

PACC In Touch Transition Course – Sept 2021

We know that supporting a young person with Learning Disabilities or Autism can be challenging at times. Young people who have difficulties with communication and understanding can significantly impact family life and even the simplest family activity can become difficult.

We also know that these young people can develop behaviours that are difficult to manage, which can become more of an issue as they grow and can result in a poorer quality of life in adulthood. Living with both behaviours that challenge and worries about the future can be difficult for parent carers of young people with learning disabilities or autism, resulting in feeling isolated and a sense that they are failing as parents. Receiving the right support and advice is essential and can make a big difference to both the experience of parent carers and the outcomes for young people with learning disabilities or autism. This is why, with funding from Shropshire Clinical Commissioning Group, PACC developed the 'In Touch' Transition course, which we are offering to parent carers of young people with a learning disability or autism aged 13-25 years.

'In Touch' aims to provide parent carers of young people with learning disabilities or autism with an opportunity to talk with others who understand their family life, to share experiences and to know that they are not alone. It will also provide specialist advice from practitioners who understand the impact of behaviours that challenge and the importance of supporting families in their caring role.

Every other session focuses on a particular theme, which enables parent carers to develop the skills and knowledge to reduce the impact of these behaviours and to plan positively for the future. The sessions in between the advice sessions take the form of a facilitated chat, led by PACC, providing a chance to talk about the themes covered in previous sessions or for participants to share how they are feeling or any worries they may have.

This course was offered online, based on PACC's experience of moving to digital support during the Covid Pandemic, when it has become clear that the flexibility of digital delivery enables more parent carers to participate in our activities. As part of the course the participants were asked about their preference for either face to face or digital delivery and every parent carer participating said that if the course had been delivered face to face, they would not have been able to attend.

Details of sessions

1. Introduction Chat
2. Behaviour as communication- an introduction to understanding why behaviours of concern happen, what keeps them going and how to make sense of them - Dr Steve Farmer – Clinical Psychologist, CAMHS LD Team
3. Chat session

4. Introducing Positive Behaviour Support (PBS). Some demystifying of the myths around this approach and taking first steps towards using PBS as a means to improve everyone's quality of life - Dr Steve Farmer – Clinical Psychologist, CAMHS LD Team
5. Chat session
6. Planning with your young person: a person-centred approach. Christine Towers (Together Matters) will introduce the 'Thinking Ahead' guides and the use of personcentred tools to think about what helps things to go well and what can cause things to go wrong in your young person's life. <https://www.togetharmatters.org.uk/>
7. Chat session
8. Planning for changes and possible emergencies. Christine will talk about building a support network for yourself and your young person to help with planning, making choices, finding opportunities and putting things in place in case of emergencies.
9. Chat session
10. Planning for health and well-being. Christine will talk about using Annual Health Checks, Health Action Plans, Hospital Passports and other resources to help your young person get support to be healthy.
11. Final review session
12. Follow up session

It is intended that this model can also be used for other age groups, with advice covering appropriate topics for that stage of the parent carer journey.

Details of Participants

13 parent carers attended across the 12 weeks

It was important that we were flexible about attendance since parent carers had frequent additional demands on their time; appointments, children off school, work commitments, transporting their young adult with additional needs to activities and in one case supporting a terminally ill family member.

Each session had an average of 10 parent carers in attendance.

The age range of young people cared for was between 12 years and 22 years, all were either learning disabled or autistic, but there was a mixture of experience of specialist and mainstream schools represented. All the parents identified behaviours of concern and some parent carers spoke about experiencing very challenging situations with their young people that included aggressive behaviour.

Participants completed a pre course questionnaire where they were asked for the following information;

- Brief introduction to your child, including strengths and difficulties, how these impact on your home/family life:
- What are you hoping to get from the course?

- Any particular topics that you want to discuss?

Summary of responses

- **Brief introduction to your child, including strengths and difficulties, how these impact on your home/family life:**

Responses included difficulties with social situations limiting opportunities and family interaction, family routine and activity being dominated by the needs of the young person with SEND, sensory issues and difficulties with change limiting opportunities and independence of the young person. The difficulties in finding suitable activities for the young person with SEND was also identified as a concern. For the parent carers of young people with autism only, anxiety leading to aggression was also identified as part of family life.

- **What are you hoping to get from the course?**

Having the right information was a key theme identified by parent carers, especially to be able to plan for the future and emergency situations such as hospital admissions. Enabling young people to reach their potential and lead full and meaningful lives was frequently mentioned, as well as being able to lessen the negative impact on the wider family.

