

Priorities within the Learning Disability Community

Report by the Carers Centre, PaCC and Amaze, Oct 2019



Contents

Title page	P1
Introduction	P2
Methodology and existing intelligence	P2
Responses to Questions	P3
Conclusions	P18

Introduction

This consultation has been requested by the Learning Disability Partnership Board with the aim of looking at the priority needs of people with Learning Disabilities, both at school and in the adult world. The focus of The Carers Centre was the carers of people with Learning Disabilities, rather than the people themselves. PaCC and Amaze asked parent carers' views and experiences in relation to their children.

A new Learning Disability Strategy

Brighton and Hove City Council is planning on putting together a new Learning Disability Strategy, as the current one expires this year. A strategy brings together needs and aspirations and is a document that highlights the situation now, where we would like to get to, how and when.

The Learning Disability Strategy aims to help children and adults with learning disabilities living in Brighton and Hove have a good, happy and healthy life, live independently, feel part of the city, and make their own choices and decisions. We sought feedback on how things have changed since the last strategy was written, where the carers would like things to be in three years' time and any thoughts around how this could be achieved.

Methodology

The Carers Centre, PaCC and Amaze looked at existing intelligence and conducted a short online survey. The online survey was based on the priority areas we had already identified from existing intelligence. The format of the survey was very simple and asked respondents to indicate where they felt a service was good or required improvement. There was also space for additional comments; a summary of comments and key points are included after each question.

The Carers Centre had responses from **28 adult carers**. Amaze identified parents caring for young people with LDs in the transition age range 14 to 25 via the Compass database, PaCC sent the online survey to all its Partners and publicized on its social media. **39 parent carers** completed the survey.

Demographics from PaCC and Amaze survey have been collated into a separate document (See attachment 1: Demographics from the online questionnaire - LDPB Oct 2019)

The information has been presented in table form so areas of need can be easily identified. The existing intelligence has been collated into a tabular format and is attached in a separate document (See attachment 2: LDPB Strategy - priorities from Amaze PaCC and The Carers Centre Sept 2019)

Responses to the online survey

Q1. How do you feel about your GP and the support your dependant or young person gets from it?			
Carers Centre		PaCC & Amaze	
Making an appointment	33% Good	Making an appointment	36% Good
Accessing the GP	33% Good	Accessing the GP	44% Good
Consultation between GP and your dependant person	37% Good	Consultation between GP and your young person	41% Good
Communication from GPs	30% Good	Communication from GPs	31% Good
Annual Health Checks	26% Good	Annual Health Checks	15% Good
		Transition from children's to adult services	8% Good

Additional comments / tell us more:

Q 1: Carers Centre survey:

"Having recently moved, the appointment system for our current GP is beyond ridiculous, you can only get an appointment if you are physically at the surgery at 8.15am - they will not take telephone appointments which is wholly impractical as it is very difficult to get to the surgery at such an early hour therefore recent health concerns are going untreated - it was in fact easier to take my son to A&E recently to get him treated than trying to get an appointment with our GP."

"My mother feels she needs more time with the GP as her dementia is robbing her of memory and the ability to process information."

"We were invited for an annual check-up but discovered the only person able to take blood samples was off sick for 2 weeks. They claim to have tried contacting us which just compounded their dishonesty as there was no record of missed calls. They also refuse to send or receive email, and the NHS SMS feedback address also fails."

"All extremely poor. Trying to get an appointment is like The Hunger Games. Specialist referrals never happen or finally get picked up after a 12+ month wait. No

one has time to listen. No one really cares about proactive health care. It's all fire-fighting."

"Making an appointment is difficult, gp lacks specialised knowledge, attitude is often poor or annoyed. Some GPs are better than others, to be fair they feel overstretched."

"Very wordy, due to processing difficulties key information needs to be chunked and ideally written. Currently I attend also and have to go over what was said as they can't take it in. Appointment tricky by phone."

"My mum will be referred to somewhere else but then we never hear back from the GP or who he has referred her to. This has happened multiple times."

