

Cygnets for Parents: Puberty, Sexual Wellbeing and Relationships *Trainer's Guide* *Introduction*

**Believe in
children**



Barnardo's

Training and
Consultancy

Supporting parents with
children on the autistic spectrum



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Puberty, Sexual Wellbeing
and Relationships
Trainer's Guide
*Introduction***

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Background

For a number of years Barnardo's have provided a parenting support programme known as Cygnet to organisations/authorities to deliver core information on autism to parents of children/young people aged 7-18 on the autistic spectrum. The core Cygnet programme has a strong and robust evidence base including an independent two-year evaluation by York University for the DFE. It has also been acclaimed with National Training Awards in 2008 and 2010.

At its base Cygnet has been developed through listening to what parents say they need rather than providing something that practitioners think they want or need. The model Cygnet has employed for gathering this information is the parent adviser model (Davis et al., 2002). Consequently, after providing core information on autism (core programme) parents were requesting additional information and support on supporting siblings and a range of topics which have been captured in these three Puberty, Sexual wellbeing and Relationships (PSR) sessions.

Over a number of years the Cygnet service has worked in partnership with parents, practitioners and consulted widely to develop these three additional sessions. The final delivery and evaluation of the sessions in Bradford, North Yorkshire, East Riding and Wandsworth provided very positive evaluative results.

Core programme content

The Cygnet core programme is delivered to parents over six two and a half to three hour sessions which sequentially work towards behaviour management relevant and appropriate for this age group of children and young people. The core sessions cover;

- autism and diagnosis
- communication
- sensory issues
- understanding behaviour
- managing behaviour
- topics chosen by parents and carers

PSR sessions content

These additional three sessions to the Cygnet core programme should last about three hours and be delivered to parents after they have completed the core programme. The PSR sessions can be delivered as individual stand-

alone sessions or all three together as a package. This guide assumes the sessions are delivered as a package in the order Puberty/Sexual Wellbeing/Relationships. If delivered differently, trainers will need to adapt their preparations, welcome and closing remarks accordingly.

Evidence suggests that if they are delivered as a three session package it can be beneficial to provide a 'free' fourth session to allow parents to come back and continue to explore some of the issues covered in the three sessions. A 'free' fourth session is not a compulsory part of the programme as in the core programme but an option worth exploring.

Topics covered by the sessions are as follows:

Puberty

- what is puberty
- understanding our body
- looking after our body
- when and where to display our body

Sexual wellbeing

- what is sex about?
- focus of arousal
- masturbation
- sex and the law
- touch and personal space

Relationships

- types of relationships
- building a relationship
- feelings and emotions
- engaging with others
- keeping safe and bullying
- finally

Free fourth session (optional)

- topics chosen by parents and carers

PSR aims and sessional learning outcomes

1. For parents to develop their understanding and confidence relating to puberty, sexual wellbeing and relationships and how they may impact on children on the autistic spectrum.
2. To offer parents the opportunity to participate in activities that they could use to explore puberty, sexual wellbeing and relationships with their children at home

3. To meet with other parents in a mutually supportive environment

Each session will have identified learning outcomes.

Who can attend?

Parents/carers should only access these additional sessions once they have attended the Cygnet core programme or other relevant parenting support programmes e.g. NAS Early Bird or Early Bird Plus programmes. Knowledge gained from these foundation programmes is needed to underpin discussion of the themes covered in these three/four sessions.

Terms used in the sessions

Autistic Spectrum Condition (ASC) / Autistic Spectrum Disorder (ASD)

Many hours could be spent agreeing the correct terminology but, for the purposes of the text in this publication, the term Autistic Spectrum Condition will be used after consulting with a group of young people on the autistic spectrum.

Children/young people

The Cygnet programme can be offered to a wide age range of parents with a child/young person on the autistic spectrum. For the purposes of the text in this publication the word 'children' will often be used to cover the age range 7-18 whilst accepting that some can clearly be defined as young people.