- **Any particular topics that you want to discuss?**

Post 16 options was a big area where families felt they needed more information along with a wish to 'understand' the system and what they need to do to support their young people effectively. Managing the impact of adolescence and puberty and knowing what options there are post school/college was also identified as something that families wanted to understand more about, along with developing social networks and making and maintaining relationships.

Summary of Issues Identified in Introductory Session

- **Post 16 "*Post 16 is a bit of a mystery!*"** - What school support is available? What does an EHCP look like and deliver post 16? What opportunities are out there and how do people find out about them?
- **Vulnerability of young people in society** – parent carers are understandably concerned about their child's future – what will happen to them as adults, how can they step back and enable a young person to be independent, while staying safe?
- **Understanding emotions/social cues** – there were concerns about the fact that young people don't always read situations correctly or respond appropriately and that this makes them vulnerable – what can parent carers do to limit the impact of this?

- **Masking** – making sure that other people understand that the young person is at times able to mask their difficulties – it doesn't mean that they have gone away
- **Anxiety** – the impact of anxiety was mentioned repeatedly – how do we get others to understand a young person's anxiety is real, how can we build a young person's confidence and reduce their anxiety?
- **Gaining work experience & life experience / living to potential** – How do parent carers support young people to have a meaningful life as adults? *"The system seems to offer so little."*
- **Appropriate activities that suit ability / appeal to interests** – Again repeatedly parent carers talk about a lack of suitable activities and social opportunities for their young people. There was a recognition that these sort of activities play such an important role in the development of neurotypical young people and their journey into adulthood and that same opportunity is not available for young people with learning disabilities and / or autism
- **Meltdowns and aggression / managing behaviour of concern** – there were a number of parent carers who were clearly living in quite challenging situations. Situations where there was a significant level of violence and controlling behaviour being exhibited. What stood out particularly was that in all these situations there was either no support / interventions being offered or contact with the system had not been effective.
- **Sibling support / young carers** – the impact on siblings was raised a number of times
- **Looking after ourselves as parent carers** – a number of parent carers were clearly struggling and felt overwhelmed by their situation. There was a sense in the group that what they were dealing with was inevitable and nobody could see how it would change. Parent carers clearly felt that the idea of looking after themselves was a nice thought but un realistic/achievable.
- **PA support / finding additional support was difficult on a number of levels** - Firstly some parent carers didn't know that this might be an option or how to request it, secondly those that had secured direct payments talked about the difficulty in finding suitable PA's

Feedback On the Course

'Thanks so much for Tuesday's meeting it was nice to feel less alone. I do struggle with confidence especially with people I don't know'

'I just wanted to say thank you for your invite to the "In-touch" group yesterday. I'm embarrassed for getting so upset in the call, so thank you for your reassurances that I belong in the group!'

'Useful for knowing rights and what questions to ask'.

'The course has been very useful, nice to be in contact and not feel so isolated'.

'I found it helpful with behaviour that is challenging, to look at triggers and to have tools for this. Particularly to then be able to speak to school to communicate that xxx is not naughty. So, when xxx was struggling this has given me the language to speak on my child's behalf. Also, to know that behaviour like being sat under the table could be anxiety'.

'It helped me to get on the case to check with GP that xxx was on their Learning Disability Register so that reasonable adjustments can be made and to get an annual health check'.

The course has 'given me different words to use and confidence and this has helped to pull these together to say what xxx wants, his voice. Also using the tools to help build up an evidence base'.

'The language learned from the course has been a powerful tool and using these tools verbally has helped xxx with choices.'

'I feel that the system undermines both parents and young people, however being able to use the right words in the system helps and having a voice is important.'

'The session also made me reflect on other behaviours my other children have had in the past and how I respond and my own behaviour – lots of food for thought!'

'The course is very interesting, and I wish that it had been part of my teacher training, especially the dimensional model of challenging behaviour which clearly shows the reduction that children with disabilities experience in this model and understanding the importance of environmental/external factors on behaviour. From experience I have had an insight into triggers of BoC but having tools like the ABC chart will really help unpick each situation and help understand it more clearly and a good resource to refer to when discussing with professionals to get support.'

'Thanks so much I really enjoyed it. Some of the things I had encountered before but never had them explained like that - like the ABC chart, we were told you write the cause, the behaviour and our response but we rarely know the cause so it was impossible to fill in! Now I understand it better we can start to use them for the benefit of us all.'

Sarah Thomas

PACC