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HELEN LAYTON BSC (Hons), MSc, PG Cert

ACCEPTABLE ACCESS TO HEALTH SERVICES FOR ADULTS ON THE AUTISM SPECTRUM

PART A: A systematic literature review of the barriers of and facilitators to gaining access to health care services for adults with Autistic Spectrum Conditions

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PART B: An investigation into the attitudes, perceived behavioural control and subjective norms of clinicians working with adults with Autistic Spectrum Conditions and a mental health difficulty.

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A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Psychology

APRIL 2018

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgments

In memory of my mum who witnessed and encouraged the inception of this project but did not get to see the end result; thank you for always supporting me.

A huge thank you to Owen, the wonderful cohort I’ve shared this journey with, my dad, my friends and my manager Linda Hammond.

Thank you to everyone who participated at every stage and my supervisors Martin Anson and Sarah Blainey. A special thanks to Sabina Hulbert for much needed stats support!

Summary of the Major Research Project

Section A is a systemised review of research examining the barriers to and facilitators of gaining access to healthcare for adults with autism. Twelve studies were identified relating to the research questions. A synthesis of the literature identified frequently reported barriers to accessing healthcare, a range of facilitators and a pilot intervention. Barriers identified related to communication between providers and patients, facilities and sensory overload, provider knowledge of autism, transition and developmentally-appropriate services, stigma about autism, lack of services and supports, as well as services not being tailored. Clinical and research implications are highlighted, including provision of training for health care professionals and a need for further research into interventions which facilitate successful access.

Section B is an empirical study which investigated whether components of the Theory of Planned Behaviour (TPB) could explain variance in IAPT clinicians' intention to carry out interventions for mental health difficulties in people with High functioning autism (HFA) or Asperger's syndrome (AS). Findings showed that the model predicted the majority of the variance in intention to carry out interventions for mental health difficulties for people with HFA or AS. The most significant components in predicting intention were indirect attitude measures, direct measures of perceived behavioural control, and indirect subjective normative referents. Past experience of carrying out these interventions was significantly associated with intention when the individual had no experience of working with people with autism previously. Clinical and research implications are presented.

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SECTION A

HELEN LAYTON BSC (Hons), MSc, PG Cert

Title: A systematic literature review of the barriers of and facilitators to gaining access to health care services for adults with Autistic Spectrum Conditions

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Abstract

Introduction: People with autistic spectrum conditions (ASCs) have been found to have an increased risk of of serious health problems, including heart disease and diabetes, but research has found that for children with ASCs access, to appropriate healthcare can be challenging. Research on healthcare services for adults with ASCs is limited; with most research in general being carried out for and on children with autism.

Aims: The current review aims to investigate the barriers to and facilitators of gaining access to healthcare for adults, as identified by people with ASC themselves, their carers/supporters and those health care professionals providing adult healthcare.

Method: A systematic literature review was completed and identified this 12 studies which used a mixture of methodologies, comprising four quantitative, six qualitative and two mixed methods.

Results: A synthesis of the literature identified frequently reported barriers to accessing healthcare, a range of facilitators and a pilot intervention.

Barriers identified related to communication between providers and patients, facilities and sensory overload, provider knowledge of autism, transition and developmentally-appropriate services, stigma about autism, lack of services/supports and services not being tailored.

Conclusions: Most of the studies were of high quality but some methodological limitations were evident.

Clinical and research implications are provided in relation to providing appropriate and accessible care for people with ASCs are discussed in this review.

Introduction

The introduction presents a conceptualisation of autistic spectrum disorder (ASD), research limitations for adults on the autistic spectrum, health care problems associated with ASD and relevant literature outlining research carried out on access to health services for those with ASD. This is followed by a consideration of what access to healthcare means and the theoretical underpinnings of the review, rationale and aims of the current review.

Autism Spectrum Disorder

In the Diagnostic and Statistical Manual Edition 5 (DSM; APA, 2013) the category of ‘autistic spectrum disorder’ is defined as “persistent difficulties with social communication and social interaction” and “restricted and repetitive patterns of behaviours, activities or interests” present since early childhood, to the extent that these “limit” and/or “impair” everyday functioning.

Research has been conducted into which terms are most acceptable to the community of people with ASCs. The author will use person-first terminology as this was found to be the preference of the UK autism community (Kenny, Hattersley, Molins, Buckley, Povey & Pellicano, 2016). Person-first terminology is the use of “person with” and then the diagnosis they have been given rather than using that diagnosis as an adjective or label to describe the person.

Kenny et al. (2016) also found a number of terms including ‘autism’ and ‘on the spectrum,’ were in endorsed more than ‘autism spectrum disorder.’

Individuals with diagnoses of autism will be referred to as those with autistic spectrum conditions (ASCs) throughout the review. This is also the preferred terminology of the Department of Health in England (Mills & Francis, 2010) but is fairly new to academic writing.

When a paper discussed in the review has distinguished between types of autism diagnosis (e.g. Asperger's, the terminology used in the paper will be conveyed). Those without autism will be referred to as "neuro-typical."

In recent years, care for people with autism spectrum conditions (ASCs) has assumed greater importance on government agendas as shown, for example, by the introduction of the "Think Autism" strategy in the UK (DoH, 2014) and similar policies prioritising service provision in the US (e.g. US Department of Health and Human Services Interagency Autism Coordinating Committee, 2012) with the recognition that services have been lacking for this group, both in awareness of autism and availability.

It has been found that rates of service disengagement are high for school-leavers with ASCs (Shattuck, Wagner & Narandorf, 2011). This indicates that access may become more difficult as people with ASCs age, however, the large majority of autism research projects are carried out with and for children, leaving significant gaps in our knowledge about how to support people with ASCs as they grow older (Howlin & Moss, 2012; Shattuck et al, 2012).

Health Problems and ASCs

People with autism have found to be at risk of developing significantly more health problems than the general population. There are a significant number of health conditions that are associated with being on the autism spectrum and requiring appropriate healthcare support from professionals.

A large-scale study in the US found that there were significantly higher rates of cardiovascular disease, diabetes, stroke and Parkinson's Disease were found in adults with autism, when compared with neuro-typical people (Croen, Zerbo & Qian, 2015). This ranged from stroke (2.12 times more prevalent) to Parkinson's (32.73 times more likely to occur). People with autism were also found to be 2.56 times more likely to die prematurely than their neuro-typical fellows.

Bolton et al. (2011) found that epilepsy rates are particularly high in adults and children with autism, with between 11 percent and 39 percent also having a diagnosis of epilepsy, in contrast to around 1percent of the general population.

Croen, Zerbo & Qian (2015) also found that adults with ASCs had significantly higher rates of all mental health diagnoses when compared to neuro-typical adults.

Access to Healthcare for those with ASCs

There is body of evidence indicating that people with disabilities experiences significant disparities in healthcare (Krahn et al, 2015; Drainoni, Lee-Hood, Tobias & Bachman, 2006).

Research carried out regarding children with autism have shown difficulties in accessing appropriate healthcare. Despite evidence of greater health care needs than the general population, it has been reported that children with ASCs have difficulty accessing appropriate healthcare, and this can lead to a high level of unmet need in this group (Tregnano & Cheak-Zamora, 2012). Their review discusses findings that children with ASCs have significantly higher utilisation of outpatient appointments, inpatient admissions and emergency department visits than neuro-typical children. However, access to healthcare was more likely to be reported as a difficulty by parents of these children and the review briefly considers some factors contributing to this. These included difficulties with with having access, such as referral problems and insurance coverage, and difficulties gaining access, such a lack of doctors specialising in ASCs.

Bruder, Kerrins, Mazzarella, Sims and Stein (2012) carried out a survey with a large sample of physicians who cared for adults, and found that they had received inadequate training in care for adults with ASCs and they also wished to have more.

What is Access to Healthcare?

"*Access to health care is concerned with the relationship between need, provision and utilisation of health services*." Gulliford et al. (2002), p19

Gulliford et al. (2002) described two ways in which access is often conceptualised in healthcare, as follows: *having* access and as *gaining* access. In order to have access the service needs to exist and be available, whereas in order for a person to gain access the person has been able to use the service. Gulliford et al. (2002) considered two further dimensions to facilitating access: firstly, services being relevant and effective; and secondly for barriers being considered from a socio-ecological perspective (e.g. views from different cultures).

The Institute of Medicine (1993) created the following model of monitoring access to healthcare. Barriers were divided into being structural, financial and personal in nature. They considered mediators of appropriateness, efficacy of treatment, the quality of providers and patient adherence and leading to outcomes of health status and equity of services. This model has been used when considering barriers that people with disabilities might face in accessing timely healthcare. Drainoni et al. (2006) found that the barriers reported by their participants fitted with the model of monitoring access (Institute of medicine, 1993) and importantly that these barriers were not mutually exclusive; they often interacted and overlapped.

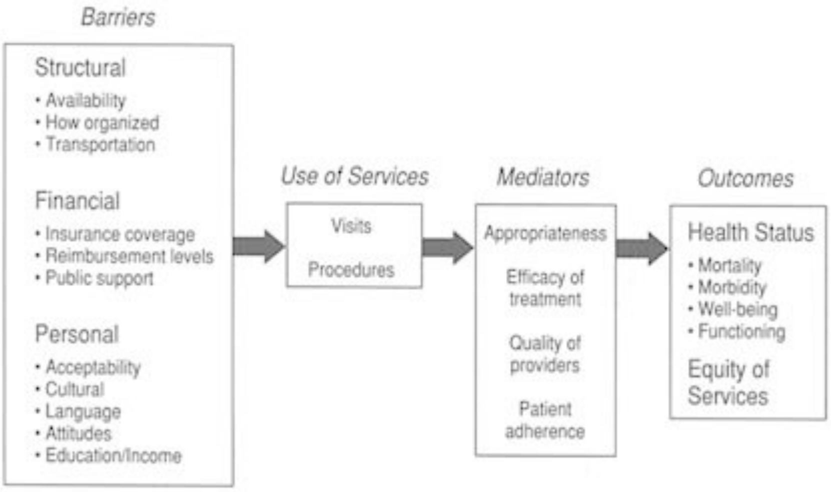

Figure 1

Model of monitoring access to healthcare. The Institute of Medicine (1993). Access to Healthcare in America (IOM) committee on Monitoring Access to Personal Health Care Services.

This review will aim to place emphasis on the process of gaining access to healthcare by examining barriers to and facilitators of successful healthcare experiences. With regards to the barriers outlined by the Institute of Medicine (1993), this review will aim to investigate barriers of a structural and personal nature, rather than financial, as these barriers were investigated in a previous review (Tregnano & Cheak-Zamora, 2012).

Theoretical Influences on the Review

"It is a rare and a precious gift to get a glimpse into another mind that operates on different assumptions and with different premises." Uta Frith, p744, The Psychologist, October 2014

This review aims to take a stance fitting with the social model of disability (Oliver, 2013) and the neurodiversity movement (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013). The social model of disability purports to show that disability is caused by the ways in which society is organised rather than the impairments of individuals.

A principle of neurodiversity is that neurological differences, such as those present in individuals with ASCs, should be recognised as difference rather than something to be cured. The movement advocates that support systems for those with ASCs should allow increased quality of life for them without adjust to the norms of society.

Existing Reviews

Tregano and Cheak-Zamora (2012) carried out a systematic review of disparities in health care for children with ASD in the US. This review focused on rates of health care utilisation for children with ASCs, the cost of this healthcare and whether there were difficulties with healthcare access. The review did not extract detailed information on what barriers to or facilitators of there may be to accessing healthcare.

Bishop-Fitzpatrick and Kind (2017) carried out a scoping review of health disparities for those with ASCs in relation to socio-demographic factors including age, race and gender identity. The review found that some socio-demographic factors were disadvantaging when combined with ASC status, this compounded physical health problems for people with ASCs.

Rationale

People with ASCs have been found to have more health problems than the general population (Croen et al. 2015) However, there is an extensive unmet need and access difficulties for people with ASCs have been reported (Tregnano & Cheak-Zamora, 2012). Previous reviews have examined what is known about the physical health of adults with ASCs, the disparities that children with ASCs face in accessing care (Tregnano & Cheak-Zamora, 2012), and how these disparities may become compounded when disadvantaging socio-demographic factors also hinder access (Bishop-Fitzpatrick & Kind, 2017). There are no reviews to the author’s knowledge examining the barriers to and facilitators of accessing successful healthcare experiences for those with ASCs. It was felt that a review examining these would be helpful for ideas improving the quality of services and addressing the difficulties that people with ASCs encounter that might discourage them from accessing services.

Aim

The aim of this review is to critically evaluate what barriers and facilitators exist for adults with ASCs when gaining access to non-acute healthcare. This is to be examined from a multi-person perspective, including the views of people with ASCs, their health care providers and their supporters or carers. The review therefore aims to answer the following questions:

1. What are the barriers to accessing non-acute healthcare for adults with ASCs?
2. What are the facilitators to accessing non-acute healthcare for adults with ASCs?

Method

Literature Search

A systematic search of the following three electronic databases was carried out in February 2018: PsychINFO, Applied Social Science Index and Abstracts (ASSIA) and Medline (Figure 2).

In addition to this the journal "Autism" was searched, and Google Scholar was used and the references were hand searched.

Table 1
Inclusion and exclusion criteria

	Inclusion	Exclusion
Study design	Empirical studies reporting original data	Studies that do not include data (e.g. book reviews).
Population of interest	Adults with ASCs Healthcare professionals working with adults or emerging adults (about to transition to adult services) with ASCs Carers/parents/supporters of adults with ASCs	Children and adolescents, unless at point of transitioning to adult services
Focus of study	Barriers to and facilitators of successful healthcare experiences for those with ASCs, including mental health care.	Access to diagnostic services

	Suggested interventions to aid successful healthcare experiences for those with ASCs.	Studies primarily considering financial barriers such as insurance access.
	Outpatient services rather than acute or inpatient care.	Studies considering only health care utilisation without indicator of what barriers and/or facilitators were present Studies considering solely socio-demographic factors Paper focused solely on clinician knowledge of ASD Study contained no extractable data on barriers or facilitators to gaining appropriate healthcare.
Language	English	Not English
Period of time	Database inception	February 2018

Search Terms

The following search terms were combined: (Asperger* OR “high functioning autism” OR “neurodevelopmental disorders” OR “HFA” OR “ASC” OR “ASD”) AND (access* or facilitat* or enable* or "quality" or "barriers" or "obstacles" or "hinder") AND (“health care” or "healthcare" or hospital or "medical care" or "primary care" or "service").

The literature search yielded 622 papers in total. Once duplicates were removed, titles and abstracts were examined to see if the paper was relevant to the literature review. If it was not clear at that stage whether or not a paper was relevant it was included for full reading to check this with the inclusion criteria.

The Preferred Reporting Items for Systemic Reviews and Meta Analyses (PRISMA; Moher, Liberati, Tetzlaff, Altman & Group, 2009) diagram is shown below in figure 1.

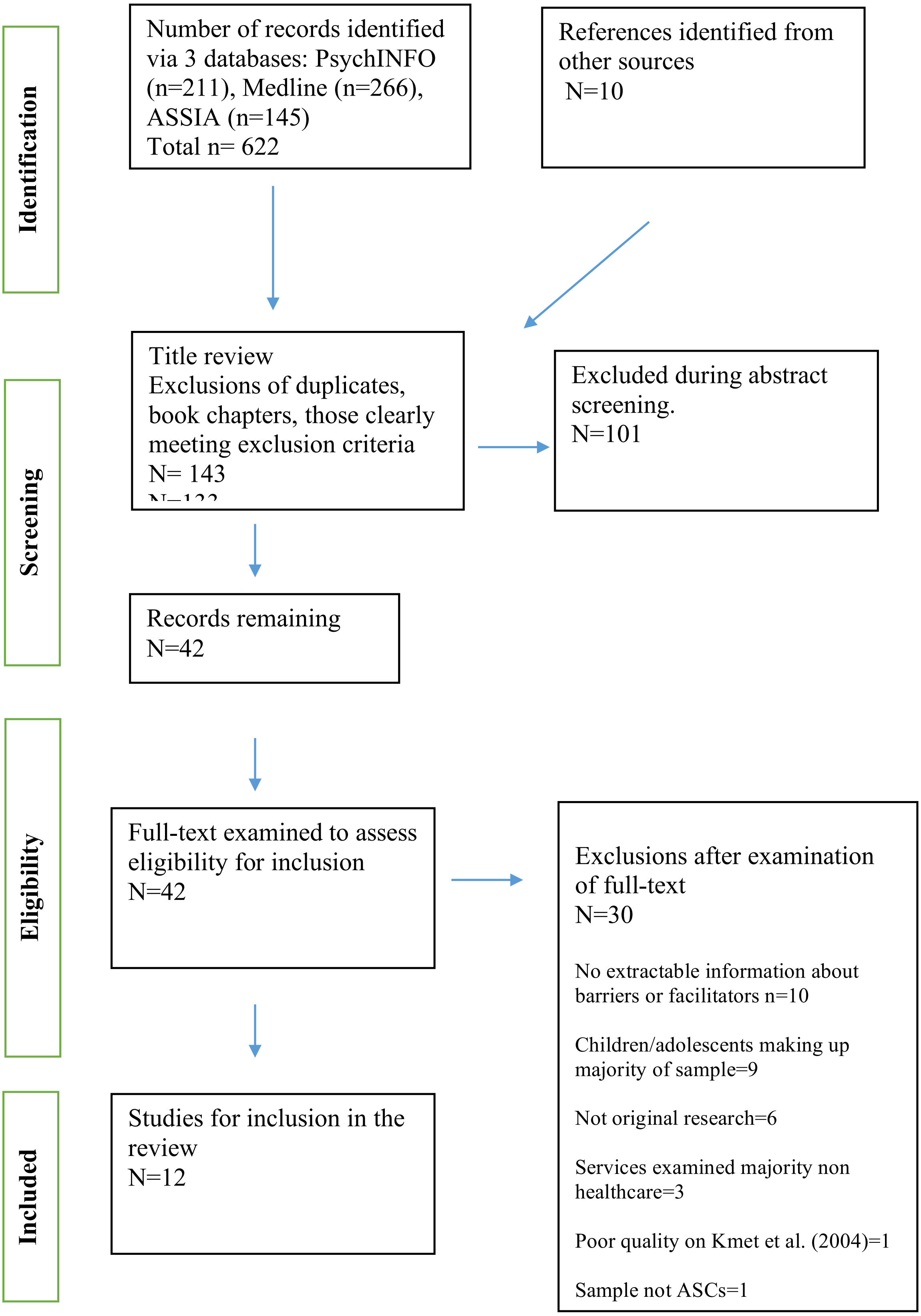

Figure 2
PRISMA flow diagram demonstrating literature search

Quality Assessment

The papers were assessed using the Standard Quality Assessment Criteria for Primary Research (Kmet, Lee & Cook, 2004), as this could be used to evaluate both qualitative and quantitative studies concurrently. Papers were assessed and awarded a quality percentage, as shown in tables 2 and 3. Papers scoring above 75% were considered to be of a good quality with the lowest acceptable cut off point being 55% (Kmet et al, 2004). One paper was excluded based on this quality assessment; Dern and Sappock (2016) scored 45% on the Kmet et al. (2004) assessment.

Search Results

The search yielded 12 papers that met the inclusion criteria. A summary of these papers can be seen in tables 4 and 5.

Structure of the Review

A quality assessment of the papers is presented followed by a table summary of the findings from the papers, relating to the aims of the review to discover barriers to and facilitators of appropriate access to healthcare. A general critique of the papers is then presented and is followed by a literature review. The discussion then considers the strengths and limitations of the current review, as well as clinical and research implications.

