social Care/ School

**“My eldest daughter has a Home2School package with her EHCP. This is on the basis that she is in full time school. Her timetable has been reduced to 3hrs per day. I have to take her school and take her home. I have approached the transport about independent training for her but told she couldn't have any”.**

**“Educating community's on SEND and sensory issues along with how this might present and how our children can be supported in the community”**

**“Beyond school he has zero support from anyone. School have now only improved as we requested Outreach be involved because school made promises that came to nothing. He is year 9 now and we are worried that all the lost time will mean he does not leave school with many, if any, GCSEs”**

**Families are reporting more frequently that they require help at home in the form of Adaptations** as

Independent living is a major issue for CYP and in helping their CYP in becoming Independent in the home. This isn't always about major construction work or adaptations but also smaller things that make life easier and more accessible for the CYP including access to equipment.

**“How can I get help with having my back garden made more safer for my child with adhd and disability so can be outside more and have his own things he can do”.**

**“Support with sensory equipment that could support my child at home”**

**“I cannot afford to have work done around the house. My conservatory roof needs replacing but I can't afford it as I am caring for my son full time. Discounts or grants towards this will be very helpful. My son loves our little conservatory as I have turned it in to a sensory room for him.”**

**“I really could do with Wolverhampton homes giving me new windows and doors to help me with here as this house is absolutely freezing. It's never warm.”**

**“Access or links to funding for large grants such as for a sensory room, strong beds, respite services etc”**

**“Equipment. I really need disabled pushchair for my son as we can't go out places unless there is a trolley”**

**Taken from our recent Parent Carer Survey 2024 in relation to Carers Conversations:**

**Preparation For Adulthood Case Study 1: What would help?**

Education for my son: he dropped out of college due to his needs not being met and no support available at break times, even though he has EHCP. More work experience placements that would want to support him. This

would make my life as a carer so much easier. Emotional and social for myself: to share everyday life struggles with other kind and supportive parent/carers of young people of same age and difficulties. Socials with other families that my son would be willing to engage with (similar age, abilities and interests). Direct work with my son: mentoring, youth/young Adult groups, young cool mentors/buddies as role models.

Support on how to understand and coping with issues Knowing what happens once they turn 16 and leave school

### **Preparation For Adulthood Case Study 2: What would help?**

More understanding of how isolating it feels for the person and their carer. Even going out and joining in with the usual activities can feel overwhelming especially if there are difficulties with challenging behaviour and feeling constantly on 'alert' and the public attitudes makes it even more stressful. If people would just give an encouraging nod and smile, it makes all the difference to people just judging or avoiding, as that makes the situation a lot more stressful. As your child becomes a young adult, there are even fewer suitable activities for you to join in as even Special Need Activity Groups offer few activities that are suitable for or even allow you to join in as there are often activities offered to the age up to 17 or 18. Special Need Schools usually have Special Needs children attending up to the age of 19. These young people may be over the age of 18 but are still needing Special Needs activities to help them with social isolation and their and their family's wellbeing. At least during school age, there is the support and companionship of Special School support but it gets more and more difficult and isolating after school age. Also, there is little suitable support or any useful coordination of what or if there is any appropriate support available. Even when you manage for as long as possible and then do seek any support, it's not really there.

Support with a personal budget from social care. health and social care in ehcp to help recognise strain on family RESPITE AND LEISURE INFORMATION

An in-depth assessment of all SEN children in the home, what support the carer needs to help fulfil their role, any financial support that would help fulfil their role.

### **SUMMARY**

In summary – As Wolverhampton's PCF, we recognise that work has started on Preparation For Adulthood within the Local Area. The issue was identified as a weakness in the last OFSTED Inspection and since then Wolverhampton has started a scoping exercise around PFA that will also include work from RISE to assist us.

There have been 2 successful SEND Career Fairs held with partners and we are keen to see these continue, with the addition of Out Of City Educated Children and Young People to be given the opportunity to also attend.

Our major concern as flagged by Parent Carer Feedback is that issues around access to certain services to start with mean that the transitions simply can't be managed successfully (the service received prior to any transition isn't adequate or timely to offer a better managed transition for PFA). This includes access to Mental Health, diagnosis for Autism, Annual Review at EHCP Short Breaks and Social Care support.

