Improving Access to Healthcare for Individuals with Autism Spectrum Disorder

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Introduction

On average, when compared to the general public, individuals with autism spectrum disorder (ASD) have a higher prevalence of long-term co-morbidities, their health care needs are often unmet, and they face increased barriers when accessing and utilising health care services [1,2,3]. Around 30% of parents of a child with ASD reported their child to have at least 1 unmet health care need, compared with only 12% of children with special health care needs. This inequality in health care provision may be explained by a lack of specialist training in the field.

Qualitative research exploring the perceptions of general practitioners and health care workers, across both pediatric and adult based services, suggested they felt they had inadequate training to provide the best standard of care possible to individuals with ASD [4,5]. These findings are supported by a 2019 study of pediatric trainees which highlighted a knowledge gap surrounding ASD resulting in discomfort when interacting with those presenting with ASD [6]. Additional ASD-specific training was recommended to overcome these barriers to effective healthcare provision.

This project aimed improve, and to reduce inequalities in, healthcare provision for those with ASD. The Health Inequalities Assessment Toolkit (HIAT)[7], provided by the Applied Research Collaboration Northwest Coast (ARC NWC) was used to identify the inequalities present. The ongoing support and knowledge from the ARC NWC, and the input provided by the public advisers, were essential in the development of this project.