Table 2

Quality assessment of studies using qualitative methods

	Tint & Weiss (2017)	Kuhlthau et al. (2015)	Cheak-Zamora & Teti (2015)	Nicolaidis et al. (2015)	Dern & Sappock (2016)	Crane et al. (2018)	Saqr et al. (2018)	Warfield et al. (2015)
Question / objective sufficiently described?	2	2	1	2	2	2	2	2
Study design evident and appropriate?	2	2	2	2	1	2	2	2
Context for the study clear?	2	2	1	1	1	2	2	2
Connection to a theoretical framework / wider body of knowledge?	2	1	2	2	2	2	2	2
Sampling strategy described, relevant and justified?	1	1	1	1	1	1	1	1
Data collection methods clearly described and systematic?	2	1	2	2	1	2	2	1
Data analysis clearly described and systematic?	1	2	2	1	0	2	1	2
Use of verification procedure(s) to establish credibility?	0	2	2	2	0	2	2	2
Conclusions supported by the results?	2	1	2	2	1	2	2	1
Reflexivity of the account?	0	0	0	0	0	0	0	0
Total %	70*	70*	75	75	45*	85	80	75

*Scores over the 75% cut-point are considered good quality (Kmet et al. 2004). Scoring: 2=yes, 1=partial, 0=no, N/A=not applicable

Table 3

Quality assessment of studies using quantitative methods

	Vogan, et al. (2017)	Lum et al. (2014)	Raymaker et al. (2017)	Nicolaidis et al. (2012)	Nicolaidis et al. (2016)	Saqr et al. (2018)
Question / objective sufficiently described? Subject (and comparison group, if applicable) characteristics sufficiently described?	2	1	2	1	2	2
Study design evident and appropriate?	2	1	2	2	2	2
Method of subject/comparison group selection or source of information/input variables described and appropriate?	1	1	1	1	1	2
Subject (and comparison group, if applicable) characteristics sufficiently described?	2	1	1	2	2	2
If interventional and random allocation was possible, was it described?	n/a	n/a	n/a	n/a	n/a	n/a
If interventional and blinding of investigators was possible, was it reported?	n/a	n/a	n/a	n/a	n/a	n/a
If interventional and blinding of subjects was possible, was it reported?	n/a	n/a	n/a	n/a	n/a	n/a
Outcome and (if applicable) exposure measure(s) well defined and robust to measurement misclassification bias? means of assessment reported?	2	2	2	2	2	2
Sample size appropriate?	1	1	2	2	1	n/a
Analytic methods described/justified and appropriate?	2	2	1	2	1	1
Some estimate of variance is reported for the main results/outcomes	2	2	n/a	2	1	n/a
Controlled for confounding	n/a	1	n/a	2	1	n/a
Results reported in sufficient detail?	2	1	2	2	2	2
Conclusions supported by the results?	1	1	1	2	2	2
Total %	85	70*	70*	90	77	93

*Scores over the 75% cut-point are considered good quality (Kmet et al. 2004). Scoring: 2=yes, 1=partial, 0=no, N/A=not applicable

Table 4

Summary of study characteristics

Study	Aims	Methodology	Sample	Measures	Barrier (B) or facilitator (F)?	Analysis	Key Findings
1.Tint and Weiss (2017)	To explore: 1) how women with ASCs perceive their service and support experience; 2) unmet service needs for women with ASCs; 3) barriers to care for women with ASCs.	Inductive semantic analysis of focus groups	n=20 adult women with diagnosed ASCs. No participants reported a diagnosis of ID.	Focus groups with topic guide.	B- Communication B-Person masking difficulties B- Provider knowledge B- Diagnosis used as exclusion criteria B- Support not tailored F- Professional seeing the person as an individual	Inductive, semantic level analysis.	Women emphasised high unmet service needs, particularly with regards to mental health concerns. Themes of masking service needs, (Mis)communication with service providers and accessing appropriate services: "a constant struggle."
2.Kuhlthau, Warfield, Hurson, Delahaye and Crossman (2015)	To consider: 1) what are the current strategies and interventions taking place in paediatric settings to facilitate successful transition to adult health care for youth with ASCs; 2) what would help this transition.	Framework approach	n= 19 Health-care professionals including 5 physicians, 5 psychologists, 7 social workers and 2 nurses. All working in transition centres.	Semi-structured interviews with interview topic guide.	F- Written medical records F- Giving resource links F- Care coordination F-Transition-specific appointments F- Transition centres F-Training for adult providers	Framework approach.	Five intervention strategies currently being used by these HCPs: providing families with written medical summaries to give to adult providers, compiling lists of available providers or community resources, coordinating care and communication, transition appointments and using transition check lists. Other strategies identified as needed were training for adult providers.

3.Nicolaidis, Raymaker, Ashkenazy, McDonald, Dern, Baggs, Kapp, Weiner and Boisclair (2015)	To gain an in-depth understanding of autistic adults' experiences with healthcare and their recommendations for improving care.	Interviews with thematic analysis	39 adults with diagnosed ASCs and 16 people who had experience of supporting adults with ASCs in healthcare setting.	Semi-structured interview, Interview topics: positive and negative experiences of care, how being on the spectrum affected care and recommendations for improving care.	B- Communication between person and provider B- Sensory sensitivities B- Challenges with body awareness B-Challenges with organisation B-Provider knowledge and incorrect assumptions about ASCs B- Provider openness to proving accommodations B-Provider skill in incorporating supporters. B-Availability of supports B-Complexity of healthcare system B- Accessibility of facilities B- Stigma about autism	Thematic analysis.	Autism-related factors that impact healthcare interactions- verbal communication skills, sensory sensitivities, challenges with body awareness, slow processing speed, atypical non-verbal communication, and challenges with organisation. Provider-level factors: knowledge about autism, incorrect assumptions about individual patients, willingness to allow written communication, use of accessible language, openness to providing other accommodations, and skill in appropriately incorporating supporters. System level factors: availability of supporters, complexity of healthcare system, accessibility to healthcare facilities, and stigma about autism.

4. Raymaker, McDonald, Ashkenazy, Gerrity, Baggs, Kripke, Hourston and Nicolaidis (2017)	To compare barriers to healthcare experienced by autistic adults and adults with and without other disabilities.	Survey	437 adult participants (209 autistic, 228 non-autistic). Adults reported that they were diagnosed with ASCs.	Questionnaire created for study: “Barriers to healthcare checklist: advocates.” A cross-disability measure developed by the Oregon Institute on Development and Disability based on systematic lit review.	Most striking differences between groups: B- Communication B- Sensory processing B- Patient provider communication B- Appointments too short	Chi-square and descriptive statistics.	Differences between groups, people with disabilities and not autism), people with autism and people with no reported disability/autism. 56 barriers were endorsed by at least 5% of the groups with ASCs, 23 barriers were endorsed by 20% or more.
5.Lum, Garnett and O’Connor (2014)	To compare the healthcare experiences of women with and without HFA.	Survey	N=58, 32 women with diagnosed ASCs and 26 women who cared for a child or adult with ASCs (they did not have a diagnosis themselves)	Questionnaire created for study through consultation with clinicians, literature review and qualitative feedback from women diagnosed with HFA. 16 general healthcare	B-Stigma. B-Perception of uninformed professionals. B- Healthcare anxiety, communication under distress and sensory sensitivities.	t-tests and descriptive statistics.	Stigma- 75% of autistic sample did not report their autistic status because they felt their disclosure would affect treatment or communication. Differences in healthcare experiences for women with and without ASCs- healthcare anxiety, communication under emotional distress, anxiety related to the presence of other patients in the waiting rooms, support

				questions, 5 maternity healthcare questions, 7 items relating to ASD diagnosis.			during pregnancy, and communication of pain and needs during childbirth. In all cases, women with ASCs were more likely to perceive difficulties/dissatisfaction than the women without ASCs. 100% of participants had experienced frustration with uninformed clinicians.
6.Vogan, Lake, Tint, Weiss and Lunsky (2017)	Autistic adults' experience of accessing and using health services, barriers to service use and unmet service needs.	Survey	40 adults with diagnosed ASD and without intellectual disability.	Autism Spectrum Quotient, Kessler-Psychological Distress Scale-6 (K-6), Need for Help Questionnaire (adapted), questions about service use and service satisfaction.	Four most common barriers: B-Not knowing where to find help, B-feeling overwhelmed with the steps to seek help, B-having difficulties describing problems/needs B-negative experiences with professional help.	Descriptive and bivariate analyses.	Adults were somewhat satisfied with the services they received but encountered multiple barriers finding and accessing services. Three quarters of participants indicated a need for additional services that they could not access. Over three quarters of participants reported three or more barriers to service use.

7.Warfield, Crossman, Delahaye, Der Weerd & Kuhlthau. (2015)	To better understand how these providers became interested in serving individuals with disabilities, their training, the challenges they face and their ideas for clinicians offering this care.	Case study research.	N=10 healthcare professionals (9 physicians and 1 nurse) who were providers of primary medical care to adults with ASD (but not exclusively).	Structured interviews using topic guide. Questions regarding: site characteristics, provider experience and background with ASD, practice environment and provision of care detail, care coordination and interactions with other medical providers, including recommendations.	B- shortage of medical and non-medical services and/or supports. In part due to financial disincentives. B- Time constraints and organisation of patient care. B- Complexity of family involvement. B-Physical environments. B-Communication challenges. B-Training level. F- Financial incentives F- Using resources and knowledgeable staff. F-Training	Framework approach.	Barriers at system-level, practice/provision levels, communication challenges and training and education.
8.Nicolaidis, Raymaker, McDonald, Dern, Boisclair, Ashkenazy and Baggs (2012)	To compare the healthcare experiences of autistic and non-autistic adults.	Survey	437 adults (209 diagnosed autistic, 228 non-autistic)	Items from 2007 Health Information National Trends Survey relating to patient-provider communicatio	B- Patient-provider communication. B- Healthcare self-efficacy	Multivariate analyses.	Autistic group reported more unmet need in healthcare, higher use of emergency department and lower utilisation of preventative services. Patient-provider communication and health

				n, healthcare self-efficiency scale, all items adapted for the study.			care self efficacy found to be lower in autistic group.
9.Saqr, Braun, Porter, Barnette and Hanks (2018)	This study sought to: 1) identify environmental and process barriers to care access in our primary care environment; 2) describe general patient self-identified barriers to medical care, and; 3) examine medication use in our adolescent and adult population as potential approaches to recognize and overcome some of the barriers patients with ASD experience.	Retrospective cross-sectional design and participatory design research.	Focus group n=10 adults with diagnosed ASCs, and chart review n=146 (Ages 15+ with diagnosed ASCs).	Focus group topic guide. Questions included: feelings about current healthcare clinic, how they think it should make them feel, barriers to visit. Chart review including assessment phone call barriers identified.	B- Communication with physician B- Waiting room and sensory issues B- Physical exam B- Anticipation of social interaction leads to anxiety and overstimulation which then affects ability to focus and communicate. B- Aversion to needles, difficulty being touched and vital signs.	Focus group analysis: thematic process used. Chart review: descriptive statistics.	Both the focus group and the pre-assessment visit chart review identified the waiting room and waiting time as barriers to care.

10.Crane, Adams, Harper, Welch and Pellicano (2018)	To explore: 1)What are young autistic people's views and experiences of mental health problems and services 2)How can we best support young autistic people who are experiencing mental health problems.	Community-based participatory research (CBPR). Survey and interviews.	130 young autistic adults (who has a reported diagnosis). 109 completed an online survey and 21 took part in detailed interviews.	Online survey created for study: this included 12 statements from the General Health Questionnaire (Goldberg & Williams, 1988) and the World Health Organization's Brief Quality of Life (WHOQOL-BREF) and semi-structured interviews.	B- Lack of suitable services. B- Mental health problems not seen as severe enough. B- Delays to access. B- Support not tailored. B- Lack of support transitioning to adult services. B- Lack of knowledge in professionals. B- Stigma. F- Professionals seeing the person as an individual.	Thematic analysis for interviews. Descriptive statistics for online survey.	How young autistic adults find it hard to evaluate their mental health, experience high levels of stigma and face obstacles when attempting to access mental health services.
11. Cheak-Zamora and Teti (2015)	To examine the health care transition of paediatric care into adulthood.	Focus group with thematic analysis	Youth with ASD (n=13), their caregivers (n=19). Youth aged 15-25. All had diagnosis of ASD.	Semi-structured focus groups	B- Little support in transition to adult services. B-Lack of understanding of ASD amongst adult healthcare providers. B- Caregivers not able to make appointments and decisions for child anymore and child not skilled up to do it by themselves.	Thematic analysis.	Parents discussions: loss of relationship with provider and a lack of support transitioning from paediatric to adult care. Providers lack of knowledge about ASD. Concerns about losing guardianship. Youth: confusion and anxiety around medical providers' role and

					B-Youth with autism experiencing anxiety and confusion about their care as parents have always dealt with it.		managing their medical lives independently.
12. Nicolaidis, Raymaker, McDonald, Kapp, Weiner, Ashkenazy, Gerrity, Kripke, Platt and Baggs (2016)	To develop and evaluate tools to facilitate the primary health care of autistic adults.	Mixed methods. Cognitive interview, test-retest reliability study and single-arm pre/post intervention comparison.	259 autistic adults (self report of diagnosis) and 51 primary care providers.	Questions regarding: Satisfaction with patient provider communication, healthcare self efficacy, barriers to healthcare and satisfaction with toolkit.	F- Toolkit.	Pre/post use comparisons	Autism healthcare accommodations toolkit (AHAT) found to be easy to use, important and useful. It’s use decreased barriers to healthcare, increased health care self efficacy and patient-provider communication.

Results

Study Quality

Use of Kmet et al. (2004) indicated that the majority of the papers examined were above the good quality cut-off of 75 percent. However, four papers included were below this at 70 percent.

Design Characteristics

Most of the studies used cross-sectional designs to investigate experiences of healthcare for those with ASCs and/or challenges associated with providing care. There were three studies using focus groups, three using semi-structured interviews, four using quantitative surveys, one using mixed methods (quantitative survey and focus group) and one mixed methods intervention study (using pre and post intervention measures and qualitative survey). The use of cross-sectional research designs meant that there was no understanding of how access may change over time, and findings may only be relevant to a particular time and circumstances; meaning they may not be generalisable.

One study (Vogan et al., 2017) used a longitudinal design to examine the experience of accessing health services, barriers to service use and unmet need.

Quantitative surveys used a variety of questionnaires to investigate but these were rarely validated measures. Many of the studies used questionnaires that were created for the study (Lum et al., 2014; Raymaker et al., 2017; Nicolaidis et al., 2016) or adapted pre-existing measures (Nicolaidis et al., 2012, Vogan et al., 2017). Acceptable Cronbach's alpha scores were reported on both studies using adapted pre-existing validated measures.

Using validated measures is important to help confirm that the measure is measuring what it claims to be measuring. Validity would also be improved by adapting scales so that they are appropriate for the population completing them but these adaptations should also then be validated.

Seven of the studies were carried out in the USA, one in the USA and Canada, two in Canada, one in Australia and one in the UK. These countries all differ in their healthcare systems and therefore the studies may be quite culturally specific both with regards to how healthcare is provided and how healthcare is viewed by the population. For example, the USA provides health care based on insurance coverage, which not all of the population have, whereas the UK has a health service which is free at the point of entry.

Sampling

All the papers reviewed had used purposive sampling to recruit their participants in order examine the views of people with ASCs, their HCPs or their carers. By sampling in this way the papers may have included only those who were motivated to take part in research, and potentially excluded those who found communicating their views more difficult. This means that this review may be less applicable to those with ASCs who do not have much language ability.

However, efforts were made in some papers to include supporters as proxy voices for those who found communication more challenging or were non-verbal, and to assist those who found communication a challenge as much as possible (Nicolaidis et al., 2015; Nicolaidis et al., 2016; Saqr et al., 2018).

Many studies required the participants to have enough language ability to give their views, via written survey (Raymaker et al., 2017; Lum, Garnett & O’Connor., 2014; Vogan et al., 2017; Nicolaidis et al., 2012, Nicolaidis et al., 2016), or via a focus group (Crane et al., 2018; Tint & Weiss., 2017; Cheak-Zamora & Teti., 2015), or via interviews (Crane et al., 2018). These studies therefore may have represented the views and experiences of people with ASCs who have language abilities.

Several studies commented on the majority of the diagnoses in the sample being Asperger’s Syndrome or high functioning autism (Nicolaidis et al., 2012; Crane et al., 2018; Lum et al., 2014; Vogan et al., 2017). However, Saqr et al. (2018) reviewed files of all those with ASC diagnoses and around 50 percent of them also had a diagnosis of an intellectual disability.

Several studies did not mention whether their participants also had an intellectual disability but referred to their participants as having enough language ability to take part in the study (e.g. focus groups). Furthermore, the studies which considered clinician views were carried out with clinicians seeing people with wide ranging difficulties on the autistic spectrum and would therefore included those who were less able to communicate.

Only four studies made an assessment of presence of ASC difficulties during the study (Vogan et al., 2017; Saqr et al., 2018; Nicolaidis et al., 2012; Nicolaidis et al., 2015) whereas the others relied on reported diagnoses.

Women were overrepresented in the studies, with two studies carried out of only women (Tint & Weiss, 2017; Lum et al., 2014), five studies with a female majority (Crane et al., 2018; Vogan et al., 2017, Raymaker et al., 2017; Nicolaidis et al., 2012, Nicolaidis et al., 2016) and three studies with a male majority (Saqr et al., 2018; Nicolaidis et al., 2015 & Cheak- Zamora & Teti, 2015). It has been found that women are more likely to participate in research (Smith, 2008) which may contribute to higher numbers of women taking part in these studies. Two studies deliberately recruited only women as part of their research question (Tint & Weiss, 2017; Lum et al, 2014). Although in recent years' research has questioned whether the prevalence of ASCs in women is higher than was reported previously, the majority of those diagnosed with autism are still male (Kim et al, 2011). This may mean that the findings of this review may be more applicable to women with ASCs than men.

Analysis

All papers using a qualitative methodology lacked a reflexivity of account in their analyses. A lack of reflexivity may indicate a lack of awareness around the researcher's own assumptions and may allow for bias in how data is interpreted.

Communication Issues

All of the papers examined considered communication difficulties as a significant barrier to gaining satisfactory healthcare experiences. There was a variety of ways in which communication was considered to be difficult; receptive and expressive language were highlighted, as well as the impact of anxiety and confusion on this.

Expressive language is important in health care interactions as it allows the patient to convey their difficulties and needs are. Difficulties experienced with expressive language included patients feeling that they could not “speak the same language” as the services (Tint & Weiss, 2017) and were unable to communicate their needs (Tint & Weiss, 2017; Vogan et al., 2017), especially when it came to explaining bodily sensations such as pain or sensory sensitivities (Tint & Weiss, 2017; Nicolaidis et al., 2015; Warfield et al., 2015).

Communication of pain seemed to be a particularly important theme, with participants with ASCs reporting that some of the ways pain had been described to them (e.g. shooting or burning) did not make sense (Nicolaidis et al., 2015), and providers commenting that a challenge of working with people with ASCs was working out how they might express pain or discomfort.

These communication difficulties seemed common, with Vogan et al. (2017) finding that 47 percent of people with ASCs surveyed had difficulty describing their problems and needs, and Raymaker et al. (2017) corroborated this finding, with “difficulty communicating” with HCPs reported by approximately a third of their large sample of people with ASCs.

Receptive communication barriers are reported by many of the papers, in particular, with reference to not being able to process information at the speed at which it is given by HCPs. Raymaker et al. (2017) found speed of language processing to be in the top five endorsed barriers by people with ASCs, with 32 percent of the sample reporting this as a problem during appointments. This difficulty in processing information at the same rate as providers, meant that these participants were unable to keep up with conversations between the provider and themselves, or follow written instructions (Raymaker et al., 2017). People with ASCs in this study indicated that appointments were too short to meet their communication needs successfully.

