

## **CYGNET 2018-19, Summary and Evaluation**

**Swindon Educational Psychology Service, May 2020**

### **1. What is CYGNET?**

Cygnnet is a licenced Barnardo's parenting support programme for parents and carers of children/young people aged 5-18 who are awaiting or have a diagnosis of Autistic Spectrum Condition (ASC). It was developed to follow on from the Early Bird course for parents and carers of pre-school aged children. The course aims to facilitate understanding of ASC and provide a much needed support network for parents. Research suggests the programme can significantly improve parent perceptions of competency (Stuttard et al., 2016).

The support programme was first developed in the Bradford area by looking at existing parent training groups, examining research findings, a pilot training group and from consultations with parents/carers and professionals. The original six session course focuses on developing a practical understanding of behaviour, what might be underlying it and supportive interventions. This course was updated in 2017. There are now a number of supplementary sessions, these include, Supporting Black and Minority Ethnic (BME) families, Supporting siblings and Puberty, Sexual Wellbeing and Relationship (PSE) support. Further information about the Cygnnet course can be found at the following website: <https://barnardos-parenting.org.uk/cygnnet-programme/>

The Barnardo's Cygnnet programme is delivered in a group format by two trainers or facilitators. Each session is designed to help parents/carers examine a specific area (such as diagnosis, social communication, sensory issues and then apply their new understanding to explore and generate different ways of supporting children). The licence agreement stipulates that trainers should have knowledge of ASC and sufficient facilitation skills.

### **2. Why was CYGNET set up in Swindon?**

Nationally research suggest that the diagnostic process can be stressful and that post-diagnosis support for parents can be limited (Crane et al, 2016). Therefore, in Swindon the Cygnnet programme is commissioned by Swindon Borough Council Clinical Commissioning Group to support parents to navigate their post diagnosis journey. It was first commissioned over six years ago in recognition of the ongoing support that many parents desired following diagnosis.

Currently Swindon Educational Psychology Service are commissioned to deliver 2 courses each academic year.

### **3. How is it organised?**

Swindon Educational Psychology Service provide a programme of eight sessions facilitated by two Educational Psychologists (EPs). This includes the six original sessions and then two sessions from the Puberty, Sexual Wellbeing and Relationship (PSE) scheme. Sessions take place weekly during term time in community hubs and last approximately 2.5 hours. Refreshments are provided and a comfort break planned into each session. Participants are provided with session handouts and activities at the start of each set of sessions. This enables them to prepare in advance and/or take notes during each session.

To support the aims that underlie the programme it is delivered in a group format with a focus on sharing psychology accessibly along with opportunities for group discussions and experiential learning. The course materials and facilitators strive to create an inclusive and supportive learning environment where barriers to learning for participants are acknowledged and removed.

#### **4. What is the feedback from parents/carers attending?**

Currently both quantitative (numerical) and qualitative (descriptive) feedback is sought from participants at the end of each session. This is used to evaluate the quality of delivery and impact of the programme. Consideration is also given to how feedback can be used to adapt the programme to meet the needs of participant within the confines of the licencing agreement.

Below are data gathered from feedback collected from 3 courses run between 2018 and 2019.

##### **a) Qualitative feedback:**

A brief thematic analysis has been undertaken to organise feedback into key themes. Quotes from participants have been used to illustrate themes.

#### **Theme 1 – Sharing and applying psychology to understand and support behaviour change**

*A real 'Lightbulb' moment to find out that children can be both under-sensitive and over-sensitive in terms of sensory issues. Also that these can change over time.*

*Strategies were helpful - Megan's mum's colours were adaptable (reference to a video from session 5). Doing our own Iceberg (a model to help unpick behaviour) is a way to focus on cause.*

*Some really useful tools. I will use SART (a model to help unpick behaviour) and re-introduce reward charts.*

*Breaking down the iceberg components into chunks to establish a working iceberg for use at my son's school.*

*I understand my child better. I see things now which I previously dismissed.*

*It helps to look deeper and have more understanding. More strategies would be really good but understanding is also important so it's beneficial. Thank you*

#### **Theme 2 - Supportive Atmosphere**

*Knowing that you are not alone.*

*I found it so refreshing to listen to people going through the same experiences.*

*Really good ice breaking session, all parents felt comfortable to discuss own situations.*

*Helpful to have opportunities to listen to and share strategies.*

*Being among the group and feeling supported by other parents.*

*Felt very welcome, very informative, well presented and felt comfortable to ask questions.*

### Theme 3 - Course Materials and Delivery

*Informative.*

*The booklet (session PowerPoints and activities) was most helpful.*

*Liked the 'Story Cubes' and thinking about positives.*

*Iceberg Principal and mindblindness task were helpful.*

*I am amazed at how things make sense when explained so carefully.*

### Theme 4 - Even Better If...

Some participants found particular sessions content heavy and believed they would have been better spread over a number of sessions. Some participants would have liked more of a focus on strategies that were specific to their child.

'Even better if...' feedback from participants appears to be dependent on a number of contextual factors:

- When a participant's child received their diagnosis (recent or some years ago) impacted their knowledge base and journey post-diagnosis.
- Participant's children often had a wide range of needs, barriers and strengths.

