

## Expert Parent Programme: Complex Health Needs Evaluation

### Methodology

In October 2020, the lead trainers for the Expert Parent Programme Complex Health Needs workshops contacted all previous attendees and invited them to participate in a 1:1 in-depth phone call, to discuss the impact of attending the workshops. This was in place of the originally planned focus groups, and 8 attendees took up the offer.

The calls were conducted by one of the trainers, as it was felt that a familiar voice would put the respondents at ease and support them to respond honestly. While we recognise the bias that this may incur, the trainer followed the same topic guide as was developed for the focus group, to minimise influence on the respondent.

The calls were recorded, with the respondents' consent, and the raw data submitted to the National Children's Bureau (NCB)'s Research team for analysis. This analysis is included below.

### Respondents

Sample: Eight

Age: 35-44 x two, 45-54 x six

Relationship: All were the young person's mother

#### 1. Summary of key themes

##### 1.1 Sharing with other families

Interviewees noted how positive it was to share with and hear from other parents who had had similar experiences. Even when their experiences were not exactly the same, it was helpful for them to hear about other families' struggles because it helped them to feel less alone in their own difficulties. It was also noted that the facilitators were able to create a comfortable environment for people meeting for the first time and covering difficult, personal topics and experiences.

*'You know, after 20 years of being a parent, living in this world, and managing the life of a child with complex care and attending many different courses and webinars, that*

*is one of the only few ones that makes me stand up and take notice, and be reminded of what's important. It is just something about the content, and again, the way it's delivered by real humans living the real life, that we all do. I just think there's something about that really connects; it clicks, it just makes it... It speaks sense.'*

### 1.2 Better understanding of legislation

Parents felt they developed a greater understanding of the law and entitlements for young people with disabilities and complex needs.

*'It raised my awareness of the legal situation, I think when it comes to parents with their children and young people with disabilities and complex health needs, I think it's the legal side of it which is unknown, and having some clarity in that is really, really helpful.'*

One parent went on to challenge her local authority with a formal complaint as she learned that they had not met their legal requirements in supporting her daughter. She noted that she had information about the Equality Act which gave her the confidence to challenge and gain a greater understanding of her daughter's legal rights.

### 1.3 How to approach professionals

The interviewees felt the training had equipped them with the knowledge and skills to approach professionals and advocate on behalf of their child. They had previously had negative experiences of professionals not taking their concerns seriously as a parent. Since the training, they felt they were able to use language with professionals in a way that leads to them being taken more seriously. They reported feeling a lot more confident going in to conversations and meetings with professionals.

*'You actually came out of there and felt, wow, this is real. There is something out there where we can get help and we can learn from each other, almost like having another voice to help you to be more assertive with professionals, shall I say?!'*

They also found that they learnt how to gather evidence before meetings and, more specifically, the kinds of evidence that would be helpful for supporting their young person.

Having more confidence in their interactions with professionals led to direct improvements in the care being received by their child, for example better annual health checks with the GP practice. Parents also reported their child feeling more able to advocate for their own needs in response to their parents' learning and newfound confidence.

### 1.4 Parental mental health improved

Parents reported their mental health had improved as a result of the learning from the training. They felt less anxious about the future because they had a clear idea of what was to come and felt more prepared.

*'I felt encouraged and positive that I knew I was in a better place than I was before the beginning of the workshop. Yes, about lots of different things. Yes, it didn't feel so bleak and so difficult.'*

Parents noted they felt heard at the workshop and felt more confident in themselves.

### 1.5 Impact of Covid-19 pandemic

Parents noted that the pandemic had led to disruptions for transitions and planning for transitions. This was causing considerable stress for some families.

*'We're still not sure how we transition to the adult years because COVID-19, the lockdown came in, so everything stopped. Our son will be 18 in April next year, so we're very stressed about this process.'*

## **2. Feedback on content**

As already evident from the first section, parents reported overwhelmingly positive comments about the training. In terms of specific feedback, this is a summary of the comments on content, handouts and length of the session:

- The handouts were useful. Some would have liked the paper handouts to be available online too.
- Some noted they would really appreciate a refresher training to go back to some of the issues covered on the day.
- Some felt slightly overwhelmed with information and thought better to spread the training out over two days.
- The pink and blue exercise and case studies were referred to as being particularly helpful.
- One parent mentioned it would be useful to do a pre-course survey of parents to check levels of background knowledge on the issues.
- One parent mentioned they would have liked the training to include some specifics on the Mental Health Act.
- The trainers having first hand experience was very helpful.

