

Engagement with people with lived experience

Tuesday 13th – Monday 19th September 2016

Purpose

In order to develop services for people with Learning Disabilities and/or Autism in Birmingham, the Birmingham Transforming Care Partnership engaged The Weaver & Young Foundation to work with families who have lived experience to inform the new service model development. The engagement exercise, facilitated by Vickey Weaver and Cathy Dale, took place in various locations due to the sensitive situations the families have found themselves in. Seven parents with lived experience were initially approached by The Weaver & Young Foundation and all agreed and expressed their willingness to partake. Unfortunately, due to the unpredictable circumstances, three of the parents were unable to attend at short notice. Three parents were recruited through The Transforming Care Team, unfortunately just one parent attended. The engagement exercise gleaned a huge amount of information, with both negative and positive feedback.

Method

Parents were recruited for this engagement exercise from a support network already established. Some parents agreed to meet as a group and a couple of the parents requested one to one engagement either through circumstance or the need/preference to speak alone. Four parents agreed to a group session, due to circumstances only two parents were able to attend. Two parents were consulted on a one-to-one basis. Another group of parents were recruited through The Transforming Care Team; these parents had completed the information cards asking to become involved in engagement processes.

People with Lived Experience - Summary

1. Mother of a young man age 16 years old with LD/ASD and behaviours that challenge which can be extreme at times. This young man lives in a specialist educational provision out of Birmingham, he has lived away from home since he was 8 years old due to behaviours that challenge. With a huge amount of support, this young man visits home for an afternoon a month, parents visit his provision every week but are unable to take him offsite alone anymore. He is recognised as a 'Looked After Child' and this process is followed by the Local Authority.
2. Mother of a young man age 14 years old with ASD/ADHD and behaviours that challenge which can be extreme at times. This young man lives in a step down provision out of Birmingham, he was "blue lighted" at the age of 13 despite 20 referrals by the parents to MASH, no interventions were put in place until he was sectioned and admitted to an Assessment and Treatment Unit in Cheshire for 3 months. He returned home with no ongoing support and this subsequently resulted in a further crisis and him being sectioned again and admitted to his current step down provision. Prior to his section he had been out of education for 5 months. His education provision has now been identified near to the step down provision, however this raises concerns as to how this young man can make a successful transition back home. He is now recognized as a 'Looked After Child' and this process is followed by the Local Authority.
3. Parent 3 – Mother of a young lady approaching 18 years old with LD/ASD and behaviours that challenge which at times are extreme. She attends a residential school out of Birmingham. Mom is now preparing for transition from child to adult services and a CHC assessment is now being progressed. This young lady also has complex health needs, presently there appears to be no provision locally that will be able to meet her support and education needs when she leaves school and will continue to be living out of Birmingham. She will be seen as a 'Looked After Child' until her 18th birthday.
4. Mother of a 29-year-old woman with Prader-Willi Syndrome living in a residential provision out of Birmingham, this current provision has been home for the last 9 years following residential college. This young woman would like to move nearer to Birmingham to strengthen her relationships with her family.

Work is ongoing with the Local Authority to facilitate this. This young lady was joint solutions funded 9 years ago.

5. Mother of a 12-year-old boy with ASD and some behaviours that challenge living at home, attends a specialist educational provision in Birmingham. He has just started his second academic year at school and mom is already worrying about and planning for transition.
6. 3 parents with lived experience were unable to attend.
7. 2 parents who indicated they would attend via The Transforming Care Team did not attend the session.

Parents had many questions about Transforming Care, the introductory information in the presentation generated much discussion and comments about the wider issues that parents felt would need to be a consideration in Transforming Care. To capture all feedback therefore the engagement is reported in two sections. A key bullet point section focuses on the draft models and the following section shares comments made in relation to other areas for consideration which have been collated and reported under subheadings including quotations from the families.

Key Points for each draft Model

Parents were aware that the engagement exercise was intended to gather thoughts and views from 'experts' prior to the final models being agreed. However parents found it difficult to understand how the statements made in relation to each model might look in practice so there were many more questions than comments about the models.

Parents agreed with the gaps and felt that in order to achieve new models of care, the following points needed to be considered to achieve the outcomes intended.

