**Research Factsheet on ADD/ADHD**

The BEST study is building on a set of new research findings that have emerged internationally in the past few years:

ADHD covers a range of different symptoms and behaviours. The condition was referred to as Attention Deficit Disorder (ADD) until 1987 when the term Attention Deficit Hyperactivity Disorder (ADHD) was introduced. Some people with ADHD have a pattern marked mostly by inattention, without hyperactivity, while others predominantly experience hyperactivity, and others again can experience both inattention and hyperactivity.

Youth with ADHD evidence disproportionate levels of academic problems, antisocial / delinquent behaviour, alcohol and substance misuse. The condition is commonly regarded as 'deviance' or 'willful disregard of rules' instead of a clinical condition. As a result, many sufferers experience family difficulties or receive a diagnosis only in adulthood. While often seen as a disorder of childhood, ADD/ADHD is a lifelong condition.

International research highlights the risk of misuse of alcohol and drugs among people with ADD/ADHD. Up to 50% of patients treated for a substance use disorder may have ADHD. One recent longitudinal study in the US has found that the odds of substance misuse are 14 times higher for adolescents with ADHD (Levy et al., 2014).

Official UK NICE guidelines state that supports for people with ADD/ADHD should be multidisciplinary and involve multiple modalities of care and support (Kendall et al., 2008). Yet treatment is predominantly medication-based. In primary care, some GPs do not see ADHD as a valid condition or one that they can assist with – citing time constrains, insufficient training, and concerns about patient misuse of medications as particularly problematic issues.

Matheson et al.'s (2013) recent UK study of adults with ADHD highlights a lack of awareness of the condition among GPs, the difficulty of obtaining a definitive diagnosis, lack of access to specialized services, and the challenge of transitioning from child to adult-oriented mental health services. Fundamentally, sufferers described ADHD as bringing chaos to everyday life. One person said: "Personal organisation is catastrophic, it's not good.... I spend 20 times the amount of time that someone of my general level of brain power ought to take, I simply cannot organise stuff in my head" (p. 7). An earlier Australian study also used the analogy of 'chaos' to describe the experience of living with ADHD as an adult (Toner et al., 2006), but also highlighted the resilience of 'striving for control'. A study of adults across seven countries by Brod et al. (2012) identified common patterns in the ADHD experience.

Young et al. (2008) carried out an interview study in the UK study of people diagnosed with ADHD in adulthood. The participants remembered feeling different as children, being treated as 'problem children' (e.g., being told they were "stupid, lazy, and disruptive" by parents and teachers, p. 495). A UK qualitative study with children with ADHD aged 9-14 reported bullying and name calling as common experiences (Singh et al., 2010).

In one U.S. survey, three-quarters of parents of a child with ADHD reported experiencing stigmatization and 40% had felt socially isolated or rejected (dosReis et al., 2010). In a UK qualitative study, Peters and Jackson (2008) found mothering a child with ADHD to be stressful and marginalizing. Parents reported that healthcare professionals were unable to give appropriate guidance and support. These findings underline the conclusion that parents

of children with ADHD require specialized support, including flexible, individually tailored support (Koerting et al., 2013). Such a model of service provision remains an aspiration in Ireland, and this situation requires action based on sound research evidence and community support.

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