## **RECOMMENDATIONS**

- A very Clear definition of what Preparation For Adulthood means is required. This should be put into terms of Life Skills for Independence for earlier ages (such as personal hygiene, food preparation etc) into the much bigger and long term meaning of teaching CYP how to lead full independent and meaningful lives.
- EHCP Annual Reviews to have a robust process for meaningful and aspirational outcome-based discussions around PFA and Independent Living Skills for CYP from age 11. This will also need to be a clearly monitored process with clear lines of accountability between the schools and SENSTART Team, Health and social care teams. We would suggest a template be added to include what can be offered on Independent Living, Skills for Independent Living and how help is accessed; Education/ Training/ Work Aspirations that are realistic; Independent Travel Training and the introduction of Connexions at the earliest possible stage.
- The same support as above for those on SEN SUPPORT.
- Travel Training offer to be widely promoted with very clear guidance on Eligibility Criteria, How the training is carried out, how it is monitored and also how effectiveness is reported back to all concerned.
- Consistent approach from Connexions for ALL CYP with SEND
- Clear Pathways for Transitions and this includes a very clear pathway for those where there is no apparent equivalent adult team. For Example – ADHD, MENTAL HEALTH and ASC. The transition between Child and Adult Services needs to be identified and discussed/prepared for well before the transition should take place. This will ensure no “cliff edge” and also provide clarity for families on what to expect from whom.
- Annual Health Checks need better promotion and take up. Clearer Guidance is needed on who is eligible for the checks for Parent Carers/ CYP and also services that are supposed to offer the Health Checks. We are aware that many GPs refuse requests for Health Checks as they also do not understand the criteria for eligibility and in turn, misinform families.
- Social Care needs to be clear on their role in Preparation For Adulthood and have a much better system of explaining eligibility criteria regarding Personal Budgets, Respite Care and Short Breaks for families that need them. The uptake of these would certainly assist many CYP with a form of Independent Living, Life Skills and feeling included in the community.
- Better Social and Leisure Activities for CYP to ensure that CYP with SEND are able to access both Local and Wider community. There needs to be much more done on the Universal Offer and recognition within HAF that their SEND offer isn't as inclusive as it needs to be. For families with CYP post 16, this is practically nonexistent.
- Discussion around PFA need to start at the very earliest opportunity and small steps can be identified to help with independent living skills.
- Clear and Accessible information on what opportunities are available for CYP with SEND alongside where support and guidance can be found.
- Consideration for a Key Worker to help navigate transition and to help with supporting a family and CYP with their needs.
- Consideration to commissioning a buddy system for CYP to help navigate Independent Living.
- A suite of Life Skill workshops for CYP and Families (where appropriate) to attend based on key themes for CYP that include but not limited to; Financial Management; benefits; Personal Hygiene; How to keep a home – cooking/cleaning; confidence and Self Esteem etc. and Personal Relationships. This could be carried out via an in-depth assessment of all SEND children in the home to identify individual needs.
- Adaptations need to be considered from all ages and not just CYP that are about to “live on their own” – the needs of the family need to be considered at an earlier stage and not led by

“what happens in Adult World”. The process and Eligibility alongside what the offer is/can be needs to be clearer.

- Commissioning need to be better informed on SEND and what is needed to ensure appropriate services are commissioned for CYP to help with Preparation For Adulthood.
- Clearer ownership at Send and Inclusion Board on what work is being undertaken in the Partnership with a focus on outcomes and not just plans or scoping. Agendas for the board need to be properly co-produced so anything any partner feels is significant is answerable at this board.

## ANNEX A

If you have had involvement from Connexions, please tell us, in the box below how valuable this service was to you and your child / YP.

46 Responses

1-33|46

ID	Name	Responses
1	anonymous	N/a
2	anonymous	Na
3	anonymous	Not sure
4	anonymous	Really good. We had a tour round WV technical college. was brilliant, I'd highly recommend it
5	anonymous	think we may have had a call from someone who was trying to help with college enrolment but they never phoned back and have not been in contact since - think they may be have been from connections but not sure as they never actually introduced themselves
6	anonymous	No not here no word
7	anonymous	Value takes time
8	anonymous	Great value
9	anonymous	It helps a lot in life
10	anonymous	Not that useful as yp didn't like being asked lots of questions by a person they didn't know.
11	anonymous	No comment
12	anonymous	The lady was very helpful
13	anonymous	I had a connexion advisor ring me to ask questions about my child and they they wrote a report for his ehcp, no advice or support was offered it was more like a tick box exercise they had to do
14	anonymous	No, I haven't
15	anonymous	Useless. It takes no account of his complex mental states.
16	anonymous	Had a connexions appointment as I forced the issue when in year 10 - they advised they would attend EHCP - didn't - now in year 12 and I can't see any input from connexions - was a tick box exercise - they didn't help at all. As for transition on EHCP - failed to review at year 9 and 10. Had a year 11 review but hardly

<b>ID</b>	<b>Name</b>	<b>Responses</b>
		inspirational or based around prep for adulthood. SENSTART don't attend and do not even know what my son would like to do - so hands off its untrue
17	anonymous	N/a
18	anonymous	They have but it doesn't change fact that as a complex child there will be very little choice of somewhere that can meet his needs as an adult for both education/social life and respite.....
19	anonymous	I was the one who contacted them because my child was in year ten already so I was expecting them to be involved.
20	anonymous	Awful service, pointless them being involved.
21	anonymous	N/A
22	anonymous	Rubbish. had no idea about supporting SEN.
23	anonymous	Very good information really helped
24	anonymous	Not that good
25	anonymous	Not before EHCP review. Wasn't aware of post 16 alternative provision
26	anonymous	Still waiting
27	anonymous	Connections have visited the school but haven't really helped my child with the next steps in to adulthood
28	anonymous	My child had an EHCP which ceased as she started an apprenticeship and I couldn't face going back to the SEN Team to get the EHCP Amended so it didn't contain so much personal and sensitive information in order for my daughter to feel ok sharing it with her college placement and work place. I was also told that the college would not meet the criteria for my daughter to have any help and it would cease anyway. I applied for the EHCP in the summer before my daughters last year and I had to push for connections involvement and my daughter wouldn't engage I had to which was fine and the lady I found helpful but there was a lot of I don't know around questions I asked
29	anonymous	They were useless - I really believe if my son told them he wanted to travel to the sun they would have told him he could be an astronaut - whilst I agree that ambition is important and that we should all be trying to do best by him, but this needs to be realistic and achievable - not setting him up to fail. There was no real solutions/ ideas/ concepts and I felt it was a waste of time as nothing of value came out of the meeting. They promised to attend his annual review - and shockingly enough because it wasn't in Wolverhampton - they couldn't attend!