Nicolaidis et al. (2012) corroborated these findings by comparing the experiences of people with ASCs and without ASCs, finding that those with ASCs were less satisfied with the communication and subsequent understanding during their appointments.

In interviews with adults with ASCs and their caregivers, Nicolaidis et al. (2015) found that the participants reported that they had experienced resistance from providers to allowing them to communicate in written format and often they did not use accessible language.

A compounding factor acting as a barrier to communication that was also found in the papers was the interaction between communication and anxiety for the person with ASCs. Saqr et al. (2018) formulated an interactive model of interaction within their focus groups with people with ASCs about their medical care. A negative feedback loop was described that began with a fear of social interaction and was perpetuated by heightened sensory sensitivity which then leading to making it hard to concentrate and interact with the provider in the appointment.

Lum et al. (2014) described a similar idea concerning communication, finding that when women with ASCs were compared to women without, they experienced greater levels of anxiety in health care appointments, and when distressed they also experienced a greater level of difficulty communicating verbally.

The focus group of adults with ASCs (Saqr et al., 2018) suggested that these difficulties could be alleviated by creating tailored communication channels between providers and patients and creating an environment that was less likely to result in sensory overload. However, the paper did not elaborate on what this might involve.

A suggested facilitator was used by Nicolaidis et al. (2016) who piloted an Autism Healthcare Accommodation Toolkit (AHAT). The toolkit was provided online for people with autism and their associated HCPs to use; it included the creation of a personalised accommodations report, worksheets for to preparing for appointments for patients, and checklists for HCPs. There was a facility for the reports to be shared with the patients' HCPs before their appointment. Part of the report that participants in this study could create using AHAT included help on how to communicate. It was found in qualitative feedback that the toolkit was considered easy to use, important and useful. It was considered by the participants to be an effective way of communicating their needs, and pre and post comparisons showed a decrease in provider-patient communication difficulties.

Facilities and Sensory Overload

The majority of the papers reported a barrier of distressing sensory experience when attending health care appointments, both in the waiting room environment and resulting from procedures during the visits. Reports of the physical environment as unsuitable were given both by people with ASCs, their carers (Saqr et al., 2018; Lum et al., 2014; Raymaker et al., date; Nicolaidis et al., 2015), and staff (Warfield et al., 2015). The waiting room was often highlighted as a source of sensory stress with over-stimulation such as noise (Nicolaidis et al., 2015; Saqr et al., 2018), overcrowding (Lum et al., 2014) and bright lighting (Saqr et al., 2018). Nicolaidis et al. (2015) found that positive experiences of healthcare appointments were attributed to quiet environments with natural lighting or a private waiting area.

Some tactile sensory experiences were also found to be distressing and were reported as a barrier. Saqr et al. (2018) found that aversion to needles, difficulties with being touched and being unable to tolerate vital signs being taken were cited as barriers.

Raymaker et al. (2017) found that a quarter of their participants with ASCs endorsed that sensory distress as having a significant impact on communication and their capacity to tolerate the appointment. This was a significantly larger percentage of the sample with autism than of those with other disabilities.

Saqr et al. (2018) implemented changes to medical visits for patients that had previously documented changes on their medical records. The medical teams then carried out the following changes: rooming the patient immediately on arrival, not performing vital signs check on arrival; notifying the patient before touching them; the patient waiting in the car until the clinician ready to see them; turning lights out in the room before entry; first appointment of the day allocation; and a security guard present but not visible to the patient. This was carried out with 23 percent of the files reviewed (17 people) and all of these appointments led to the patients being successfully assessed by the clinician. There was no information about whether this group had experienced successful appointments previously with or without adaptation so the outcome can therefore only be interpreted tentatively.

Warfield et al. (2015) found that clinicians who had identified themselves as providing care to those with ASCs reported several facilitators for people with ASCs when attending their appointments. In these appointments, patient lists were reviewed everyday and those with ASCs were prioritised in order to reduce their waiting times, and/or an arrangement was made to provide access to a smaller waiting room.

Provider Knowledge of Autism

Studies examining the views of people with ASCs, carer views and those of HCPs indicated that a lack of knowledge on the part of providers about autism represented a barrier to gaining healthcare.

People with ASCs reported that professionals made incorrect assumptions about them in relation to their autism and they felt that there was a general lack of knowledge as to what autism was and how they could be supported (Nicolaidis et al., 2015). People with ASCs in Crane et al. (2018) reported concerns about seeking support from professionals who did not have enough knowledge about what autism was and 100 percent of the women with ASCs in Lum et al. (2014) reported frustration with “uninformed clinicians.”

Tint and Weiss (2015) found their participants with ASCs often attributed their difficulties with communication to having to interact with “inexperienced experts.” Frustration was expressed about professionals not understanding the global impact of having an ASC.

Cheak-Zamora and Teti (2015) and Nicolaidis et al. (2015) found that parents/carers of people with ASCs felt similarly that HCPs were lacking in knowledge about autism. This was perhaps more prominent with parents in Cheak-Zamora & Teti (2015) who were parents of emerging adults transitioning to adult services and meeting new professionals serving adult populations.

Studies examining the views of HCPs also considered lack of relevant HCP training in ASCs as a challenge to this group’s willingness to to provide care for people with ASCs, due to the impact of their confidence (Warfield et al., 2015; Kuhlthau et al., 2015). Participants in the study by Warfield et al. (2015) suggested facilitators that were ways of sharing knowledge about autism, including the creation of localised lists of resources and support (e.g. communication techniques), and connecting up with the patients’ paediatrician and other clinicians who were knowledgeable about autism.

Transition and Developmentally-Appropriate Services

The papers selected for review were chosen because they explored adult experiences of healthcare. Emerging adulthood was considered within these experiences as these young people would be attempting to gain access to adult services for the first time; therefore, two papers were included as they presented facilitators and barriers to transitioning to adult health care (Kuhlthau et al., 2015; Cheak-Zamora & Teti, 2015).

Although the two papers above were designed to consider this transitionary period, it was highlighted in other papers as important (Tint & Weiss, 2015; Crane et al., 2018), and many others highlighted provider expectations of adult-style independence in healthcare (Vogan et al., 2017; Raymaker et al., 2017; Nicolaidis et al., 2012).

Cheak-Zamora and Teti (2015) qualitatively examined the views of youths with ASCs and their caregivers and found that health care challenges were common in transition to adult services and that there was a perceived lack of support from providers with this issue. All of the caregivers described that there was a lack of preparation for their children in moving services and many expressed concerns about their child reaching an age where they were expected to manage their own health care, whilst parents were no longer allowed to contribute.

This reduction in support was described in other studies; for example, in the study by Crane et al. (2018) adults with ASCs stated that the adult services were much less supportive, that they were not prepared for this, and that they felt they could not manage their mental health care independently in the way that they felt adult services expected from them to.

This finding from a study examining views of mental health provision is echoed in other studies examining physical health services. Raymaker et al. (2015) examined barriers that people with ASCs faced accessing healthcare compared with people without ASCs but with other disabilities, and found that many factors endorsed, linked to self-efficacy in health behaviours. For example, 23 percent of the group with ASCs found following up care difficult (e.g. taking drugs as prescribed), compared with 13 percent of the group with a different disability. Lack of confidence and finding the healthcare system hard to navigate were also indicated by significantly more people with ASCs than with other disabilities.

Vogan et al. (2017) also found that over half of the participants with ASCs in their study felt overwhelmed with the steps to seek help and 66 percent did not know where they could find help for their health needs.

Nicolaidis et al. (2012) found that health care self-efficacy was lower in the people with ASCs taking part in their study compared with neuro-typical people when measured using an adapted health self-efficacy measure. This scale included measures such as “I can get reliable information about my health.”

Kuhlthau et al. (2015) carried out interviews with HCPs to investigate what facilitators they felt necessary to enable successful transition for people with ASCs from child to adult services. Training for adult HCPs and medical students was one of their recommendations; this included education about ASCs and how to work with people with ASCs.

Nicolaidis et al. (2016) found that after participants with ASCs used their AHAT, their self-efficacy in navigating the healthcare system was rated significantly higher. Many participants also reported that they felt empowered to to self-advocate more effectively.

Stigma

Stigma associated with having a diagnosis of an ASC was considered a barrier in four studies (Nicolaidis et al., 2015; Crane et al., 2018; Lum et al., 2014; Vogan et al., 2017).

Participants in Nicolaidis et al., (2015) were hesitant to disclose their diagnoses due to a fear that they would subsequently be discriminated against due to this. The impact of providers holding misconceptions was considered as contributing to this fear; for example, one participant shared an experience of HCPs assuming that she could not experience empathy because of her ASC.

In focus groups of people with ASCs in Crane et al. (2018), stigma about autism was a factor the participants considered made them less likely to seek professional help for their difficulties.

These findings were corroborated further by the study by Lum et al. (2014) in which 75 percent of the women with ASCs did not report their autistic status because they felt this disclosure might affect subsequent treatment or communication following this. Vogan et al. (2017) also found that around a quarter of their participants with ASCs felt that fear of labelling, or stigma, was a barrier to health care service use.

Lack of Available Services and Support

Although this review was aimed at considering barriers and facilitators to gaining access to healthcare services, a theme that emerged from the papers examined was that participants were experiencing difficulties having access to services due to their availability.

Crane et al. (2015) considered mental health services in particular, with participants with ASCs commenting on a lack of available services both for mental health and autism in general. When participants had attempted to access mental health services, they reported not having access due to their problems not being severe enough, thus access was only gained when a crisis point had been reached.

Nicolaidis et al. (2015) highlighted the availability of supporters as being a significant barrier to providing care for people with ASCs. Both formal and informal supports were considered important, so as to manage the complexities of the healthcare system.

Warfield et al. (2015) found that staff identified a shortage of medical services, staff and non-medical services and supports for those with ASCs as were a barrier to receiving care. Participants in this study hypothesised that HCPs were not voluntarily working with people with ASCs due to the financial implications of spending more time with patients.

Holistic and Person-Centred Thinking

Crane et al. (2018) found that young adults with ASCs felt that mental health services were not tailored to their needs and that this lead to them withdrawing from services. The young adults in the study stated that they were not sure which of their difficulties were linked to their ASCs and which to their mental health; they suggested that this meant their support needed to bridge both effectively. They identified as good practice staff being able to see that everyone is unique and applying that to their work together.

Participants in the study by Tint and Weiss (2017) reported similar concerns; that there was a need for more individually tailored supports. The metaphor of a square peg in a round hole was used by one participant when describing how they felt they did not "look the part" to receive appropriate services.

Discussion

This review aimed to synthesise the literature investigating barriers and facilitators to gaining appropriate access to healthcare for people with ASCs. The literature suggested that there are a number of perceived barriers to healthcare for people with ASCs and these were cited by people with ASCs, carers/supporters of those with ASCs and medical staff working with them. Conversely, where there are barriers there was also often a suggestion of how these difficulties could generate facilitators, and examples of these were given, including a study in which the authors used these researched barriers to create a toolkit. The barriers identified were communication issues, facilities and sensory overload, lack of provider knowledge about ASCs, lack of support in transition to adult services, stigma about autism and absence of holistic and person-centred thinking. These barriers found within the literature broadly reflect categories of potential barriers highlighted by the social disability model: environmental, attitudinal and organisational (Oliver, 2013). As Drainoni et al. (2006) found in their research with people with disabilities, categories of barriers overlap and intersect with each other. For example, in this literature the barriers of stigma about autism may have quite a strong attitudinal component, however it may also be influenced by organisational issues such as a lack of training in ASCs. Equally, stigma may impact on the provider desire to obtain training.

The findings of this review focusing on adults with ASCs are concordant with research carried out with children with ASCs, in which a review considered their access to healthcare to be difficult which resulted in unmet need (Tregnano & Cheak-Zamora, 2012). This review focused on children also commented on a lack of doctors specialising in ASCs which was similar to the findings this review.

Strengths and Limitations of the Review

Patient experience and access to healthcare have been considered in this review in terms of barriers and facilitators to gaining access to healthcare. Gaining access refers to the patient being able to get use from a service that is appropriate for meeting their needs, rather than whether or not they have access a service that is in existence or not. This divide was considered of importance in order to capture the barriers that exist within services that are available in order to guide intervention within these. However, it could be said that this divide is a little artificial as in reality gaining access cannot exist without having access (i.e. you cannot gain access to a service you cannot have). There needs to be a consideration of the wider context of service use and availability and this is also culturally specific (e.g. healthcare access for those in the USA is influenced by insurance whereas in the UK it is not).

There were a variety of methodologies used in the papers in this review. Although this can be beneficial for triangulating findings, it can be difficult to bring together results and compare them to form a synthesis.

It is clear from the review that people with ASCs face a multitude of barriers when attempting to gain access to appropriate healthcare. However, the review does not provide an indication of the scale of the problem; how often people with ASCs are experiencing difficulties in access.

With all of the papers included in this review using a purposive sample, this may present some bias in who might take part in these studies. Several studies compared the experiences of people with ASCs with people without ASCs, both people with other difficulties (Raymaker et al., 2017) and neuro-typical populations (Lum et al., 2014; Nicolaidis et al., 2012) which is helpful in understanding what elements might be specific to being diagnosed with an ASC. Studies without this comparison could be criticised for examining issues that might be relevant to the health care systems as a whole rather than specific issues relating to ASC diagnosis, for example, Crane et al. (2018) found that people with ASCs felt they had to be in crisis to get support for their mental health difficulties, where it could be argued that this is true of most populations attempting to access mental health services.

Clinical Implications

This review highlights a perceived lack of knowledge about creating successful healthcare interactions with those with ASCs, both from the perspectives of people with ASCs, their supporters and their HCPs. Therefore, training would be recommended for HCPs in the following domains: adjusting communication, differences in and adjustments for sensory experiences, as well as features and the global impact of having an ASC.

Intervention to strengthen the relationships between the community of people with ASCs and professionals would be beneficial. This could involve outreach on behalf of professionals to local groups and organisations or yearly check-ups for people with ASCs. This could help to reduce stigma felt by people with ASCs in combination with the above recommended training that could debunk myths about features of ASCs. It would also provide people with information about the services that are available to them.

Adaptations to the physical environment of the appointment session should be considered. This includes paying attention to both what the waiting room and health appointment room is like; size, space, people that might be there, noise and lighting. In addition, or if these changes are not possible, HCPs should ensure efforts to book appointment times in collaboration with patients.

Patients should always be warned before they are touched by HCPs as this may cause distress.

Along these lines, best practice would involve making contact with the patient before their appointment. This could involve appointment times, introductions to the HCP and service, enquiring as to adaptations that might facilitate a successful appointment and gaining an understanding into what methods of communication the person might find the most helpful. These pre-appointment contacts would be of great importance when the person is transitioning from child to adult services and would promote confidence in the person and person's family. This pre-visit information gathering could be carried out in different ways: phone call with the person or carer or online such as the toolkit mentioned in this review. Longer or additional appointments should be considered as needed.

Transition is considered a key time for difficulty in access and interventions should be aimed at making this process more appropriate. There should be preparation to this transition for the person and a joint meeting between the child provider, the person (and supporter if needed) and the new adult provider. This would enable the sharing of information for use in future appointments, as well as promoting confidence and a pathway to independence.

HCPs should be made aware from training that adults with ASCs may need additional support in managing their healthcare away from the appointments. Interventions regarding this should be considered in a systemic way, for example, would it help for the person to have a dosette box if they find taking medication difficult. Resources around the healthcare system that the person is part of would also be helpful (e.g. who to contact when they have a problem).

Research Implications

Gaining access to healthcare service for people with ASCs is an under-researched area, particularly in comparison with research into autism as a whole and research carried out with children with autism. There is a lack of intervention studies as to what might be helpful for this population in gaining successful healthcare interactions. This could include putting in practice and evaluating some of the above recommendations.

The majority of the studies were carried out in the USA and Canada, countries in which healthcare is provided via insurance. It would beneficial for more research to be carried out in the UK so that adaptations relating the NHS could be considered full.

Only two of the studies considered appropriate access to mental health care. It would beneficial to carry out research in this area, particularly as by the nature of these appointments they are likely to be more in depth and involve greater clinician involvement (e.g. longer appointments).

Two studies examined HCP views in providing healthcare. It could be beneficial to examine the views of HCPs further, perhaps with focus on the difficulties reported by people with ASCs (e.g. stigma). Participatory action research with service users could be beneficial in examining this (Nicolaidis et al, 2011).

Conclusions

In conclusion, the literature tells us that there are a number of barriers to appropriate healthcare that people with ASCs experience as they navigate the system. Often as a result of these barriers people with ASCs, their carers and HCPs have developed or suggested facilitators to improving this access, and in practice some of these have been shown to improve elements of the appointments.

The main barriers identified were regarding communication, appropriate physical and sensory environments, HCP knowledge about ASCs, stigma, holistic person-centred thinking, transition and developmentally appropriate services and the availability of services.

The implementation of recommended strategies could be beneficial to this group, as well as then evaluating the success of these strategies.

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HELEN LAYTON BSC (Hons), MSc, PG Cert

ACCEPTABLE ACCESS TO HEALTH SERVICES FOR ADULTS ON THE AUTISM SPECTRUM

PART B: An investigation into the attitudes, perceived behavioural control and subjective norms of clinicians working with adults with autism spectrum conditions and a mental health difficulty.

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Abstract

Background: People with autism may experience higher rates of mental health difficulty, yet access to appropriate mental health support and services has been recognised as challenging.

Aims: This study aimed to explore whether components of the theory of planned behaviour (TPB) could explain variance in IAPT clinicians' intention to carry out interventions for mental health difficulties in people with high functioning autism (HFA) or Asperger's syndrome (AS). It also explored the effect on intention of past experience of carrying out these interventions.

Method: There were two stages to the study. The first stage involved a qualitative elicitation study, which investigated attitudes, subjective norms and perceived behavioural control factors in carrying out the interventions. The second stage was a questionnaire-based study. The questionnaire was created following content analysis of the qualitative data, and was completed by clinicians currently working in Improving Access to Psychological Therapy (IAPT) services (n=88). The data were then analysed using multiple regression.

Results: The theory of planned behavioural model predicted 56.5 percent of the variance in intention to carry out interventions for mental health difficulties for people with (autism spectrum conditions (ASCs). The most significant components in predicting intention were indirect attitude measures, direct measures of perceived behavioural control, and indirect subjective normative referents. Past experience of carrying out these interventions was significantly associated with intention when the individual had no experience of working with people with ASCs previously.

Conclusion: Further explorations of unaccounted variables impacting on intention to carry out interventions for mental health difficulties with people with ASCs could be valuable. Clinical implications include additional training for therapists in ASCs and development of adapted materials if part of the intervention. Future research could focus on therapy efficacy other than for cognitive behavioural therapy and in-depth accounts from therapists and service users with ASCs as to their therapeutic experiences.

Introduction

The introduction considers what autism spectrum conditions (ASCs) are, the language used to describe them, how mental health difficulties and ASCs occur together and what might exist to support people with ASCs with their mental health difficulties. Difficulties in accessing mental and general health support are then reviewed, followed by a discussion of ways in which research and development in this area could be driven by theory, in the form of the theory of planned behaviour, and the aims and rationale for the current study.