Carers Centre Key Points: Communication and access are still major issues. Annual Health Checks are the least satisfactory area.

Q 1: PaCC & Amaze survey:

"Assumptions were made by the practice as soon as the vulnerable child turned 16yo that the parent couldn't make appointments on their behalf, even though the child needed the parent to do so. Not all visits to the surgery are negative, but no reasonable adjustments are made for autistics and things like being kept waiting (sometimes way past allotted time) are very difficult for autistics. This applies for autistic adults over 25 also. Consultation with GP could also have been scored negative from the aspect that there is no understanding of ASD and assumptions are made. Service is reactive rather than proactive. Despite it being well-known that autistics are more vulnerable to specific additional health problems no screening is undertaken, nor dots joined together. Cannot score annual health checks as there are none. I have therefore scored as negative. There was no transition from children's to adult services and a forced and inappropriate transition (CAMHS refused the urgent referral) before attaining legal adulthood was made in the midst of a crisis, a lot of mistakes were made causing a lot of stress and distress in the family. No understanding of ASD again, inflexible and they breached their own publicly stated rules"

"My son is 16, severe learning difficulties including nonverbal so he must be supported by parent at every appointment, do not know what happens in respect of adult services, nor has anyone told me"

"Doctor tends to speak to carers and not my child. Not received any support from GP now in adult services and not received a yearly checkup"

"GP surgery recently closed down, so have to go further for another one. Despite being with some of the same doctors for years, they appear extremely unaware of the young person's condition and profile and had to be reminded about"

checks/diagnosis. They are never proactive in terms of suggesting support or services, and know less than parents know. Especially once the young person is nominally an 'adult'. No annual health checks in place for them”

“GP appointments are impossible to schedule. Seaside view operates at a snail's pace - specialist referrals take forever or just never happen. I do not feel that anyone has a particularly good sense of the health needs of my child. We are on meds that reduce my child's white blood count so my child has had a nasty cough for THREE months. We just keep getting sent away.”

“I have a 20 year old with autism. He cannot explain himself well enough in the time given for an appointment. I go along as his carer and they do speak directly to him but he looks to me for reassurance. He needs longer than the usual appointment time as he stutters, goes off the point etc. A longer (double) appointment would help a lot”

PaCC and Amaze Key Points: Communication and access are still major issues and also GP knowledge about disabilities and additional needs. Annual Health Checks should be carried 'annually'. More information is needed in relation to transition into adult's services.

Q2. How do you feel about NHS Wellbeing and Mental Health services for your dependant or young person?			
Carers Centre		PaCC & Amaze	
Info about available services	45% Good	Info about available services	13% Good
Accessing the services	30% Good	Accessing the services	10% Good
Communication from the services	30% Good	Communication from the services	13% Good
The assessment process	25% Good	The assessment process	10% Good

Additional comments / tell us more:

Q 2: Carers Centre survey:

“There is no information that comes through to the people who really need it - we are always told your GP is your first call but as previously explained trying to access our GP is extremely difficult.”

“Appalling. We are on a 12-month waiting list, which means a downward mental health spiral until we are seen. How has this service been allowed to be so seriously underfunded?”

"Feel the Alzheimer's society aren't interested anymore. No admiral nurses. The Council Adult Social Services and Carers Hub have been our life-lines."

"Even mental health services, who are responsible for diagnosing ASD couldn't get that right. CAMHS were beyond appalling and when the person was 17yo they refused to take them when in mental health crisis, having been to A&E and confirmed as urgent case. I had to battle adult services to take them (two days of countless phone calls and a huge amount of stress), even though A&E said medication was needed, they tried to fob us off to the wellbeing service which is for low priority cases and cannot medicate. Across the board there is a lot of autism ignorance."

"Poor access due to underfunding. Was told could only get help for my depressed and anxious dependant if they were self-harming or had an eating disorder."

"Extremely difficult to obtain assessments and to be referred. It took almost 2 years to see a psychiatrist and would have been even longer to see a specialist in autism."