<b>ID</b>	<b>Name</b>	<b>Responses</b>
30	anonymous	Connections told my daughter that not worth going to University as she would not succeed
31	anonymous	Do not know who they are
32	anonymous	Needs to involve disabled people working in the organisation to inspire CYP who are worried about the future
33	anonymous	Very disappointing

46 Responses

34-46|46

<b>ID</b>	<b>Name</b>	<b>Responses</b>
34	anonymous	My daughter didn't engage well, but I spoke in depth with them and they were helpful
35	anonymous	We had conversations regarding our options for our son's post 16 placement and we think we made the right decision with support from Connexions.
36	anonymous	Via The Orchard Centre
37	anonymous	They have completed an assessment and written a plan.
38	anonymous	Useless service
39	anonymous	No very helpful
40	anonymous	No Involvement
41	anonymous	Na
42	anonymous	Na
43	anonymous	I have a child aged 12 who is yet to be diagnosed with adhd, I am currently awaiting CHAMS to contact me in regards to her again as her school has real issues with her outrageous behaviour now, she has stopped masking her behaviour now, this has affected her home and school life and her sister has always been quite physical towards her (her little sister is physical towards her big sister)
44	anonymous	Nothing
45	anonymous	No good wot so ever
46	anonymous	Connexions have been very supportive of the plans we have formulated but did not actively contribute to those plans or come up with any information or ideas themselves.



## ANNEX B

What support would be useful when preparing children and young people for adulthood?

04 Responses

1-84|104

ID	Name	Responses
1	anonymous	Transitions involving the child and their needs I guess would be useful. Linked with all the child's support network people
2	anonymous	1. Don't forget those YP who don't have EHCP's but have SEN and additional support at school 2. Listen and hear what a family is telling you
3	anonymous	Bring speakers to school as children are available. For the local authority to provide funding to the charities and volunteering groups to help them to provide resources for this.
4	anonymous	Not sure
5	anonymous	More information
6	anonymous	Not be scared to talk about future outlook. I was discouraged from asking or "worrying" about my son's future by Inspire. All I wanted was to be made aware of current services and support available to have an outlook on the future.
7	anonymous	Working with them to help them gain life skills such as budgeting, cooking, shopping, using public transport. Support for them to gain suitable employment so they can gain independence. Having someone/ somewhere they can contact to ask questions and get support for things they are unsure of.
8	anonymous	A transition team or board of multi-agency professionals who sit over health, education and social care from both children and adult services so that families are not thrown off a cliff edge at 17/18
9	anonymous	Should start whilst young so that correct needs are identified
10	anonymous	For children and adult services to work together and communicate.
11	anonymous	Travel training Better information on what 16+ provision offers what in terms of help/support and not just what courses are offered
12	anonymous	My daughter recently went to an event to meet with and speak to Colleges/6th forms but as a SEN child she didn't communicate and only picked up 1 leaflet of information. More should be done to help with communication between professionals and students who are SEN, teachers could have got information for the students so at least they came home with some information for parents rather than nothing???

<b>ID</b>	<b>Name</b>	<b>Responses</b>
13	anonymous	Travel training! I find this is quite slow going, this is something that our young kids with EHCP need from the teenager years. this is paramount for their independence moving towards adulthood.
14	anonymous	It would be great if children and young people who don't go to school locally as there isn't a school in Wolverhampton to support their needs aren't forgotten about
15	anonymous	Help to look for apprenticeship and permanent work. Help with finding suitable college courses. Advice on managing money.
16	anonymous	Life skills. Understanding bills, money management. Cooking , washing, what takes to keep a home clean
17	anonymous	holistic family sessions to see what support the YP needs and what the family are capable of doing themselves and where the gaps are with regular reviews to see how the transition is going
18	anonymous	Coping mechanisms for themselves when dealing with the outside world. How to communicate with others and communicate his own needs have a better understanding of people people's emotions and behaviours Day to day life skills like shopping, money, how to care for themselves how to make decisions and choices. Work skills
19	anonymous	Real life skills, self-management. Less focus on employability and more focus on knowing where to go for support & friendships as a SEND adult.
20	anonymous	Local children centre
21	anonymous	Psychological effects are important
22	anonymous	Great value
23	anonymous	Early introduction to parents so we can be prepared. Advice given on what's available.
24	anonymous	School support
25	anonymous	Having a key worker to support us.
26	anonymous	Need information how manage their monies and what benefits they can get
27	anonymous	By post
28	anonymous	More than a tick box exercise
29	anonymous	You need their college to be fully aware of the help they need. Don't leave it to the school, speak to the college directly and visit the Senco staff yourselves.

