

NEW WRITING*

Barnardo's Cygnet – making a difference

Andy Morris



Andy is the Cygnet Parenting Support Programme Co-ordinator. He has worked for nearly 30 years with children and young people on the autistic spectrum in community and residential settings. His background, experience and qualifications in social work, training, research and

development have come together to enable him to help young people, parents, Barnardo's and partner agencies put the Cygnet programme together.

Summary

Cygnet is a parenting support programme for parents and carers of children/young people aged 7-18 who have a diagnosis of an Autistic Spectrum Condition. The programme has been provided for parents and carers with positive results in the Bradford district for the last five years leading to its publication by Barnardo's last July. Cygnet provides parents with the opportunity to come together to share and gather knowledge and skills in a supportive environment, building confidence to meet children and young people's needs. Parents can have a lot of involvement with professionals up to and around the time of diagnosis, but can feel there is little available to them afterwards – at a

time when they have a lot of questions about their child and what can help them. There are also some parents who may not have been able to, or wanted to, access advice or information locally. Children's needs also change over time so information and advice may need to be updated to be relevant for the child/young person today. The Barnardo's Cygnet programme delivered by local professionals provides these opportunities for parents.

* Though this article is newly written for IQJ, some elements have already been used by Barnardo's elsewhere.

Why Cygnet?

The underpinning value in the development of Cygnet is the belief that if parents have access to appropriate knowledge, skills and support they can often find practical solutions to build confidence in family life. (The term 'parents' is used here to include carers – who can be anyone who has direct involvement with the child, e.g. grandparents, uncles, aunts or support workers.) It is acknowledged that parenting is a challenging job. Research has suggested that 75% of parents and carers want help with their

parenting at some time or another during the time their child is growing up.¹ This has also been acknowledged in recent legislation and the latest government strategies primarily targeted towards families linked with the criminal justice and child protection systems.

Parents of children on the autistic spectrum not only face the usual positive and difficult challenges of parenting but quite a few more. The autistic population is vulnerable to an extent that is not widely recognised, not just in childhood but also in later life. Mental health, criminal justice and social services bear the later 'hidden' financial costs. Families not only bear financial costs but emotional and social costs throughout the life of the individual and, in the case of suicide, when their life is over.²

Bradford and district has a higher than normal prevalence of disabled children. The identification of autistic spectrum conditions has also had a correlated significant increase over many years in Bradford. In response to this demand and the hidden costs to families and the authority a Multi-agency Autism Group designed an action plan for Bradford and district in December 2002. Top of their recommendations was the need to provide appropriate support and training for families, particularly those with older children. This view was reinforced in the National Autism Plan of 2003:

Training for families must be ongoing as individual needs change according to age and circumstances. All authorities should offer a variety of training courses for parents/carers in the understanding and management of ASC and any additional behavioural difficulties.³

Many authorities offer a parenting support service, under licence, for younger children with a diagnosis of autism up to the age of 8 through the National Autistic Society Early Bird or Early Bird Plus programmes. As there was a demand but little opportunity for parents to access local parenting support for older children and young people on the autistic spectrum, Barnardo's with multi-agency support devised their own parenting support package known as Cygnet for those in the 7 -18 age bracket.

Partnership & Collaboration

Cygnet has been developed by looking at what is done in existing parenting services, examining

research findings, setting up a pilot group and by working in partnership with young people, parents, carers and professionals. Cygnet has been produced, managed, funded and run with multi-agency support. The trainers who present the programme all have a detailed knowledge of autism and come from a variety of backgrounds and agencies. As an acknowledgement of good practice, Cygnet, along with its partner agencies, was a National Training Award winner for the Yorkshire and Humber Region in 2008 in the *Partnership and Collaboration* category.

