

Listening to the Experiences of Young People with Learning Disabilities and Difficulties when accessing Health and Social Care Services in St Helens.

Report - March 2019

Report produced by the
Healthwatch St Helens Support Team





Background

In January 2019, Healthwatch St Helens were asked to gather experiences from individuals and parents/carers of young people, aged 18 to 25 years with learning difficulties/disabilities.

Colleagues from Children & Young People's Services at St Helens Council wanted to know what young people and their families were experiencing so that they could identify what was working well and where improvements needed to be made. The focus was on the transition between young people's and adult services, in particular.

This work follows on from work we did in the past around access to services across St Helens for people who are on the autism spectrum. This report can be found by visiting: www.healthwatchsthelens.co.uk.

How we engaged with local people

We contacted local schools, support groups and parent carer groups, among others, to ask for people who were willing to share their stories with us to get in touch. We also used our social media channels, monthly newsletter and colleagues at Halton & St Helens Voluntary & Community Action to get the message out there.

Our aim was to gather real life stories from people with both positive and negative experiences of transitioning from young people's to adult services in St Helens.

Over a period of six weeks we received ten stories which we have gathered together in this report to assist the Integrated Children's Health team to understand the challenges that are being faced by young people with learning difficulties/disabilities and their families.

We would like to make it clear that the patient stories included in this report contain the views and opinions of the people who shared their stories with us, not those of staff or volunteers at Healthwatch St Helens. We do not report patient comments as being absolute fact and we fully acknowledge that any patient feedback we include in reports is based on the individual's perception of the service they received.

In the words of local young people and their families...

- **Young person's story 1**

The following experience was told to us by a lady who has a daughter who is 19 years of age. Her daughter has development delay, visual problems, speech difficulties and has problems with mobility. When this lady spoke to us she was quite irate and wanted to voice her concerns.

'There is no information at all about social workers, telephone numbers ... nothing. No one to get in touch with about transitioning. We wouldn't know who to get in touch with, no-one will take responsibility for adulthood. We make all our own health appointments, and have no relationship with our GP. We have been with that surgery for over five years but never see the same GP.'

She went on to say that there were only two transition meetings from Lansbury Bridge to Mill Green, there should be more. She added that there is *'no guidance'*.

She added that provision for post 19 was: *'None - unless your child is capable of going into mainstream. The nearest one to us is Kirkby, which might as well be another country. There are no places available there in any case. Christ knows what we are going to do'*.

- **Young person's story 2**

R is 19 years old and has Down's and autism. He is non-verbal. His parents told us that things were much better when R was a child. At around 15 years of age, everything started to go downhill with R's care. He had speech therapy at Lansbury Bridge, but none at Mill Green.

It was around this time that communication from Social Services became poor. R's dad told us that there have been no health checks at all and there are no reviews or support of any kind. The transition should have taken place in October 2018 and the family are still waiting. He tells us that no social worker was allocated and he heard from another parent that no social workers will be allocated to individuals now; there is a Duty Social Worker, nothing more.

R's dad said he is going to try 'Active8', but no one has contacted him to ask him to look around. He reiterated several times while speaking to us that he is *'just not happy with things'*. He feels that what would improve services for him is for Social Workers and the Council to give more support to families. He explained that he was ill a couple of

weeks prior to speaking with us, and he had no one to look after R; he felt helpless. He also mentioned that he called Direct Payments a few days before and they did not know of him, nor R.

- **Young person's story 3**

J contacted us in response to a letter she received from Mill Green School following our request for experiences of young people 18-25 years and their transition into adult services.

J is a Governor of Mill Green and Lansbury Bridge schools and sits on the Listen for Change steering group. Her son is 18 years old and has Down's. J told us that children's services was a *'whole lot better'* than adult services.

J explains how her son made the transition from child to adult services, then seemed to go back into transition, then back into adult services. *'For someone that doesn't know what I know, it would be a nightmare'*. J ensures that every medical appointment she makes for her son, for example dermatology, is the first appointment of the day, making things much easier regarding transport there.

J has nothing but praise for Whiston Hospital, where her son has had three stays over three years. She worries about the future, as he leaves Mill Green this year and there are only two places available for him, both of which are out of borough. She feels that *'nobody talks to you'* and she would like to see places in St Helens for *'less able young people'*.