<b>ID</b>	<b>Name</b>	<b>Responses</b>
30	anonymous	More options for complex needs
31	anonymous	Being given and referred to the same help that they are given as children. Young people with special needs to just get better overnight.
32	anonymous	Anything would be a start
33	anonymous	more special schools - not for me for friends kids.
34	anonymous	Knowing what specialist support is available post 16 and 19 what colleges are available for children with severe learning difficulties and what is available after they leave school, I even asked connexions for a list of places as they said there not allowed to name places , I google searched all I can find is special schools , colleges seem harder to find
35	anonymous	Lectures, team discussions and other activities
36	anonymous	Listen to the waft the parents and YP are saying and actively move in that direction.
37	anonymous	Teach them about the changes in their bodies and what causes them.
38	anonymous	Careers fair
39	anonymous	my child is currently in primary education and due to start secondary school in September however no discussions have been made to support his future.
40	anonymous	Again - Educated out of City so nothing for our son is offered - health forget him, social care forgets him - services certainly don't work together
41	anonymous	Ehcp has not been updated to include this information. There is no prep for adulthood, yp is not making any progress, in fact is regressing and challenging behaviours are becoming hard grained and habitual
42	anonymous	More information and talk to my child
43	anonymous	Getting him into a school setting,
44	anonymous	How to deal with periods - parent carer support
45	anonymous	Everything needs to start earlier rather than at 16 or 18
46	anonymous	Basic life skills
47	anonymous	N/a
48	anonymous	Been waiting 12 months for an appointment from the gem centre from updates

<b>ID</b>	<b>Name</b>	<b>Responses</b>
49	anonymous	It's so scary thinking that there are so few decent options for my child at 19 plus....I would like to think he could start to be treated like any other adult but with very specific needs. I think the transition period should start earlier and be more about moving these children away from parents taking on all their future care...
50	anonymous	.List of organisations to help .How to access correct courses . help needed with transport to college . what's next and what level of support can be offered to help make transitions easier for yp
51	anonymous	Information on services available
52	anonymous	To guide the parents on female menstrual cycle and so on.
53	anonymous	Practical life skills, including applying maths to everyday life. How to search for jobs and run a household
54	anonymous	Not just those with an EHCP need support. What happens if he fails all his GCSES because he wasn't given enough support in school. What then? What are his options how will he get a job. Unless a person has an EHCP they are ignored by the local authority and given minimal support by school. He can't remember what he was asked 5 mins before how will he remember to pay bills on time?! He was 12 before he could remember his own birthday, is 14 and struggles to remember the date of Christmas Day, but he gets very little support in school and nothing from anyone but us out of school
55	anonymous	for the local authority to support schools to help SEND leaders to teach this and to provide workshops for parents/carers to teach the use of language etc.
56	anonymous	Work experience building confidence up
57	anonymous	Sessions to help with cv building. Confidence and self-esteem building.
58	anonymous	Benefits support, further education.
59	anonymous	How to deal with others opinions of themselves
60	anonymous	Support in job seeking, decisions on higher ed and prep for adult life for all SEND not just for those with an ehcp
61	anonymous	More easily accessible knowledge for their future like ,work life ,university life etc
62	anonymous	How they can be progress to university, find a job, living independently
63	anonymous	Home educated needs more information

<b>ID</b>	<b>Name</b>	<b>Responses</b>
64	anonymous	I think visual timelines on their year book or class room. School term to college/ university/ work time. Also training around money and safety
65	anonymous	N/A
66	anonymous	Support for my child on SEN support she is overlooked and no opportunities to prepare
67	anonymous	A folder with all the services that cover various needs like dentists, wheelchairs, nurses
68	anonymous	sex education and preparation for going into the wider world
69	anonymous	An EHCP with the correct support
70	anonymous	Involvement from year 9, 10. Wasn't given the option
71	anonymous	Life skills
72	anonymous	Real life support and situations
73	anonymous	More details
74	anonymous	Not a lot tbh I'm seen
75	anonymous	Helping me to find the best payday for the next step in their education because she has to stay in education until she is 18 but we're not sure what support is available
76	anonymous	Work with the child to gain independence and explain more to the parents/carers, I still don't understand what any of this means and I feel I am on my own with finding things out or I go to the parent/carer groups for help, often what should be offered is not and it's a fight to get the help, it's all too stressful and complicated
77	anonymous	Specialist support examples of YP who have benefited from support given and outcomes
78	anonymous	Currently waiting for my child to transition to high school in September he's in year 6
79	anonymous	I think social care should be made to attend Prep for adulthood Annual Reviews - regardless of whether child is known to social care. As cyp transitions their social care needs will inevitably change and input from care will probably be needed. Health has no input if child isn't known to paediatrics but yet a child can still be under the care of consultants/ hospital and GP's - these NEVER INPUT - Surely the Annual Health check info should be used in prep from adulthood (from age 14 plus) - oh yes - sorry that's if they are EVER done
80	anonymous	Better support transferring to adult services

<b>ID</b>	<b>Name</b>	<b>Responses</b>
81	anonymous	Key workers to coordinate services for every CYP
82	anonymous	Educating parents and school how to go about each child
83	anonymous	Coordinated working between all services
84	anonymous	Teaching off practical skills.

