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A parent-led intervention for autistic children with severe to profound intellectual disability: A proof of concept study

Rationale and Overview of the Evidence Base

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What is this document about?

This document provides an overview of the rationale and evidence-base for a parent-led support package we are currently developing at Aston University. Our project is based on theories taken from Cognitive Behaviour Therapy (CBT), namely the importance of psychoeducation about anxiety, and the development of an individualised stepped process of approaching situations currently avoided by the individual (where it negatively impacts their wellbeing). The intervention has been developed in collaboration with 17 families of autistic children who have an intellectual disability, and with experienced clinicians who work with autistic children with anxiety and intellectual disability. Each element of the project will be collaborative and individualised to the child and to the family, taking care to consider alternative reasons why a child may avoid situations (e.g., physical discomfort due to sensory sensitivities). This will ensure that the support and strategies are appropriate and ethical, and will have a greater likelihood of improving the quality of life and wellbeing of the autistic child and their family.

Why have we written this overview?

We have written this overview in response to a request by a parent for further information regarding the evidence base underpinning the intervention and we hope it will be of interest to other parents and autistic people. In addition, we are aware that behavioural strategies have not always been applied ethically by researchers in the past. We wish to provide information to the autistic community about what we intend to achieve during our intervention, and why we believe our approach will be effective for reducing anxiety and improving quality of life.

What are we hoping to achieve?

We hope to develop a way of supporting autistic people with intellectual disability who experience anxiety. Specifically, our project focuses on those who speak few or

no words. It is well documented that autistic people have a greater likelihood of experiencing mental health difficulties. However, there has been very little research into reducing anxiety experienced by autistic people, and research is almost non-existent for children who also have an intellectual disability and speak few or no words. This means that autistic people who speak few or no words experience more anxiety than neurotypical individuals, yet do not have access to evidence-based support to improve their wellbeing.

What do we know already?

Research with the neurotypical population has been conducted and we have a good understanding of what makes anxiety worse overtime. One of the things that increases anxiety is avoidance, and our research has indicated that autistic people also avoid situations, or may be supported by caregivers to avoid situations, when they experience anxiety (Moskowitz et al., 2017; Tarver et al., 2021). Therefore, strategies from the neurotypical population may be useful for reducing anxiety, if they are adapted for the autistic population and take into consideration the needs and characteristics of autistic individuals (e.g., sensory sensitivities), to ensure they are applied ethically. The summary below describes how we have taken strategies developed for the neurotypical population, and the small number of studies with autistic individuals, to develop the current project.

Are autism and anxiety separate? Is there any evidence that anxiety is just part of autism?

Between 42% and 79% of autistic children report experiencing anxiety (Kent & Simonoff, 2017). Anxiety symptoms can overlap with autism characteristics, leading to difficulties assessing anxiety in autistic children (Moskowitz *et al.*, 2013; Hagopian & Jennet, 2008). However, although symptoms may overlap and autistic individuals are significantly more likely to have difficulties with anxiety, anxiety is *not* considered a core feature of autism; research identifies that anxiety and autism characteristics can be independent of one-another (Renno & Wood, 2013).

What is the evidence-base for anxiety interventions?

The National Institute for Health Care and Excellence (NICE, 2013) outline the recommended treatment approaches for social anxiety in both adults and children without intellectual disability. Similar evidence-based strategies are recommended by the NHS for phobias and generalised anxiety disorder. These are summarised below:

- Individual Cognitive Behaviour Therapy (CBT) consisting of psychoeducation (learning about the mechanisms for anxiety), exposure to feared or avoided situations and opportunities to rehearse skills in feared situations.
- Psychoeducation and skills training for parents (particularly when the child is young) to encourage the children to engage in the exposure tasks and reinforce engagement and success in exposure to feared or avoided situations, and skilful responses.
- For adults, the addition of work around the identification and modification of 'core beliefs' is included.

NICE guidelines such as these are established following an extensive review of the existing literature around the treatment of anxiety in children and adults. The evidence base is not as comprehensive for the child population as it is for the adult population, therefore evidence from the adult population was also used for developing the guidance.

Exposure is evidenced as an effective treatment for a range of anxiety difficulties, including specific phobias (Olatunji, Cisler & Deacon, 2010). Exposure has been reported as an effective treatment in adults for phobias and anxiety-related avoidance for several decades (Foa & Kozak, 1986), and such bodies of research (Hope, Heimberg & Turk, 2006; Warner et al, 2016) have contributed to the NICE guidelines that practicing clinicians use for children and adults without intellectual disability today, which, as highlighted above, advises exposure to feared or avoided situations (NICE, 2013). In a paper published after the publication of the 2013 NICE guidelines, Peris *et al.* (2015) identified that the exposure elements (along with cognitive restructuring) of a CBT programme for children were the key factors associated with change.