Carers Centre Key Points: Information is seen as available by almost half of respondents, but services are not viewed positively.

Q 2: PaCC & Amaze survey:

"I have never been told about any of these services or what is available"

"CAMHS are so overwhelmed and under staffed that the waiting list just to get assessed takes months and in those months there is no service to talk to or ask for advice, CAMHS are not fit for function, and they are failing so many children"

"My child was referred to CAMHS via their speech therapist. Assessment process was fine although there were no after school appointments, which caused significant distress for my child who hates missing school. I feel very strongly that no diagnosis was given of autism when my child is significantly autistic. I do wonder if this was determined by a need to reduce the number of diagnosis? One does wonder"

"Assessment process is always what the person CANNOT do. You fill in reams of questionnaires, go to endless meetings, exchange emails, have phone calls, and all finally to find out that the service has been cut or doesn't apply or is inappropriate or whatever. Not at all joined up and very demoralising for the person concerned"

"Mental health needs a massive wake up and more trained staff are needed as"

there are so many young adults suffering with mental health, I feel like there is no one to turn too sometimes for my worries and my son, too many suicides happening ,, not good!

“CAMHS seem to look at the family and how parents deal with situations as the source of any anxiety, depression etc. in the young person. CAMHS did not understand autism (Asperger) whatsoever. The waiting list time is too long, and there is no support whilst you're on waiting list, and you're in crisis”

“Mental health practitioners aren't qualified or specialised in working with ASC young people. We have found this has alienated my daughter from accessing MH support as her needs are misunderstood. It's a huge gap in services and creates further harm to an already marginalised group. The theory that ASC is misdiagnosed trauma is common within MH who focus on a train informed approach. This approach disregards the needs of ASC young people in a system when it is already overwhelming challenging to get specialist support and needs recognised”

PaCC & Amaze Key Points: More information about services available is needed. Waiting times are a huge problem. Specialist skills of workforce. More flexibility on appointments available. Overall more joined up services.

Q3. How do you feel about accommodation and housing for your dependant or young person?			
Carers Centre		PaCC & Amaze	
Support from services	36% Good	Support from services	15% Good
Communication from services	36% Good	Communication from services	8% Good
Clarity about planning for the future	10% Good	Clarity about planning for the future	10% Good
Information regarding options available for your dependant person	18% Good	Information regarding options available for your dependant person	10% Good
		Advice on planning for financial changes that follow from the young person moving out	3% Good

Additional comments / tell us more:

Q 3: Carers Centre survey:

“My sister has been looked after well and is living in Council sheltered accommodation.”

"Have been waiting for over 2 years for an accommodation offer."

"The cared for person would be unable to be independent from family at the present time, is highly vulnerable despite IQ and academic ability. I have not been offered a carers assessment and wouldn't trust them anyway due to past experiences. Autism law statutory guidance is not followed by services and nobody holds them to account. No information has ever been offered when the cared for person turned 18yo for the future options. The person has not been offered their own assessment of need either and I am a disabled parent carer with another cared for (below 18yo) child. The only communication we have ever had from services has been dishonest, ignorant and at times malicious, which has not only not been of any benefit to our family but has caused immense trauma."

"My son currently lives with me but I do worry about anything happening to me that after going through the trauma of losing a parent would he then be made homeless?"

Carers Centre Key points: Knowing what will happen in the future when parents not around is seen as requiring improvement (at least) by 90%+ of respondents. There is seen as a lack of information and care from support services by some responders.

Q 3: PaCC & Amaze survey:

"Zero information given and zero assessments of needs for anyone"

"My son is just 18 so doesn't need any separate housing. I am not sure how to move forward as the option of college does not seem to be available to someone who can't perform academically. But college isn't just about formal education. I am trying to help my son develop budgeting skills, but this is major challenge. He gets into subscriptions really easily, but they are very challenging to get out of. He doesn't really know how to use the apps, discounts and websites that make things more affordable. He is vulnerable to exploitation. Everything costs more as he can't plan and often makes mistakes/loses and breaks things so money is a major worry in terms of him being successful at independence"

"There is no choice for accommodation and given one option and no other providers, poor communication and being messed around as provider pulled out then it was all go again. Transition now being rushed"

"Rubbish, much more is needed in this area for accommodation and housing, my son always worries that he will be homeless in the future, every parent should receive info on accommodation and housing for their young adult children"

“Not had any communication whatsoever about help with future life plans for my son aged 20 with Aspergers. No idea what support is out there for assisted living, for example, despite being proactive and trying to find out.”