Children and Young People's Model

Crisis support, planning and prevention:

- Describe how the **Seven Day Crisis Support Service** will support the young person to stay in education and involve other agencies not just the individual and their family
- Clarity in the Model as to who is who and what they do for each agency involved. Describe at what point it gets escalated to the **Crisis Support Service** and by whom
- A description of how agencies will work together to deliver person and family centred outcomes so that non crisis time is kept at the forefront of decision making to support **Planning and Prevention**.
- To include **overnight respite** that can meet the needs of the children and young people and give parents and other siblings a break - not simply an advice service that is home focused to support **Planning and Prevention**
- To link to Education, Health and Care Plans to support Planning and Prevention across agencies.

Provide support/education to families to manage complex and or behaviours that challenge

- Describe what levels of behaviours are acceptable for families to experience. Some guidance needs to be included to ensure a consistency in supporting families and their access to support.
- Acknowledge the "physical violence" that many families and in particular mothers experience.
- Upskilling of all professionals and providers also to ensure that education & other placements do not fail. More pressure is put on families if school keep contacting them as they can't manage the behaviour in school.
- All support that the child/young person and their family need should to be included in EHC Plan.

Review inpatient placements and support discharge

- Work closely with education providers in Birmingham to ensure a local school provision is available to support a successful discharge and transition home

- Include highly skilled professionals who understand Learning Disabilities and Autism to support a successful discharge in a timely way linking with the young person at home and at school.
- To ensure an EHC Plan in place or updated if already in place.

Both Models need to link – to ensure that there are no gaps in provision during transition.

Good Transition Planning needs:

- A timely link/process between the two models so that young people do not fall through the gap into adulthood and then require impatient care.
- Multi-agency communication to understand what provision young people need as adults in good time to inform adult model of provision.
- To update the EHC Plan that supports the young person up to the age of 25, consideration needed in both models as to how this happens for young people in these circumstances.

Adult Model

4 out of the 5 families we spoke to were parents of young people not adults.

All families agreed with gaps and the changes described but felt the following needed to be considered:

Positive intensive support

- Describe how it will ensure communication with Social Care, Housing Providers, Police, Paramedics, Third Sector and families who support in non-crisis times and identify when the person is becoming unwell.
- Clarity in Model as to who is who and what they do to support the individual and their families/carer and for each partner agency to see how they work together to support individuals to stay well.

Forensic Support – an explanation was needed as to what this was and who it was for. Agreement was that this was essential and needed to be robust.

Community Hubs

- It was unclear what the purpose of the Community Hubs was and therefore a number of queries were identified:
- What will be their purpose? Is it a social provision for people to attend, does it include accommodation? Parents felt the term implied a drop in provision so needed more information regarding purpose and design.
- How would people access this and who could refer.
- What links will there be with those supporting individual to stay well such as families, housing provider, social care and Third Sector.

Hospital Avoidance Suite

- 4 beds in a city the size of Birmingham seem insufficient.
- 24 hours to manage a crisis seems too little time.
- What happens if crisis is not managed?

There was a general sense of fear for parents of younger people that the adult model seemed rather fragile to manage the complex situations that present to the individual and the families. Families want to be supported to manage their family members but need the right support to do this.

Summary of discussions collated under themed headings

Strengthen Links and Communication with other agencies

Communication between all agencies is necessary for both models to develop person centred services and a meaningful life. Health, Social Care, Education, Housing Providers and Third Sector need to work together to support both models.

Understanding who is who and what they do across agencies was a key issue for people, having the information about what services were available in advance of a crisis situation and how agencies work together to support this.

Finding the right educational provision for these young people is the biggest challenge. More involvement from health would be appropriate as many parents have no input from health when working through an Education and Health Care Plan (EHCP). Parents of young people placed in a Residential School Provision did not know that this was funded by Health, Social Care and Education together as placement is not reviewed by a health professional.

Agencies working together to develop support services was identified as a need, having overnight and other short breaks that could meet the needs of the children and young people who displayed behaviours that challenge.

Many parents especially all the mothers we spoke to have had experience of what can only be described as Domestic Violence from their children, some starting at a very young age. Agencies need to work together to provide holistic support both within education settings and other services to support the Family to keep close connections to their loved one, to be safe themselves and for other siblings. One mom told us of her fear for a long time that her child would hurt his sibling and then that child would be taken away and she would have to manage the behaviour of the child she needed support with.

Transition Planning is vital

Planning in a holistic person-centred and joined up way to ensure people do not fall between the gaps is essential, the EHC plan for young people currently in education should facilitate this.

For those young people who are continuing to develop their skills, further education is of great importance to parents, there has been a lack of information and support about Transition Planning and whose responsibility it is and this means trust has become an issue for parents.