- **Young person's story 4**

S has Pierre-Robin syndrome, and has severe disabilities. He is 19 years old. His mother told us that the community paediatrician was *'very hit and miss'*. S has been seen regularly but by different professionals, there is no continuity with Social Services. He had a social worker in the past, but there was poor communication, as they seemed to move into different jobs. *'The rules and regulations between child and adult social workers are poles apart'*.

S's mother went on to tell us that he last had an educational health review at college just before Christmas 2018, but no social worker turned up for this appointment. *'As far as I am concerned that was the most important one, but no one turned up'*.

She said, *'Communication is the key, we really needed help, so I emailed Social Services, we got no reply, I left it for a while and finally someone replied and informed me that they no longer had a*

transitional department. S had gone into adult services, but we had no social worker. We now have a Social Worker, who is newly qualified and unfortunately, does not know the system very well. We felt left in limbo’.

S’ mum added that, although classed as an adult, S is still a child, and every day is stressful, becoming more so, as he gets older. She identified Active8, and Kirkby for when S leaves Mill Green in June 2019, but she said she will need to find funding.

- **Young person’s story 5**

K is now 21 years and has had lots of therapy in the past. She has autism and is a high-functioning young lady. She graduated from college in June 2018 and wanted to pursue a career in healthcare. In order to do this she needed some work to help with her phobia of vomit (emetophobia). K self-referred to Minds Matter on February 2018 and had a prompt consultation. She was told that it may be 3 or 4 months before she got an appointment, and was offered a website link in the meantime.

K’s appointment was on 8th August 2018. After two sessions, her therapist announced that K needed a therapist more experienced than him, and so he would need to put K back on the waiting list.

A new appointment came through for 4th October 2018. K found her new therapist easy to talk to and felt a good connection with her. After four sessions with her, K felt that she was ‘actually getting somewhere’. On the 12th October, which was classed as a ‘review session’, K told us that her therapist said, *‘you keep contradicting yourself’*. K explained that she did not understand what she meant and believed that the therapist was annoyed with her. The therapist added, *‘you are not doing your relaxation techniques and so the therapy will not work’*. K told us that she had felt she was moving forward, and got upset. She reports feeling totally shocked to be told that she needed to go home and think about her behaviour over Christmas. She asked the therapist for examples of what she meant but she wasn’t given an answer.

K’s next appointment was for the 2nd January 2019 and the therapist told her that she was being re-assigned to another therapist. She told her that she had thought about what she had said but still did not understand what the issue was. The therapist implied that she was annoyed at the fact that she had given K a piece of information that K had challenged. She was told that the therapist felt that *‘I wasn’t “opening up” and that I didn’t trust her’*.

The therapist hugged K and said *'good luck'*. K was sent a text from her, informing her that she would be speaking to her manager about transferring K to another therapist and that she would be placed back onto the waiting list.

- **Young person's story 6**

M and his wife are foster carers for a young lady who is now 18 years old. M said that the family has had a positive experience so far with children's services. There were no problems with communication and she has a dedicated social worker, who is *'really good'* and they have called upon her for help several times. M's foster daughter is being transferred to PSS. This should have happened in September 2018, but they are still waiting and have been told it would be February 2019 before their case goes to the panel. M said it has been such a long drawn out process, he wishes she could just stay at Mill Green.

- **Young person's story 7**

K is now 25 years old. When she became 18, her mother tells us that she felt like they had *'fallen off the face of the earth.'*

K's mum said that lots was done for her daughter before she reached adulthood, but afterwards if the parent is *'not on the ball, it's easy to fall off the radar, there is nothing at all after 18. We were left high and dry.'*

She had to contact podiatry, audiology, ENT, epilepsy services and continence services to continue care for K. She said that the family was *'thrown out of Alder Hey'* and she has had a GP put his hand in front of her face to stop her talking, saying they wanted to speak to K (who did not understand what was being asked of her).

Around 18 months ago, K needed surgery on her ears, she was frightened so would not give consent. Her mum tried to give her consent, as she was aware how much the operation was needed, but as K was an adult, she needed to give consent. In the end they both signed consent forms and the operation was then *'put back'* because K's epilepsy was not controlled; that needed to be investigated and brought under control.

K's mum now has a portfolio that she includes every piece of correspondence she receives about K's care. She does this because she has *'lost count'* of the amount of times that an appointment has been cut short because a Consultant did not have a copy of a certain report.