104 Responses

85-104|104

<b>ID</b>	<b>Name</b>	<b>Responses</b>
85	anonymous	Longer transitions, more personalised transitions
86	anonymous	More information around support available for families at an earlier stage so we can prepare before we get to that point
87	anonymous	More social skills and emotional/behavioural support/mentoring required in mainstream skills and more access to vocational opportunities where there are difficulties in academic attainment and Ofsted expectations. Careers interviews should begin a lot earlier for those with SEN to include workshops and involvement of parents to also support our children from transport/travel issues to what future employment options would look like for a young person who struggles in the world already. As parents we don't know the guarantees of future employers to support young adults with ASD/disabilities but more realistic life skills should also be part of the curriculum, ultimately it starts with parental support but if outside support doesn't continue into adulthood, I feel this is why so many young people and adults with disabilities lose so much faith and hope when it comes to having opportunities and independence.
88	anonymous	young people groups in the local areas.
89	anonymous	Meeting with parents and yp to show what's out there and how to get support if needed
90	anonymous	Basic life skills but I think as a special needs parent we're always going to worry more for them
91	anonymous	No health no care
92	anonymous	Helping build confidence & helping her to find where is best to send her for 6th form or college
93	anonymous	Cooking cleaning, residential nights away .
94	anonymous	Anything would be useful we have had nothing
95	anonymous	Peer support, learning independence away from family environment

<b>ID</b>	<b>Name</b>	<b>Responses</b>
96	anonymous	Help with transition to high school would have been so valuable. We have just found out & accessed the independent travel training service but had no idea about it previously.
97	anonymous	Not sure
98	anonymous	A place to learn cooking, safety, how to pay bills, how to save, how to prioritise, healthy eating, travel training
99	anonymous	Having information on what's available support wise or the next step information
100	anonymous	Needs to know what he will do when he leaves school
101	anonymous	Take anxieties and child mental health more seriously
102	anonymous	My daughter is 11. I do some independence work with her as she is home educated but we have no other involvement at the moment.
103	anonymous	I don't know I have had no support with this
104	anonymous	We have a very supportive social worker who has worked very hard to assist with our son's transition and this has been absolutely crucial.

## Annex C-

What could help prepare your child/young person for adulthood?

80 responses **80** Responses

<b>ID</b>	<b>Name</b>	<b>Responses</b>
1	anonymous	Life skills
2	anonymous	I don't know
3	anonymous	Life lessons, supported living
4	anonymous	Educational sessions in an ASD friendly environment or setting worded with care
5	anonymous	Unsure
6	anonymous	To not be scared of people.
7	anonymous	Earlier diagnosis and more practical skill/self-help skills at school...
8	anonymous	I have no idea as my child has no understanding of consequence of her actions and no understanding of time, personal space, Sarcasm or money
9	anonymous	Bit too early yet to consider
10	anonymous	More social /life skills lessons
11	anonymous	Confidence building sessions. Help learning to access the city via public transport, easy access to information.
12	anonymous	More help from school and to know what's out there
13	anonymous	More Support for the future
14	anonymous	Money skills, cooking and independence skills.
15	anonymous	Not sure
16	anonymous	More support from a key worker
17	anonymous	A better world
18	anonymous	More support
19	anonymous	Social integration
20	anonymous	Don't know where to start with this
21	anonymous	Confidence and life experience outside of the house



<b>ID</b>	<b>Name</b>	<b>Responses</b>
22	anonymous	By talking and educating
23	anonymous	Support becoming more independent
24	anonymous	Nothing that is currently available.
25	anonymous	Support from organisations and the NHS
26	anonymous	Due to how complex he is he hasn't got the right support in general
27	anonymous	Life skills
28	anonymous	Classes
29	anonymous	Independence classes
30	anonymous	Life skills lessons, cooking, day to day activities
31	anonymous	life skills
32	anonymous	More support on how to live in the big wide world without a dependent
33	anonymous	Not sure
34	anonymous	More support and a system that actually works for the yp rather than being left out
35	anonymous	Life skills
36	anonymous	Better transition services in schools to support this
37	anonymous	Information advice and options
38	anonymous	More SEN schools ,key workers for home schooled kids also would be great having youth clubs that have kids with disabilities with cooking lessons how to spend money etc I think this would give them confidence .
39	anonymous	Life skills. Mental health support
40	anonymous	-
41	anonymous	Counselling. Check ins. Support. Therapy
42	anonymous	Diagnosis and support for us as a parent on how to prepare them
43	anonymous	Any advice would help, we have no information or don't know where to look
44	anonymous	Needs social skills support, needs effective communication skills developing

<b>ID</b>	<b>Name</b>	<b>Responses</b>
45	anonymous	Life skills lesson to enforce work at home
46	anonymous	Anything !!! We were offered aDNACPR at out GP appointment !!!
47	anonymous	starting from now age 9
48	anonymous	Increase his independence, confidence in himself, the ability to make decisions, ( he finds making any decisions very difficult) he needs at the moment constant reassurances, social skills ,life skills he is not very open to being taught anything from his parents, to learn it is okay to make mistakes
49	anonymous	Truth being told about work opportunities and not being able to live independently
50	anonymous	Financial awareness
51	anonymous	Workshops for family Ranging from sex education life skills further education getting ready for the workplace etc
52	anonymous	The correct education setting
53	anonymous	Training information
54	anonymous	I'm not sure she is very anxious, has a lack of understanding most things this is where I worry
55	anonymous	Better services transitions from child services. We were literally discharged from New Cross paediatricians and left.
56	anonymous	Support for her self-esteem and confidence
57	anonymous	More specific information and support from medical professionals
58	anonymous	Independent life
59	anonymous	More keyworker support and social support in schools rather than just focus on academic achievement
60	anonymous	More strategies put in place, more appointments with relevant people
61	anonymous	Things from dressing and washing herself to being able to cross the road
62	anonymous	comprehension skills and how to build these
63	anonymous	The places that can cater for him being closer and we can trust them! I feel like he should have been prepared a lot sooner by having access to more opportunities like time away from parent earlier. We need more colleges that take the two to one challenging one that still can learn and more creative ideas for adult care packages