Autism Spectrum Conditions

In the Diagnostic and Statistical Manual Edition 5 (DSM; APA, 2013) the category of “autistic spectrum disorder” is defined as “persistent difficulties with social communication and social interaction” and “restricted and repetitive patterns of behaviours, activities or interests” present since early childhood, to the extent that these “limit” and/or “impair” everyday functioning. It is thought that around 1 percent of the population are on the autism spectrum (Brugha, McManus, Bankart, Scott, Purdon & Smith, 2011)

A Note About Language

Those with diagnoses of autism (as a whole) will be referred to using the term “autistic spectrum conditions (ASCs)”; where appropriate the terms high functioning autism and/or Asperger’s syndrome will be used to refer to people with ASCs who do not have an intellectual disability (ID), and therefore would not meet criteria to access ID services. The term “ASCs” is used to cover the whole autism spectrum unless made clear that people with high functioning autism (HFA) or Asperger’s syndrome (AS) are being thought about. The author acknowledges the removal of Asperger’s Syndrome from the DSM-5 (APA, 2013); however, in a recent study it was found that those with ASCs varied the language they preferred to use to describe their autism (Kenny, Hattersley, Molins, Buckley, Povey &

Pellicano, 2016). The UK autism community endorsed a number of terms in this study, including ‘autism’ and ‘on the spectrum,’ as well as preferring person-first terminology (e.g. person with autism), whereas “autism spectrum disorder” was endorsed to a lesser extent (Kenny et al. 2016). The term “neuro-typical” will be used to refer to those without autism and considered to be of “normative” development. The study will also use the term “intervention” to describe working with someone having difficulties with their mental health, as opposed to using the word treatment, which assumes a diagnostic or biomedical perspective (BPS, 2015).

Mental Health and Autistic Spectrum Conditions (ASCs)

Mental health was identified by UK autism charity Autistica as being the number one suggested research priority for those with ASCs (Crane, Adams, Harper, Welch & Pellicano, 2018), and has recently been debated in UK parliament with particular reference to serious case reviews relating to those with ASCs receiving poor care for their mental health difficulties (House of Commons, 29th March 2018, Vol 638).

Mental health difficulties have been found to affect 79 percent of adults with ASCs (Lever & Geurts, 2016), and rates of suicidal ideation are high (66 percent) in adults with ASCs (Cassidy et al, 2014). Despite these rates of difficulties being found, research has indicated that people with autism report difficulties when accessing mental health services (National Audit Office, 2009; Rosenblatt, 2008; DoH, 2014).

Studies have shown that adults with HFA or AS may be more vulnerable to difficulties with their mood; those with Asperger’s were found to be over nine times more likely to report suicidal ideation, and 35 percent of adults with HFA have made plans to attempt suicide (Cassidy et al, 2014).

Rosenblatt (2008) highlighted those with high functioning autism (HFA) as particularly vulnerable to “falling through the gap” between learning disability and mental health services.

“I’m on the high-functioning end [of the autistic spectrum] and so I don’t fit with mental health, I don’t fit learning disability. I just fall through the gaps between departments, whether it’s in the health service or social services. I just don’t fit anywhere.” Taken from Griffith, Totsika, Nash and Hastings (2011) p, 540.

The above quote from ‘Sheila’ is concordant with statistics on those with ASCs accessing social care; the percentage of those with ASCs and intellectual disability found to meet the social care eligibility criteria was 80.4 percent, whereas those with both an ASC and mental health difficulties was 4.8 percent (Public Health England, 2017). This finding suggests that the needs of this group are not being met.

In the UK only seven percent of autism research being carried out with adults (Autistica, 2018), little research has been conducted into the barriers facing adults with ASCs accessing or attempting to access mental health services. At the time of planning this project there were no published studies focusing on these issues specifically (see Appendix A for literature search). However, after mental health was endorsed as a research priority by young people with autism, a community-based participatory research project investigated the experience that people with autism had of mental health difficulties and accessing mental health services to address these (Crane et al., 2018).

The results of the study showed that many participants found it difficult to know if what they were experiencing were difficulties with their mental health, and if they did recognise this they did not know where they could seek support for this (Crane et al, 2018).

“Barriers to support” was a prevalent theme in the analysis of Crane et al. (2018). Participants felt that there was a lack of available mental health services, and that help was only offered at the point of crisis. They were reported as feeling that services were not tailored to their needs, particularly in relation to their ASCs. This finding has been mirrored in other findings from general health settings for ASCs as will be discussed further below.

A study examining the views of women with ASCs accessing mental health services found that they perceived these services as not tailored to their needs, which left them feeling like a "square peg in a round hole" (Tint & Weiss, 2017). Participants in this study described experiencing negative interactions with mental health workers in which they felt the MHWs were unwilling to change their therapy interventions so that they were more appropriate for their needs. Provider knowledge of autism was also raised as an issue for the participants in accessing care.

What Support is There to Access?

The Improving Access to Psychological Therapies (IAPT) programme began in 2005 and is often the first point of access to mental health services for those living in England, either via self-referral or GP referral (NICE, 2011). The context of the current UK mental health system in is one of stepped care; the recommended approach is that the least invasive intervention is tried first and that this is based upon the severity of the person's difficulties at assessment. Those considered to have a mental health difficulty that is outside of IAPT's remit may be referred to a community mental health team or specialist service that supports the person with a specific difficulty, for example, hoarding. (NICE, 2011).

For neuro-typical populations CBT and other modalities are used routinely within IAPT services for a variety of different difficulties. Low intensity CBT is often considered the first intervention, followed by high intensity CBT, or different intervention modalities that might be provided by a psychologist or counsellor such as Dynamic interpersonal therapy (DIT) or Interpersonal therapy (IPT).

As it stands currently there is a paucity of research regarding what might help support people with ASCs with their mental health difficulties other than pharmaceutical options or

CBT and third wave interventions such as mindfulness (Spain, Sin, Chalder, Murphy & Happe, 2014). In the above mentioned review by Spain et al. (2014), it was found that CBT was successful in reducing mental health difficulties for those with ASCs.

Those with ASCs and an intellectual disability (ID) are often eligible to access interventions through specialist teams providing support for those with IDs, whereas those considered to have HFA or AS are not able to access these teams if they are not considered to have an ID (Rosenblatt, 2008).

General Health Services and ASCs

General health services have been found to present difficulties for those with ASCs in both access to, and accessibility of appropriate intervention within services. Barriers were evident in the following areas: communication between the person and professionals (e.g. Tint & Weiss, 2017; Nicolaidis et al., 2015); the provider not having enough experience or knowledge of ASCs (Nicolaidis et al, 2015; Lum, Garnett & O'Connor., 2014; Warfield, Crossman, Delahaye, Der Weerd & Kuhlthau., 2015), Cheak-Zamora and Teti, 2015); expectations of adult-style independence (Vogan, Lake, Tint, Weiss & Lunsky, 2017; Raymaker et al., 2017); and stigma (Nicolaidis et al., 2015; Lum et al., 2015).

Facilitators for successful interventions that have been proposed include practical changes such as scheduling appointment times as quieter times of day (Saqr, Braun, Porter, Barnette & Hanks, 2018), staff training (Warfield et al., 2015) planned transitions to adult care (Kuhlthau, Warfield, Hurson, Delahaye & Crossman, 2015) and the use of an online toolkit to guide both clinicians and people with ASCs (Nicolaidis et al., 2016).

The Views of Mental Health Workers

To date there appears to be minimal research into mental health worker (MHW) views on working with people with ASCs, as demonstrated by the literature search in Appendix A. One study that has considered interactions with mental health care staff in particular was conducted by Jackson, Brookwell, Lavender and Williams (2011), who interviewed mental health workers (MHWs) and individuals considered to have an ASC who were receiving support from their community mental health teams. MHWs reported difficulties with engagement, with the biggest barrier to developing a relationship being a lack of social reciprocity in their clients. Difficulties appeared to relate both to characteristics commonly considered to be features of ASCs, such as concrete thinking, and also the MHWs doubting their own competence in working with what they perceived to be a complex group.

Murphy and McMarrow (2015) investigated MHW views of working with adults with ASCs within a psychiatric secure setting. Through a survey used with staff, mostly of a nursing background, they found that 40 percent of them felt they did not have adequate skills and knowledge to work successfully with people with ASCs. They also found that 90 percent of the MHWs wished to have additional training to address this. Around half of the staff group thought that therapy would be beneficial for people with ASCs, which indicates a large proportion of staff do not think this group would benefit.

There were two further studies that examined staff views of mental health interventions with children diagnosed with ASCs.

Brookman-Frazee, Drahota, Stadnick and Palinkas (2012) investigated therapist perspectives on working with children considered to have an ASC and found that working with these children was perceived as being challenging and frustrating. The challenges they identified were slow progress and lack of improvement, coordination of care and system issues, lack of client insight, and difficulty building rapport.

Vulcan (2016) investigated the lived experience of psychotherapists working with children diagnosed with ASCs. They reported challenges to the core aspects of psychotherapeutic work, such as difficulties with reciprocal interactions, representations, symbolic thought and play.

The Theory of Planned Behaviour

In a systematic review of social cognitive models applied to health care professionals (Godin, Belanger-Gravel, Eccles & Grimshaw, 2008), the theory of planned behaviour (TPB) (Ajzen, 1991; Ajzen & Fishbein, 2005) was reported as the most widely used model, with the greatest predictive power. Examples of its previous use with health care professionals include investigations of the intention of clinical psychologists to carry out research (Eke, Holttum and Haywood, 2012), and the intention of clinicians to use self-help materials (Levy, Holttum, Dooley & Ononaiye, 2016).

This theory postulates that the intention to carry out a behaviour can be predicted by attitude, subjective norms and perceived behavioural control (Ajzen, 1985). In terms of attitude, the theory considers the predicted consequences of carrying out the behaviour; the subjective norms are thought of as the perceived social pressures to carry out a behaviour; and the perceived behavioural control is viewed as how much control the person feels they have over carrying out the behaviour (Ajzen, 1985).

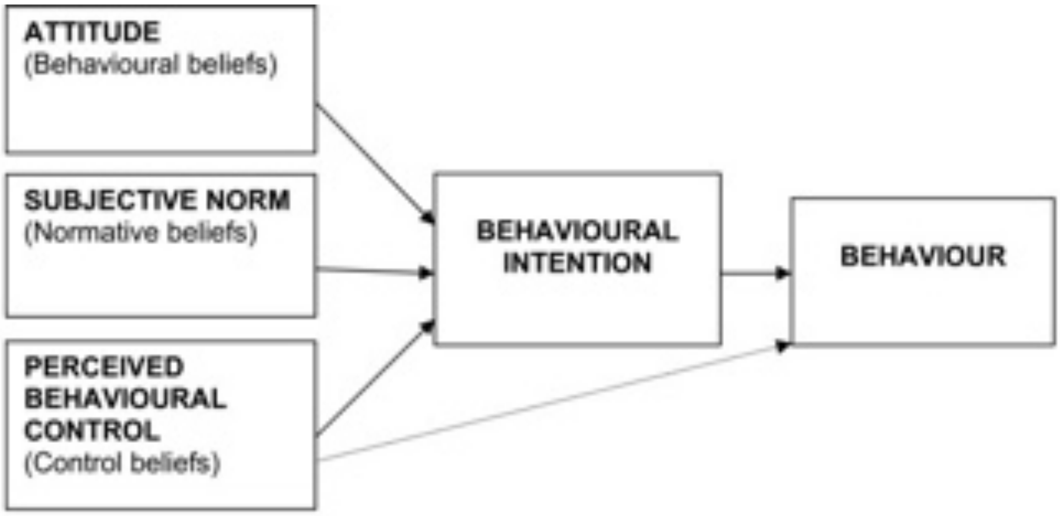

Figure 1.
The theory of planned behaviour (Ajzen, 1991; p.182)

The TPB model was considered to be a beneficial approach to examining the factors that might contribute to health care professionals' intentions to carry out interventions for mental health difficulties with someone with and an ASC. It was felt that this provided a framework that has previously been used successfully with health care professionals. It also would give the opportunity to examine the barriers to and facilitators of supporting someone with their mental health difficulties from the perspective of the clinician.

Previous research using the TPB (Azjen,1985) has added past behaviour as being a predictor of intention (e.g. Norman, Connor & Bell, 2000; Levy et al, 2016). As shown above, those with ASCs have reported a perception that their health care providers lacked experience and knowledge of working with people with ASCs (e.g. Tint & Weiss, 2017). Medical staff and mental health workers have also reported a lack of experience in working with those with autism (e.g. Warfield et al, 2015). Therefore, past experience of carrying out interventions with people with ASCs was added as an exploratory factor in this study.

Rationale

As those with ASCs have reported difficulties in accessing physical and mental health services, and there seem to be difficulties reported by the clinicians working in these services as well, there is an argument for investigating what clinicians consider enables or makes difficult carrying out these interventions for mental health difficulties. As illustrated above there has been minimal research in this area, and putting this into a theoretical framework could potentially further our understanding of the difficulties experienced by people with ASCs and also result in clinical implications. The project aimed to access a large sample of clinicians across primary care, which is commonly the first point of access for support with mental health difficulties in the UK.

Aims

The aim of the study was to further understanding of what barriers and facilitators there are in providing mental health interventions in IAPT for those with ASCs, and to investigate these via clinician attitudes, subjective norms and perceived behavioural control, in relation to behavioural intention to work with individuals considered to have HFA or AS (as part of the theory of planned behaviour; Ajzen, 1985). The study takes an exploratory approach due to a lack of research in this area. Past experience is also investigated as this has been found to account for variance in intention in previous studies (e.g. Norman et al, 2000). An exploratory item analysis will also be carried out to investigate which beliefs might signicantly influence intention to carry out interventions. This is suggested as being of benefit by Francis et al. (2004) as this knowledge could then be used to guide intervention that might increase intention.

Hypotheses

1. Attitudes, subjective norms and perceived behavioural control will be significantly related to the intention to carrying out an intervention for mental health difficulties in someone who also is considered to have HFA or AS.

2. These factors will explain a significant proportion of the variance in intention to work with someone with HFA or AS and a mental health difficulty.

3. Past use of an intervention for a mental health difficulty with someone considered to have HFA or AS will be directly related to intention to use an intervention in the future with someone considered to have a mental health difficulty and HFA or AS. The more someone has carried out these interventions in the past, the more likely they are to intend to carry them out again.

Method

Design

The study used mixed methods across three stages of data collection, as recommended by Francis et al. (2004). Stage one involved an online qualitative elicitation questionnaire examining behavioural beliefs, subjective norms and perceived behavioural control when thinking about carrying out an intervention for people with ASCs and a mental health difficulty. This questionnaire was semi-structured using guidelines from Francis et al. (2004). In stage two a pilot questionnaire was created based on the qualitative data collection and carried out by participants for review. This questionnaire was formed from a content analysis carried out in stage one and consisted of statements for evaluation using a Likert scale. This questionnaire also included statements regarding the intention of the participant to carry out these interventions (Francis et al. 2004).

Stage three was the final data collection using the updated piloted questionnaire, incorporating changes based on feedback from the pilot.

Ethics

Ethical approval was gained from Canterbury Christ Church University ethics panel (Appendix B) and also through the Health Research Authority (HRA) for individual NHS trusts that were involved in the study. A prize draw was used as an incentive to complete the online questionnaires, with the prize being one of two shopping vouchers of £30 in value. After accessing the survey web-link, the first page forms the information sheet and button to indicate consent (Appendix C). Debrief sheets are shown in Appendix D.

Stage One- Elicitation Study

Participants

All participants were those working clinically in IAPT services. Recruitment of participants was via service leads for each IAPT service, who emailed an invitation to take part in the study to their teams (Appendix F). The email included a link to a Qualtrics for each online survey.

Sixteen participants were recruited from two NHS IAPT services, one in South-West London, and the other in the North of England. Twenty-two staff accessed the questionnaire with sixteen going on to complete it. Demographic variables were also collected at this stage in order to capture any bias in the homogeneity of the sample. The sample size recommended by Godin and Kok (1996) was 25 for the elicitation study; however, many studies have successfully used fewer participants than this (e.g. Levy et al. (2016) used seven).

Table 1
Demographic information of participants in the elicitation stage

Characteristic	N (%)
Gender	
Male	5 (31%)
Female	11 (69%)
Age	
18-24	1 (6%)
25-34	7 (44%)
35-44	4 (25%)
45-54	2 (13%)
55-64	2 (13%)
Ethnicity	
White British	12 (75%)
White Irish	1 (6%)
White other background	1 (6%)
Asian or Asian British- Pakistani	2 (13%)
Professional Background	
Psychological Wellbeing Practitioner	4 (25%)
CBT therapist	7 (44%)
Clinical or counselling psychologist	2 (13%)
Other	3 (19%)

Vignette Creation

A convenience sample of five clinicians working across four different IAPT services was consulted for guidance on writing fictional examples of common IAPT referrals, in order to create realistic vignettes that might assess intention to work with this client group. The clinicians' professional backgrounds were as follows: three CBT therapists; one psychological wellbeing practitioner (PWP); and one clinical psychologist.

Measures

Questionnaire to Elicit Beliefs

Using the protocol set out in Francis et al. (2004), an elicitation questionnaire was constructed and sent out to establish commonly held behavioural beliefs, subjective norms and perceived behavioural control about carrying out psychological intervention with those with ASCs (shown in Appendix G). This questionnaire required qualitative responses to open-ended questions asking participants their views on the potential positive and negative outcomes for carrying out the interventions (behavioural beliefs), if there were individuals or groups they felt would disapprove or approve of them carrying out the interventions (subjective norms) and any factors that would enable or make it difficult to carry out the interventions (perceived behavioural control).

Procedure

Vignette Production

Appendix H shows the questions asked to produce vignettes to measure intention. Francis et al. (2004) suggests different ways of measuring this, including a generalised intention using standardised questions, intention performance, and intention simulation. Both generalised intention and intention simulations were included for the pilot questionnaire. Intention simulations were included in an attempt to present a more valid measure when it came to complex clinical decision making, Francis et al. (2004). Francis et al (2004) recommends establishing these vignettes by exploratory study or consultation with colleagues in the field. The questions asked to generate these vignettes are shown in Appendix H and data was collected using Qualtrics. Once collected these vignettes were amalgamated to produce 10 vignettes of “typical” IAPT referrals. These were then adapted to include the person having a diagnosis of an ASC after consultation between the lead researcher and two supervisors. This involved including common difficulties reported by people with ASCs (e.g. routine disruption causing anxiety). The questions for each vignette were about the participants’ intention to carry out the intervention and the response format to these was “yes” or “no.”

Stage Two- Creation of Pilot Questionnaire

Participants

Participants from the elicitation questionnaire who had indicated that they would be willing to comment on the completed pilot questionnaire were contacted at the email address that they they had provided for this.

Nine participants accessed the web link, with five of them completing the questionnaire in full and one partial response. Demographic information for the participants that completed or partially completed the pilot questionnaire is shown below.

Table 2
Demographic information for participants in the pilot stage

Characteristic	n
Gender	
Male	2
Female	4
Age	
25-34	3
35-44	2
55-64	1
Ethnicity	
White British	5
Professional Background	
PWP (or training)	1
CBT therapist (or training)	3
Clinical or counselling psychologist (or training)	1
Other	1

Perceived current caseload with ASCs	
0	3
1-5	2
5-10	1
Perceived caseload over last year with ASCs	
0	2
1-5	3
5-10	1
Perceived caseload ever with ASCs	
0	
1-5	3
5-10	
10-15	1
20-30	1
100-105	1

Procedure

The responses from the elicitation study were analysed using content analysis, by both the author and the lead supervisor, which produced themes with a frequency count.

As suggested in Francis et al (2004), the most frequently occuring 75 percent of content for each domain (behavioural beliefs, subjective norms and perceived behavioural control) was then selected to be transformed into statements. This produced the following number of themes for each category: 18 for attitudes, seven for subjective norms and nine for PBC. They are shown in the appendix I with their relative rankings and the percentages of the overall data they accounted.

