



## PaCConnect on Transition to Adulthood - November 2023

This report is a working document to be shared with Education, Health and Care Professionals, with the purpose of PaCC updating the document to share information around processes and provision with parent carers.

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## Introduction

The Parent Carers' Council (PaCC) is a parent-led carer forum which represents parents and carers of children and young people, up to 25, with additional needs and disabilities who live in Brighton & Hove. In November 2023, PaCC organized a PaCConnect around Transition to Adulthood. To facilitate attendance in an inclusive way, we held two sessions, one in person and one online; a total of 65 parent carers and 10 people from LA and NHS attended the two sessions.

The in-person session was structured into four groups - Learning Disability (LD), Physical Disabilities and Complex Health Needs, Neurodiversity with and without disabilities, and Social Emotional Mental Health (SEMH) - each group had a facilitator and a note taker.

The online session had two break-out rooms - one for LD, Physical Disabilities and Complex Health Needs, and one for Neurodiversity with and without disabilities and SEMH - each room had a facilitator and a note taker.

To facilitate the discussion and gather as much feedback, suggestions, and ideas as possible, it was decided to divide each group/ topic into four 'areas': health, community inclusion and relationships, housing/independent living, education, and training. It is important to underline the intersectionality of the four 'areas' and the fact that they overlap with each other.

Feedback, suggestions, and ideas from parent carers who attended the PaCConnect are collated on this report which is divided into four sections:

- Children and Young People with Physical Disabilities and Complex Needs
- Neurodivergent Young People (with and without Learning Disabilities)
- Young People with Social Emotional Mental Health Needs
- Neurodivergent Young People (with and without Learning Disability) who have SEMH Needs

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## Findings from Parent Carers of Children and Young People with Physical disabilities and Complex Needs

### 1. Health

- Some very positive feedback re the transition to Adult Cardiac Services, and Adult Cardiac service going forward.

#### 1a. Processes

- Transition planning needs to start earlier to avoid the dangerous cliff edge at 18.
- Families ask for a full YP health MOT at around 16 (to 18) to allow the handover to adult services to be much better.
- Clearer plans are needed in how to manage the specific needs of adults with learning disabilities, and that adults with LD are treated equally.
- Parents want to feel listened to, to keep their adult children safe.

*'Parent's want to feel listened to, to keep their adult children safe. Mental health support for young people with a learning disability is too hard to access, or is unsuitable, leading to high concern around accessing health interventions.'*

- Health Passport: are they effective. Parent carers are best to advise, health passports may be out of date and hospital staff must understand that families have a huge administrative burden to keep all paperwork up to date.
- Parent carers ask how you can get an adult child added to a parent's NHS profile for ordering repeat prescriptions. Is this through the surgery?  
*'Clearer information needs to be available around parental responsibility, what happens at 18? There is high anxiety around the risks of poor health outcomes for young people who do not have capacity, or need a high level of support to make good health decisions e.g.: vaccinations, health checks etc.'*

### 1b. Annual Health Checks:

- Parent Carers want to build a relationship with the GP well in advance of 18. eg: coming to the house to do Annual Health Check plus creating a positive access to health action plan for the future.
- Consistency across GPs and annual health checks is needed.  
*'My son has just been offered his first health check. They offered me a phone appointment, and I had to insist on him having an in-person appointment for it to be meaningful. We haven't been sent any documents to look at or prepare with beforehand'*

### 1c. Provision Gaps

- Families report confusion around the Royal Alex's hospital treatment plans for ongoing healthcare plans from 16- 18.
  - Families feedback that mental health support for young people with a Learning Disability is too hard to access, or is unsuitable, leading to high concern around accessing health interventions.
  - What happens if a YP has an accident etc out of area and is non-verbal? How does the hospital/health service know how to communicate with YP & who to contact?
  - Summary Care Record – this is viewable on your NHS app Significant medical emergency – what happens for over 18s. Our families are often in crisis.  
*'My young person has complex medical needs and has several severe medical complications. It seems like at 15 the health services start to tail off, it is known within parent carers that ages 16-18 starts to all tail off as it will become an Adult Care issue after 18. It seems like all young people need to have a full MOT around 16 (to 18) to allow the handover to adult services to be much better'.*
- 'Young person is 20 years old; adult services now want to speak to him more than me, the parent, he likes to please so doesn't always say the correct response that is fully accurate. At 20 this child has learning disability, and parents need to be included in their appointments, making decisions and their understanding. The care the young person has received with cardiac adult services have been excellent'.*

### 1d. Clear and accessible information needed for families

- Clearer information needs to be available around health transitions, there is confusion around some transitions at 16 and some at 18.
- Clearer information needs to be available around parental responsibility, what happens at 18. There is high anxiety around the risks of poor health outcomes for YP

who do not have capacity, or need a high level of support to make good health decisions eg: vaccinations, health checks etc.

