With Parents in Mind: Can shared decision making support parents at CAMHS?

In Bonis' (2016) review, she highlighted that several factors may impact the continued or frequent use of <u>CAMHS</u>, and little is known about parents' decision to use or not use services (Carlon et al., 2015). Therefore, understanding the unique needs of primary caregivers (parents) to enhance involvement in their child's mental health care is valuable. Parents of children with mental health challenges report they feel "stressed beyond their limits" (Bitsika et al., 2013, p 540). This can impact their ability to parent effectively and to manage or be involved in their child's mental health care (Ludlow et al., 2011; Myers et al., 2009). A systematic review by Jackson et al. (2008) found that when parents are faced with child health decisions, the emotions (e.g. anxiety, despair) make decision making even more difficult. By asking the question, what are parents' decision support needs? This review found emerging themes of "the need for information", "having control over the process" and "talking to other" (Jackson et al., 2008).

Shared decision making (SDM) is defined as a process in which clients and clinicians work in partnership to make decisions about care and treatment (The Health Foundation, 2014). In CAMHS, decisions such as how, when and where to seek help (Wolpert et al., 2015); agreeing treatment options when more than one option is available; agreeing the goals of treatment (Bradley et al., 2015) or agreeing diagnostic tests (Berger et al., 2017) are constantly being made. Exploring SDM as a triad relationship between clinicians, children and parents where clinicians and service users (i.e. children and parents) share the evidence (information) when faced with the task of making decisions, and where service users are supported (talking to others) to consider options to achieve informed preferences, may be of value. In this unique situation, the key characteristics of SDM in relation to the process will be (1) that all members of the triad are involved (sense of control) in the decision-making as developmentally appropriate and 2) that an agreed decision is made by all members of the triad.

It is anticipated that the degree to which individual members of the triad be involved will vary in different aspects of the process depending on the legal context, capacity, experience and expertise of the participants and type of problem. However, this area of research is of great importance and may have practical implications such as improving individuals' experience of CAMHS.

## References

Berger, Z., Brito, J., Ospina, N., Kannan, S., Hinson, J., Hess, E., . . . Newman-Toker, D. (2017). Patient centred diagnosis: sharing diagnostic decisions with patients in clinical practice. *British Medical Journal*, p.j4218.

Bitsika, V., Sharpley, C. F., & Bell, R. (2013). The buffering of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 533-543.

Bonis, S. (2016). Stress and Parents of Children with Autism: A Review of Literature. *Issues in Mental Health Nursing*, 153-163.

Bradley, J., Murphy, S., Fugard, A. J., Nolas, S. M., & Law, D. (2013). What kind of goals do children and young people set for themselves in therapy? Developing a goals framework using CORC data. *Child and Family Clinical Psychology Review*, 8-18.

Carlon, S., Carter, M., & Stephenson, J. (2015). Decision-making regarding early intervention by parents of children with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 285-305.

Jackson, C., Cheater, F. M., & Reid, I. (2008). A systematice review of decision support needs of parents making child health decisions. *Health Expectations*, 232-251.

Ludlow, A., Skelly, C., & Rohleder, P. (2011). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology*, 702-711.

Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heartache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 670-684.

The Health Foundation. (2014). *Person-centred care: From ideas to action*. London: The Health Foundation.

Wolpert, M., Harris, R., Hodges, S., Fuggle, P., James, R., Wiener, A., . . . Fonagy, P. (2015). *THRIVE Elaborated.* London: CAMHS Press.

This contribution was made possible by funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 722561