Parents/carers

The Cygnet programme can be accessed by either parents or carers. Carers can be anybody with meaningful direct involvement in a child's life, eg, grandparents, uncles, aunts, shared carers or support workers from school. They should attend a programme with the consent and alongside the child's parents. For the purposes of the text in this publication the word 'parent/s' will often be used to include both parents and carers.

Sex

The word can have two meanings:

- Biological: People are born as male, female, or intersexed.
- Sexual behavior: Usually involves touching oneself or another person in ways that stimulate sexual feelings and pleasure. Sexual behavior includes many different ways of touching which can range from holding hands or massage to masturbation or intercourse (vaginal/oral/anal).

Sexuality

Human sexuality is the way in which we experience and express ourselves as sexual beings (Rathus et al, 1993).

In addition to us all being human beings, we also are all sexual beings! Sexuality is a normal, healthy, natural part of who we are throughout every stage of our lives. It is not one defined thing but a combination of many aspects of our lives. Our sexuality includes not only sexual behavior but also our gender, our body, how they work and our values, attitudes, beliefs and feelings about life, love, and the people our lives touch. Children learn about their sexuality from the day they are born. It is important to let children feel good about their sexuality from the beginning. This will make it easier for them to ask questions about their bodies and sexual feelings later on in life. Parents can initiate conversations about sexuality using many different themes - relationships, communication, respect, body image as well as intimacy and sexual behavior. This is a way to share values and factual information enabling young people to move towards loving relationships and make healthier, safer and better-informed decisions related to sexuality.

Sexual health/Sexual wellbeing

Being healthy is important, whether physically, emotionally, mentally or socially. One way for young people to stay healthy is to have information to help them understand their bodily changes during puberty, sexuality and how they may appear to others.

Sexual health is not only about diseases or dysfunctions. Sexual health is about staying safe and having a good, respectful and positive outlook on sexuality and sexual relationships. This opportunity should be available to all children and young people whatever their degree of disability. A positive and confident attitude to sexual health will lead onto good sexual wellbeing and the opportunity for young people to manage their personal sexual needs positively.

Puberty

Puberty is a normal phase of development that occurs when a child's body changes into an adult body and prepares itself for the possibility of reproduction.

Relationships

Dictionary definition: "The way in which two or more people are connected". This definition can clearly cover a wide range of relationships but for the purpose of these additional sessions we have concentrated on looking at the following themes:

- making and building friendships and relationships
- keeping safe

The sessions on puberty and sexual wellbeing can lead parents down a path which suggests that the relationships session will concentrate on

sexual relationships. However, the building blocks for healthy physical, platonic and safe relationships are dependent on an understanding of many emotional skills in the first instance. Therefore, this session provides the foundations to establish and build those emotional skills which may then be used to develop more intimate and sexual relationships.

These themes came out of questionnaires and focus groups with parents about their priorities for this session particularly as it could be so wide ranging.

General principles of the sessions

Why it is so important to support young people on the autistic spectrum with issues relating to puberty, sexual wellbeing and relationships

Sexuality is a central aspect of being human throughout life and is experienced and expressed in thoughts, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.

Many of the component parts that make up the concept of 'sexuality' are abstract and require good levels of communicative skills, social understanding and the ability to know that other people have feelings, beliefs and desires that may or may not be similar to our own.

Individuals on the autistic spectrum will go through the physical changes of puberty and develop sexual needs, feelings and drives no matter how child-like their other behaviours may seem to be and will typically struggle with the more abstract aspects of learning. Consequently, they may have difficulty understanding and coping with their changing bodies and the impact of their behaviour on others.

If young people on the autistic spectrum are not given the opportunity to access the 'tools' to help them manage their potentially confused understanding of their bodies, sexual desires and understanding of relationships they are open to exploitation or at worse ending up in the criminal justice system.

Individuals on the autistic spectrum are likely to experience sexual drives, behaviours or feelings with which, at some point in their lives, they may need support.

Difficulties experienced within the three core areas and sensory issues that define the autistic condition can present many challenges to parents and carers. These need to be understood before we can consider providing parenting support opportunities that specifically target issues relating to puberty, sexual wellbeing and relationships.