- Families want more information about the role of the Learning Disability nurses at the Royal Sussex hospital, how do families access this support and is the support meaningful, can the LD nurses share information about how they can support transitions from the Royal Alex to the Royal Sussex, being able to meet them at the Royal Alex would help support YP in the change.

### **1.e Parent carer concerns**

- Parent Carers feedback that their own health is significantly impacted from the parent carer experience, and they are desperate to see progress around information, processes and gaps in provision across all areas covered at this meeting
- Feedback from parent carers state concern re use of constraint when in health appointments.
- Do Not Resuscitate is an area of concern for families – information on this is needed. *‘Shocking experience of accessing crisis support for our young person with LD earlier this year. No easily identifiable pathway for crisis behaviour support. Rectified eventually & accessed LD nurse but only with the endeavours of a very helpful & kind health practitioner known to us who we had to reach out to and ask for emergency signposting support, if we hadn’t had this relationship with this professional, it is terrifying to think what may have happened’*

## **2. Community inclusion and relationships**

- Families rated Different Planet Arts for their provision of coming to the house.

### **2a. Processes**

- Workforce planning must be prioritised across all areas of Social Care.
- The PA recruitment/Direct Payment system is not working- pay is insufficient, and the responsibility of being employers is too high for some parent carers. *‘My child is going to college a year early, from Downs View School to Downs View Link College. So much anxiety for parents because we are not part of conversation and decisions. Several children moving early, severe lack of communication’*

### **2b. Provision Gaps**

- The loss of Extratime has had a huge impact on families, and not only reduces respite for families but also impacts social opportunities for YP with LD.
- Families fear for school holidays as there is no/very little provision for YP with complex support needs including PMLD.
- More services need to respond to the needs of YP with complex needs eg: Amazing Futures.
- Young people and their parent carers are keen to see the LGBTQ+ community for making space for YP with LD, as currently there is not much space within the LD community being Gay.
- Peer support within the LGBTQ+ community would help YP with LD to build with understanding and understanding appropriate behaviour.
- There was a good suggestion that groups within the LGBTQ+ community could support other organisations like Gig Buddies etc.

### **3. Housing and independent living**

- Plenty of cooperative housing for all sorts of communities across the land including in Brighton. It can be done with willingness, vision, cooperation & flexibility.

#### **3a. Processes**

*'My daughter wants to live more independently; we've been to panel, approved by housing, agreed to supported shared housing. Told on a list; not heard anything else, no idea what the list is and what other information is available. Need information on processes and timescales'.*

- Planning for housing needs to start earlier for specific learning disability/profound and multiple learning disabilities. How does the process start, who initiates it.
- Parent Carers want joined up working between children's and adult services.
- Parent Carers report that timescales are far too long when a housing plan is asked for. e.g.: A young person wants to live more independently – the case has been to panel and has been approved by housing who agreed to supported shared housing. The next step was the family were told they were on a list, but after a long time they have not heard anything else –they have no idea what the list is and what other information is available.
- Parent Carers want professionals to acknowledge emails and give a clear timescale around action plans.
- Is there a designated person who is allocated to a family / YP when going through the housing process – families would like one person to contact with questions etc?
- Families say that a crisis also takes too long time to resolve.
- Families would like to understand how planning for adults with LD fits together from a strategic point of view alongside all other housing planning, is there data around need that is used to ensure that forecasts are correct.

*'Planning for housing needs earlier for specific learning disability/profound and multiple learning disabilities. Joined up from children to adults; better information and communications, clarity across departments, made available to parents'*

#### **3b. Provision Gaps**

- Some young adults need to be living in the heart of the city, to access community activities. The risk of having to live further away is that the adult's social mobility gets dramatically reduced and outcomes are compromised.

