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Knowledge Exchange Seminar Series (KESS)

Parent training in evidence-based practice for Autism

The number of children being diagnosed with Autism Spectrum Disorder (ASD) is rising and with this there is a growing number of children waiting to be diagnosed (BBC, 2014). Despite the fact that it is parents who carry the greatest burden of caring for their children, there has been little investment in effective parent training

. There is an urgent need for parents to learn practical skills that they can implement in their own home to improve quality of life for their child and family. It is generally acknowledged that early intervention is essential in addressing the needs of children with ASD. Given limited resources (i.e. time, suitably qualified professionals) and costs, it makes sense to educate parents as key persons in their child's educational and health development. Research has shown that appropriate parent training in evidence-based practice for families with children with ASD benefits children's developmental outcomes and reduces family stress. Also, given the importance of early intervention and the time taken to complete the diagnostic process, giving parents key skills as early as possible can ameliorate issues associated with ASD. Even in those cases where ASD is not diagnosed good parenting skills have been established.

Parents are experts in understanding their own children. They are also the people who spend the greatest amount of time with their children. From this perspective, parents are an untapped resource when it comes to their children's educational, social, and health development. Decades of research clearly show that parental involvement is linked to greater developmental outcomes in children with a diagnosis of Autism Spectrum Disorder (ASD). For example, Schopler and Reichler (1971) highlighted the importance of including parents of

children with autism as an integral part of any programme. Without parental input the gains made in interventions were unlikely to be maintained over time and generalised to new settings.

Given the unique circumstances of each family (e.g., number of parents in full time employment, number of siblings, socio-economic background, severity of symptoms, etc.) it is possible to tailor interventions to any family environment. For example, in situations where a formal educational programme cannot be put in place, incidental teaching methods can be introduced to allow parents to take advantage of naturally occurring teaching opportunities, such as placing preferred items out of reach to encourage children to request those items in an appropriate manner. Depending on the individual child this could mean using a single word, signing, or using a facilitated communication programme such as PECS (Picture Exchange Communication System).

Although parents of children with a diagnosis of ASD are in a unique position to impact positively on their child's development, they are also in the stressful situation of raising a child with a pervasive developmental disorder. Many parents report feeling that they were offered little assistance and support having received a diagnosis of ASD (Stahmer & Gist 2001). As well as the issues surrounding the triad of impairments (social deficits, communication skills issues, rigidity of behaviour) parents also face the strains brought about by behavioural issues such as general non-compliance, poor sleep patterns, restricted food intake (from both the perspective of amount of food ingested to restricted range of foods ingested), educational issues, and social issues.

A report sponsored by the Royal Irish Academy in 2007 found that parents from Northern Ireland and the Republic of Ireland faced huge problems in the quality of family life if they had a child with ASD (Keenan et al., 2007). For example, families reported that they were restricted in pursuing personal, educational, occupational, and employment interests. Parents of children with ASD also experienced considerably more psychological distress than the general population (i.e., 88% of parents reporting their stress levels as highly stressed or quite stressed). Physical health was also an issue with 25% of participants suffering from chronic health conditions.

Parents also experienced distress and felt that they did not receive sufficient support or advice and information during and after diagnosis and the statementing process. They also noted significant distress when trying to access home, family, or respite support. As a result they sought non-statutory support (e.g., charitable organizations) or relied on their family for support instead. In some cases parents had moved house, or were prepared to move house, to gain appropriate services for their children (Keenan et al. 2007).

Research analysing the coping mechanisms of parents with children with ASD also underline the need for teaching parents in effective strategies for working with their children. For example, Hastings et al. (2005) identified four types of coping strategies used by parents. These are 1) active avoidance coping, 2) problem-focused coping, 3) positive coping, and 4) religious/denial coping. Differences in coping strategies across mothers and father were noted with mothers more likely to use problem solving strategies whereas there was no difference between mothers and fathers when it came to levels of emotional responding (i.e., avoiding stressful situations and denial). Mothers were also more likely to seek help. “Our data are consistent with other studies of families of children with autism in that active avoidance coping appears to be maladaptive (associated with more stress and mental health problems), and positive approaches to coping may be adaptive -associated with less stress and fewer mental health problems” (Hastings et al. 2005. p.388).

