



Activities and services for young people aged 14-25 with Learning Disabilities (LD) – the views of Parent-Carers (April 2023)

As part of the Adult Learning Disability Strategy, Brighton & Hove City Council asked PaCC, The Carer's Centre, and Speak Out carried out a survey collecting information from families, individuals and carers. The aim of the survey was to investigate how activities, services and opportunities for training, voluntary work and employment may have changed before and after the Covid 19 pandemic.

Our survey was sent out in April 2023 to parent carers who have young people with learning disabilities aged 14 to 25, asking them to complete it online. We asked about: activities like clubs, services, plus a few questions about work and college.

Survey Findings

1) About the young people with learning disability:

- Most parents told us that their young people had moderate or severe learning disability
- A few had mild learning disability or profound learning disability
- Most of the young people had challenging behaviour
- Half needed help to get around
- Three used a wheelchair some or all of the time
- All the young people needed help with things like washing, dressing, eating
- Some needed other people to help them all the time
- There was a mix of male and female young people – most were male
- Half of the young people were under 18; half were aged 18-25

2) Activities, services, work and learning

a. Activities:

- Young people were doing a range of activities in 2019 (before the pandemic) as for example

clubs after school or college; holiday clubs; sports; swimming; zoo visits, bowling, days out

- In 2023 they were doing less clubs but more sports and swimming
- Half of the parents told us their young people had less activities in 2023 than in 2019; the others felt things had stayed the same. Most parents thought availability of activities had got worse. A few felt things were the same. None reported things being better now.
- The main reason for young people stopping activities was being 'too old' to continue going,

Other reasons included: not being interested anymore; the activity had stopped running; cost; loss of confidence and not having PA support - *"There's nothing for them to do out of college, can't get a PA been trying for 18 months so there's no weekend or after college activities anymore."*

Parents talked about their young people missing activities they used to do, but for others they needed something new, a parent wrote: *"He is not bothered that we don't go because he out-grew it, but there is nothing for his age group locally and he needs an adult to accompany him."*

- How have things changed?

Parents mainly commented that there were less options now than before the pandemic – particularly once their child turned 18. Parents also talked about their children struggling to take part in what was available as they grew older. A mother said - *"Easter has been the hardest holiday so far. My child is wanting to do more activities but there's no options no funding and mixing with regular children can create many issues. Activities done in 2019 are becoming less possible because my child doesn't want to mix with much younger children."*

- Why do you think things have got worse?

Very limited places - *"Because there is NOTHING for her to do! Two weeks of holiday from college - 2 weeks - and [just] 1 day offered at Extratime holiday club. ONE DAY."*

"Less funding for organisations all round means now we are all scrambling for activities, and all are oversubscribed."

Lack of choice - *"There were not many activities available even in 2019, Extratime is the only club there is for my child which is disappointing not to be able to choose where I'd like to send my child. I'm grateful for Extratime but even they struggle to cater for my child's needs as his interests are limited."*

"We are lucky to be in Brighton at least with voluntary sector organisations like Parable, Carousel etc. However, there is a woeful lack of appropriate day care/holiday provision unless young person happy to attend Grace Eyre. Reliance on volunteers to go to evening activities like Blue Camel or Purple Clubhouse. there is only so long that I can continue doing this for!"

- What would you like to see on offer?

Age-appropriate club with transport; full time holiday club provision; day trips / outings and more sports and leisure: e.g., football club, table tennis, gym sessions; SEND accessible music events; SEN swimming at more suitable times and life skills clubs, like cooking classes - *"Holiday club available for 3 or 4 days out of every 5. My daughter is sociable and needs to see her friends and CANNOT see them ANY OTHER WAY. We are beyond isolated, it feels like we're locked up."*

b. Services:

- What has changed?

Parents talked about using a range of services. A few parents mentioned that their child's anxiety and fear of going outside the home meant they were not getting the services they needed. Parents also told us that things changed a lot when their child became 18 - *"Everything changes when [they] become 18 and we are still on waiting lists almost 18 months later."*

"Absolutely rubbish, especially as they have become an adult and the lack of support, physio, OT services are so different. No regular consultant to oversee all medical issues, as you had with a paediatrician [children's doctor]."

A parent commented that the move to supported living meant that the services provided by their child's school were no longer available. Some things are better – telephone or video consultations, especially when the doctor doesn't need to actually see the child in person. Most parents felt the availability of services had got worse – a few thought things had stayed the same. One parent felt services were better for their young person now.

c. Work:

We asked parents of young people aged 18 or over if their young person was in paid or unpaid work – none were in 2019 nor now in 2023. Of the few parents with young people over 18, most felt work wasn't applicable.

For those parents that did feel work was a possibility for their young person they commented about – *“Lack of job opportunities and feeling that this had got worse, for example, volunteer programmes closed. Their child would need support to be in work and that help had been “cut to the bone”.*

d. Learning and outcomes for young people aged 14-25:

A few parents talked about a lack of teaching assistant support for their young person. Parents expressed concerns over college options with a lack of choice in the city once a young person reaches 16.

For those with severe or profound learning disability parents commented that there is just one option depending on age and stopping around 23 years old. Parents called for provision to be made available to at least age 25.

Those with mild or moderate learning disability: parents commented that there were no suitable options in the city, so young people have to find provision elsewhere.

e. Learning for young people aged 14-25

“[I’m] dismayed that still no provision has been made for one substantially large cohort of young people post 19 [years old].”

“It’s a shame educational placement is not extended to 25. There are very limited alternatives. We have been offered one half day at a day centre but it’s taking ages to get it started.”

What’s going on happen next:

Officers from Brighton & Hove City Council will collate the three organisations’ survey findings and publish a report for the community to read. PaCC have raised concern with officers that the survey response numbers were low and that it is important for the council to recognise that different mechanisms to receive feedback from families must be thought about as families report survey overload and fatigue. PaCC is also looking at different ways to gather parent carer feedback, we recognise that surveys are not the only way to do this.

PaCC hope that this important area of work will influence service providers to provide a more equitable and frequently offered activities and opportunities for adults with a learning disability and also positively impact young people transitioning to adulthood. We will update you with next steps in the Autumn term 2023.