#### **3c. Clear and Accessible Information needed for Families**

- Information is needed on different types of housing options and eligibility criteria eg: residential placements/supported accommodation, approved providers, and housing/residential social care organisations. Can this be put on the Local Offer.
- Improved information and communications are needed with clarity across departments as to who does what.
- Families need information on processes & timescales around housing plans and when they're asked for.

#### **3d. Ideas from parent carers**

- BHCC need to develop a transition pack and suggest that West Sussex's version could be adapted. How does social housing work alongside the city's long-term plan

for housing in the city, in terms of aligning homes within accessible and affordable housing targets?

- Sharing from 'older parents' to current parents would be useful, who could organise this.
- Housing case studies: it would be helpful to have case studies across different areas of need e.g.: blog to help families at the start of this journey.
- Parent carers have great ideas around thinking outside of the box re housing and what does good look like etc. It would be sensible for the council to help facilitate these conversations.
- Parent groups have worked collectively to achieve a good, shared accommodation alongside a robust care package. It's already happening for some families who co purchase, how can other families find out more about these options.

### **3e. Young People and Housing Options**

- What materials can be provided for the young people with housing requirements? Literature needs to be at a level that can be used with YP with LD
- How much are the families and the YP involved with the offers available? For example – some YP will be more independent than others.
- It is vital for the YP to have the correct setting with the right support, so they can have a meaningful life.
- Young people living in shared houses can be limited by the availability of carers to take them out in the evening, and often get plans get changed because of staffing issues. How are these essential aspects of access to the community monitored?
- Parent carers will sometimes opt to keep their adult child living at home so they can ensure they are able to have an active social life.

## **4. Employment, Education and Training**

### **4a. Processes**

- The pathway through education is 0-25. If a Young Person finishes education at 21 then the pathway should continue. How does this happen? eg: When a YP is going down the route of a more outdoors route (like working with animals) – once they finish at college there is nothing for them to go onto. If they finish their education at 21 what are they supposed to go onto – young people need a linear pathway to 25
- Families have concerns that EHCPs can't change or cease without a meeting with the YP & family. Families report that EHCPs are ceased at the end of a college placement, and they are not invited to consider further options.
- Families cite issues such as a YP goes to college outside of Brighton and Hove meaning internships at the out of area college can't be offered, this means the YP is unable to pursue their specific interest e.g.: animal care. What are the next steps and who do they talk to about options within B&H. Can Amaze and the Local Offer help here.

### **4b. Provision Gaps**

- BHCC acknowledges that lack of provision for Young People who fall in gap between profound & multiple & higher functioning who are more equipped to navigate mainstream FE colleges.

- Families report that Team Domenica have been helpful in signposting for work experience, families would like to see this further developed for YP with a wider range of needs.
- Aspirations and the scope of opportunity for young people with LD and PMLD need to improve, alongside improving support to achieve meaningful adult lives.
- An expansion of supported internship in Brighton and Hove is needed, families would like more information.

#### **4c. Clear and accessible information needed for families**

- Information on work experience and volunteering options need to be on the Local Offer. This must include opportunities and meaningful activity for more complex needs including YP with health needs and communication needs to access different working environments.
- Families want more information about Grace Eyre, Ambito and any other Adult Social Care providers in the city.
- Parent Carers want BHCC to look at other models of housing e.g.: the Preston model, Linden Farm in Surrey, the Simon Trust etc.
- BHCC are creating an accessible webpage around housing and independent living, and they want to work with PaCC to organize feedback on what could be useful to be on the web page.
- Parent Carers want a housing meeting to learn more about the existing providers in the city, and for a discussion around what can be created.

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## **Findings from Parent Carers of Neurodivergent Young People (with and without Learning Disabilities)**

### **5. Health**

#### **5a. Processes**

- Parent carers would like shorter waiting lists for neurodivergent assessments, as they are currently very long. YP are then having to be transferred to adult services because the waiting lists with children's services are so long. This creates unnecessary stress and system navigating for families.
- Pathway transitions for Fetal Alcohol Spectrum Disorder (FASD), Autism and ADHD are unclear, with some parent carers feeling that they are not in place at all.
- Clearer pathways for the prescribing and reviewing of ADHD medication and melatonin when someone is transitioning to adult services.

#### **5b. Provision Gaps**

- Parent carers feel there is a real gap around support for young person whilst they are on a waiting list as well as for parent carers.