Table 3

Most frequent behavioural beliefs from elicitation study

Themes	Example response	Frequency of Responses
The therapist would be fearful or feel negatively about the intervention	"I am aware of my own reactions to clients presenting with HFA or AS. Frustration, irritation, finding it difficult to understand and relate with my experiences."	7
The outcome would be the same as for any other client without this diagnosis	"As with any other client, not all interventions work and some make people worse."	6
The intervention could make the person worse and/or cause them to experience difficult emotions	"The person experiences emotional distress because of the intervention, which they find difficult to regulate."	5
The intervention would improve wellbeing	"Depending on their mental health problems they hopefully will learn how improve their emotional wellbeing."	5
The intervention would allow the person to learn CBT principles/skills	"They may learn to be objective with their thoughts and notice certain unhelpful thinking patterns that effect their mood. For example black and white thinking."	5
The intervention would result in behavioural change	"I have noticed that as a CBT therapist using cognitive methods can often be challenging and can lead to 'battles' of logic, but that behavioural approaches can work quite well."	4
The intervention would reduce the person's distress	"It would enable them to live their lives more fully and with less distress."	4
They would have a better understanding of their difficulties	"There would be a number of potential positive outcomes for working with people with HFA or AS, such as an increased understanding of their problem."	3
Their quality of life would be improved	"Improved quality of life to positively impact a client's quality of life."	3

The person would not engage with the intervention	“The person does not engage in the change process, through lack of insight/understanding.”	3
There will be no significant changes for the person	“I believe that change or any improvements to their emotional wellbeing and functioning will be minimal.”	3
The rigidity of the person would result in minimal change	“They rigid thinking may be hard to challenge and leave them feeling confused or stressed.”	3
The person could learn to take perspectives of others	“They may gain skills in communicating their perspective and learn how to view the perspectives of others.”	2
CBT needs adapting for the person’s autism or it won’t work	“In the CBT model it can be hard for them to relate abstract concepts, metaphor and empathy, therefore the model has to be adapted slightly. Not doing this could result in the client becoming distressed or confused.”	2
Interpersonal difficulties will make it difficult to carry out intervention	“Interpersonal difficulties lead to the intervention being either only partly, or not at all effective.”	2
The person would be able to manage their mental health difficulties better	“acquiring practical ways to manage their mental health related symptoms In their day to day life to improve their general wellbeing”	2
The person won’t understand the intervention	“Lack of understanding reinforcing perceived disability”	2
The intervention would not go well because of communication problems	“Communication problems, i.e. a possible lack of empathy or understanding of relational dialogue”	2

Table 4

Most frequent normative referents from elicitation study

Themes (Normative referents)	Sample Responses	Frequency
Colleagues/clinicians would approve	"I imagine most clinicians would approve of this."	4
People with experience in this area would approve	"Those with experience or specific training in this area (i.e. how to adapt therapy styles if necessary, what difficulties you may encounter and how to deal with these)."	3
The family of the client would approve	"Family and friends etc would welcome increased access to psychological interventions for those with HFA or AS."	2
General Practitioners (GPs) would approve	"Their GP"	2
Non-specialist clinicans/those with no experience of client group would not approve	"People who lack experience or training."	4
Service managers would not approve	"Service managers who have more concerns regarding targets and may not see this support as cost effective."	3
Services would not approve	"Services which have not been commissioned to do so."	2

Table 5
Most frequent control beliefs from elicitation study

Themes (Control beliefs)	Sample Responses	Frequency of Responses
Lack of training	"Training on specific factors that may come up when working with those with HFA or AS and how to adapt interventions to ensure use of ease and understanding for both therapist and patient."	17
Not enough sessions	"Constraints in number of sessions and session length, which would prevent from building a good relationship with the client, and from making sure the client can communicate and understand."	9
Lack of written resources	"The service has no pre-prepared materials that we could draw on."	9
More time outside of sessions for preparation/supervision/reflection	"In IAPT there is very limited time to prepare for interventions so there is little scope to spend time adapting materials or the intervention unfortunately."	9
Not enough session time	A time allowance for sessions to over run if needed to deal with emotional distress	6
More specialist supervision or consultation	"Good supervision with someone who is supportive of working with such individuals."	5
Wider support system	"Having present someone who knows the person well to assist in assessment."	4

Lack of experience	"More practice with such patients"	3
Lack of knowledge	"I do not have enough background knowledge about HFA or AS in order to make reasonable adjustments to psychological intervention."	2

Using stems suggested by Francis et al (2004), two questions per theme were created to establish both the strength of the salient belief and the positive or negative evaluation that corresponded to it. For example, one salient belief relating to attitude was that carrying out the intervention would result in the person with an ASC having a better understanding of their difficulties. This would then be measured in terms of how likely the participants thought this was (using a 1 to 7 Likert scale, with 1 being unlikely and 7 being likely), with a corresponding question about whether or not the participant thought this was desirable or not (using a -3 to 3 Likert scale). This method of mixing a bipolar and unipolar scale is recommended by Francis et al. (2004) as a way of creating a weighted score that indicates the direction of the attitude towards, pressure to and likelihood of carrying out a behaviour.

Francis et al. (2004) also recommended using direct measures to establish participant beliefs and therefore these were also created using the recommended stems.

A Qualtrics study was created containing the pilot questionnaire items, and the web link to access this was sent to elicitation participants who had indicated they would be contactable about the next stage of the development (n=12).

The pilot data was downloaded from Qualtrics and analysed using the Statistical Package for Social Sciences (SPSS) Version 23. Some variables were recoded (reversed and put in multidimensional scales) in accordance with Francis et al. (2004). Composite scores were then computed for indirect and direct measures.

Cronbach's Alpha analysis was run for each of the direct and indirect measures. The only acceptable scores were for indirect attitude (a=0.714), direct attitude (a=0.938), indirect intention (0.952) and direct intention (0.918).

A series of bivariate correlations were also carried out between variables; this was carried out with bootstrapping due to the small sample size. This showed that there were two significant correlations: indirect intention with direct intention; and indirect intention with indirect attitude. The remaining presented insignificant correlations, of which there was a mix of negative and positive correlations (Appendix J).

The responses to the intention simulation vignettes were also examined and there was some doubt over their validity, with the majority of participants responding "yes" they would carry out the intervention on all ten scenarios.

Using Qualitative feedback from the Pilot Questionnaire

Questions used to generate qualitative feedback on the pilot questionnaire are shown in Appendix K. Feedback was used to make changes for the final questionnaire. This included adjusting response endings for several questions, and clarifying what might be meant by an "intervention" by adding an example. The majority of participants said that the questionnaire was too long and too repetitive. This was considered important, as the intended sample were clinicians in IAPT who are known to have high caseloads (Rizq, 2012) which is likely to impact on their available time. Therefore, after consultation with the research supervisors, eight items were removed and/or amalgamated. The removed and altered questions can be seen in Appendix L.

The vignette response option was changed from "yes/no" to a Likert scale asking the participant to ask how likely it would be that they would carry out the intervention. It was thought that this might be slightly less vulnerable to social desirability bias than selecting "yes" or "no".

Stage Three-Final Questionnaire

Participants

Participants were recruited through emails sent to twelve IAPT teams, from seven NHS trusts. The majority of these trusts were located in the South-East of England, and London. Towards the end of data collection, recruitment was later extended to social media via Facebook, a professionals' forum and Twitter, adverts for which can be seen in Appendix M. In total, 145 IAPT clinicians accessed the survey and 88 went on to complete it.

Table 6
Demographic information of participants in the final questionnaire

Characteristic	n
Gender	
Male	15 (17.2%)
Female	72 (82.8%)
Age	
18-24	4 (4.6%)
25-34	55 (63.2%)
35-44	20 (23%)
45-54	4 (4.6%)
55-64	4 (4.6%)
Ethnicity	
White British	59 (67.8%)
White Irish	2 (2.3%)
White- Any other background	13 (14.9%)
Mixed- White and Asian	2 (2.3%)
Asian or Asian British- Indian	4 (4.6%)
Asian or Asian British- Any other	3 (3.4%)
Asian	1 (1.1%)
Black or Black British- African	2 (2.3%)
Chinese	1 (1.1%)
Any other ethic group	
Professional Background	
PWP (or training)	24 (27.6%)
Graduate Mental Health Worker or Assistant Psychologist	3 (3.4%)

CBT therapist (or training)	41 (47.1%)
Clinical or counselling psychologist (or training)	14 (16.1%)
Other	5 (5.7%)
Perceived current caseload with ASCs	
0	45 (51.7%)
1-5	41 (47%)
Missing	1 (1.1%)
Perceived caseload over last year with ASCs	
0	27 (31%)
1-5	59 (66.6%)
10	1 (1.1%)
missing	1 (1.1%)
Perceived caseload ever with ASCs	
0	13 (14.9%)
1-5	35 (40.2%)
6-10	30 (25.2%)
11-20	11 (12.6%)
21-30	2 (2.3%)
100+	3 (3.4%)
missing	1 (1.1%)

Measures

There were six predictor variables: direct attitudes; direct perceived behavioural control; direct subjective norms; indirect attitudes; indirect perceived behavioural control; and indirect subjective norms.

The dependent variables were direct intention and indirect intention (via vignettes responses). Demographic questions also formed part of the questionnaire, as follows: age; gender; ethnicity; and professional background (shown in Appendix N).

Past experience was measured as a continuous variable based on three questions regarding how many people with ASCs the participants had experienced on their caseloads. The final questionnaire can be seen in Appendix O with the scoring key in Appendix P.

Procedures

The data in stage two were collected over a period of seven weeks in February and March of 2018. The anonymous survey link was distributed via email, on Facebook professionals' groups, twitter and a professionals' forum. In each distribution, contact details of the lead researcher and lead supervisor were provided.

Data were anonymous with the exception of participants having the option whether or not to provide their email separately so they could receive a summary of results and for entering the prize draw. These email addresses were downloaded from Qualtrics by a research assistant in order to complete the prize draw at the close of the study.

Results

Data Cleaning and Screening

The final data were transferred to and analysed by SPSS version 23. The data were screened for missing responses, which were replaced with a value of 999. Responses were considered in the analysis if 80 percent of the main questionnaire was complete.

There were found to be no differences in the demographic factors of those beginning the questionnaire but not completing it and those who did complete it.

Validity of Indirect Measures

Bi-variate correlational analyses were carried out to investigate the relationship between direct scales and their corresponding indirect scale, as created by the elicitation study.

Table 7

Correlation analyses for direct and indirect subscales

Direct-indirect subscale	Pearson's r	Effect size
Attitude	0.442**	Medium
Subjective Norms	0.155	Not significant
Perceived Behavioural Control	0.354**	Medium
Generalised Intention and Intention Simulation	0.493**	Medium

As can be seen above, three of the direct measures were significantly correlated with their corresponding indirect measures. These were attitude, perceived behavioural control and intention, which all had a medium effect sizes. These findings support the validity of the indirect constructs and suggest that these measures may be contributing to the same construct. However, one indirect subscale did not significantly correlate with its direct counterpart, and this was the subjective norm scale.

Analysis of Demographic and Additional Variables

The variables considered were age, gender, ethnicity, professional background, experience of people with ASCs (or possible) on caseload currently, over the past year and ever.

There was only one significant correlation found between these variables and components of the TPB model. This was for age and indirect PBC, $r=0.268$, $p<0.05$, suggesting that as age increased so did feelings of control over carrying out an intervention. Consequently, these demographic variables were omitted from the main analysis of the TPB model.

Scale Reliability Analysis

Internal reliability was calculated using Cronbach's alpha, as shown in the table below (table 8) and Appendix Q. The Cronbach's alpha for the three-items on the direct subjective norms scale was found to be 0.44. The subjective norm measures were also not correlated between indirect and indirect measures of this scale. Therefore, the item perceived by the researchers to be likely to provide the most face validity was chosen to be included in the analysis. The item that remained was "It is expected of me that I carry out these interventions."

Items on all of the other scales remained. As shown below they all presented with acceptable Cronbach's alpha scores of above 0.6 and this is the level suggested by Francis et al. (2004).

Table 8

Scale reliability analysis for questionnaire measures

Variables	Number of items	Cronbach's alpha
Direct attitude	4	0.918
Indirect attitude	18	0.699
Direct SN	1	Single item
Indirect SN	6	0.671
Direct PBC	4	0.619
Indirect PBC	7	0.655
Generalised Intention	3	0.675
Intention simulation	5	0.857

Bivariate correlations of the scales can be seen in Appendix Q

Statistical Assumptions

The final data were screened for normality by inspecting Q-Q plots and histograms, all of which were satisfactory. The Kolmogorov-Smirnoff tests were found to be significant, but as the visual inspections had been satisfactory, and an analysis of residuals for multiple regression were satisfactory, analysis was continued. Cook's distance and Mahalanobis distance were examined for each regression and no case removal was needed.

Descriptive Statistics

Descriptive statistics were produced for the main components of the model, as well as the questions considering previous experience.

Table 9
Descriptive statistics and theoretical range of the variables

Predictor variable	Theoretical range	Minimum	Maximum	Median	Inter-quartile range
Direct attitude	4 to 28 (4 items)	10	28	23.5	7
Indirect attitude	-378 to +378 (18 items)	26	215	141	63.75
Direct SN (single item)	1 to 7	1	7	5	3
Indirect SN	-126 to +126 (6 items)	-38	+87	26	36
Direct PBC	4- 28 (4 items)	6	24	15	6.75
Indirect PBC	-147 to +147 (7 items)	-123	-4	-48.5	35
Generalised Intention	3-21 (3 items)	6	21	16	4
Intention simulation	5-35 (5 items)	10	35	30	8
Frequency on caseload now	Continuous	0	4	0	1
Frequency on caseload past year	Continuous	0	10	1	2
Frequency on caseload ever	Continuous	0	100	5	8

Values in indirect scales were computed composite scores, computed by calculating the value on a scale ranging -3 to 3 and its counterpart ranging 1 to 7. These were then added together to create an overall score.

Testing the Hypotheses

The first research hypothesis was that attitude, subjective norms and perceived behavioural control would be significantly related to intention to carry out an intervention for mental health difficulties for those with HFA or AS. The second research hypothesis was that these factors would explain a significant proportion of the variance of this intention. Regression analyses were used to test these hypotheses and these were the carried out in steps (Appendix S).

Table 10
Multiple linear regressions for the theory of planned behaviour

	Dependent Variable	Independent variables	Beta	Model R squared	F
Step 1					
Model 1	Direct attitudes	Indirect attitudes	0.442**	0.196**	20.906
Model 2	Direct attitudes	Indirect attitudes	0.446**	0.200**	6.990
		Indirect subjective norms	0.011		
		Indirect PBC	-0.066		
Model 1	Direct PBC	Indirect PBC	0.354**	0.125**	12.304
Model 2	Direct PBC	Indirect PBC	0.361**	0.158**	5.243
		Indirect attitudes	0.175		
		Indirect subjective norms	0.036		
Model 1	Direct SN	Indirect SN	0.770**	0.593**	125.393
Model 2	Direct SN	Indirect SN	0.777**	0.596**	41.379
		Indirect attitudes			
		Indirect PBC			

Step 2	Generalised Intention	Direct attitude Direct SN Direct PBC	0.345** 0.150 0.389**	0.361**	15.798
Step 3	Generalised Intention	Direct attitude Direct SN Direct PBC Indirect attitudes Indirect SN Indirect PBC	0.176** 0.045 0.335** 0.314** 0.317** 0.060	0.565**	17.532
Step 2	Intention Simulation	Direct attitude Direct SN Direct PBC	0.011 0.038 0.345**	0.125*	3.853
Step 3	Intention Simulation	Direct attitude Direct SN Direct PBC Indirect attitudes Indirect SN Indirect PBC	-0.110 -0.495 0.270* 0.208 0.258* 0.141	0.256**	4.478

**p<0.001, *p<0.05

As can be seen in Table 10, direct components of the TPB model accounted for 36.1 percent of the variance in generalised intention to carry out these interventions, F= (3,84) = 15.798, *p*<0.01. When the indirect measures were added to the model it was found that together with direct components, these were able to account of 56.5 percent of the variance in generalised intention, F (6,81) = 17.532, *p*<0.01, viewed as a large effect size ($f^{2=}1$). This therefore supports research hypotheses one and two regarding the components of the model being able to significantly predict the majority of intention to carrying out the interventions. However, there is still 43.5 percent of the variance unaccounted for.

Hypothesis three was to consider whether or not past experience of carrying out intervention for someone with autism would be significantly related to the clinician's intention to carry out these interventions in the future. Bivariate correlations mentioned previously had not found any significant correlations between the measured variables of experience carrying out these interventions currently, in the past year or ever. However, a significant percentage of the sample were not carrying out these interventions currently (51.7 percent), had not carried them out in the past year (31 percent), or had never carried them out (14.9 percent). Therefore, a t-test was carried out looking at those who had never worked with someone with autism on their caseload and those who had. Generalised intention was found to be significantly higher for people who had worked with someone with an ASC before compared to those who had not, t=-3.833, p<0.01. Hypothesis three is therefore partially supported.

Scale Item Exploratory Analysis

A further exploration of whether attitudes, subjective norms and perceived behavioural control were related to a clinician's intention to provide intervention involved looking at individual items that might be related to intention.

The variance in the following regressions is unlikely to be unique to the scale items recognised as significant in predicting intention and therefore results are tentative and to be interpreted with caution.

Table 11
Multiple linear exploratory stepwise regression: significant beliefs in predicting intention

Model	Predictor variables	Beta	R squared
1 (Indirect attitudes)	(all)	-	0.429
	Attitude (Improve Quality of life)	0.121**	0.286
	Attitude (Significant changes)	0.056**	0.066
	Attitude (go badly due to interpersonal difficulties)	-0.067**	0.077
2 (PBC direct)	(all)	-	0.383
	PBC (confidence)	0.236**	0.348
	PBC (difficulty- ease)	0.20*	0.035
3 (Subjective norms indirect)	(all)	-	0.246
	SN (Service)		0.195

	SN (colleagues)	0.040**	0.041
		0.038*	
4 (Attitudes direct)	(all)	-	0.176
	Good: bad	0.346**	0.176
5 (PBC indirect)	(all)	-	0.341
	PBC 2 (training)	0.579**	0.267
	PBC 1 (experience)	-0.280**	0.074

**p<0.001, *p<0.05, only significant results shown in table.
Both stepwise and forced entry regressions were run and the differences were found to be negligible.

Three behavioural beliefs were shown to have a significant contribution to the intention to carry out interventions and accounted for 42.9 percent of the variance, F(3,72)=18.002, *p*=0.000. These were improvements in quality of life, which accounted for 26.8 percent of this variance, significant changes which accounted for 8.4 percent, and the intervention going badly due to interpersonal difficulties, which accounted for 7.7 percent.

Two direct items of perceived behavioural control were shown to have a significant contribution to the intention to carry out interventions and accounted for 38.3% of the variance, F(2,82)=24.446, *p*=0.000. There were two PBC items that contributed to this variance: confidence accounted for 34.4 percent and the level of perceived difficulty accounted for 3.4 percent.

Two indirect subjective norm items were shown to have a significant contribution to the intention to carry out interventions and accounted for 24.6 percent of the variance, F(2,79)=12.854, *p*=0.000. These were service norms, which accounted for 19.5 percent of the variance and the norms of colleagues, which accounted for 4.1 percent.

One direct attitude item significantly contributed to the intention to carry out interventions and accounted for 17.6 percent of the variance, F(1,86)=18.309, p=0.000.

Two indirect PBC items were found to significantly contribute to the variance in generalised intention to carry out interventions and accounted for 34.1 percent of the variance, F=(2,80)=20.74, p=0.000. These items were training which accounted for 26.7 percent of the variance and experience which accounted for 7 percent.