“Social worker started planning this, then quit, no replacement social worker given. We are now stuck”

PaCC & Amaze Key Points: More information/choice about what’s available and more assessments are required. More joined up services.

Q4. How do you feel about physical activities and healthy diet choices available for your dependant or young person?	
Carers Centre	PaCC & Amaze
Information about what’s available 33% Good	Information about what’s available 33% Good
The variety of and suitability of physical activities 17% Good	The variety of and suitability of physical activities 39% Good
Extra support for accessing activities, e.g. transport, buddies etc. 13% Good	Extra support for accessing activities, e.g. transport, buddies etc. 21% Good
Information about healthy diet 29% Good	Information about healthy diet 39% Good

Additional comments / tell us more:

Q 4: Carers Centre survey:

“I have instilled in my son the benefits of healthy eating but with his OCD regarding food hygiene it is not always easy to get him to eat properly and regularly - not enough information is out there regarding supporting agencies or charities which could help my son.”

“Never received any information about any of this.”

“There is no support. A suitable buddy service is desperately needed to enable social activities.”

“Have had nothing out to us.”

“I have to spend time researching myself - it’s practically non-existent.”

Carers Centre Key points: Some responses seem to indicate that people would prefer it if information was sent to them rather than being accessible online. Most people felt variety of and support to access services require improvement.

Q 4: PaCC & Amaze survey:

"Nothing that takes into account difficulties of autistics without learning disabilities (ASD is a learning difficulty but no support is provided apparently based on IQ which is irrelevant). Buddy service needed to enable access of social opportunities. School need to supply buddy and socialising service but don't"

"As far as I am aware there is not one single physical activity available in Brighton for my son to attend. He requires 1:1 support in order to access anything"

"Albion in the Community, Brighton Table Tennis & Extratime all great & thank God for those. Woeful lack of care provision & activities in summer holidays though"

"Some transport support is provided but often only during 'term time' leaving more than half the year without any way to be more autonomous and putting an enormous strain on family resources/energy"

"These information events look promising but are mainly for young adults (18+). There is a complete lack of activities available to 14-17 year olds in the community. No youth clubs, no after school clubs, no transport or support to access mainstream provision. This is large-scale discrimination. Shameful"

"Exercise and diet are dealt with at school, with an emphasis on health and wellbeing"

"PE is a big trigger for meltdown for my daughter in school but no alternatives are offered such as walk and talks and forest schools are no longer offered which used to promote her in engaging in physical activities"

"The Compass provides great info!"

"My daughter needs full support to access community activities. We have 4 hours a week and so need to plan carefully how this is used to the best. PAs are hard to find and there is a high turnover rate. My SLD daughter in mainstream secondary school does not benefit from the extended day offer, which is Special school, located. She accesses a mainstream after school club for 4-11 year olds when I work (luckily she loves it and the scheme is great at making it more age appropriate for her) as there is no other provision available for older students who do not fall in special school cohort but who are unable to be left unsupervised. There is a real shortfall in provision for this cohort. Some funding needs to be redirected from extended day to mainstream secondary school to fund TA time to support students"

in accessing after school clubs. My daughter has only ever attended drama/school production rehearsals and this was only made possible due good will and to school finding some budget to pay the TAs - this when school is already under resourced. This all feels very fragile that access to after school activities is not ring fenced; the school could easily say that our kids are unable to attend this in the future, as they do not have the funding to continue”

PaCC & Amaze Key Points: There are some examples of good services around but funding needed for more. A buddy system and better possibilities to socialise. Transport to and from activities should be provided the whole year, not just during term time.