#### **5c. Clear and accessible information needed for families**

- Transition pathways

- Transitioning from CAMHS to adult services, when a young person is on a waiting list for assessment and whether they will join the adult waiting list at the beginning.
- Information about the prescribing and reviewing of medication when a young person transitions to adult services, including around shared care agreements.
- Adult services for dyslexia, developmental coordination disorder, tics and Tourette syndrome, fetal alcohol spectrum disorders (FASD).
- When a young person receives a later diagnosis, and children's services aren't there to signpost them to adult services.
- How different services work together when someone has more than one neurodivergent condition, which is often the case.
- What support is available during the transition to adult services.
- The role of a school nurse during transition and who will provide this service after.
- The role of Family Hubs during transition, especially as they support families until a young person is 25 if they have SEND.

## **6. Community inclusion and relationships**

### **6a. Provision Gaps**

- Parent carers feel that more mentoring and buddy systems available for their YP would really support them.
- There is a lack of opportunities to form and maintain friendships, especially when YP are unable to leave their home.
- Colleges providing nurturing groups/days/courses for children with EHCPs is valuable as they give them time with children outside the course they are doing. This could be made available for young people without an EHCP.

### **6b. Clear and accessible information needed for families**

- Parent carers would like information about social groups and activities their young person can attend.
- How parent carers can support their young person to be part of social groups and have friendships and relationships if they are unable to leave their bedroom or home.

## **7. Housing and independent living**

### **7a. Provision Gaps**

- Preparing children to be ready for independent living as adults, such as around finances etc.
- There is a shortage of suitable housing for young people, which makes it harder for them to live independently.
- There needs to be more support around conflict within the household when there are people living there with multiple neurodivergent conditions .
- It has been difficult for neurodivergent young people when they have been offered shared housing with a shared kitchen and bathroom, especially as they don't know or feel safe with the other people using them.
- Autistic young people being housed with people with MH difficulties is a worry for parent carers.
- Lack of services for neurodivergent people.
- Parent carers do not feel that the Youth Advice Centre (YAC) has enough available as a service for those who are neurodivergent.



- There is a gap with supporting young people who are experiencing emotional based school avoidance at college.

### **7b. Processes**

- Parent carers said that it is hard to know where to begin to find suitable housing for their YP and how their YP can access this themselves.
- If a YP starts to spiral with their mental health, when they live independently, it is hard for families to know which service can help them.

### **7c. Clear and accessible information needed for families**

- How to support and teach their child or young person the key skills they will need when living independently. Which services can support with this.

## **8. Employment, education and training**

### **8a. Provision Gaps**

- Parent carers feel that neurodivergent young people being able to be use their strengths and special interests will help them to engage with these areas. For this to happen, broad options for employment, education and training must be made available to them.
- It is important that a young person's cultural background and diversity is taken into consideration as Brighton & Hove has a very diverse community.
- Parent carers raised the inconsistency with the knowledge universities have when supporting neurodivergent young people. This is particularly concerning when a young person attends a university away from home and living independently for the first time. Parent carers feel that the transition to higher education for neurodivergent young people needs to be strengthened.
- Parents recognise the pressure placed on neurodivergent young people around employment and training and asked whether young people are happy when working or accessing training?
- Neurodivergent young people can experience difficulties in employment because workplaces don't always have the right knowledge, understanding and level of acceptance around neurodivergent conditions.
- Parent carers feel that the transition to further education needs to be strengthened for neurodivergent young people.
- There needs be a greater focus on neurodivergent conditions such as Tics and Tourette syndrome, developmental language disorder and ADHD.

### **8b. Clear and accessible information needed for families**

- How parent carers can support their young people to focus on and use their interests during transitions related to education, employment, and training.
- Parent carers would like to know how they can help their neurodivergent young people to reach their goals.
- Brighton and Hove City Youth Council to provide information about what neurodivergent young people want and need.

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## Findings from Parent Carers of Young People with Social Emotional Mental Health Needs

### Health

#### 9a. Processes

- The transition age is too rigid and needs to start earlier.
- The transition pathways include young people aged 15 – 25 years and mental health services need to be tailored to that age group.
- Processes are too rigid and don't give room for them to be individual to what a young person needs or be person centred.
- Pathway transitions for assessments, waiting lists and medication are unclear.
- Young people recently turning 18 have not been able to access any service as they didn't make it into CAMHS due to the waiting list closing before the young person got access to support.
- Colleges don't always share transition booklets with young people and their families.
- Young people have been rejected from the SCDS team and after their mental health needs have been assessed they are still not getting right support.

