Parent Support

Literature Review

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Parenting a child on the autism spectrum can be a hugely rewarding experience (McConnell, Savage, Sobsey, & Uditsky, 2015; Phelps, McCammon, Wuensch, & Golden, 2009). It can also be stressful for a variety of reasons, with parents often reporting stress levels that exceed those among parents of children with other developmental conditions (Craig et al., 2016; Dabrowska & Pisula, 2010; Estes et al., 2009; Hartley, Seltzer, Head & Abbeduto, 2012; Hayes & Watson, 2013). Unfortunately, there is a paucity of programmes designed to buffer the stressful experiences of families of autistic children in the United Kingdom (UK). Some of the few existing programmes are one-off and short-term (e.g., the National Autistic Society’s 8-session EarlyBird programme; Shields, 2001) while others are derived from the US or Australia (e.g., Triple P parenting program; see Whittingham et al., 2009). Some initial research has begun looking at the efficacy of UK specific programmes (e.g. Barnardos’s Cygnet parenting support programme; Stuttard, Beresford, Clarke, Beecham & Morris, 2016) none of these programmes have been fully evaluated for use with culturally- and socioeconomically-diverse families living in inner-city London, who often need sustained and individualised support that acknowledges potential cultural differences in perceptions of autism (Bernier, Mao & Yen, 2010; Tincani, Travers, & Boutot, 2009) and parental coping strategies (Lai & Oei, 2014).

The focus of research on stress in parents of a child on the autism spectrum has moved away from looking at if they experience higher levels of stress than parents of children with other developmental conditions to why this is the case and what factors can help mitigate it (Hayes & Watson, 2013). Parents face multifaceted stressors that can pile up and exacerbate one another (Ekas & Whitman, 2010; Ludlow, Skelly & Roholder, 2011), including managing behaviours that challenge, a lack of support from friends, family and the wider community as well as judgments from others, which parents perceive to be borne out of a lack of understanding of autism (Ludlow, et al., 2011). Individual factors, such as personality (Ingersoll & Hambrick

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1 Identity-first language is the preferred language of many people on the autism spectrum (see Sinclair, 1999) and their parents (Kenny et al., 2016). In this article, we use this term as well as person-first language to respect the wishes of all individuals on the spectrum.
optimism (Faso, Neal-Beavers & Carlson, 2013; Lee, 2009) and coping style (Hall & Graff, 2011) have all been identified as mediating the stress experiences of parents. However, such are the demands placed on parents that external support plays a crucial role in promoting positive wellbeing (Bromley, Hare, Davison, Emerson, 2004; Khanna et al., 2011).

Unfortunately, the ability of various types of external support to meet the needs of parents is vastly under-researched (Karst & Van Hecke, 2012; Vasilopoulou & Nisbet, 2016) – despite the fact that social support has been associated with increased positive mood (Pottie, Cohen, & Ingram, 2009) and parenting efficacy (Weiss, 2002) as well as decreased stress (Barker et al., 2011; Ekas & Whitman, 2010). In existing studies on external support, parents have reported that they are poorly supported by professional services, which are also difficult to access (Altiere, & von Kluge, 2009; Ludlow et al., 2011; Meirsschaut, Roeyers, & Warreyn, 2010; Woodgate, Ateah, & Secco, 2008). The lack of support to help manage stress can negatively impact upon parents’ self-efficacy (Kuhn & Carter, 2006), decreasing parents’ perceived ability to cope, increasing the impact of stressors and potentially leading to an increased sense of isolation and further reduction in their experience of social support (Donenberg & Baker, 1993; Schaaf, Toth-Cohen, Johnson, Outten & Benevides, 2011). This in effect creates a cyclical process that potentially perpetuates a higher level of stress experienced by parents. It is therefore vital to examine parents’ perspectives on the efficacy of existing support and areas where limited support exists so as to be able to modify support systems to improve parental and family wellbeing.

Respite support, (Chan & Sigafos, 2001; Harper et al., 2013) often referred to as ‘short breaks’ in the UK (Preece and Jordan, 2007) and support from other parents, both off- and online (Huws, Jones & Ingledew, 2001; Mandell & Salzer, 2007; Mackintosh, Myers & Goin-Kochel, 2005; Wynter, Hammarberg, Sartore, Cann, & Fisher, 2015) have been identified by parents as highly beneficial.
References