When considering the content of these sessions, it is important to remember the individuality of young people on the autistic spectrum and their preferred communication and learning styles.

It might be entirely appropriate for example, to use a predominantly descriptive learning approach to give information to one individual i.e. use of photos, signs, symbols to reinforce appropriate behaviours in the appropriate place, for example dressing/undressing, masturbation or touching others. We call this a 'What to do? Where to do it? How to do it?' approach.

However, another individual might need a more comprehensive programme of sex and relationships education, including information of a more detailed nature regarding puberty, sexual wellbeing and relationships with different ways of expressing sexuality safely within an appropriate social context. Visual aids may support this learning alongside other approaches such as social stories or using some of the activities used in these sessions with children to gain their understanding of how they view situations

Remember these sessions should be viewed as a providing parents with a toolkit from which they can choose the most appropriate tool for their child, preferably alongside educational, extended family and community support.

These three sessions cover wide topic areas and not all of the issues that can arise will be covered. The areas of focus have been based upon parental feedback from group sessions and questionnaires. This is particularly relevant for the relationships session which may more useful to parents of children in a mainstream setting.

Remember that autism is a spectrum condition which means there is enormous variation in how individuals with autism develop their skills and knowledge (see the website of the National Autistic Society www.nas.org.uk for more information).

Introductory notes for trainers

An activity-based programme

These three additional PSR sessions have a different delivery style to the Cygnet core programme. Because of the nature of the subject matter and again after consultation with parents it was felt that a far more activity-based programme would put parents at ease more quickly and therefore enhance learning and mutual support.

Each session has an icebreaker activity followed by six sequential activities that provide the framework to support parent's learning and often offer opportunities for the activities to be replicated in the home environment.

As with the core programme:

- There should be no more than 12 parents attending each session.
- Preferably the same two licensed trainers should deliver each session.
- The room should be laid out to offer optimum opportunities for interaction as outlined in the trainers notes.

Materials

Materials provided to deliver these three additional sessions are:

- **Trainers' Guide:** this book which includes session plans with approximate timings providing a summary of each session and notes providing detailed information on the content of each session.
- **Activity Resources package:** a set of resources including sets of picture cards, a body outline, laminated scenario cards etc. to enable trainers to deliver up to seven activities in each session.
- **CD:** this contains pdf files for printing out parent's notes and handouts, paper-based activity resources such as quiz sheets for each session and paperwork (attendance sheets and evaluation questionnaires)
- **DVD:** this contains video clips for the Relationships session and a video to show trainer's how activities work in practice, modelled by parents.

Prejudices and values

Everyone has prejudices, it is human nature to make judgments but trainers need to manage their own and parents/carers prejudices and values within a framework of promoting equality and diversity as outlined in Barnardo's basis and values: www.barnardos.org.uk/get_involved/jobs/promoting_equality_valuing_diversity/our_basis_and_values.htm

As with the core programme it is important for trainers to start these sessions with a **group agreement**. This should provide clarity about the framework under which the programme will operate particularly during these sessions when differences of personal, cultural or religious differences can come to the fore.

Example: Parents may want to know more about same sex relationships but other parents in the group may not agree with homosexuality due to personal or religious beliefs. An agreement that includes respect and the need to provide an environment that engenders the promotion of accepting difference is vital to supporting Barnardo's basis and values.

Cultural and religious beliefs

Culture can be defined as a set of shared attitudes, values, goals, and practices. Consider individual's different backgrounds and needs. Religion is the belief in a god or gods. Individuals can believe in the same religion but have different rituals and practices.

As trainers we need to be aware of our own religious and cultural beliefs and try not to let these interfere with facilitating the group.

Never make assumptions about someone's culture or beliefs, use a plain and straightforward language and ask if there is anything you need to know or are unsure of particularly in relation to this subject matter.

Examples of different beliefs

Different religions have different beliefs around the subject of puberty and sexual wellbeing.