#### 9b. Provision Gaps

- Talking therapies for adults are under-subscribed but is oversubscribed for children and young people. This impacts greatly on the transition between children to adult services. There needs to be better communication.
- The School Mental Health Service is appreciated by parent carers but they feel that the support it stops at too young an age.
- There is a gap in mental health services for young people who are aged between 16-18 years.
- GP are not always pulling together different health issues, creating difficulties for young people.
- Relationships between services and with young people and their families during transitions is not robust enough.
- Services are not adapted to developmental stage, they are focused on someone's age, creating barriers to young people being able to engage with services and interventions.
- There is a lack of continuity of offer, and this can impact on the trust a young person develops with an adult service.
- When using reports for disability benefits applications, it proves difficult as the home impact is hidden.

#### 9c. Clear and accessible information for parent carers

- Information is needed for families when a young person enters systems later.

### 10. Community inclusion and relationships

- Family Hubs, Amazing Futures, mASCot, Hangleton & Knoll Project and Crew Club are very appreciated by parent carers.
- Accessing services, therapies and interventions online works well for some young people.

**10a. Processes**

- Parent carers feel that there needs to be a strategic overview of how group of young people meet and socialise and then use youth groups and education to form the glue to bind it together.
- Raising the profile of SEMH needs will make it easier for community groups to receive funding and for YP to receive Personal Independence Payments (PIP).

**10b. Provision Gaps**

- Church youth groups are valued, so how can they be replicated for young people who don't attend a church?
- It would be helpful for young people to receive peer support by older young people.
- The loss of youth work and the lack of outreach means that parent carers and young people are having to be proactive with trying to find the equivalent elsewhere.

**11. Housing and independent living****11a. Processes**

- When a young person has SEMH needs, it means there are more support needs to organise and it can be very difficult to access services to help with this.
- Transitions are needed at an earlier age, so young people don't need services in the first place.

**11b. Provision Gaps**

- There is a huge gap with independent living for young people with SEMH needs, with parent carers feeling that someone else makes decisions for young people with regards to this.
- There are gaps with existing services – Community Integrated Care (CIC), Brighton Housing Trust and YMCA don't always have someone who can support and work with parent carers.
- Parent carers feel that there is a reliance on charities and the private sector to provide for young people and their families.
- Young people end up in mental health crisis because of a lack of support and then can't access housing because of their SEMH needs.
- There is a lack of youth projects.
- There is a lack of continuity of staff and provision, which is important for young people with SEMH needs.
- Parent carers feel that Shared Lives is not appropriate for young people with SEMH needs and there needs more planning and relationship building.
- Supported living is also not appropriate for young people with SEMH needs and there is a lack of stability for them. There is no support for young people who display distressed behaviour.
- Parent carers feel that supported housing for vulnerable people with SEMH needs is not fit for purpose.

*'Shared lives is not appropriate. There is a need for more planning and relationship building. And so for supported living, i.e. lack of stability. Behaviour that challenges'*

**11c. Clear and accessible information for families**

- Parent carers feel that there is no information available to them.

## **12. Employment, education and training**

- Parent carers value the Youth Employment Hub, supported employment and Access to Work.

### **12a. Processes**

- Need to ensure that families and employers are aware of and know relevant legal frameworks.
- There is a gap around information, for example 'What employers and education need to know if autistic?' 'How do I find out?'.

### **12b. Provision Gaps**

- Trauma is preventing young people from leaving the house and there is no support for them or their parent carers.
- Supported internships don't support young people with employment if they have SEMH needs without a learning disability.
- There is a lack of post 16 work experience and volunteering opportunities for young people with SEMH needs. Amex is no longer offering this.
- Careers advisors in mainstream education are not always skilled enough and not joined up with being able to give advice to young people with SEMH needs.
- There needs to be more tailored offers available.
- There needs to be people who are easy to access to support young people and their parent carers when going through this transition stage.
- The level of knowledge and skills that that employers have in place to support young people with SEMH needs in the workplace fluctuates.

### **12c. Clear and accessible information needed for families**

- Information is available if someone is already in the system, but not for those who aren't – what is the doorway into services?
- Parent carers feel that if the Local Offer was improved, there would be more information available to them.