<b>ID</b>	<b>Name</b>	<b>Responses</b>
64	anonymous	Support from social services, to allow carer support in the way of direct payment, so my child can gain some independence for the future without it being a parent. We as parents are not always going to be around.
65	anonymous	Post education support re employment
66	anonymous	A diagnosis, at least then employers would be obligated to make reasonable adjustments
67	anonymous	Communication, consistency
68	anonymous	Lots of things that don't happen. She goes to college and this was a stepping stone from school to adult, but this was still a very difficult path. Again, teachers lack of understanding about autism, too much noise, busy place, peer pressures. It results in slow and bumpy road to the adult world. Help with applying for jobs and you know they can do, as she can have the wrong expectation in some job rolls.
69	anonymous	Key person to help them navigate choices for education, training and employment. Help to understand how their autism impacts their lifestyle. Help them set goals and pathways to achieve them.
70	anonymous	He needs longer in paediatric service to make up for lost time and lack. Of support from local services
71	anonymous	Answers
72	anonymous	Working with my son to prepare him for adulthood
73	anonymous	School curriculum
74	anonymous	Early access before there go to senior school
75	anonymous	More support
76	anonymous	Ehcp were trying for one
77	anonymous	More support from the education sector
78	anonymous	Learning independent skills
79	anonymous	Anything would be nice
80	anonymous	School did the lot work with him talking to him about it

## ANNEX D –

What would support and help your young person in accessing work or training? have you come across any barriers? or any positive experiences?

27 responses **27** Responses

ID	Name	Responses
1	anonymous	All barriers
2	anonymous	Unsure
3	anonymous	More job opportunities for 16+ year olds. Training for employers to understand of how autism varies in its presentation. More accessible. Employment in every way possible
4	anonymous	A work buddy in the work place
5	anonymous	We did it ourselves and my daughter started an apprenticeship without a formal interview etc
6	anonymous	My child is going to need a lot of help and support if she we're to get a job & I don't feel like that help or support is there for her at all. I don't know of any organisations locally that support or help young people with autism to find work or training. That's the main barrier.
7	anonymous	He's 15 at the moment and has been going to nova training 2days a week then provision centre the other 3days but only half days. I'm hoping once it's time he would be able to go to nova full time
8	anonymous	Yes barriers. two jobs she has had both I offered information on diabetes awareness. Both were quite closed and told her to "come back when you're better and more settled with your diabetes" Positive experiences were a link from a teacher at The Orchard centre taking her and a couple of other students post GCSE's to do some volunteering at a local food bank
9	anonymous	None
10	anonymous	no one gives any leeway for asd company's don't want to know
11	anonymous	My daughter being scared of change and not being very independent
12	anonymous	Na
13	anonymous	No there yet
14	anonymous	-
15	anonymous	Again, any help would be great

<b>ID</b>	<b>Name</b>	<b>Responses</b>
16	anonymous	Lack of understanding of the issues faced
17	anonymous	Although my son isn't 16 yet I'm very concerned that as he hasn't got an EHCP that a lot of opportunities are closed to him and I see him struggling a lot
18	anonymous	Information and options need to be shared with parents not just young person so that we can support better with decision making and being prepared
19	anonymous	My son tried accessing work help and was treated appallingly. Struggled to speak to this new person on the phone. Was told I know he has autism but he needs to grow up by an advisor. I was shocked and appalled. He refused to engage after this and stayed in college. People who have those beliefs shouldn't be supporting young adults with autism.
20	anonymous	Sports in living life and in study
21	anonymous	Already mentioned these barriers
22	anonymous	Yes, young person doesn't want to be treated any differently to peers, so doesn't want to access support that is available to them post college.
23	anonymous	Her college has provided her with work placements in a nursery - 0 to 5 years of age. She is liking this very much. This type of work is accessible with job opportunities. She was very stuck on the idea of being a paramedic, which would have not been suitable, due to stress. She likes nursery environments as repetitive, structured which autistic people can be happier.
24	anonymous	I don't think my child has the self-esteem, ability or confidence to work.
25	anonymous	Online provision, virtual work experience
26	anonymous	N/a
27	anonymous	Just no information from school and not being involved or invited to get advice for career development

## ANNEX E

3.

If you have ticked other above please add anything else you feel would help.

19 responses **19** Responses

ID	Name	Responses
1	anonymous	Support in place before age 11
2	anonymous	Plans with social care and in ehcp annual review
3	anonymous	Planning and prep from within school to help with lifestyles and help to access places in wolves such as library or community shops. Something like a buddy to help independent living.
4	anonymous	Support and key worker
5	anonymous	can't even tell time properly or wash without prompting and as much as I try to promote this self care there really is nothing that identifies this type of need to help work on it.
6	anonymous	I would like my sons aspirations for when he gets older to be the focus in his Annual reviews and steps put in place for him to reach those as most at such things like learning to drive, learning to cook, learning to be independent financially, hopes to find a job, make a difference in his community, to be active and lead a healthy life,
7	anonymous	Life skills
8	anonymous	Life skills
9	anonymous	Life skills, useful knowledge
10	anonymous	Life skills
11	anonymous	Buddy to help do leisure
12	anonymous	Knowing what options are out there and what support is available
13	anonymous	easy way to find out about support
14	anonymous	More help and support is needed in the communities and more funding
15	anonymous	If there was a place where parents and carers could go for support to find the corrects techniques to help our children/young person with SEND.
16	anonymous	More help and advice