All other items were not found to be significant in a stepwise multiple regression. These are shown in full in Appendix S.

Qualitative Findings

Clinicians were asked at the end of the questionnaire if there was anything else they wished to add about their experiences of working in IAPT with people with HFA or AS. Fifty-four responses were provided, which were content analysed by the lead researcher and lead supervisor independently and then brought together to reach concordance (Appendix T).

The participants highlighted organisational issues, client-related views, and wider issues such as findings from research. The most cited organisational issues were a lack of training in ASD (n=12), and a lack of time in terms of length of sessions, number of sessions and time to prepare (n=10). A lack of resources was also a commonly cited difficulty with providing interventions to this client group (n=9), in particular a lack of adapted materials such as worksheets. Findings from published research was identified as a wider issue around what evidence base exists for therapy for mental health difficulties and autism, and the uncertainty around this.

These findings mostly fit with the views expressed in the elicitation study. There were, however, a few additional issues that were brought to light in this open-ended question. These were mostly related to wider issues, not specific to the organisation or the individual clinician and perhaps more related to views around CBT, diagnosis and/or training background. This included “not making diagnostic assumptions” about the client with a diagnosis of an ASC, and the individual needs of the client being considered rather than making adaptations based on a diagnostic label.

There were also differing view points about CBT and other therapies; these included that there are benefits to CBT, that many CBT techniques might not be well suited for someone with an ASC, and the view that other therapy (e.g. counselling) might not be effective.

There was also a wider issue of determining what intervention is necessary when thinking about carrying out an intervention that was focused on mental health. This included the importance of distinguishing the difficulties experienced by the person as a result of low mood, from longer standing difficulties that might be related to their diagnosis of an ASC.

Discussion

This exploratory study aimed to achieve further understanding of what clinicians perceived were the main barriers to and facilitators of carrying out interventions for the mental health difficulties of someone with HFA or AS. This was to be explored in a theoretical framework in the form of the theory of planned behaviour (Azjen, 1985) and therefore there was a focus on clinician attitudes, subjective norms and perceived behavioural control towards carrying out an intervention. The study used a mixed methodology to investigate common beliefs amongst IAPT practitioners about carrying out interventions, which were then used to create a questionnaire to collect quantitative data across a larger sample.

The data supported the theoretical framework of TPB as applicable when considering intention to carry out interventions with someone considered to have HFA or AS, explaining over half of the variance in intention.

The following scales were found to be significant predictors of generalised intention, in order of effect size: direct PBC with medium positive relationship, indirect subjective norms, direct attitude. All of these scales showed medium positive relationships with generalised intention, with the exception of direct attitude which showed a small positive relationship. The direct subjective norm single item and indirect PBC scale did not significantly add to this.

This suggests that those with a more favourable attitude towards carrying out these interventions, those who felt more control over doing so, and those who felt more social pressure to, were more likely to do so.

In this study, the direct and indirect measures of attitudes towards carrying out the interventions accounted for a significant proportion of the variance, whereas only indirect measures of subject norm (specific to the context rather than general) and the direct measures of perceived behavioural control were found to influence intention. This demonstrates that the inclusion of direct and indirect measures can be beneficial, as suggested by Francis et al. (2004).

Both direct and indirect components of the TPB were found to contribute to the variance in intention simulation, however, less so than was found in generalised intention. Similarly to generalised intention, the variance was found to increase when indirect scales were added to the regression analyses.

When considering the contribution of specific item in the intention to carry out the interventions, there were a number of items that were found to be present both in the qualitative analysis and in analyses of variance through multiple regression.

Attitudes

Eighteen behavioural beliefs were found in the analysis stage of the elicitation study and when analysed further in the final questionnaire, three of these were found to add to the variance in intention to carry out the interventions.

Items on the indirect attitude scale that significantly added to the variance were as follows: whether or not the intervention would improve the person’s quality of life; whether there would be significant changes for the person; and whether the intervention would go badly because of interpersonal difficulties. Previous literature examining the views of MHWs working with those with ASCs also considered the importance of interpersonal difficulties, reporting a felt lack social reciprocity of their clients (Jackson et al, 2011) and difficulty building rapport (Brookman-Frazee et al, 2012).

A lack of improvement was also cited by MHWs (Brookman-Frazee et al, 2012) which may link to concerns over whether significant changes could be made as a result of therapy.

Subjective Norms

In the qualitative part of this study seven normative referents were identified, both positive and negative, as being potentially influential in the participants' lives in indicating whether the interventions should be carried out. In quantitative analyses, two of these scale items were found to be significantly influential in the person's intention: the views and actions of their colleagues and the service they were working in. Previous research has examined staff team norms in the NHS relating to particular mental health difficulties. One such study (Artis & Smith, 2013) examined team norms towards self-harming and highlighted the participants placed importance on fitting in with a team and acting congruently with their norms.

Perceived Behavioural Control

Six indirect measure items were added to the questionnaire after qualitative data collection. The two items found to be significant in the exploratory item analyses were: a lack of training in ASCs and a lack of experience in working with people with these diagnoses. A lack of training and experience in providing care for people with mental health difficulties and ASCs has been reported in previous research as an issue, identified both by clinicians (Murphy & McMarrow, 2015) and service users with ASCs (e.g. Tint & Weiss, 2017). Both of these control beliefs found in the exploratory item analysis were also found in the additional qualitative question analyses.

In the exploratory item analysis, the direct measures of PBC found to contribute significantly to the variance were related to the perceived self-efficacy of the participants in providing interventions. Self-efficacy is the personal judgement of capability as to whether an individual can perform a behaviour (Bandura, 1977). Previous literature examining MHW views of working with people with ASCs had found that they had doubted their competence in working with a group they saw as complex (Jackson et al. 2011).

Past Experience

Nearly half of clinicians taking part in this study currently had at least one person on their caseload who thought might have HFA or AS, or had a diagnosis.

Past experience of carrying out these interventions was hypothesised as being a factor which might affect someone's intention to carry out an intervention. It was found that having no past experience of this kind was significantly different to having any experience; however, intention did not seem to increase as this experience increased. Experience was highlighted in the both qualitative data collections of the study, and was found to be a significant item on the PBC scale; adding a significant amount of variance to generalised intention.

Past experience has previously been found influential in clinician intention, (e.g. intention to use self-help materials in therapy; Levy et al, 2016).

Unaccounted Variance

Although the TPB model was able to predict more than half of the variance in intention to carry out an intervention for mental health difficulties with someone with HFA or AS, there was still a large amount of unexplained variance remaining.

The analysis of the qualitative question in the final questionnaire could point to some additional factors that were not explored within the TPB model.

This analysis found that wider factors, such as the findings from autism research, might influence whether or not a clinician saw the intervention as beneficial. Participants indicated that they were not sure of the evidence base for particular interventions.

Another finding of this qualitative analysis was that there was some confusion as to what difficulties might be related to changes in someone's mental health or whether they were associated with the person's ASC, and indeed whether this mattered.

Previous research had indicated difficulties with mental health services experienced by service users with ASCs and these had centred around a lack of tailored interventions and the perception that the clinician did not have much knowledge or experience of autism.

Knowledge was included in the pilot questionnaire in a question relating to PBC, however, this was removed after the questionnaire length was reduced due to feedback. It could have been beneficial to have included this in the final questionnaire.

Clinical Recommendations

Staff reported a lack of training in autism at every stage of data collection; elicitation, pilot, the final questionnaire and again in the qualitative question as part of the final questionnaire. A lack of training was found to be significant in the clinician's intention to carry out the interventions and therefore is of importance going forward both so that service users with ASCs are able to build a relationship with clinicians who have the best chance of understanding them, and so that clinicians can increase their self-efficacy in this area. Self-efficacy measures were also found to predict intention so this corroborated these findings.

Additional training in ASCs for clinicians should include more than a generic introduction to autism. It would be beneficial for training to cover the current literature base around autism and mental health, including adaptations to therapy and communication, positive examples of therapy and therapeutic relationships, as well as formulating the differences between what might be long-standing difficulties with social interaction (and the consequences of these) and what might be difficulties with mental health that have developed.

These training needs may require sharing with commissioners and within wider NHS structures in order for these to be implemented. The findings provide evidence for the importance of NHS wide training initiatives (e.g. Think Autism; DOH, 2014) that have been attempted previously.

Sharing these findings with managers and commissioners of IAPT teams could emphasise the importance of a top-down display of positive attitudes to working with people with ASCs in IAPT. This may also involve considering how referrals are screened and relayed to clinicians, the allocated time the clinicians have for thinking about and working with people with ASCs, and providing appropriate support and supervision, especially as this may be the first time the clinician has worked with someone who has an ASC.

Services may want to consider the proportion of people who are coming to the service with diagnoses of ASCs and which clinicians are seeing them. If it is the case that particular clinicians are seeing the majority of people with these diagnoses, then perhaps this should be reviewed to support those clinicians who have not worked with them in order to support their learning experiences.

Research Recommendations

As an exploratory study, the findings are a first-step in understanding what might contribute to successful therapy interactions for people with ASCs. There was a considerable amount of variance in intention to carry out the interventions that was unexplained and therefore future research addressing this would be beneficial.

The literature would benefit from in-depth accounts from people with ASCs about their experiences of therapy and what might facilitate a positive interaction with mental health services and therapy.

CBT has been found to be related to positive outcomes for those with ASCs and mental health difficulties, it would be beneficial to investigate the efficacy of other types of therapy.

The “Think Autism” strategy (DoH, 2014) made clear that autism training should be made available to all staff working in the NHS, yet findings from this study have shown that staff feel they lack training in understanding ASCs. Research using theories in organisational change might be beneficial in establishing barriers to this implementation.

Limitations

The study could have benefited from re-testing at a further time point to establish the reliability of results over time. This was planned with the pilot sample but the sample was too small to produce any interpretable results.

The use of social media as a recruitment strategy has been criticised for the selection of participants being biased (Ruths & Pfeffer, 2014). It is also likely that the questionnaire attracted those who have an interest in working with people with autism or have done so, therefore there are difficulties with the sample being generalizable to other clinicians working in IAPT.

The final questionnaire provided hypothetical situations in the form of vignettes in order to investigate the participant’s intention to carry out an intervention. The vignettes ask the participants to imagine they have a choice about this and then make a decision based on vignette as to whether they would be likely to assess or carry out an intervention. However, there may be situations where there is no choice at all about working with someone and this is not considered in this scenario which assumes a choice can be made. This may have had an impact on their external validity.

Another potential limitation is around the language used in the questionnaire. The author designed the survey with the term “intervention” to describe doing a piece of work with someone with HFA or AS on a mental health difficulty. This terminology was chosen to fit with the BPS guidelines on clinical language for psychologists (BPS, 2015), however, there were two comments made, once in the pilot and once in the final questionnaire, about this being an unknown terminology and this being confusing.

Without a comparison group in the study it could be argued that there is difficulty in establishing whether the barriers and facilitators that affect intention could also be common to neuro-typical people accessing IAPT. The IAPT programme has been criticised for focusing on targets rather than considering the emotional needs of their service users (Rizq, 2012) and therefore some elements of the model could be prevalent for everyone attempting to gain support from these services.

Conclusions

The theory of planned behaviour was found to be effective in explaining variance in clinician intention to carry out an intervention for mental health difficulties with someone with HFA or AS.

Specific factors that were found to be significant in predicting this were: a lack of training in ASCs, a lack of experience in working with people with HFA or AS, beliefs about whether the intervention could improve the person’s quality of life and lead to significant changes for the person, what the clinician’s current service or colleagues think or do, and their own perceived self-efficacy.

In addition to these factors it was found that those with no experience of carrying out interventions with people with HFA or AS, were less likely to intend to do so.

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HELEN LAYTON BSC (Hons), MSc, PG Cert

ACCEPTABLE ACCESS TO HEALTH SERVICES FOR ADULTS ON THE AUTISM SPECTRUM

PART C

Appendices of supporting materials

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Psychology

APRIL 2018

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Appendix A

Search of the literature about mental health professionals' attitudes towards working with people with ASCs

List of sources searched:	Date of search	Search strategy used, including any limits	Total number of results found	Total relevant and suitable to the topic
PsycINFO	March 2018	(autis* or asperger* or "HFA" or "ASD") and (therap* or psychologist or "mental health worker" or counsellor) and (Attitudes or views or experience or barriers) Limited to English language and peer reviewed journals.	178	2
PubMed	March 2018	(autis* or asperger* or "HFA" or "ASD") and (therap* or psychologist or "mental health worker" or counsellor) and (Attitudes or views or experience or barriers) Limited to English language and peer reviewed journals.	305	1
ASSIA	March 2018	(autis* or asperger* or "HFA" or "ASD") and (therap* or psychologist or "mental health worker" or counsellor) and (Attitudes or views or experience or barriers) Limited to English language and peer reviewed journals.	101	0

Appendix B

Letter from ethics panel

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Appendix C

HRA approval

This has been removed from the electronic copy.

Appendix D

Consent forms

Elicitation study

Research project on what helps or hinders therapists from carrying out psychological interventions with those considered to have High Functioning Autism or Asperger's Syndrome and mental health difficulties.

My name is Helen Layton and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I am inviting you to take part in the initial stage of a study that forms part of my degree and which may later be submitted to an academic journal for publication.

I am carrying out research with therapists working in Improving Access to Psychological Therapies (IAPT) into their experience and perceptions of working with those considered to have High Functioning Autism or Asperger's Syndrome that have been referred for intervention for mental health difficulties. I am interested in what might hinder or help clinicians to work with this population to carry out psychological interventions.

I would be grateful if you could answer the questions below and base your answers on your beliefs about these aspects rather than aspects that clients may identify.

There are no right or wrong answers to the following questions and making them as detailed as possible would be greatly appreciated in order for me to use these to create a questionnaire. The idea of this questionnaire is to use your responses to create a further questionnaire that can then be circulated to a wider group nationally.

Your right to withdraw

Taking part in the study is voluntary and you may withdraw from it at any time. If you do decide to take part in the study you will be asked to indicate your consent by clicking on the continue to questionnaire button at the bottom of this page.

What is the process if I take part?

To fill in an online questionnaire that takes around 15-20 minutes to complete.

Confidentiality

All survey data will be stored securely and anonymised until the completion of the study.

Contact Information

If you have any problems, questions or concerns about this study you can contact h.layton171@canterbury.ac.uk as the principal researcher or martin.anson@canterbury.ac.uk as academic supervisor if you would like this to be independent of the principal researcher.

What if there is a problem?
For formal complaints or for voicing concerns with someone independent of the study, you can contact Professor Paul Camic (Research Director at Salomon's Centre for Applied Psychology) at paul.camic@canterbury.ac.uk.

Thank you for taking the time to read this information sheet. Please press continue if you wish to take part.

I confirm that I have read and understood the above information for this study. I understand that participation in this project is voluntary and that I may withdraw from this study at any time during the online survey process without needing to give a reason. I agree to participate in the above study.

Consent/info sheet for pilot

PILOT STUDY: What do therapists think about carrying out psychological interventions for mental health difficulties with someone who is considered to have High Functioning Autism (HFA) or Asperger's Syndrome (AS)?

My name is Helen Layton and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I am inviting you to take part in the second part of a study that forms part of my doctorate and which may later be submitted to an academic journal for publication. Before agreeing to take part in this study it is important to consider the information below so that you are aware of what the study involves and why it is being carried out.

What is the purpose of this study?
The study is investigating the views of therapists in primary care mental health settings on carrying out interventions for mental health difficulties with those considered to have HFA or AS.

Why have I been invited to take part?
You have been contacted after carrying out our elicitation study and indicating you might be able to take part in the next step- the pilot. Participants are being asked to participate based on their occupation and whether they are currently working in primary care mental health services in the UK. Participants will need to be in clinical roles to take part i.e. assessing and/or treating clients. This is likely to include psychological wellbeing practitioners, graduate mental health workers, assistant psychologists, CBT therapists and clinical and counselling psychologists. The only requirement being that you are working clinically in an IAPT service. There will be around 60-70 participants taking part in the study.

Your right to withdraw
Taking part in the study is voluntary and you may withdraw from it at any time by clicking "withdraw" or closing your browser. If you do decide to take part in the

study you will be asked to indicate your consent by clicking on the "continue" button at the bottom of this page.

What is the process if I take part?
You will fill in an online questionnaire that takes around 20 minutes to complete. The questionnaire will consist of statements that are about carrying out interventions for mental health difficulties with people with HFA or AS. You will be asked to provide ratings for each statement on a 7-point scale. There is also an open-ended question after this which will ask you to consider any other factors that you think may be relevant. In order to have a good picture of those who take part, we will also ask some demographic questions.
There will then be some questions about how you found filling out the questionnaire.

Confidentiality
All survey data will be stored securely and anonymised.

What are the possible benefits of taking part?
In taking part you will be adding to a limited research base around autism, mental health and staff perceptions of interventions with this group. Your participation may help inform whether interventions and training for staff might be useful.

Contact Information
If you have any questions or concerns about this study you can contact h.layton171@canterbury.ac.uk as the principal researcher or martin.anson@canterbury.ac.uk as academic supervisor if you would like this to be independent of the principal researcher.

What if there is a problem?
For formal complaints or for voicing concerns with someone independent of the study, you can contact Professor Paul Camic (Research Director at Salomon’s Centre for Applied Psychology) at paul.camic@canterbury.ac.uk.

Thank you for taking the time to read this information sheet.
I confirm that I have read and understood the above information for this study. I understand that participation in this project is voluntary and that I may withdraw from this study at any time during the online survey process without needing to give a reason. I agree to participate in the above study.

○ Continue

○ Withdraw

Pilot study

PILOT STUDY: What do therapists think about carrying out psychological interventions for mental health difficulties with someone who is considered to have High Functioning Autism (HFA) or Asperger’s Syndrome (AS)?

My name is Helen Layton and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I am inviting you to take part in the second part of a study that forms part of my doctorate and which may later be submitted to an academic journal for publication. Before agreeing to take part in this study it is important to consider the information below so that you are aware of what the study involves and why it is being carried out.

What is the purpose of this study?

The study is investigating the views of therapists in primary care mental health settings on carrying out interventions for mental health difficulties with those considered to have HFA or AS.

Why have I been invited to take part?

You have been contacted after carrying out our elicitation study and indicating you might be able to take part in the next step- the pilot. Participants are being asked to participate based on their occupation and whether they are currently working in primary care mental health services in the UK. Participants will need to be in clinical roles to take part i.e. assessing and/or treating clients. This is likely to include psychological wellbeing practitioners, graduate mental health workers, assistant psychologists, CBT therapists and clinical and counselling psychologists. The only requirement being that you are working clinically in an IAPT service. There will be around 60-70 participants taking part in the study.

Your right to withdraw

Taking part in the study is voluntary and you may withdraw from it at any time by clicking “withdraw” or closing your browser. If you do decide to take part in the study you will be asked to indicate your consent by clicking on the "continue" button at the bottom of this page.

What is the process if I take part?

You will fill in an online questionnaire that takes around 20 minutes to complete. The questionnaire will consist of statements that are about carrying out interventions for mental health difficulties with people with HFA or AS. You will be asked to provide ratings for each statement on a 7-point scale. There is also an open-ended question after this which will ask you to consider any other factors that you think may be relevant. In order to have a good picture of those who take part, we will also ask some demographic questions.

There will then be some questions about how you found filling out the questionnaire.

Confidentiality
All survey data will be stored securely and anonymised.

What are the possible benefits of taking part?
In taking part you will be adding to a limited research base around autism, mental health and staff perceptions of interventions with this group. Your participation may help inform whether interventions and training for staff might be useful.

Contact Information
If you have any questions or concerns about this study you can contact h.layton171@canterbury.ac.uk as the principal researcher or martin.anson@canterbury.ac.uk as academic supervisor if you would like this to be independent of the principal researcher.