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## **Findings from Parent Carers of Neurodivergent Young People (with and without Learning Disability) who have SEMH Needs**

## **13. Community inclusion, friends, and relationships**

### **13a. Provision Gaps**

- Siblings can be impacted by a young person's lack of relationships, and they can become isolated because they can't have their friends around. If a young person receives DLA/PIP and their sibling doesn't, it can create jealousy around finances.
- There is a lack of support for young people when they reach 25+.
- Young people's voices need to be heard.

### **13b. Clear and accessible information needed for families**

- There needs to be more transparency around panels and decision making.

## **14. Housing and independent living**

### **14a. Provision Gaps**

- A young person was sent to YAC – but there wasn't anything available there to support them with their additional needs. This triggered a Front Door for Families referral because a 5-year-old was living in the house. After 12 months, there is still no way forward for the young person or their family.
- Families are experiencing cramped accommodation, with parent carers sleeping in their lounge and their children needing their own bedrooms because of their SEND.
- Supported housing – the level of support provided is too low e.g. more support is needed with finances, working, cooking, making appointments, paying rent and dealing with paperwork. BHT's shared housing only lasts 12 months and throughout the year it is stressful knowing they have to leave to find own tenancy and job.

### **14b. Housing Info at the meeting:**

Brighton and Hove Housing Commissioner to feed into housing allocations policy work, about families needing another bedroom as parent carers are sleeping in the lounge.

A Brighton and Hove Housing Commissioner explained there should be market development of a neurodivergent housing offer through the current development of the Dynamic Purchasing System (DPS), it would be helpful to have further discussions around this.

As the Autism Strategy is focused on autism and participation work focused on autistic people, we need to consider what work can be undertaken for neurodivergent conditions that aren't autism.

## **15. Employment, education and training**

- Supa Jam a positive development.

### **15a. Processes**

- Options and pathways are complex.
- Parents need single point of contact for planning, viewing of placements, transport.
- Parent carers feel that their young people are pushed into college to pursue Math's and English qualifications when they don't want to.

### **15b. Provision Gaps**

- If a young person isn't attending college etc. there is no access to life skills development opportunities. How can young people receive this?
- There needs to be more opportunities for work experience that young people want and are interested in e.g. Theme parks.
- The threshold for supported internship is too high.
- Careers advice for young people – specialist SEND tailored advice is lacking.
- Parent carers are especially frustrated when young people have academic ability but can't attend an education setting due to their anxiety.

- Parent carers feel that an EHCP is needed in order to access support in higher education.

### **15c. Clear and accessible information and opportunities for parent carers**

- Parent carers don't know what they don't know, they need to be told or have information available to them.
- Can there be Face2Face in the evenings.
- Parent carers would like to be able to have a parent carer group or a WhatsApp group for families of 18 to 25 years old so they can keep in touch.

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### **Other important feedback**

#### **The Carers need's assessment is not fully understood by parent carers**

- The process and the remit of what should happen is unclear.
- What are parent carers rights when their child reaches 18.
- insufficient time is given to this part of the assessment.
- It takes time to build effective relationships with key professionals to achieve better outcomes for CYP, themselves and siblings.

#### **Legal Processes**

- **Deputyship** – information needs to be available.
- **Court protection order** - is there information available on the Amaze website? The cost of this protection is too high for many families.
- Clarity around **Mental Capacity Act** – parent carers ask for more information on who has the decision-making power relating to health decisions. Parents fear misuse of the Menta Capacity Act.
- **Renaissance Legal** – Families give excellent feedback about this organisation and their information sessions.

#### **Consent and parent carers acting on behalf of their young person**

- From the age of 18-20, some parent carers say that adult services want to speak to the Young Person more than parents, this is a risk, as some YP like to please, meaning the YP doesn't always say the correct accurate response.
- Many young adults with LD still need their parents to be included in appointments, to support making decisions and communicate understanding between the YP and the health staff.
- It becomes difficult when parents aren't privy to the details regarding their child because their child hasn't given consent – the young person thinks they can manage on their own and they can't.
- If a child is not accepting of their neurodivergence, parent carers not having consent can make this situation even more difficult.
- Parent carers don't feel that their concerns are listened to until child gives consent for them to be involved.