Good Transition Planning will inform the adult model and what provision we need locally to support young people who face challenges into adulthood. One mom said “How do you plan for the future when your child is out of area”, “why do I have to travel 2 hours to look at provision that might meet my daughters needs in the future? Why do we not have this type of provision in the City the size of Birmingham?”

The question also asked was do we not know how many young people we are planning for, can we not count how many young people are currently out of Birmingham and plan to prevent need for in patient provision in crisis.

Education and Training

A significant number of children and young people start their journey out of Birmingham due to the lack of the right education locally. This links to early support and intervention also. An EHCP stays with a young person until they are 25 years old and covers both models. The skills and expertise of staff in Birmingham need to be developed to support these children and young people. Parents identified these points and their concern over the lack of suitable provision in Birmingham.

Parents wanted specific services for people with Autism and those working with them must have appropriate training. Remembering that every person is an individual with different needs. This is particularly relevant when provision is provided by independent providers, also that there should not be an over-reliance on this.

Prevention

Early intervention is required, many parents struggle with many different situations and with early intervention and support, some young people and adults may have a very different outcome and could possibly still be living within their community.

Parents are fearful and are often let down by the system. Many of the families are experts and would embrace working with the system and agencies instead of having to fight it and them.

Having services locally that can meet the needs of the individual and support their families to continue to support them is essential. Agencies need to work together to deliver this.

Transparency is key and understanding that the parents are the experts on their child. One mom said about her son's inpatient care that staff "only see a snapshot of the child (age 13) did not ask parents or find out about our child" This young man was sectioned twice as he was sent home without an appropriate package of support and is now a 'Looked After Child'.

What does good look like?

Parents were keen to know what 'success and good' would look like, how it would be measured and by who. The question was raised again that if we are sending children and young people out of Birmingham why are we not looking at what these settings are doing well and trying to replicate them in Birmingham.

Parents wanted to know what the vision was for future care services and felt then it would be good to work back to where we are at now and plan how to get there.

Parents were concerned about the over reliance on Independent Providers and who they are and how they are monitored. Those parents who have spoken with or have experience of Independent Providers felt there was a lack of real expertise and skills within the workforce, two parents commented that there seemed to be more of a focus on how it looked rather than the skills of staff and the services that were being delivered.

Working together to make change - work in partnership with parents across all aspects of both models.

Parental involvement in this engagement was welcomed and appreciated. On-going engagement will need to be bespoke, as parents face many challenges but would like to be consulted on changes to the current system. Engaging with parents with lived experience would need to be extremely sensitive. Parents with children that are looked after are disconnected from other parents of children with disabilities and have a very different lifestyle and set of needs.

There is a lot of fear amongst families who often feel let down by the system when it comes to the care of their loved one. Parents want to know the truth about how difficult it is going to be, they feel very strongly that they are the experts on their child not service providers. Parents of young people with challenging needs that will need highly resourced provision in the future are aware of the challenges their child brings to others, they are fearful every day that an incident may occur that may result in them needing to move to more secure provision.

Parents want to work in partnership to make a difference.

Conclusion

Involving parents and the wider family is a must; one parent told us "involving parents is essential for a good outcome". Parents feel positive that Transforming Care is happening and that there is a recognition that there are problems and gaps with the current systems and processes. There is recognition that this is a huge responsibility but the significance of getting it right for the individual, is massive for the whole family. As one mom said "you don't have children to give them away". Parents want transparency and to be treated on an equal footing - one mom said "I know how expensive my son's support is and I worry how it will continue at such a cost and who will deliver this".



for people with learning disabilities and autism in Birmingham

Parents want to use collective expertise (yours and theirs) to inform provision for Birmingham children, young people and adults and not be reliant on the Independent Sector. To do this will take time and effort to ensure that the diverse and often complex situations people with lived experience find themselves in can be understood and engagement adapted accordingly. The engagement process has also identified that an ongoing conversation would be beneficial rather than adhoc engagement with families who might be new to the Transforming Care Programme.

To engage in a meaningful and productive way with a parent with lived experience, sensitivity is needed to understand their circumstance and respect how different they feel from other parent/carers. Some parents have already faced the stigma first hand from other carers because they were unable to continue to support their child at home. All the parents we spoke to wanted to keep their child at home and go to great lengths to have a meaningful relationship with them which is made more difficult by distance. The journey for all the parents we spoke to is lifelong.

Vickey Weaver & Cathy Dale

On behalf of

The Weaver & Young Foundation C.I.C.