Q5. How do you feel about employment, education, training and volunteering available for your dependant or young person?			
Carers Centre		PaCC & Amaze	
Information on what is available for your dependant person	36% Good	Information about what’s available	28% Good
Support for your dependant person, either on-line or face to face	23% Good	Support for your dependant person, either on-line or face to face	18% Good
Opportunities available	23% Good	Opportunities available	15% Good

Additional comments / tell us more:

Q 5: Carers Centre survey:

“No information has ever been sent to us.”

“All support to the cared for person has been provided by myself the carer and according research done. We are unaware of any support or opportunities.”

“From what I have researched so far, volunteering & training opportunities are woefully inadequate. A great shame because in my son's case at least, he has much to offer & wonderful personality.”

“Have just seen an employment officer for first time and hopeful they can find a voluntary or training position for him. It seems a very slow process though.”

Carers Centre Key points: Information on what is available is the highest scoring in terms of satisfaction; however, there are still a majority of responders that are not aware of options available.

Q 5: PaCC & Amaze survey:

"This is an area of immense difficulty for us. I think I have a reasonable amount of information now, but he won't engage with it. I don't feel like he or I was listened to enough when he started secondary and was struggling with many aspects of school life. When he refused to go I was put under a lot of pressure to try and get him there, which just made things MUCH worse"

"Nothing available. Not youth training available like when I was a teenager"

"Mercifully not at that stage yet. Did attend one initiative at Amaze but level of questionnaire aimed at young people was significantly above the level my child could access so we didn't continue with the project. The only info we have received about post 16 volunteering opportunities was an info session at Amaze"

"The only things we have found, WE have found. No one has been able to help. And that is just for volunteering. Finding any PAID work is almost impossible. Employers think it is a privilege for young people to gain experience with them, and don't want to pay. There are few suitable jobs out there anyway. Add difficulties with transport or other difficulties and there is nothing visible. It is a CONSTANT battle to try to find an organisation that might be suitable and that might have a vacancy and that might be workable. It is well publicised that within the disability group, a very low % ever find work compared to the general population even if they have same/better qualifications. There is also a tendency to lower expectations as well as opportunities for/of those with disabilities, and so much less than active encouragement, there was in fact discouragement for the young person to continue their education, at every stage"

"My son doubts himself, he actually needs a support worker to knock on door and help him apply for jobs and go on the interviews with him,, also needs help if he got a job to not doubt himself, so informing interviewer that he needs a bit of support and understanding for a while"

"I don't know what our options are and it's a big worry"

"Transition planning needs to start so much earlier. Year 9 reviews need to be improved in terms of creating SMART aspirational goals. Better multi agency working to achieve this and clear accountability. Mainstream secondary schools need resources to focus on this - to provide work experience and meaningful careers advice. It has to start in school - too late when they reach 16. See the

Gatsby benchmark Holistic approach so our kids are able to access other programmes e.g. D of E and NCS to undertake volunteering. This all requires resources - PA/TA support to make this a reality. No resources means it falls on parents to do this - which doesn't help with independence and means that children of parents unable to do this miss out"

PaCC & Amaze Key Points: Better transition planning and more information on what's available. Ongoing support, e.g. support worker, to help young people searching and applying for jobs.

Q6. How do you feel about financial support and benefits for your dependant or young person?			
Carers Centre		PaCC & Amaze	
Information about the welfare system	29% Good	Information about the welfare system	31% Good
Support with claiming benefits in general		Support with claiming benefits in general	
	33% Good		41% Good
Support applying for Universal Credit	5% Good	Support applying for Universal Credit	8% Good

Additional comments / tell us more:

Q 6: Carers Centre survey:

"Please end Universal Credit. If you cared about people, this would be a priority. I fear for my child's future."

"No support for us as parents, we depend on charities like The Carers Centre and Amaze to advise."

"Online support and explanations for DLA is OK. But very long form."