- Parent carers would like to see tick boxes on forms, rather than being continually asked. This will help with getting consent across all services.

### Money and benefits

- Parent Carers need more information on Capacity re financial decision making. What do families need to do between 16 – 18 years old to be ready eg: legal guardianship, trusteeship, Employment Support Allowance, Trust Funds, Universal Credit, other benefits etc.
- Feedback suggests that the role of a transition caseworker would be very helpful, someone who is knowledgeable. If not ongoing support, at least 1 off session 1:1. The year 9 Annual review could start this process.
- There is confusion around the charging issues for YP over 18 e.g.: further education support and transport to the FE college, often the LA expects the supported living provider to fund, and the supported living provider expects LA to fund.
- Families want more information on claiming Disability Reasonable Expenditure cost.

### Early identification and intervention

- Early identification and intervention, will prevent young people reaching crisis, meaning they may need to access less services, which could lead to a smaller transition for them.
- Earlier transition planning - when a young person has SEND but no EHCP planning should start when they are 16, not 18.
- Early identification is essential and will create an easier transition to adulthood, with potential less service involvement needed.
- Training for SENCOs being strengthened, leading to quicker identification of ND conditions.
- Young people are traumatized by their school experience, parent carers then exhaust all possible all educational options leading to young people not gaining any GCSEs with no idea what to do next.
- There needs to be a greater focus on life skills being taught early, so many of them have become daily routines for young people to help them with independent living.
- Parent carers feel that the lack of alternative provision for school age children, leads to children not receiving the qualifications they would have got if a suitable education was in place. This then has a huge impact on their future education, employment and training and the options available to them. It can also lead to neurodivergent young people accessing these at an older age, wasting years of their life.

### Culture and ethos

- Having a neuro-affirmative culture and ethos, that is also accepting of all differences will help create a sense of belonging for children and young people, decreasing their risk of experiencing mental health difficulties. This may lead to them having smoother and smaller transition as they will need to access less services and have greater employment, training, education, community, and housing opportunities.
- Neurodivergent young people experience social paranoia and social anxiety because of the trauma of needing to mask who they are. This can then impact on their relationships and college attendance.
- Not try to fix YP, society standardises wrongly and needs to change.
- Personal, social, health and economic (PSHE) education in school not always being taught through a neurodivergent lens and lessons being communicated in a way that neurodivergent pupils will understand, creating difficulties for neurodivergent young people with friendships and relationships. Parent carers are concerned that this could

increase their young people's risk of being exploited, taken advantage of by friends or remaining in an unhealthy relationship.

- With education, it is important to remember that children with cultural diversity are five times more likely to be excluded, with this increasing with the intersectionality of being neurodivergent too. Being excluded can have a huge impact on current and future education, training and employment opportunities and experience.

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**Summary:****Parent Carers of Children and Young People with Physical Disabilities and Complex Needs****Health:**

- Initiate transition planning earlier to avoid issues at age 18.
- Provide comprehensive health assessments around age 16-18 to facilitate handover to adult services.
- Improve clarity and consistency in managing the specific health needs of adults with learning disabilities.
- Address confusion around hospital treatment plans and mental health support accessibility.

**Community Inclusion and Relationships:**

- Address gaps in services and social opportunities for young people with complex needs.
- Advocate for LGBTQ+ inclusion and peer support within the LD community.
- Facilitate cooperative housing initiatives to address diverse community needs.

**Housing and Independent Living:**

- Start housing planning earlier, ensure joined up working between children's and adult services, and streamline processes.
- Provide clearer information on housing options, eligibility criteria, and support services.
- Facilitate parent groups to share experiences and explore innovative housing solutions.

**Employment, Education, and Training:**

- Ensure a continuum of support beyond age 21, provide tailored pathways to employment, and expand supported internship opportunities.
- Enhance information on work experience, volunteering options, and adult social care providers.

**Parent Carer Concerns:**

- Improve communication and responsiveness from health and social care professionals.
- Provide clearer information on legal processes, parental responsibilities, and crisis support pathways.
- Address concerns regarding the use of constraint during health appointments and Do Not Resuscitate orders.
- Develop transition packs, facilitate parent networking, and share case studies to support housing planning.