According to Islam, when a boy has a wet dream or reaches the age of 14 years and 6 months he reaches puberty. This is called *balugh*. For a girl this happens when her period begins or at the age of 12 years old.

These and other questions that parents asked related to sexual wellbeing from an Islamic perspective are considered by three Imams in additional notes to this Guide – see Appendix included as a pdf file on the CD.

According to Judaism, when a boy reaches 13 years old he becomes accountable for his actions and is changing into an adult. Boys often have a *Bar Mitzvah* which is held as a coming of age ceremony and celebration. For girls this happens at 12 years old and they have a *Bat Mitzvah*.

Some Catholics may believe that it is wrong to use birth control because it prevents procreation (reproduction). Also sex before marriage may not be acceptable as it is viewed that all licit (not forbidden, lawful) sex should be unitive (expressed love). Masturbation could also be seen as not acceptable according to religious beliefs.

Who can deliver Barnardo's Cygnet PSR sessions?

Unlike the Cygnet core parenting support programme only **licensed, named trainers** can deliver Cygnet additional sessions on PSR. This is to ensure quality of provision particularly in relation to the subject area and offers an enhanced form of accountability.

To deliver Cygnet PSR sessions, trainers are required to have a certain amount of experience of working/living with children on the autistic spectrum and a requisite knowledge base as outlined in the introduction to the core programme. They should also:

- Have a good awareness of puberty and adolescence, relationships and sexual health in relation to autism.
- Feel confident saying and hearing words with sexual connotation.
- Be prepared to work with parents on sessions that are activity-led.
- Provide an up-to-date skills, knowledge and experience form to verify trainer's details.
- Be prepared to wear an ID badge for the purposes of verification during delivery of the sessions.

Each authority/organisation purchasing Cygnet PSR sessions will need to:

- Provide evidence that they are already delivering National Autistic Society Early Bird/Early Bird Plus programmes or have purchased the Cygnet core programme.
- Sign a Cygnet PSR license agreement that enables up to six licensed, named trainers per authority/organisation to deliver Cygnet PSR sessions. This is similar to the license of the core programme which emphasises good practice in relation to the delivery of Cygnet with 3 additional caveats:
 - only named trainers on the license can deliver PSR sessions
 - the license is renewable after three years for a small fee
 - return all materials if the license agreement is broken.

Training required to deliver Cygnet PSR sessions

Option 1

If named trainers can satisfy the skills, knowledge and experience criteria specified and are comfortable with the content of the sessions there maybe no need for additional training to support delivery. As part of the PSR programme content, all named trainers can access a training DVD which will show parents modelling all activities from the PSR sessions.

Option 2

As with the core programme many organisations/authorities may feel more comfortable and confident about delivering the PSR sessions after receiving training from the programme developers about its framework, content and the nuances of delivery. It also offers a team of trainers focused time to think about planning and delivering Cygnet in their area with independent advice and support.

Support for trainers

Each organisation/authority will need to provide trainers with time away from other commitments to deliver the programme consistently and successfully. This includes time for preparation, delivery, debriefing and write-ups.

Barnardo's Cygnet service can offer advice and information relating to programme content, additional materials and license commitments. They can also give parents and practitioners contact details for their nearest Cygnet providers (go to www.barnardos.org.uk/cygnet/ and look under Cygnet Providers).

Finally – fun

This is probably the most important message to get across. The purpose of the sessions is serious but they can nevertheless be fun. This is not rocket science! If the training is one-dimensional, the trainer appears disinterested or parents feel patronised or threatened, they will not engage with the training. Conversely, a session with a lot of variety and an interesting and interested trainer who's attentive to parents' needs is more likely to get a positive response and enhance learning.

This message is particularly important in these three sessions when parents maybe feeling apprehensive or potentially embarrassed discussing such topics in front of a bunch of strangers. Getting off to a good start in the first session is therefore vital to putting parents at ease.

References

Davis, et al (2002) *Working in partnership with parents*, The Parent Adviser Model, Pearson assessment

Rathus, et al (1998) *Essentials of human sexuality*, Allyn & Bacon