ParentsPlus

Special Needs Programme

FACILITATORS MANUAL

An evidence-based course for parents of adolescents
with an intellectual disability.

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Programme Aims

The **Parents Plus Special Needs (PPSN) Programme** is an evidence-based course for parents of older children and adolescents (11+ years) with an intellectual disability.

The PPSN programme was written and coordinated by John Sharry, Social Worker and Adjunct Professor of Psychology in UCD, Aoife O'Leary, Assistant Psychologist and Gráinne Hampson, Speech and Language Therapist in partnership with parents and professionals working in disability services throughout Ireland.

Who is the Parents Plus Special Needs Programme for?

Primary target group

The PPSN Programme is primarily targeted at parents of adolescents who have an intellectual disability in the mild, moderate or severe range and who are 11- 18 years old.

The PPSN programme is suitable for adolescents with a **primary diagnosis of an intellectual disability** but who may have additional diagnoses such as Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) as well as physical disabilities and medical conditions.

Can the PPSN programme be used for young adults?

The PPSN programme can also be used with young adults 18 to 25 years old. Many of the challenges for parents of young adults with intellectual disabilities are similar to those of parents with adolescents, meaning that the programme will have similar benefits. In addition, during the transition to adult services many parents experience a fall off in service support so this can be a good time to run the PPSN programme with families.

Can the PPSN programme be used with children younger than 11 years?

Some elements of the PPSN programme are relevant for all age groups, particularly the 'Parent Self-care' sections and some of the 'Supporting Families' and 'Supporting Children' sections. However, many other parts, specifically target the needs of adolescents with an intellectual disability and are focused on issues such as the transition into adult services etc.

If you are running a PPSN programme group, you can include some parents with children with intellectual disabilities who are younger than age 11. In these instances it is best to meet them in advance and explain the content of the course and to check they still want to attend.

However, if your main target group is parents of younger children with an intellectual disability, we generally recommend that you use adapted versions of the age specific Parents Plus programmes.

The Parents Plus Early Years programme is successfully used with parents of children with special needs who are aged 1 to 8 years. Some of the video footage in the PPEY was made with parents of children with a mild intellectual disability and within the programme there is the potential to make individual videos with families whose children have a moderate or severe intellectual disability to tailor it to their needs. For parents of children with an intellectual disability who are aged 8-11 years, a combination of the Parents Plus Early Years and Children's programme is recommended.

In delivering the Parents Plus Early Years or Children's programmes to parents of a child with intellectual disabilities, you can draw on some of the ideas and relevant session plans from the Parents Plus Special Needs Programme.

Please contact Parents Plus for further advice on how to adapt the programmes for the needs of your client group.

Can the PPSN programme be used with adolescents without an intellectual disability but who have additional needs?

Many services work with parents of adolescents in the normal range of intellectual ability who have additional needs such as Autism Spectrum Disorder (ASD), Dyspraxia, a physical disability or Attention Deficit Disorder (ADD). For this parent group, we recommend that you use the age specific Parents Plus programmes in an adapted format.

For parents of adolescents, we recommend that you use the **Parents Plus Adolescent programme** as your core format and include extra session inputs to address the issues relevant to the specific disability. Some parts of the PPSN programme can be included in the session plans as needed. All the 'Parent Self-care' sections and some of the 'Supporting Families' sections are relevant for these families and you can include these as needed.

In addition, some of the 'Supporting Children' sections might be relevant, depending on the disability. For example, when running the group with parents of adolescents with high functioning ASD, you might use some of the ideas on positive communication and routines (in sessions 1, 2, and 3). Please contact Parents Plus for further advice on selecting the ideal programme for your client group.

Goals of the Parents Plus Special Needs Programme

This PPSN programme does not concentrate on specific diagnoses or disabilities. Instead, it supports parents in managing issues that are common for families who have an adolescent with an intellectual disability. These goals include:

For parents

- Understanding the journey of parenting an adolescent with special needs
- Managing parental stress and improving self-care
- Supporting siblings (brothers and sisters) and family relationships
- Supporting parents and their relationship with each other
- Establishing good family routines
- Managing problem behaviours
- Advocating for your children

For adolescents

- Supporting good friendships and social opportunities
- Building self-esteem, confidence and independence
- Supporting education and development
- Dealing with puberty, sexuality and relationships
- Preparing for future transitions and adulthood

The overall goal is to support parents and to help them to have close, connected family relationships and to bring up their children to be happy and reach their full potential.

Source of ideas

Literature Review

Previous research has shown that parents of an adolescent with an intellectual disability are faced with a unique set of challenges when raising their son or daughter (Peer & Hillman, 2014). Some of these challenges include: navigating their child's transition to adulthood, supporting their social skills and friendships and managing their sexual development and puberty (Hamilton et al., 2014). Research has also highlighted challenging behaviour as a key area with which this cohort of parents needs greater support. Parents have found that behaviour support strategies that worked well when their child was younger are not always age appropriate or effective when they are dealing with an adolescent and they feel unsure of how best to adapt strategies to manage ongoing behaviours (Hamilton et al., 2014).

Research has also identified significantly increased levels of stress in parents of adolescents with an intellectual disability. This can result in the mental and physical health of these parents being compromised in addition to the quality of the relationship they share with their child being lowered (Peer & Hillman, 2014). Many parents experience burnout as a result of trying to balance several competing demands for other members of their family with the high level of support their child requires (Hamilton et al., 2014). Parents are often overwhelmed by appointments and other demands and struggle to find time to care for their own needs. For many parents, their self-care is non-existent, which leaves them with depleted resources to care for their child.

Parents often describe experiencing an acute sense of grief when their child is diagnosed with having an intellectual disability. However, research further notes that this grief can reoccur in adolescence and young adulthood particularly around key transitional times such as finishing school and starting college or a job. These moments can evoke keen sadness as they highlight for parents how other children are progressing which can remind them of the future their child never had a chance at enjoying. Professionals working in disability services have highlighted the importance of parents forming connections with other parents with whom they can share these unique experiences as they are the people who will be best able to understand what they are going through (Hamilton et al., 2014). Parents echoed these sentiments, saying that while they received a lot of input from services in their child's early years, this support dwindled as their child grew older, leaving them feeling increasingly isolated. It can be of great comfort for parents to speak to others in similar situations, to share their experiences and to know that they are not alone. Equally, parents reported that it is these connections with other parents that are often their best sources of advice, encouragement, empathy and compassion when dealing with challenging circumstances relating to their child. (Hamilton et al., 2014).

In supporting parents of an adolescent with an intellectual disability to cope with these issues, a number of parenting programmes have been developed and evaluated internationally. Hudson, Reece, Cameron and Matthews (2009) evaluated the effectiveness of the parenting programme Signposts, which aimed to improve challenging behaviour in people with an intellectual disability aged 3-16 years. Results showed a mean effect size across all age groups, however, the lowest effect was for adolescents aged 13-18 years (Hudson et al., 2009). Additionally, the Building Bridges Triple P programme has shown a benefit for parents of high functioning adolescents with ASD without an intellectual disability (Mazzucchellia et al., 2018). These results further highlight the need to develop an effective parenting programme that is tailored specifically to meet the needs of parents of an adolescent with an intellectual disability.