What if there is a problem?
For formal complaints or for voicing concerns with someone independent of the study, you can contact Professor Paul Camic (Research Director at Salomon's Centre for Applied Psychology) at paul.camic@canterbury.ac.uk.

Thank you for taking the time to read this information sheet.

I confirm that I have read and understood the above information for this study. I understand that participation in this project is voluntary and that I may withdraw from this study at any time during the online survey process without needing to give a reason. I agree to participate in the above study.

○ Continue

○ Withdraw

Final questionnaire

What do therapists think about carrying out psychological interventions for mental health difficulties with someone who is considered to have High Functioning Autism (HFA) or Asperger's Syndrome (AS)?

My name is Helen Layton and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I am inviting you to take part in a study that forms part of my degree and which may later be submitted to an academic journal for publication. Before agreeing to take part in this study, it is important to consider the information below so that you are aware of what the study involves and why it is being carried out.

What is the purpose of this study?

The study is investigating the views of therapists in primary care mental health settings on carrying out interventions for mental health difficulties with those considered to have HFA or AS. Access to mental health services has been found to be difficult for this population and clinicians may have opinions and ideas as to why this might be.

Why have I been invited to take part?

Participants are being asked to participate based on their occupation and whether they are currently working in primary care mental health services in the UK. Participants will need to be in clinical roles to take part i.e. assessing and/or treating patients. This is likely to include psychological wellbeing practitioners, graduate mental health workers, assistant psychologists, CBT therapists, clinical and counselling psychologists. The only requirement being that you are working clinically in an IAPT service. There will be around 60-70 participants taking part in the study.

Your right to withdraw

Taking part in the study is voluntary and you may withdraw from it at any time by clicking "withdraw" or closing your browser. If you do decide to take part in the study you will be asked to indicate your consent by clicking on the continue to questionnaire button at the bottom of this page.

Prize draw

All participants who complete the questionnaire and provide their email addresses will be entered into a prize draw to win one of two £30 Amazon vouchers.

What is the process if I take part?

You will be asked to fill in an online questionnaire that takes around 20 minutes to complete. The questionnaire will consist of statements that are about carrying out interventions for mental health difficulties with those with HFA or AS. You will be asked to rate how much you agree or disagree with each statement. There is also an open-ended question after this which will ask you to consider any other factors that you think may be relevant. In order to have a good picture of those who take part, we will also ask some demographic type questions.

Confidentiality

All survey data will be stored securely and anonymised until the completion of the project. If you chose to enter the prize draw by providing your email address then this will be stored securely and separately from your responses.

What are the possible benefits of taking part?

- In taking part you will be adding to a limited research base around autism, mental health and staff perceptions of interventions with this group.
- Your participation may help inform whether interventions and training for staff might be useful.

Contact Information

If you have any questions or concerns about this study you can contact h.layton171@canterbury.ac.uk as the principal researcher or martin.anson@canterbury.ac.uk as academic supervisor if you would like this to be independent of the principal researcher.

What if there is a problem?

For formal complaints or for voicing concerns with someone independent of the study, you can contact Professor Paul Camic (Research Director at Salomon's Centre for Applied Psychology) at paul.camic@canterbury.ac.uk.

Thank you for taking the time to read this information sheet

I confirm that I have read and understood the above information for this study. I understand that participation in this project is voluntary and that I may withdraw from this study at any time during the online survey process without needing to give a reason. I agree to participate in the above study.

○ Continue

○ Withdraw

Appendix E

Debrief sheet for all stages

Thank- you for taking the time to complete the questionnaire. I hope that your input here will contribute to further thinking around those considered to have Autistic Spectrum Conditions and mental health difficulties.

Once again, if you would like to discuss any aspect of the study further or provide any feedback you can contact myself, Helen Layton at h.layton171@canterbury.ac.uk or for someone independent of the study paul.camic@canterbury.ac.uk.

Thank-you.

Appendix F

Recruitment emails

Elicitation study

My name is Helen Layton and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I am looking for those working in IAPT/primary care talking therapy services to complete a questionnaire examining clinician views about carrying out interventions for mental health difficulties with those considered to have High Functioning Autism or Asperger's Syndrome.

I would be very grateful if you could click on the link below and answer some questions for me. There is also a chance to win one of two £30 Amazon vouchers.

https://cccusocialsciences.az1.qualtrics.com/jfe/form/SV_8vsFdNUwo8Vm1eZ

Best wishes and many thanks for reading this,

Helen

Pilot study

Dear IAPT colleagues,

I am contacting you with the second questionnaire of my study on therapist views of carrying out interventions in IAPT with people with Autistic Spectrum Disorders.
Thank you for agreeing to be emailed and thank you in advance for any feedback you can provide me with; this will be very valuable taking this forward.

Follow this link or copy into your browser:
https://cccusocialsciences.az1.qualtrics.com/jfe/form/SV_eYbVcoKtuvLZmNT

Warm wishes,
Helen

Final questionnaire

Dear IAPT colleagues,

My name is Helen Layton and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. As part of my doctorate I am looking for those working in IAPT/primary care talking therapy services to complete a questionnaire. This questionnaire is examining clinician views about carrying out interventions for mental health difficulties with those considered to have High Functioning Autism or Asperger's Syndrome. This questionnaire is for anyone working clinically in IAPT, no experience of autism required.

I would be very grateful if you could click on the link below and answer some questions for me. There is also a chance to win one of two £30 Amazon vouchers.

https://cccusocialsciences.az1.qualtrics.com/jfe/form/SV_9LxnhwB45Erwf1X

Any questions about taking part in this study, I am contactable at h.layton171@canterbury.ac.uk.

Best wishes and many thanks for taking the time to read this!

Helen

Appendix G

Questionnaire Development Materials

This has been removed from the electronic copy.

Appendix H
Vignette consultation

Dear IAPT consultees,

I'm writing to ask for some fictional examples of common IAPT referrals in order to create realistic vignettes for my doctorate research.

It would be most helpful if in the vignette/bullet points if you considered some of the following:

- How the referral came to you e.g. team meeting, picked up from a spreadsheet etc
- Who made the referral
- Some demographic information about the service user
- Their social circumstances
- Their presenting difficulties
- Anything else that you consider typical in a referral

Appendix I

Content analysis for elicitation questionnaire

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Appendix J
Pilot bivariate analyses

		DM ATT	DM PBC	DM SN	DM INT	IN ATT	IN PBC	IN SN	IN INT
DM ATT	Pearson's correlation	1							
	Sig. (2-tailed)	-							
DM PBC	Pearson's correlation	0.230	1						
	Sig. (2-tailed)	0.661	-						
DM SN	Pearson's correlation	-0.616	-0.98	1					
	Sig. (2-tailed)	0.193	0.854	-					
DM INT	Pearson's correlation	-0.338	-0.281	0.363	1				
	Sig. (2-tailed)	0.578	0.647	0.549	-				
IN ATT	Pearson's correlation	-0.249	0.480	0.181	-0.373	1			
	Sig. (2-tailed)	0.634	0.335	0.732	0.536	-			
IN PBC	Pearson's correlation	-0.250	0.585	0.141	0.540	0.691	1		
	Sig. (2-tailed)	0.633	0.222	0.789	0.348	0.129	-		
IN SN	Pearson's correlation	0.362	0.117	0.166	-0.908	0.295	-0.381	1	
	Sig. (2-tailed)	0.550	0.852	0.790	0.092	0.629	0.527	-	
IN INT	Pearson's correlation	-0.266	0.472	0.194	1.000**	1.000**	0.695	0.286	1
	Sig. (2-tailed)	0.610	0.345	0.713	0.000	0.000	0.126	0.641	-

DM ATT=Direct measure of attitude, DM PBC= Direct measure of perceived behavioural control, DM SN= Direct measure of social norm, IN ATT= Indirect measure of attitude, IN PBC= Indirect measure of perceived behavioural control, IN SN= Indirect measure of social norm, IN INT= Indirect measure of intention.

Appendix K

Questions to review pilot questionnaire

This has been removed from the electronic copy.

Appendix L

Removed and altered Questions from pilot

Question altered or removed	Reason
Two items from PBC scale – time in session and length of session amalgamated into time in general.	Similar construct measured
PBC item "knowledge of autism". Similar to questions around experience and lowest number in content analysis (n=2)	Similar construct measured and lowest on content analysis
SN1- those experienced with autism	Negative correlations with 4 other SN variables and Cronbach if deleted rising from x to 0.817.
Five vignettes	Little variance and too long. Subject to more social desirability bias than a Likert scale answer.

Appendix M

Advert for Facebook professionals group

My name is Helen Layton and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I am looking for those working in IAPT to complete a questionnaire examining clinician views about carrying out interventions for mental health difficulties with those considered to have High Functioning Autism or Asperger's Syndrome.

I would be very grateful if you could click on the link below to find out more! There is also a chance to win one of two £30 Amazon vouchers.

[link]

Appendix N

Demographic questions on the questionnaires

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Appendix O
Final Questionnaire

This has been removed from the electronic copy.

Appendix P
Scoring Key for Questionnaire

This has been removed from the electronic copy.

Appendix Q

Cronbach's alpha for direct and indirect scales

Scale: Subjective norms indirect measure

Case Processing Summary

		N	%
Cases	Valid	82	93.2
	Excluded[a]	6	6.8
	Total	88	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	N of Items
.671	6

Scale: Subjective norms direct measure

Case Processing Summary

		N	%
Cases	Valid	85	96.6
	Excluded[a]	3	3.4
	Total	88	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	N of Items
.434	3

Inter-Item Correlation Matrix

	I feel under social pressure to carry out the interventions - Strongly agree:Strongly disagree	It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree	People who are important to me want me to carry out these interventions - Strongly agree:Strongly disagree
I feel under social pressure to carry out the interventions - Strongly agree:Strongly disagree	1.000	.338	.047
It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree	.338	1.000	.198
People who are important to me want me to carry out these interventions - Strongly agree:Strongly disagree	.047	.198	1.000

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted

I feel under social pressure to carry out the interventions - Strongly agree:Strongly disagree	8.27	4.795	.274	.115	.319
It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree	7.15	4.345	.381	.148	.085
People who are important to me want me to carry out these interventions - Strongly agree:Strongly disagree	7.89	7.096	.148	.040	.505

Scale: Attitude indirect measure

Case Processing Summary

		N	%
Cases	Valid	76	86.4
	Excluded[a]	12	13.6
	Total	88	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.699	.685	18

Scale: Attitudes direct measure

Case Processing Summary

		N	%
Cases	Valid	88	100.0
	Excluded[a]	0	.0
	Total	88	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.918	.918	4

Scale: Perceived behavioural control direct measure

Case Processing Summary

		N	%
Cases	Valid	85	96.6
	Excluded[a]	3	3.4
	Total	88	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.619	.628	4

Scale: Perceived behavioural control indirect measure

Case Processing Summary

		N	%
Cases	Valid	83	94.3
	Excluded[a]	5	5.7
	Total	88	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.655	.625	7

Scale: Generalised intention measure

Case Processing Summary

	N	%

Cases	Valid	86	97.7
	Excluded[a]	2	2.3
	Total	88	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.675	.671	3

Scale: Intention simulation measure

Case Processing Summary

		N	%
Cases	Valid	83	94.3
	Excluded[a]	5	5.7
	Total	88	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.857	.864	5

Appendix R

Bivariate correlations from final data set

		DM ATT	**DM PBC**	**DM SN**	**DM INT**	**IN ATT**	**IN PBC**	**IN SN**	**IN INT**
DM ATT	Pearson’s correlation	1							
	Sig. (2-tailed)	-							
DM PBC	Pearson’s correlation	0.225*	1						
	Sig. (2-tailed)	0.035	-						
DM SN	Pearson’s correlation	-0.56	-0.007	1					
	Sig. (2-tailed)	0.605	0.947	-					
DM INT	Pearson’s correlation	0.426	0.482**	0.104	1				
	Sig. (2-tailed)	0.000	0.000	0.337	-				
IN ATT	Pearson’s correlation	0.442**	0.151	-0.017	0.509**	1			
	Sig. (2-tailed)	0.000	0.161	0.879	0.000	-			
IN PBC	Pearson’s correlation	-0.31	0.354**	0.092	0.230*	-0.072	1		
	Sig. (2-tailed)	0.776	0.001	0.395	0.031	0.503	-		
IN SN	Pearson’s correlation	0.121	0.106	0.155	0.463**	0.208	0.233*	1	
	Sig. (2-tailed)	0.261	0.326	0.150	0.000	0.051	0.029	-	
IN INT	Pearson’s correlation	0.097	0.351**	-0.033	0.493**	0.292	0.274*	0.296*	1
	Sig. (2-tailed)	0.380	0.001	0.761	0.000	0.007**	0.011	0.006	-

DM ATT=Direct measure of attitude, DM PBC= Direct measure of perceived behavioural control, DM SN= Direct measure of social norm, IN ATT= Indirect measure of attitude, IN PBC= Indirect measure of perceived behavioural control, IN SN= Indirect measure of social norm, IN INT= Indirect measure of intention

Appendix S

Regression analyses from final data set

Direct attitudes regressed on indirect items

Model Summary[c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.442[a]	.196	.186	1.08237	
2	.443[b]	.196	.168	1.09455	1.890

a. Predictors: (Constant), MeanIndirectAtt

b. Predictors: (Constant), MeanIndirectAtt, MeanIndirectPBC, MeanIndirectSN

c. Dependent Variable: MeanDirectAtt

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	24.492	1	24.492	20.906	.000[b]
	Residual	100.752	86	1.172		
	Total	125.244	87			
2	Regression	24.608	3	8.203	6.847	.000[c]
	Residual	100.635	84	1.198		
	Total	125.244	87			

a. Dependent Variable: MeanDirectAtt

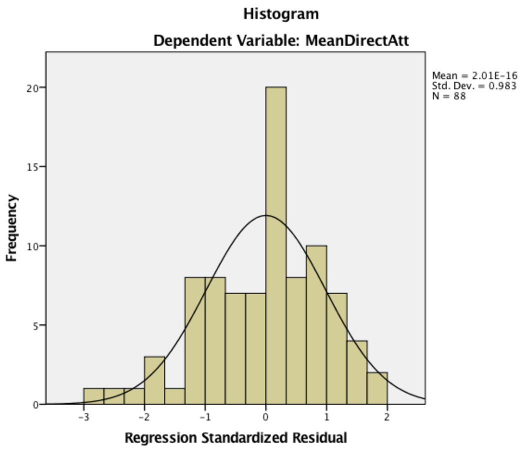
b. Predictors: (Constant), MeanIndirectAtt

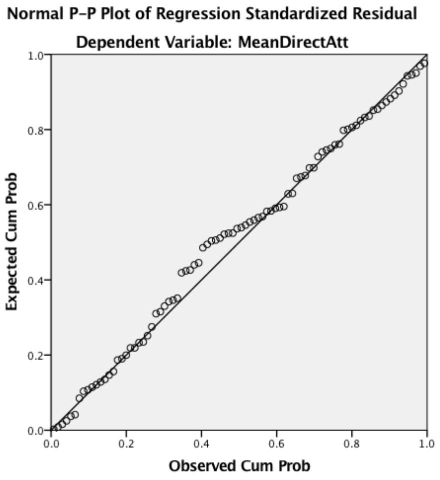
c. Predictors: (Constant), MeanIndirectAtt, MeanIndirectPBC, MeanIndirectSN

Coefficients[a]

		Unstandardized Coefficients		Standardized Coefficients		
Model		B	Std. Error	Beta	t	Sig.
1	(Constant)	4.006	.371		10.805	.000
	MeanIndirectAtt	.225	.049	.442	4.572	.000
2	(Constant)	3.975	.435		9.141	.000
	MeanIndirectAtt	.221	.051	.435	4.315	.000
	MeanIndirectSN	.009	.029	.032	.311	.756
	MeanIndirectPBC	-.002	.032	-.007	-.067	.947

a. Dependent Variable: MeanDirectAtt


Histogram
Dependent Variable: MeanDirectAtt
Mean = 2.01E-16
Std. Dev. = 0.983
N = 88
Frequency
20
15
10
5
0
-3
-2
-1
0
1
2
Regression Standardized Residual


Normal P-P Plot of Regression Standardized Residual
Dependent Variable: MeanDirectAtt
Expected Cum Prob
1.0
0.8
0.6
0.4
0.2
0.0
0.0
0.2
0.4
0.6
0.8
1.0
Observed Cum Prob

Predicted variable: subjective norm direct item regressed to indirect factors

Model Summary[c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.255[a]	.065	.054	1.546	
2	.271[b]	.073	.040	1.558	1.724

a. Predictors: (Constant), MeanIndirectSN

b. Predictors: (Constant), MeanIndirectSN, MeanIndirectAtt, MeanIndirectPBC

c. Dependent Variable: It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	14.274	1	14.274	5.968	.017[b]
	Residual	205.680	86	2.392		
	Total	219.955	87			
2	Regression	16.128	3	5.376	2.215	.092[c]
	Residual	203.827	84	2.427		
	Total	219.955	87			

a. Dependent Variable: It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree

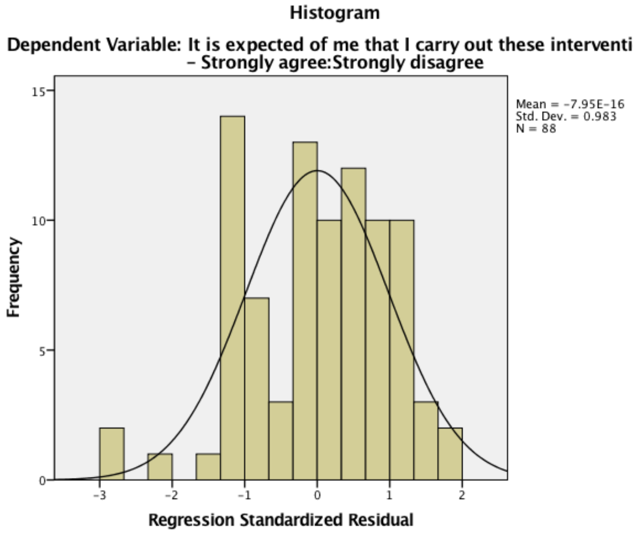
b. Predictors: (Constant), MeanIndirectSN

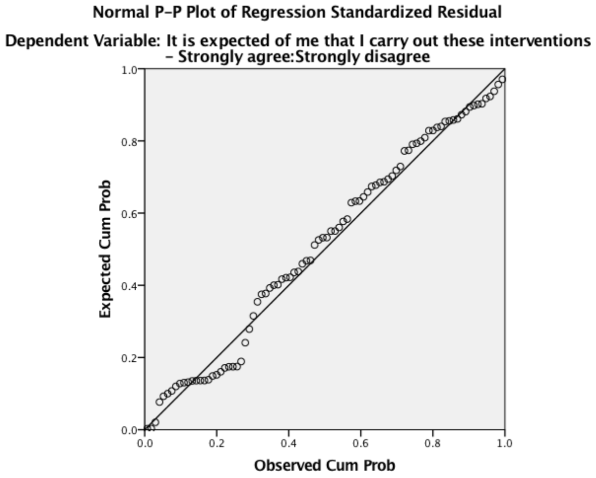
c. Predictors: (Constant), MeanIndirectSN, MeanIndirectAtt, MeanIndirectPBC

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	4.039	.244		16.582	.000
	MeanIndirectSN	.094	.039	.255	2.443	.017
2	(Constant)	4.347	.619		7.025	.000
	MeanIndirectSN	.086	.041	.232	2.091	.040
	MeanIndirectAtt	.001	.073	.002	.020	.984
	MeanIndirectPBC	.040	.046	.095	.869	.387

a. Dependent Variable: It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree





