**Title**: iKNOW Feasibility Study – Parents/Carers Perceptions

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**Introduction** Behaviours that challenge (BtC) are shown by approximately 10% of children with intellectual disability and both prevalence and severity increase with age in childhood. Thus, early identification of children at highest risk for BtC, and delivery of preventative interventions is essential. The i-KNOW (understanding and knowing about behaviour) programme has been designed as a proactive, preventative intervention before BtC emerge.

**Method**: Parents/carers of children (aged 1-8 years) with confirmed or suspected developmental difficulties were assessed for eligibility using a risk algorithm (i-RISC, derived from the SAD-SQ) and stratified into i-KNOW intervention workshops (risk of high severity BtC, n=50) or remote learning (risk of moderate severity BtC, n=13). The 6-week psychoeducation programme equipped parents/carers with knowledge of functional communication strategies, facilitating their child’s communication of needs and preferences. Semi-structured interviews evaluated the feasibility and acceptability of the i-KNOW intervention in an NHS clinical setting. An interview schedule was developed by the research team and reviewed by Speech and Language NHS clinician trained in the iKNOW protocol. Interviews were delivered online by a researcher using zoom. The semi-structured interviews were limited to an hour, audio-recorded and transcribed verbatim. Interview data from 11 parents/carers was transcribed and evaluated with thematic analysis.

**Results**: Findings indicated that the iKNOW intervention impacted caregiver perception and enhanced communication ability of children at the highest level of clinical risk for BtC. Moreover, thematic analysis of parental reflections of the intervention identified three main themes: (1) need for community; (2) need for accessibility; and (3) need for early intervention for children with specific profiles.

**Discussion:** While some families report feeling empowered by their preparedness for BtC, others experience heightened uncertainty, necessitating a day-by-day approach to care management. These findings underscore the need for interventions that are both sensitive and adaptable to individual caregiver needs, highlighting the importance of personalisation in future trial designs. Further investigation is necessary to understand the underlying causes of changes in caregiver well-being and prioritising caregiver well-being should be a key focus in the development of future interventions. Additionally, strategies to ensure the sustainability of support networks within communities beyond the intervention period must be incorporated to enhance long-term outcomes. This study will inform a future trial to assess efficacy of the i-RISC and i-KNOW programme in community practice.

**References:**

Davies, L. E., & Oliver, C. (2016). Self-injury, aggression and destruction in children with severe intellectual disability: Incidence, persistence and novel, predictive behavioural risk markers. *Research in developmental disabilities*, *49*, 291-301.

Walters, L. R., Groves, L., Allen, D., Bain, D., Cooper, V., Daniel, L., Garstang, J., Jones, C., Kaur, K., Khan, A., Liew, A, McCleery, J., Oliver, C., Rose, J., Simkiss, D., & Richards, C (In Prep) Assessing the feasibility of the i-KNOW preventive intervention programme for individuals at Clinical High Risk for Behaviours that Challenge.

Groves, L., Davies, G., Oliver, C., Allen, D., Bamford, C., Bell, L., Brown, C., Cooper, V., Daniel, L., Garstang, J., Jones, C., McCleery, J., Liew, A., Rose, J., Simkiss, D., Steenfeldt-Kristensen, C., Welham, A., & Richards, C (In Prep). The development and validation of models of risk for behaviours of concern in children with developmental disabilities: a novel machine learning approach

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