<b>ID</b>	<b>Name</b>	<b>Responses</b>
17	anonymous	Services actually existing for complex needs Adults. Cant transition into provisions that don't exist.
18	anonymous	More parent preparation workshops offering professionals to advise on things like money, benefits etc
19	Anonymous	My son's place at a mainstream College was withdrawn as they couldn't meet his needs. He's above the average levels at special settings, so he's not in education at all at the moment. He's 18. There's no provision for him and nobody cares.

**ANNEX F** If you ticked no ,Regarding confidence in accessing independent Travel Training - please give further detail her

31 responses **31** Responses

<b>ID</b>	<b>Name</b>	<b>Responses</b>
1	anonymous	Struggles with anxiety. Can i trust the staff
2	anonymous	Not heard of the service
3	anonymous	Don't know enough about it or how staff are trained for send
4	anonymous	My child is a runner and never goes out on her own
5	anonymous	Very unaware of surroundings vulnerable
6	anonymous	It hasn't been raised. I know what it is but don't know how to access the support
7	anonymous	However. Not offered it.
8	anonymous	Don't know about it
9	anonymous	Can't tell time/lives in own world. Would be gr8 to know if help could be give
10	anonymous	Hes very vulnerable
11	anonymous	This was refused to my son as he goes to school.out of wolverhampton
12	anonymous	I dont know if it will be safe
13	anonymous	Dont know what it involves
14	anonymous	I dont kniw what it is to say if they could access it

<b>ID</b>	<b>Name</b>	<b>Responses</b>
15	anonymous	Ive never been told what this is, he has never been offered any preparation for adulthood support what so ever so how can I say he could or couldnt do it
16	anonymous	High levels of anxiety
17	anonymous	Dunno wat it is to say yeah
18	anonymous	Wuldnt understand
19	anonymous	Too young to cope
20	anonymous	Only 12, not able to cope yet
21	anonymous	No sense of danger
22	anonymous	Has bad social anxiety, struggles to go out and even with support hates being in public spaces
23	anonymous	Never heard of it. Molly isn't good at managing people
24	anonymous	My son has anxiety and needs me to go with him at all times.
25	anonymous	With my child's level of needs and understanding, I do not feel my child will be able to travel safely independently
26	anonymous	my child absolutely would not be able too travel independently
27	anonymous	Has comprehension difficulties
28	anonymous	Will never be appropriate or safe for someone with such complex needs. Needs 2:1 care and support with all needs
29	anonymous	My son has severe learning disability and needs supervision at all times
30	anonymous	She's too vulnerable and can not even cross the road on her own
31	anonymous	He has no sense of safety or direction, he would run into roads and not know when to get off buses or anything else



## ANNEX G

If you ticked no/other please additionally put what age you feel it should begin below

24 responses **24** Responses

ID	Name	Responses
1	anonymous	11
2	anonymous	He is 14 nothing is being discussed. Should have started in primary school
3	anonymous	I feel should be done at all stages and what could be put in place to support
4	anonymous	10
5	anonymous	I think from High school age life skills should be taught
6	anonymous	As soon as possible. Under aspirations for the future. Then should be made aware of how and when to access support. Appears to depend on who you see as to whether or not you get the information
7	anonymous	As soon as possible. Especially at the start of secondary. But getting any information or support feels like a constant and exhausting battle
8	anonymous	11
9	anonymous	I don't think it can be discussed early enough because there is no appropriate offer anyway. How can you start to prepare for adulthood when I can't get services now for him.
10	anonymous	11
11	anonymous	As soon as possible
12	anonymous	5
13	anonymous	Unsure but the sooner the better
14	anonymous	I don't know when it should be happening but my son never had none of this so you have FAILED him so much
15	anonymous	Child is 12, no support yet
16	anonymous	My son is 15, never heard of before this questionnaire
17	anonymous	There should be clear options available to all children who have disabilities, regardless of needs. This would stop the parental worry about what the future holds and allow mental preparation for the future. I've asked what options are available to different services, and seem to always get "Their too young to worry about this now, it's a long way off" etc

<b>ID</b>	<b>Name</b>	<b>Responses</b>
18	anonymous	Never heard of it
19	anonymous	12
20	anonymous	10
21	anonymous	11 years old
22	anonymous	10
23	anonymous	I think about 10
24	anonymous	13

## ANNEX H

Please add anything further you would like to share regarding Preparation for Adulthood below.

23 responses **23** Responses

<b>ID</b>	<b>Name</b>	<b>Responses</b>
1	anonymous	School are uselss supporting my son. No prep for adulthood or SEND support is taking place even though he has a diagnosis and is on the sen register
2	anonymous	we need help guidance and support
3	anonymous	How to live in society, emotional building as people are.cruel
4	anonymous	Preparation for adulthood should start early so steps can be put in place from a young age to prepare for adulthood...it may require years of support to be able to manage money, cook independently, live independently, hygiene, cleaning, managing a home, making meaningful friendships and being part of a community. So starting at 11, 14, 16 or 18 is leaving it too late. I will not have my son on the fringes of society. He wants to be a active and healthy person. My son wants a job and become independent but the opportunities are just not out there and neither is the support to get him there within his ehcp.
5	anonymous	I dont know what transport training would involve. Can i trust them with my child, will they be safe?
6	anonymous	I dont know enough, who do i talk to. I feel like there is no information out there for me
7	anonymous	My child is 11, why has none of this been spoken about to me?