**Parent Carers of Neurodivergent Young People (with and without Learning Disabilities)****Health:**

- Shorten waiting lists for neurodivergent assessments to reduce stress and system navigation.
- Improve clarity and establish clearer pathways for transitioning to adult services, especially for conditions like Fetal Alcohol Spectrum Disorder (FASD), Autism, and ADHD and with medication.

**Community Inclusion and Relationships:**

- Provide more mentoring and buddy systems for young people.

- Address the lack of opportunities for forming and maintaining friendships, especially for those who are homebound.

#### **Housing and Independent Living:**

- Prepare young people for independent living, address shortages in suitable housing, and provide support for conflicts within households.
- Ensure safe and suitable housing arrangements, avoiding housing with incompatible roommates and addressing gaps in support services.

#### **Employment, Education, and Training:**

- Offer diverse options for employment, education, and training that accommodate neurodivergent strengths and interests.
- Strengthen transitions to higher education and address inconsistencies in university support for neurodivergent students.
- Provide clear information on how to support neurodivergent young people in achieving their goals and utilising their interests during transitions.

### **Parent Carers of Young People with Social Emotional Mental Health (SEMH) Needs:**

#### **Health:**

- Start transition planning earlier and tailor mental health services to young people aged 15-25.
- Ensure clear pathways for assessments, waiting lists, and medication transitions.
- Address gaps in talking therapies and ensure better communication between child and adult mental health services.

#### **Community Inclusion and Relationships:**

- Acknowledge and appreciate existing supportive services like Family Hubs and community projects.
- Utilize online platforms for accessing services and interventions.

#### **Housing and Independent Living:**

- Address gaps in independent living support and housing options, especially for young people with SEMH needs.
- Provide continuity of staff and services, avoid reliance on charities, and ensure appropriate housing options.

#### **Employment, Education, and Training:**

- Value existing employment support services and ensure awareness of legal frameworks.
- Address gaps in post-16 work experience, tailored support, and career advice for young people with SEMH needs.

### **Parent Carers of Neurodivergent Young People with SEMH Needs:**

#### **Community Inclusion, Friends, and Relationships:**

- Siblings can be impacted by a lack of relationships among young people with SEMH needs, leading to isolation.
- Lack of support for young people transitioning to adulthood (25+).
- Transparency around decision-making processes and panels.

#### **Housing and Independent Living:**

- Insufficient support available in youth advice centers for young people with additional needs.
- Families experiencing cramped accommodation and inadequate support in shared housing situations.

#### **Employment, Education, and Training**

- Complex options and pathways for young people.

- Parents need a single point of contact for planning, placements, and transport.
- Lack of access to life skills development opportunities for young people not attending college.
- Limited opportunities for work experience tailored to young people's interests.
- High threshold for supported internships and inadequate specialist careers advice for young people with SEMH needs.
- Parent carers require better guidance and information to navigate available support and opportunities effectively.

#### **Understanding Carers' Needs Assessment:**

- Lack of clarity and understanding among parent carers about the process and rights, particularly when their child reaches 18.
- Uncertainty around legal processes such as deputyship, court protection orders, and the Mental Capacity Act.
- Positive feedback about Renaissance Legal's information sessions.

#### **Consent and Acting on Behalf of Young People:**

- Challenges parent carers face when young adults need support but are not consenting to parental involvement.
- Desire for tick boxes on forms for consent across all services.

#### **Money and Benefits:**

- Need for more information on financial decision making and benefits between ages 16-18.
- Suggestions for the role of a transition caseworker and clarity on charging issues for young people over 18.

#### **Early Identification and Intervention:**

- Importance of early identification and intervention to prevent crises and facilitate smoother transitions to adulthood.
- Calls for earlier transition planning and strengthening of SENCO training for quicker identification of ND conditions.
- Concerns about lack of alternative provision leading to wasted educational opportunities.

#### **Culture and Ethos:**

- Advocacy for a neuro-affirmative culture and ethos in education to decrease mental health difficulties and improve opportunities for neurodivergent young people.
- Concerns about PSHE education not being taught through a neurodivergent lens, potentially increasing risks for neurodivergent pupils in friendships and relationships.
- Intersectionality of cultural diversity and neurodivergence leading to increased exclusion rates, impacting future opportunities.

#### **NEXT STEPS**

Please contact PaCC at [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) for any questions or feedback.

This working document will be uploaded to the PaCC Website <https://paccbrighton.org.uk/reports/> and information will be added as PaCC receive this from professionals.