#### b) Quantitative feedback

<b>Feedback Questions 2018 and 2019 (2 courses)</b> Please note that questions were subtly different for each session evaluated	<b>% of participants answering 4 or 5 out of 5 (0= not at all/poor, 5 = very much/excellent)</b>
Did you find the information received prior to the course helpful?	80%
Did you feel the presenter/s were helpful in the way they explained the topics?	99%
Were the topics in the sessions helpful?	84%
Did you find the information on... (e.g. diagnosis / social stories/sensory needs/iceberg principal & managing a child's behaviour) helpful?	79%
<b>Feedback Questions 2019 (1 course only)</b> Different questions reflect evaluation of the <i>new</i> Cygnet course materials	<b>Average rating on a scale of 0-10 (0=not at all/poor, 10=very much/excellent)</b>
How Relevant was the session to you?	8.6
Were the session aims clear?	8.9
How well did the session meet its aims?	8.4
How was the knowledge of the trainer(s)?	8.7
How clear was the delivery / presentation?	9.1
How useful were the handouts and training materials / resources?	8.8
How well did the trainer(s) handle any equality and diversity issues?	9.4

## **5. What is the longer-term impact of the programme?**

In 2019 Year 1 students from the Bristol Educational Psychology Doctorate course were commissioned to undertake a small scale research project to explore parental perceptions and impact of the Cygnet course. Three parents were interviewed and a thematic analysis was undertaken to identify central themes in relation to the research brief. Parental experiences of the course compliment questionnaire data and are therefore robust evidence of the overwhelmingly positive experiences of parents.

The five themes identified in the research are outlined below:

### **Theme 1 – Understanding of the child’s behaviour**

The results of the research indicate that parents adapted their parenting style as a result of a greater understanding of their child’s behaviour. There was a greater understanding of what was underlying behaviour and therefore different approaches were used to meet underlying needs. This led to more positive outcomes for the child.

Parents also valued being provided with scripts and ways to help others understand their child. In particular this involved helping siblings, wider family members and family friends to understand their child. Some participants wondered about how the programme could be used to facilitate greater understanding in schools and the wider community.

### **Theme 2 – Social Support**

Parental support was a strong theme throughout the data set and included the subthemes; building a support network, sharing experiences in the group and group atmosphere. Sharing experiences in the Cygnet training group was perceived by all three parents as a key strength of the programme.

The researchers theorised that sharing experiences with other parents normalised parental experiences and led to greater feelings of self-efficacy (the belief that we can achieve a particular goal) around parenting their child.

### **Theme 3 – Practicalities of Attendance**

All participants commented that they found it difficult to accommodate the schedule of the course within the working week. This impacted whether one or both parents could attend. One participant stated that their partner would have liked to attend but would not have been given time to do so during the working day.

At the time of the research project, 10 sessions were offered to parents. Participants shared that committing to attending 10 sessions had been difficult to manage with other home and work commitments.

### **Theme 4 – Child and Parent Relationships**

As a result of participating in the programme parents identified feeling more confident in handling situations with their child that they used to find difficult;

*“Anytime we are getting towards the end of the school holidays or going back to that routine she will be escalating. But I know it’s coming, and I can handle it now. Whereas before I think I was always a bit on the back foot”.*

Improved relationships between parents and their children were found to have a positive impact on parenting style. Parents felt that they were pre-empting and managing

dysregulated behaviour more positively, resulting in better communication and calmer times together.

### **Theme 5 – Course Content and Delivery**

The research suggests that the facilitator role is crucial to parental engagement in the programme. Facilitators were perceived to help foster a supportive environment which enabled parental sharing. This in turn helped to normalise parental experiences and therefore support feelings of parental confidence and self-efficacy.

One participant reflected that it would be helpful if one of the facilitator roles could be taken by a parent with an autistic children themselves. It was felt this might support even greater parental engagement and the sharing of practical strategies and tools.

Participants also shared that they would have valued opportunities for more individualised input from facilitators on how to manage specific situations.

### **6. How are we continuing to develop the Cygnet offer?**

Feedback from evaluations and the findings of the research undertaken in 2019 highlight a number of further development points for the delivery of the Cygnet programme in Swindon. A number of these have already been acted upon:

- In response to feedback about the practicalities of attending 10 sessions the Cygnet programme has now been reduced to 8 sessions.
- In response to feedback about the facilitator role, the Educational Psychology Service are trialling co-delivery between an Educational Psychologist and trained and supported parent volunteer who has a child with a diagnosis of Autistic Spectrum Conditions.

The feedback has also highlighted a number of further areas for potential development.

- Feedback highlighted the need for greater flexibility and acknowledgment of the practicalities of attending parenting programs during office hours. One way to achieve this might be to deliver an evening Cygnet course.
- Participants within the research shared their belief that greater and more sustained change might be possible if others in the community could access the Cygnet programme. This included school staff, wider family members and friends. This belief sits comfortably within psychological principles of how change happens. Engaging with wider systems, for example, school systems, wider family systems and community systems contributes to a shared understanding of what might be underlying unexpected or difficult to manage behaviour. Evidence from course evaluations and the research suggest that understanding behaviour had a lasting impact on parenting style and confidence. It is therefore likely that this impact could be increased by greater knowledge and understanding within systems that families and their children reside.
- Feedback from the research and evaluations suggest that there was sometimes a mismatch between parental expectations and the content of the Cygnet programme. Some parents desired individual consultations with an EP along with personalised interventions. These desires may represent high levels of parental anxiety around capacity to support their child. Moving forwards consideration will need to be given to how to manage parental expectations. The aims of the course

may need further clarification in pre-course communication and during introductory sessions.

## **References**

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism, 20*(2), 153-162.

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