ID	Name	Responses
8	anonymous	I feel my child has been so let down. Why has none of this ever been told to us
9	anonymous	I feel so ignorant, what is my child missing out on
10	anonymous	FAILED FAILED and FAILED over and over again by a local authority that never cared about him
11	anonymous	Having a disabled child makes you worry what the future will look like for them

## ANNEX I



*'giving a voice to parents & carers of children with additional needs'*

### **VOICE4PARENTS REPORT ON HAF FEEDBACK RECEIVED – SUMMER 2023.**

Over the past 18 months, Voice4Parents have received significant feedback that suggests that the HAF SEND offer doesn't meet the needs for many SEND Families.

With this in mind and the Short Break summer Activities offered via V4P this summer, we have taken the opportunity to ask further questions on whether families access HAF and if not why not.

#### **Do your child/young person access HAF activities?**

Yes 135

No 99

Unsure 42

The following comments were received from families in regards to HAF:

- My daughter is selective mute and has autism and will not attend HAF activities
- I cannot get to any HAF activity as I'm on my own with 3 children all different ages
- Not school age yet
- I never took them to activities because with 5 children and one disabled it is very hard
- He is unable to access most activities due to his needs. We try to access some but they do not always provide food
- We have never used the code. Don't know how to use the code or what we could book?

- My SEN children cannot cope in new environments and being around other children or adults.
- Home is their safe space when not in school.
- Struggle to use as childcare to work as no HAF activities at SEN schools or that will provide 1:1
- Have to attend an activity with them -this is generally not allowed, lots are now fully booked, or not suitable
- CYP doesn't as I'm not confident they could manage his behavior
- Activities do not cater for my child – not fully accessible
- Don't understand what HAF is or how to use online
- Find it difficult to get out due to my son been house bound
- Time not taken to know my CYP – He is shy
- She is unable to access as isn't even accessing school at the minute so I have no chance of getting her by herself to a club by herself were awaiting appointments had some
- The activities on HAF are not suitable for my child I cannot leave my child with strangers he cannot communicate
- As a family with a severely disabled boy in it - we rarely can-do family activities so the HAF IS NOT appropriate for us and you have to participate to get the free meals.
- She has anxiety and refuses to leave home
- HAF activities are not suitable. Age and SEN appropriate
- My son has adhd and Social issues so won't interact with others so cannot access with either of my children as I can't leave my son to take my daughter
- My child cannot currently attend the activities as I will have to stay with him but I also work part time and unable to do this. His little brother also isn't able to attend as he is not in full time school yet. My son who is in school is disabled and isn't able to attend normal HAF activities.
- My child has siblings who he likes to do activities with and he doesn't like going to activities on his own he gets anxious
- Unable to attend these activities due to anxiety
- Home Educated so not acknowledges as eligible
- Under 5 so can't qualify
- I have received the vouchers however they are always no vacancy when I make inquiries.
- Wouldn't cope with a full day of activities
- All places are too far away and none are local to us
- Most of the activities are not suitable for my child and would struggle with chosen food and can't be attended by parents
- Can't attend as his behavioral needs aren't catered for
- She won't engage with them and refuses to go due to her autism.
- Can't attend as daughter is 17
- Hard to get out without carers or help and finding activities all 4 children will take part in
- There's nothing suitable for her age/ interests to go to.
- He doesn't participate in activities due to social anxiety and transport issues
- No SEND Offer
- It is difficult to get my eldest daughter with SEND into HAF activities. She has violent challenging behavior issues and needs support from adults 2:1
- Activities can't meet his needs.

Further to this we were also made aware that even though HAF is meant to provide a meal for CYP – SEND needs aren't taken into account by SEND Providers/LA and that many parent carers have faced

additional financial hardship over the holiday periods due to the additional cost of providing food for their CYP – food that most times would be provided free of charge via free school meals.

The following comments were received in regards to meals provided via HAF:

- CYP has to take a pack lunch due to not liking food and 2<sup>nd</sup> child doesn't like dairy
- Her ARFID means she won't eat what is available
- Fussy eater
- The food is not appropriate for them with restricted diets
- He finds it difficult to eat others food. We have to pack something.
- Will only take packed lunch due to only eating certain foods due to autism and sensory difficulties
- Do not provide food that she will eat
- Food isn't suitable for him
- Unsafe to eat orally, peg/pump fed
- He doesn't like to eat different food from different packing and different smells of food. It makes him irritates and upset too.
- My oldest daughter has free school meals when she's at school but due to home educating our other two, we cannot access free school meals for them.
- He is entitled but never goes due to him being Autistic it's a shame they can't provide a voucher of some kind for children that don't like to attend the club's due to their needs
- unsuitable - my son needs meals blended and he cannot eat foods he is not familiar with as his diet is so restricted to his "safe foods", he cannot eat solids or chew food.
- Limited diet
- Blended diet that isn't catered for
- Doesn't like the food there