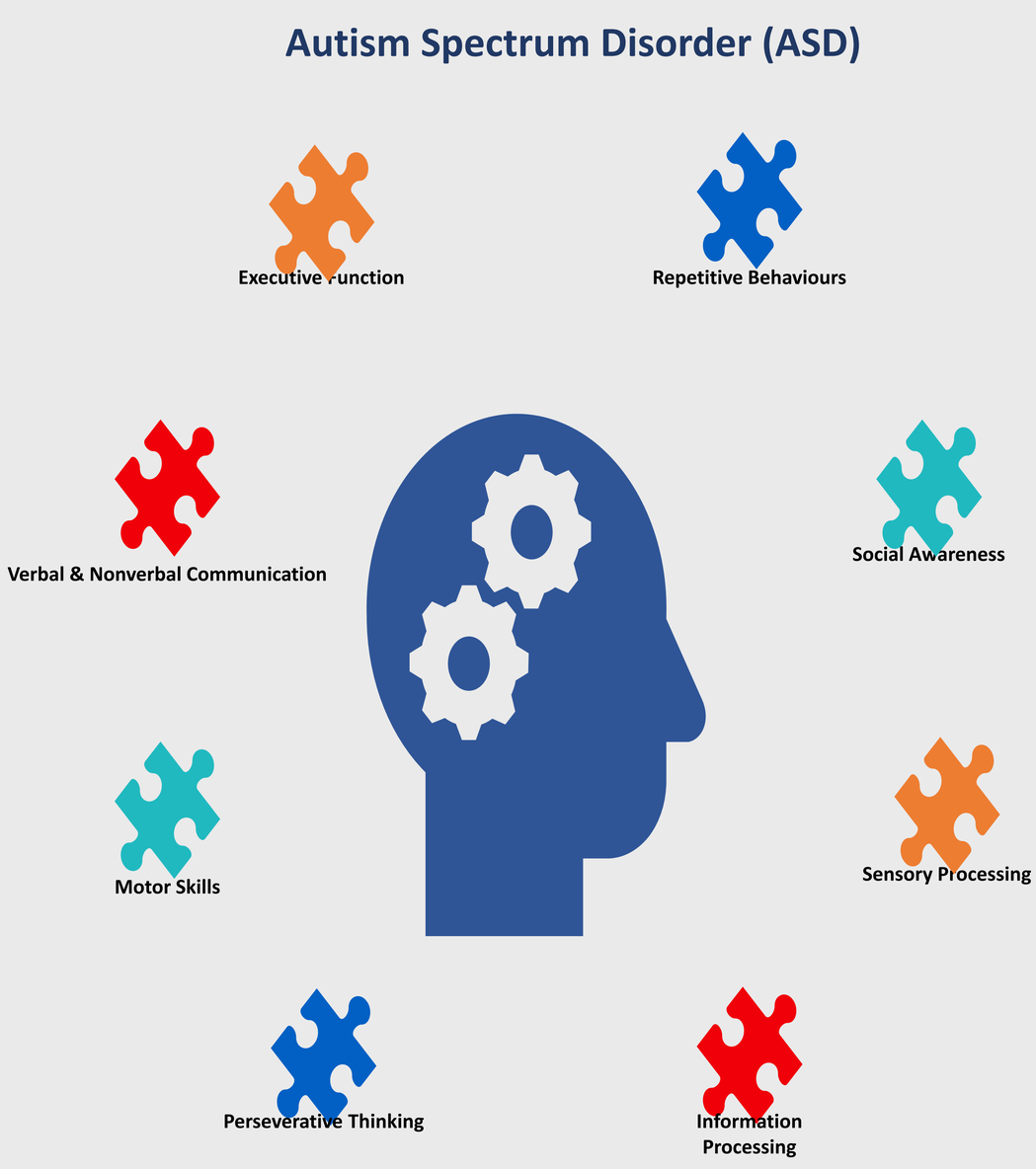
Aims

1. To explore the barriers and facilitators experienced by those with ASD, and/or their carers, when accessing and utilising health care services

2. To explore methods to reduce the health inequalities faced by individuals with ASD when accessing health care services

3. To develop an intervention to improve, and reduce inequalities, in health care provision for those with ASD

4. To evaluate the effectiveness of, and fidelity to, the intervention



The story so far…

The literature

Rapid Conversion Evidence Summaries (RaCES) use existing systematic reviews (SR) to develop summaries of the available evidence for practice. To inform the development of an evidence-based intervention, a RaCES was undertaken. No existing SR focused solely on the needs of those with ASD, therefore Doherty et al (2019)[8] which explored barriers and facilitators to healthcare for people with intellectual disabilities and/or ASD, was the subject of the RaCES.

Six main themes relating to barriers and facilitators were identified (table 1).
The findings suggested the provision of ASD-specific training for healthcare professionals had the potential to overcome barriers and facilitate equitable healthcare provision for individuals with ASD.

Implementation

The Consolidated Framework for Implementation Research (CFIR)[9], which guides effective preparation for the implementation of interventions, was utilised to consider any possible barriers/facilitators that may present themselves in this project.
The HIAT was used to consider how the proposed intervention would effect the socio-economic causes of health inequalities. It was identified that the implementation of this project could allow for prompt access to high-quality healthcare to those with ASD, potentially preventing the unequal consequences of ill-health.
The Political, Economic, Social, Technological, Legal and Environmental (PESTLE) factors were evaluated to help identify which factors could impact on the intervention.
A logic model was completed to clarify the inputs, outputs, and outcomes of the project, and to inform the evaluation. An analysis of the Strengths, Weaknesses, Opportunities and Threats (SWOT Analysis) was also conducted alongside the logic model.

Intervention development

Consideration of the design, delivery, content, and cost was required to ensure effective delivery of relevant training in the setting. For example, would commissioning of existing training be sufficient, or would the development of bespoke training be required. Similar questions arose around the method of delivery, online vs face to face, meeting the preferences of the healthcare professionals and service demands.
Research into what training is currently available was undertaken, finding an array of courses and materials. Whilst there was no one course mandated for the use in health care settings, it was noted that the Oliver McGowan association are currently working on this.

Theme	Barrier	Facilitator
Training	Insufficient training	Need for training recognised
Knowledge & Awareness	Lack of knowledge, understanding and awareness around ASD and ID	Warm, friendly, and caring attitudes can be facilitating
Communication	Lack of awareness about different communication needs/ styles	Use of alternative communication styles available
Fear & Embarrassment	Caused by insufficient understanding of needs and adjustments	Reasonable adjustments can be made
Lack of involvement in healthcare decision making	Lack of involvement of the individual. Often rely on input from family, carers, and support workers	Joined up approach and Tailored services are highly regarded
Time	Long wait times and insufficient time spent with the individual	None noted

Table 1-List of 6 themes reported and a summary of the barriers and facilitators.

To be continued…

- There are still a decisions to be made regarding the most efficient and effective way to develop the training.

- Evaluation of the effectiveness of the intervention is required. A combined approach has been suggested to test:
  - Participant knowledge with pre and post training knowledge questionnaires; and
  - Patient outcomes through the production of a histogram comparing trainee uptake and ASD patient experience over a period of time.

- The fidelity to the intervention would also need to be assessed. A suggested method of evaluation would be to collate data on session attendance, interaction during sessions (if face to face), and proportion of staff trained. Trainee feedback can also be collected via post training questionnaires and focus groups.

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