Why is 'graded exposure' considered to be a key factor in anxiety interventions?

The mechanisms behind anxiety disorders are widely understood to be related to individuals' engagement in 'safety behaviours' (e.g. Wells et al., 1995), that is, behaviours that prevent a feared outcome from occurring (Salkovskis, 1991). Avoidance is a safety behaviour presenting in many anxiety disorders; this is described by Arnaudova *et al.* (2017) as the "execution of repetitive avoidance, which a) limits daily activities and impairs general functioning; b) can be provoked by stimuli, which do not pose any objective threat to the individual's health or well-being; c) is associated with a high level of distress." Avoidance maintains anxiety, as it does not teach new skills to help respond to, or cope with, the situation (Hayes & Wilson, 1994).

Graded exposure seeks to support an individual to gradually reduce avoidance behaviours and break the cycle of anxiety (Piccirillo, Taylor-Dryman & Heimburg, 2016). A commonly-used example is that of a spider phobia; in an exposure treatment plan, an individual may begin by looking at photographs of spiders, then watching videos, before finally observing a spider from a distance, only moving onto the next step when they can tolerate the previous without distress. Exposure work is typically used to support individuals to access situations that though feared by the individual, are everyday activities. Gradually exposing an individual to a situation (within their tolerance) develops new associations between the situation and the individual's response, by teaching that the situation *can* be accessed without negative outcomes (Myers and Davis, 2007).

Have any anxiety intervention studies included autistic individuals? Were they helpful?

There is currently little research into anxiety interventions for autistic children with severe to profound intellectual disability (Vereenoghe *et al.*, 2018). A recent study, however, explored the effectiveness of family-based exposure therapy protocol for autistic children with anxiety, without intellectual disability and showed promising signs for the effectiveness of such an intervention (Storch, 2020). A further study (Rodgers, Herrema, Honey & Freeston, 2018) used a programme that incorporated 'Behaviour Experiments' (Bennett-Levy *et al.*, 2004) to support autistic adults to increase their tolerance of uncertainty (intolerance of uncertainty and avoidance of uncertainty has been linked to anxiety in autistic individuals). The participants reported that the programme was helpful, collaborative and individualised.

A study that used self-report measures (where participants rate their own experiences, not the experiences of others) identified that autistic children who had elevated anxiety symptoms reported poorer health-related quality of life, and poorer physical, emotional, social and school functioning than autistic individuals without elevated anxiety symptoms (Adams, Clark & Keen, 2019). Therefore, the lack of interventions for anxiety is likely to have long term implications in many domains of a child's life and it is important that this is addressed.

The limited evidence base for autistic children with severe to profound ID, combined with the increased likelihood of mental health difficulties within the autistic population and the already established evidence for the effectiveness of a graded-exposure approach, have contributed significantly to the rationale for developing the current project.

How will we ensure the individual needs of autistic people are met?

The aim of the current project is to reduce anxiety related avoidance and/or escape behaviours, however this will not be through graded exposure alone. As recommended by NICE (2013), a large portion of the project will involve parent/carer psychoeducation about anxiety, which they can then apply to understand anxiety in their own child. The exposure element of the project will be led by the parent/carer between sessions, who will be able to monitor the impact that the exposure is having on their child, adjusting the scenario accordingly with the advice of the research team. The research team and the parent/carer will work together to develop a toolkit of strategies to support their child to regulate their emotions during the exposure activities, such as communication aids, reward systems and encouraging self-soothing activities. Parents/carers will use an individualised 'SUD's' scale (subjective units of distress, distributed between 0-100) to identify when they should stop an exercise, and therefore prevent their child from experiencing excessive levels of distress during the intervention.

Throughout the project we will remain mindful of the individual needs of the autistic person, using a variety of measures such as the Sensory Experience Questionnaire (Baranek *et al.*, 2004) to ensure we are aware of how individual differences will need to be considered. Parent/Carers will be supported to consider alternative reasons for reported anxiety behaviours, such as sensory distress, or pain, and will be encouraged to seek alternative support if these are identified.

We hope that this extended summary of the rationale has been helpful. If you have any further questions about the rationale, or other elements of the study, please contact Dr Jane Waite at j.waite@aston.ac.uk or 0121 204 4307.

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