Dunn et al. (2001) noted that parents of children with autism experience more stress and are more susceptible to negative outcomes than parents of children with other disabilities. They examined the relationship between stressors, social support, locus of control, coping styles, and negative outcomes such as depression, social isolation, and spousal relationship problems. Their results showed that higher levels of depression were correlated with low feelings of control and avoidance as a coping strategy. Low feelings of control and escape as a coping strategy were also correlated with increased feelings of social isolation.

Low levels of social support were further correlated to increased levels of spousal relationship problems.

Escape-avoidance was found to correspond to increased depression, isolation, and spousal relationship problems. The authors note that “it may be particularly beneficial to discourage the use of escape-avoidance including hoping for miracles, having fantasies, using food or drugs, and avoiding others. Distancing, another emotion-focused style that includes going on as if nothing has happened, trying to forget the situation, and making light of the situation, also corresponded to increased depression” (p.49).

In view of the above, it is critical that parents are given training in positive strategies that will help improve the quality of life for both the child with ASD and also the family. Research has shown that parent education reduces family stress (Koegel et al. 1996). Evidence also shows that parental involvement in their childrens’ interventions leads to better outcomes in measures such as nonverbal (Anderson & Romanczyk 1999) and verbal communication (Stahmer & Gist, 2001), behaviour management (Lutzker & Steed, 1998), higher levels of appropriate play skills (Stahmer, 1995), joint attention (Vismara & Lyons

2007), imitation and social responsiveness (Ingersoll & Schreibman, 2006), and greater levels of positive parent- child engagement (Mahoney & Perales 2003).

Ingersoll et al. (2006) note that the National Research Council (2001) recommended parent training as an essential component of successful intervention programs for children with autism but that it is rarely funded in early childhood special education programs. It is therefore vital that parents are given the skills to generalize the positive behavioural repertoire that children develop in educational settings outside the home as well as put in place programmes that allow the child to learn effectively in their home environment.

It is evident from the published research above that parents with a child with a diagnosis of ASD are an untapped resource, but equally are under a great deal of stress. In N. Ireland we have had a successful awareness campaign about autism. Now we need to move into Stage 2 because awareness of autism by itself will not empower parents with the practical skills to manage their children and the associated issues that generate stress. Given the importance of early intervention it is clear that parental input can make a critical impact in those early months before and during a formal diagnosis. When parents are taught in the use of evidence-based practice to deal with their child's behavioural issues, levels of stress drop amongst parents and the developmental outcomes for their children are improved. In Canada and in 37 American states, evidence-based practice is seen as medically and educationally necessary by statutory agencies. Currently those 37 American states have passed legislation mandating insurance companies to provide evidence-based treatment for Autism. In the United States the gold standard treatment is Applied Behaviour Analysis (ABA).

With this in mind, two Leonardo Da Vinci Lifelong learning programmes were carried out in 2008 and 2011 lead by Ulster University in conjunction with European partners (i.e., Spain, Germany, Norway, Italy, the Netherlands, Iceland, Sweden, and Portugal). The STAMPP (Scientific Treatment for Autism: A Multimedia Presentation for Parents and Professionals) Projects addressed a serious mismatch in Europe between increasing rates of autism diagnosis and the availability of professionals trained in ABA. The multimedia presentation was based on an educational pack called "Simple Steps" (www.simplestepsautism.com) developed in conjunction with a local autism charity (Parents Education as Autism Therapists). Through the use of video footage tutorials, animations, and interactive exercises, parents were taught the basic principles of behaviour analysis to allow them to 1) understand why their child's behaviour was occurring, 2) reinforce the appropriate behaviours in which their child already engaged and teach new skills, 3) decrease those behaviours which inhibit a child's ability to function successfully in their community, and 4) develop data-driven, evidence-based programmes in conjunction with their ABA professional.

Feedback from the projects showed that parents strongly agreed that the tool helped

them

- understand their child's behaviour
- decrease inappropriate behaviour
- teach new skills

Parents also noted that the multimedia presentation was easy to understand and use, and made a significant difference to their child and family. The resource was also available continuously and was therefore easily accessible when required.

Policy-makers have not been fully informed about the benefits and the importance of parent training in ameliorating the effects of Autism on family life. Based on research undertaken, this presentation recommends that government in Northern Ireland invest in parent training as a cornerstone of evidence-based practice, while drawing on a European project that originated in Northern Ireland to meet the needs of parent training through the use of internet-based training in evidence-based practice.

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