She ensures she now has everything with her. *‘There is absolutely no communication between services’.*

With regard to annual health checks, *‘things have not improved over the years, and the health checks are over in a couple of minutes, they are meaningless. It’s just lip service’.*

With regard to what might make transition smoother, *‘they need to not make you feel that you have been thrown off a cliff, and parents to be made aware of services.’*

- **Young person’s story 8**

‘I have to say this is not a good experience’. Initially, we were told we would be transferred by my daughter’s 18th birthday. This was delayed as there wasn’t a social worker available to take our case. The children with disability team were told we would stay with them until she was 25, with a possibility of transferring over if it was suitable. At this time, we were told we needed a social worker, not a family support worker, who we had had for a number of years and was brilliant.

The social worker came to meet us and attended a review meeting with a promise of a call the next day. That was on the 4th July 2018. To this date, I have had no phone call.

‘January 2019, I rang the social worker to be told we had been transferred over to adults and I needed to ring them. They did find me a number to call. Upon ringing adult social services was advised that we haven’t yet been allocated a social worker and we are sitting in the transitional team and they couldn’t give me a date when we would be allocated a social worker. Given that my daughter is in her final year at Mill Green and provision for September needs to be arranged, the whole service is shocking. It is adding more stress onto what is already a stressful time trying to find a suitable provision for September.

Improvements: ‘Keep families informed. I found out by chance that we were no longer under the children’s disability team. Don’t transfer families without having a contact name or number’.

- **Young person’s story 9**

P rang with her experience of her son, O. O is 19 years old and has learning disabilities. P can’t remember the last time Social Services were involved. She said someone rang to arrange to attend an appointment, but didn’t show up.

'This is O's last year in Mill Green and we thought someone would ring us and let us know what will be happening.....nothing at all. I have rang Social Services numerous times, and have been spoken to abruptly on occasions, being passed from pillar to post. We get told that no one knows who is dealing with us. I know of the CDP, but that's it. O has not been seen by a specialist or paediatrician for years and years. He has a yearly GP check, but that's it. No-one knows what anyone else is doing.'

Improvements: *'Give families a dedicated worker that knows what they are doing.'*

- **Young person's story 10**

A is 22, she has left Mill Green School and is currently in her 3rd year at Active8. Her mum, R, explained that she felt that health professionals can be unrealistic of what they expect of A and R sometimes feels that the professionals don't think that R is acting in A's best interests. R said she knows A better than anyone and she just has a 'gut feeling' about this.

Ruth also told us that she has to keep 'a really close eye' on appointments, as they seem to get further and further apart. They can be told that this is 'the last time at Alder Hey', then they get another appointment through, it's very unplanned. R appreciates that there is 'more work, but less people' and said, 'I feel like a manager, not a mum'.

R finds it hard to deal with so many people regarding A and it would be so nice to have someone to help out. They now have a new Social Worker, who has been off sick for the last two scheduled appointments, so R cannot comment on how this is working out for her family at the moment.

R has 'nothing but praise for the GPs at Garswood Surgery, they do everything to include me, I feel like an equal'.

Improvements: *'Instead of them saying we are going to work together - DO IT'.*

Conclusion

We have been able to conclude, from the stories and experiences that we collected, that communication appears to be poor between teams and local people still feel that they are left waiting around for information or for a professional to contact them around the young person's future support.

Healthwatch St Helens acknowledges that there have been a lot of changes to services for people with learning disabilities and difficulties in St Helens, not least the introduction of the neurodevelopment pathway. This appears to have addressed many of the difficulties that young people waiting for a diagnosis were experiencing, and the biggest challenge still seems to be getting the transition right, from Young People's Services to Adult Services.

The experiences gathered for this report were sent to Sharon Fryer (Assistant Director Integrated Children's Health) and Julie Hoodless (Designated Clinical Officer for Special Educational Needs and Disabilities).

Outcome

Initially, the plan was to share this report with the cohort of professionals working with this client group at the "Preparing for Adulthood" (PFA) workshop. However, it was decided that it would be more beneficial for training in PFA to be provided for clinicians working with this group of people.

Healthwatch St Helens request to be kept informed on any actions that have come from the stories we collected and of any future plans to improve services, particular around transition, for young people in our borough.

We would like to thank everybody who put us in touch with local young people and their families and who shared a story with us and enabled us to produce this report.