"It has been a nightmare. When DLA was first applied for it was refused and I had to appeal. They say it's needs based and not diagnosis based, but the reality is that it is diagnosis based. As local NHS service failed to diagnose, it wasn't until a 2nd opinion diagnosed that DLA was obtained. When the switch to PIP was made it resulted in a financial loss and it seems to be one appeal after another. The cared for person is unable/unwilling to manage their own finances, so it's all on me. I have had help from Amaze in completing DLA applications before as my own disability

was detrimental in correct completion of the form and DWP ignored the additional comments. From everything I have heard about UC I don't like the sound of it. The whole system is confusing and obstructive."

"My sister is lucky right now and gets the appropriate benefits. They have not been taken away from her at this time."

"Very stressful and often confusing. Professional staff not always interested or helpful. Carers centre factsheet was a good source of information but need more especially when unexpected replies from professionals." These themes were repeated by several responders"

Carers Centre Key points: Information is seen as available but often long and confusing especially as many carers will have to complete forms almost entirely on their own (for the dependant). Charities often a valuable source of information and support but may not be able to deal with technicalities of individual cases. Universal Credit viewed extremely negatively!

Q 5: PaCC & Amaze survey:

"I don't have UC. My son has PIP, it's at a level that does not even cover half of the extra tutoring he has had. The education changes at GCSE were supposed to introduce half GCSES for kids at the lower end, the top end was sorted and the low end forgotten. So now my son cannot progress because he cannot get Maths GCSE"

"Amaze has been so helpful in this area. It means, at least there is one thing I don't have to worry about!"

"The PIP payments and direct payments hardly scratch the surface of 1:1 childcare costs that working parents face for their young adults and the direct payments are suppose to be for allowing parents/carers some respite!!!"

"Again another monstrous battle to secure payments for mobility/ for daily living, reams of forms, documentations endlessly having to be produced to PROVE and JUSTIFY what is a lifelong condition. Disgusted really. And the payments are not enough to live on independently by any means"

"Wish that he had a money advisor to talk too and advise him how to spend wisely"

"Amaze have been fantastic in supporting us with claims we would be lost without them. The benefits themselves aren't enough though and I need to work more which adds more pressure to my daughter"

PaCC & Amaze Key Points: Benefits system is seen as challenging young people on 'proving' why they need benefits. A system that penalises young adults. PIP not covering expenses faced by a family supporting young adult with disability.

Q7. Any other topic or issue that you feel the Learning Disability Strategy should focus on for the next three years?	
Carers Centre	PaCC & Amaze
Support for young adults especially following transition at 18	Private ASD diagnosis and recognition that NHS rules state they cannot be rejected
The Council needs to change its working culture and how it engages with families.	Enforcement of statutory duties arising from Autism Strategy et al.
Get human contact back into the lives of carers and dependents	Stop resisting EHCPs for those kids with multiple needs
Have key workers and pro-active approach rather than reactive	Schooling for kids with autism
Day centres and respite/residential options	When schools use interventions to accommodate the needs of neuro diverse learners, pay more attention to the individual's needs. I know this is a big ask with stretched resources. But to give an example the school gave my son a time out card so if he was overwhelmed he could leave the classroom and go to another room. But what was he supposed to do when he got there? There really needed to be some attention paid to his sensory needs.
Mandatory Autism training for all public facing staff in public bodies	Help for home schoolers
Weight loss	More after college club/activities with 1:1 support and transport
Smoking advice and prevention	Housing: having a choice, not just one provider
Sexual health	Services in schools whilst waiting for CAMHS appointment
Communication training including simple format written information	Encouraging and incentivising employers to take on young people with LDs.
Employment and volunteering options	Post 16 educational provision for students who fit neither the DVLC nor Sussex Downs profile
Access to GPs	Really helping young adults with disabilities
More information and better activities for both children and adults with Learning Disabilities	

about money, employment and how to live in the real world. Work placements to gain experience for disabled people. Helping with volunteering. Paid work network. Post 16 and employability - clearer pathways and better choice/ personalised packages. Work opportunities for adults with learning difficulties and complex needs.