The Programme acknowledges parents as the experts in the care of their own children and young people. No one knows a child or young person as well as a parent, yet becoming a parent does not come with any instant qualification or training pack. Most of what we learn usually comes from watching parents, relatives and friends. Usually this works fine or we can learn fairly quickly from a number of other sources on general childcare. A child or young person on the autistic spectrum will present all the usual parenting challenges plus quite a few more and there are not many places to go for advice and mutual support.

The Barnardo's Cygnet Programme provides the opportunity for parents and carers to obtain advice and information on the additional challenges which autism can present within a group of people who share similar experiences. This is achieved by:

- building on parents' knowledge of their child and on their positive child care experiences
- presenting professional knowledge in a varied format making the information easy to understand with practical applications
- developing a mutually supportive group who share advice and experiences

A parent commented after completing Cygnet:

Speaking to other parents can help you see problems from another point of view or even just make you feel better knowing that it's not just you and your child experiencing difficulties.

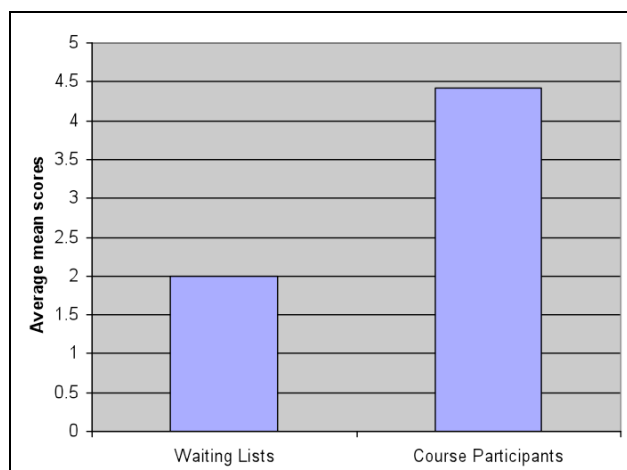
The Programme is presented quite informally in groups of usually no more than twelve people. There are six sessions which each last 2 ½ - 3 hours and a follow-up session three to four months later. Parents are encouraged to attend all sessions as they interlink with each other to build towards improved behaviour management.

The difference?

The quality of the Programme has been measured by parents' evaluations of each session with three-month follow-up evaluations which consider the difference the Programme has made to parents' confidence in relation to managing the needs of a child/young person with an autistic spectrum condition. Northumberland University have also carried out an independent evaluation of the programme.⁴

The following Table is taken from their report and on page 28 the report says:

This indicates that the parents who completed the course were more confident in dealing with the specified behaviours than the parents in the waiting list group.



Confidence Rating – average mean scores

Managing the needs and challenges of a child or young person on the autistic spectrum is a big responsibility and can be very hard work. There is no magic solution which is going to change that but we have shown it is possible to make a difference with Cygnet offering the right tools, with parents' commitment, and with a consistent approach.

A parent commented three months after completing Cygnet:

We both found the course very supportive, informative and very useful. We don't always get things right but we get things right more often since Cygnet.

Other parents and carers have commented:

- *Fantastic! Really enjoyable and helpful!*
- *Our biggest problems are related to behaviour so understanding our son's behaviour properly is a very big step!*
- *This has given me the tools to help with my child's communication.*
- *I can now identify my child's sensory issues and have an idea of practical strategies.*
- *The support of other group members is really valuable.*

Professionals have commented:

- *We recommend Cygnet to all families where a young person receives a diagnosis of ASC in this age bracket.*
Consultant child psychiatrist, Bradford
- *The programme is excellent in its accessibility to parents, carers and practitioners.*
Barnardo's Children's Service Manager, Waltham Forest
- *The materials are clear, well researched and well paced.*
Autism outreach teacher, Leeds

References

1. Sure Start Children's Centres: Practice Guidance, HMSO, 2006.
2. Willey, L. *Asperger Syndrome in Adolescence*. Jessica Kingsley, 2003
3. Le Couteur. *National Autism Plan*. National Autistic Society, 2003.
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4. Raghavan, R. *Cygnets Autism Spectrum Training Report*. Northumbria University. 2008.
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