Respite for 18+ year olds

Information and transparency for 18+ year old services

Stop playing lip service to supporting the EHCP 22+ years

Transportation

Gym membership

Classes to learn/activities

Disabled persons bus pass eligibility. I believe if a person is disabled or mentally impaired and qualify for PIP they should qualify for a disabled persons bus pass without the need for further assessments. A bus pass has helped my son so much to improve his independence and therefore self-esteem, but he cannot cope with paying money or interacting with the driver....yet he doesn't qualify for disabled pass although he needs help to travel to unfamiliar places and cannot cope with communicating with driver

Independence training

Specialised ASC practitioners within MH services

Relationships and communication issues

Self-care, body image and self esteem

Proactive and regular contact

The 16 hour offer needs addressing on purely equality grounds

Q8. Please look at the list below and pick the three topics which are the main priorities for you and your dependant or young person

Carers Centre	PaCC & Amaze
1) Financial support and benefits	1) Employment, education, training and volunteering
2) Wellbeing and Mental Health services	2) Wellbeing and Mental Health services
3) GP Services	3) Financial support and benefits
4) Employment, education, training and volunteering	4) Accommodation and housing
5) Accommodation and housing	5) GP Services
6) Physical activities and healthy diet choices	6) Physical activities and healthy diet choices

Additional comments / tell us more from PaCC & Amaze:

“Socialising support and enablement. Recognition of vulnerability of autistics irrespective of IQ. Not cutting parents out of the picture when they turn 16 or 18. SEN Transport for post 16”

“Listening to parents. I have heard too many say everything is a battle. Early help would be best; maybe it would even save precious resources when they are a bit older... If the right help was put in place early on”

“Better support / more of current services being provided ie Outreach / Extratime youth club”

“If the young person has OPPORTUNITIES, in education/ volunteering/training then that immediately boosts their mental health and makes them feel like a member of society. Financial support is essential because it is massively expensive to live with a disability. Accommodation and housing would come next but as there is generally a housing crisis, it is unlikely that adequately staffed and facilitated housing would be achievable in less than a decade”

“Post 22 training and development. Services for day-care and respect for friendship opportunities for young people”

“Our priorities are education, activities generally (not limited to physical), and transportation”

“Disabled bus pass to improve independence as takes away the need to communicate with driver and most importantly, bus driver knows instantly that the person has special needs (not all disabilities are visible). My son won't use the Helping Hand card as it's too obvious he's different but a disabled bus pass is more discreet. We have bought him an annual pass as it gives him independence in areas that he knows well on journeys that we have practised well. Autism specific youth club/ similar events for socialising for young people in their 20's with Asperger as these people have difficulty socialising and communicating so do not necessarily cope best at an ordinary youth club or a PHAB club”

“Support to access services that they need if they leave parental home”

“Independence training and a buddy system for young person to go and w young people do without their parents”

“More opportunities for ASC people to socialise”

“Access to latest technology to assist with condition management could be improved”

“We are in the fortunate position that we as parents can provide financial, practical and emotional support to our daughter”

.....

9) Conclusions from Carers Centre survey:

1. The top priorities of need identified are:

- Financial support and benefits. Forms are confusing and the system is seen as designed to prevent rather than assist
- Wellbeing and Mental Health services
- GP services – communication and access

2. Generally, information is usually seen as more easily available than services themselves but the majority of responders consistently rate the availability of information and services as requiring improvement.

3. Training of staff in public bodies re how to communicate with people with Learning Disabilities and/or Autism is seen as lacking but essential.

10) Conclusions from PaCC and Amaze survey:

1. The top priorities of need identified are:

- Employment, education, training and volunteering
- Wellbeing and Mental Health services
- Financial support and benefits

2. Parent carers ask for improvement on communication from services and access to services. More professionals to support young adults and more awareness of disabilities.

3. More information on what’s available/what to expect and planning around transition.

4. More opportunities for young adults to access activities and be supported to access them.

5. Welfare system that supports young adults, instead of challenging them.