Predicted variable: subjective norm direct item regressed to indirect factors

Model Summary[c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.354[a]	.125	.115	1.01349	
2	.396[b]	.157	.127	1.00681	1.807

a. Predictors: (Constant), MeanIndirectPBC

b. Predictors: (Constant), MeanIndirectPBC, MeanIndirectAtt, MeanIndirectSN

c. Dependent Variable: MeanDirectPBC

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	12.638	1	12.638	12.304	.001[b]
	Residual	88.336	86	1.027		
	Total	100.974	87			
2	Regression	15.826	3	5.275	5.204	.002[c]
	Residual	85.148	84	1.014		
	Total	100.974	87			

a. Dependent Variable: MeanDirectPBC

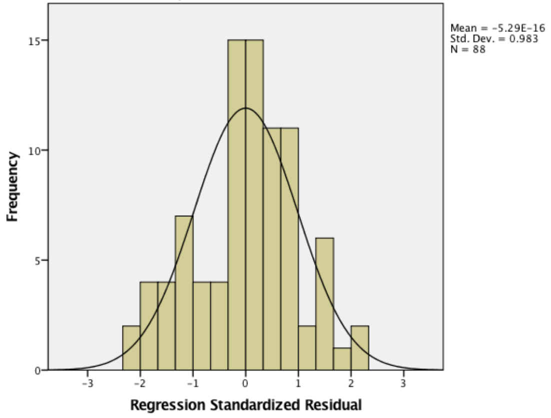
b. Predictors: (Constant), MeanIndirectPBC

c. Predictors: (Constant), MeanIndirectPBC, MeanIndirectAtt, MeanIndirectSN

Coefficients[a]

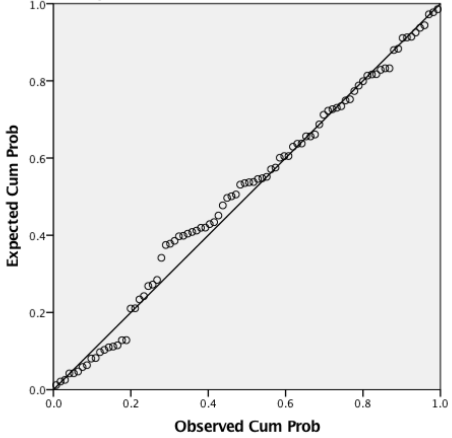
Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	4.475	.229		19.541	.000
	MeanIndirectPBC	.102	.029	.354	3.508	.001
2	(Constant)	3.938	.400		9.846	.000
	MeanIndirectPBC	.107	.030	.371	3.573	.001
	MeanIndirectAtt	.083	.047	.181	1.757	.083
	MeanIndirectSN	-.005	.027	-.018	-.174	.862

a. Dependent Variable: MeanDirectPBC



Histogram

Dependent Variable: MeanDirectPBC



Normal P-P Plot of Regression Standardized Residual

Dependent Variable: MeanDirectPBC

Generalised intention regressed on direct and indirect items

Model Summary[c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.601[a]	.361	.338	.81997	
2	.752[b]	.565	.533	.68882	2.034

a. Predictors: (Constant), It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree, MeanDirectAtt, MeanDirectPBC

b. Predictors: (Constant), It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree, MeanDirectAtt, MeanDirectPBC, MeanIndirectSN, MeanIndirectPBC, MeanIndirectAtt

c. Dependent Variable: MeanGenIntention

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	31.866	3	10.622	15.798	.000[b]
	Residual	56.478	84	.672		
	Total	88.343	87			
2	Regression	49.911	6	8.319	17.532	.000[c]
	Residual	38.432	81	.474		
	Total	88.343	87			

a. Dependent Variable: MeanGenIntention

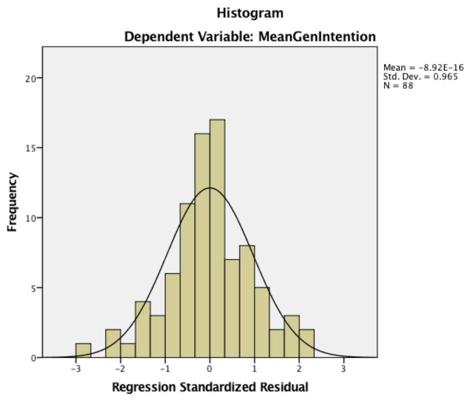
b. Predictors: (Constant), It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree, MeanDirectAtt, MeanDirectPBC

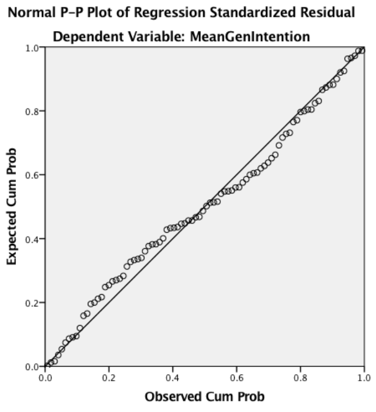
c. Predictors: (Constant), It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree, MeanDirectAtt, MeanDirectPBC, MeanIndirectSN, MeanIndirectPBC, MeanIndirectAtt

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	1.800	.534		3.373	.001
	MeanDirectAtt	.290	.075	.345	3.847	.000
	MeanDirectPBC	.364	.084	.389	4.320	.000
	It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree	.095	.056	.150	1.712	.091
2	(Constant)	1.885	.507		3.714	.000
	MeanDirectAtt	.148	.070	.176	2.106	.038
	MeanDirectPBC	.314	.076	.335	4.114	.000
	It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree	.029	.049	.045	.594	.554
	MeanIndirectPBC	.016	.022	.060	.730	.467
	MeanIndirectAtt	.136	.036	.317	3.782	.000
	MeanIndirectSN	.074	.019	.314	3.943	.000

a. Dependent Variable: MeanGenIntention





Intention simulation regressed on direct and indirect items

Model Summary[c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.353[a]	.125	.092	1.18998	
2	.506[b]	.256	.199	1.11795	1.664

a. Predictors: (Constant), It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree, MeanDirectAtt, MeanDirectPBC

b. Predictors: (Constant), It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree, MeanDirectAtt, MeanDirectPBC, MeanIndirectSN, MeanIndirectAtt, MeanIndirectPBC

c. Dependent Variable: MeanIntentionSim

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	16.367	3	5.456	3.853	.012[b]
	Residual	114.700	81	1.416		
	Total	131.067	84			
2	Regression	33.581	6	5.597	4.478	.001[c]
	Residual	97.486	78	1.250		
	Total	131.067	84			

a. Dependent Variable: MeanIntentionSim

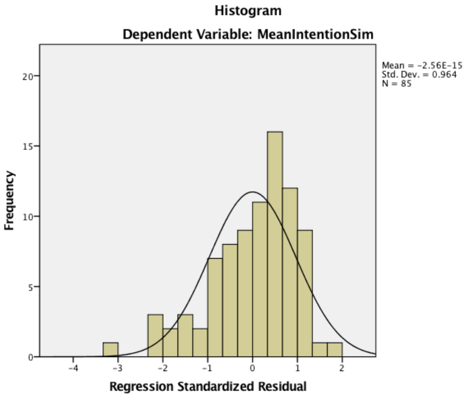
b. Predictors: (Constant), It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree, MeanDirectAtt, MeanDirectPBC

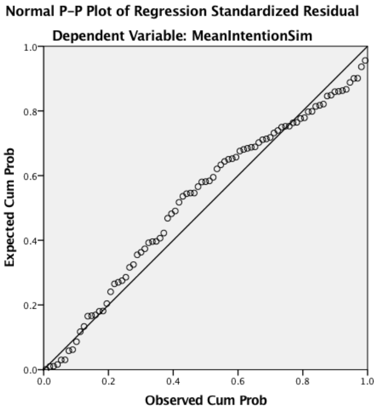
c. Predictors: (Constant), It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree, MeanDirectAtt, MeanDirectPBC, MeanIndirectSN, MeanIndirectAtt, MeanIndirectPBC

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	3.955	.816		4.849	.000
	MeanDirectAtt	.012	.119	.011	.099	.921
	MeanDirectPBC	.393	.124	.345	3.180	.002
	It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree	.030	.082	.038	.366	.715
2	(Constant)	4.388	.884		4.966	.000
	MeanDirectAtt	-.122	.122	-.110	-1.003	.319
	MeanDirectPBC	.307	.124	.270	2.478	.015
	It is expected of me that I carry out these interventions - Strongly agree:Strongly disagree	-.039	.080	-.051	-.495	.622
	MeanIndirectPBC	.047	.037	.141	1.298	.198
	MeanIndirectAtt	.141	.059	.258	2.372	.020
	MeanIndirectSN	.060	.031	.208	1.964	.053

a. Dependent Variable: MeanIntentionSim





Generalised intention regressed on indirect attitude items

Model Summary[d]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.517[a]	.268	.258	.86975	
2	.594[b]	.352	.335	.82355	
3	.655[c]	.429	.405	.77886	1.847

a. Predictors: (Constant), ATT_11

b. Predictors: (Constant), ATT_11, ATT_4

c. Predictors: (Constant), ATT_11, ATT_4, ATT_12

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	20.458	1	20.458	27.044	.000[b]
	Residual	55.979	74	.756		
	Total	76.437	75			
2	Regression	26.926	2	13.463	19.850	.000[c]
	Residual	49.511	73	.678		
	Total	76.437	75			
3	Regression	32.760	3	10.920	18.002	.000[d]
	Residual	43.677	72	.607		
	Total	76.437	75			

a. Dependent Variable: MeanGenIntention

b. Predictors: (Constant), ATT_11

c. Predictors: (Constant), ATT_11, ATT_4

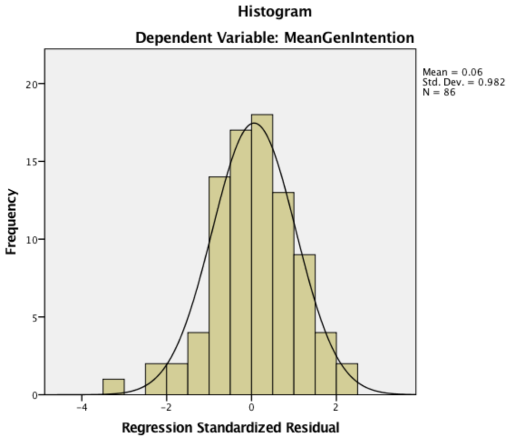
d. Predictors: (Constant), ATT_11, ATT_4, ATT_12

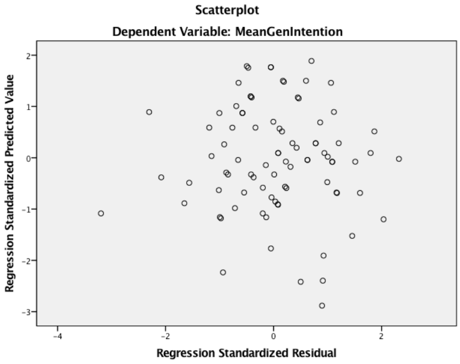
d. Dependent Variable: MeanGenIntention

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	3.408	.360		9.467	.000		
	ATT_11	.121	.023	.517	5.200	.000	1.000	1.000
2	(Constant)	3.378	.341		9.908	.000		
	ATT_11	.091	.024	.390	3.789	.000	.839	1.192
	ATT_4	.056	.018	.318	3.088	.003	.839	1.192
3	(Constant)	4.242	.426		9.955	.000		
	ATT_11	.067	.024	.286	2.775	.007	.749	1.335
	ATT_4	.063	.017	.357	3.635	.001	.825	1.212
	ATT_12	-.067	.022	-.292	-3.101	.003	.893	1.119

a. Dependent Variable: MeanGenIntention





Generalised intention regressed on indirect factors of subjective norm

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.441[a]	.195	.185	.89336
2	.496[b]	.246	.226	.87029

a. Predictors: (Constant), SN_1

b. Predictors: (Constant), SN_1, SN_4

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	15.458	1	15.458	19.369	.000[b]
	Residual	63.848	80	.798		
	Total	79.306	81			
2	Regression	19.471	2	9.736	12.854	.000[c]
	Residual	59.835	79	.757		
	Total	79.306	81			

a. Dependent Variable: MeanGenIntention

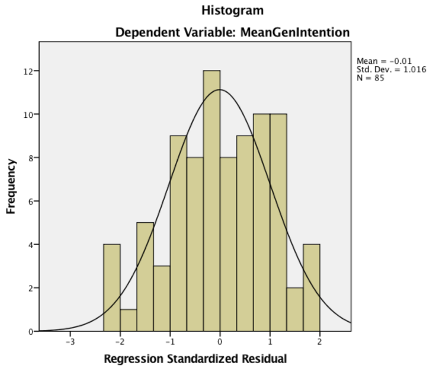
b. Predictors: (Constant), SN_1

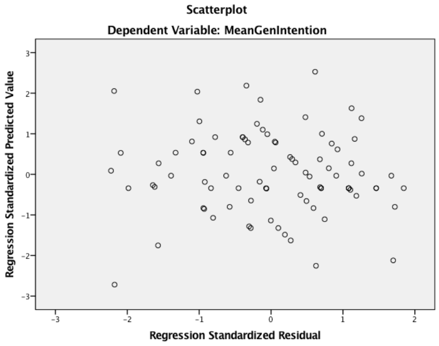
c. Predictors: (Constant), SN_1, SN_4

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	5.133	.101		50.836	.000
	SN_1	.057	.013	.441	4.401	.000
2	(Constant)	5.061	.103		49.011	.000
	SN_1	.040	.015	.308	2.712	.008
	SN_4	.038	.016	.262	2.302	.024

a. Dependent Variable: MeanGenIntention





Generalised intention regressed on indirect factors of PBC

Model Summary[c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.517[a]	.267	.258	.83791	
2	.584[b]	.341	.325	.79912	2.400

a. Predictors: (Constant), PBC_2

b. Predictors: (Constant), PBC_2, PBC_1

c. Dependent Variable: MeanGenIntention

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	20.705	1	20.705	29.491	.000[b]
	Residual	56.869	81	.702		
	Total	77.574	82			
2	Regression	26.487	2	13.243	20.738	.000[c]
	Residual	51.087	80	.639		
	Total	77.574	82			

a. Dependent Variable: MeanGenIntention

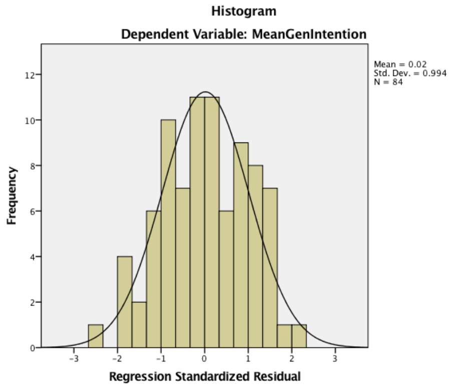
b. Predictors: (Constant), PBC_2

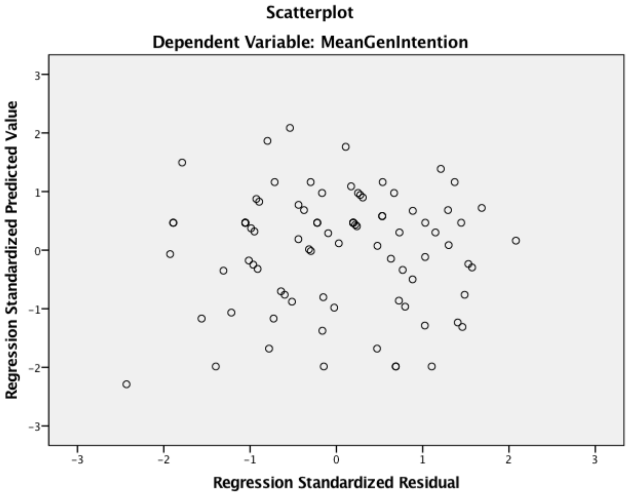
c. Predictors: (Constant), PBC_2, PBC_1

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	5.728	.128		44.783	.000
	PBC_2	.067	.012	.517	5.431	.000
2	(Constant)	5.511	.142		38.896	.000
	PBC_2	.075	.012	.579	6.223	.000
	PBC_1	-.058	.019	-.280	-3.009	.004

a. Dependent Variable: MeanGenIntention


Histogram
Dependent Variable: MeanGenIntention
Mean = 0.02
Std. Dev. = 0.994
N = 84
Frequency
0
2
4
6
8
10
12
−3
−2
−1
0
1
2
3
Regression Standardized Residual


Scatterplot
Dependent Variable: MeanGenIntention
Regression Standardized Predicted Value
3
2
1
0
−1
−2
−3
−3
−2
−1
0
1
2
3
Regression Standardized Residual

Generalised intention regressed on direct factors of PBC

Model Summary[c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.590[a]	.348	.340	.81830	
2	.619[b]	.383	.368	.80096	1.750

a. Predictors: (Constant), I am confident that I could carry out these interventions - Strongly disagree:Strongly agree

b. Predictors: (Constant), I am confident that I could carry out these interventions - Strongly disagree:Strongly agree, For me to carry out these interventions would be - Easy:Difficult

c. Dependent Variable: MeanGenIntention

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	29.677	1	29.677	44.320	.000[b]
	Residual	55.578	83	.670		
	Total	85.255	84			
2	Regression	32.649	2	16.324	25.446	.000[c]
	Residual	52.606	82	.642		
	Total	85.255	84			

a. Dependent Variable: MeanGenIntention

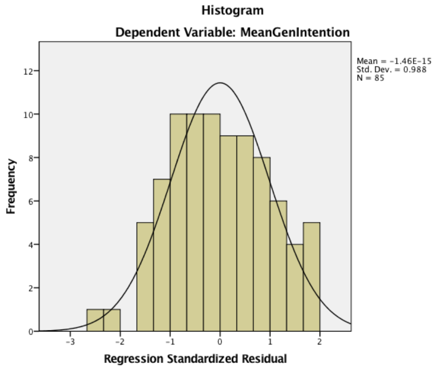
b. Predictors: (Constant), I am confident that I could carry out these interventions - Strongly disagree:Strongly agree

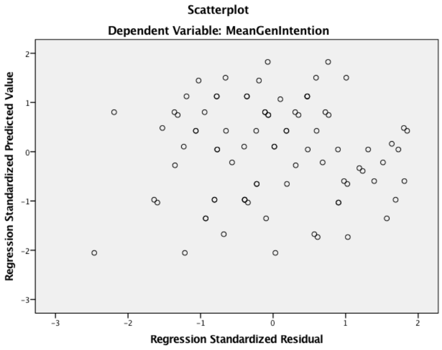
c. Predictors: (Constant), I am confident that I could carry out these interventions - Strongly disagree:Strongly agree, For me to carry out these interventions would be - Easy:Difficult

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	3.732	.245		15.205	.000
	I am confident that I could carry out these interventions - Strongly disagree:Strongly agree	.353	.053	.590	6.657	.000
2	(Constant)	3.538	.256		13.797	.000
	I am confident that I could carry out these interventions - Strongly disagree:Strongly agree	.236	.075	.395	3.148	.002
	For me to carry out these interventions would be - Easy:Difficult	.200	.093	.270	2.152	.034

a. Dependent Variable: MeanGenIntention





Generalised intention regressed on direct factors of attitude

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.419[a]	.176	.166	.92029	1.758

a. Predictors: (Constant), Overall I think that carrying out interventions for mental health difficulties for someone with Asperger's or high functioning autism is... - Good:Bad

b. Dependent Variable: MeanGenIntention

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	15.506	1	15.506	18.309	.000[b]
	Residual	72.837	86	.847		
	Total	88.343	87			

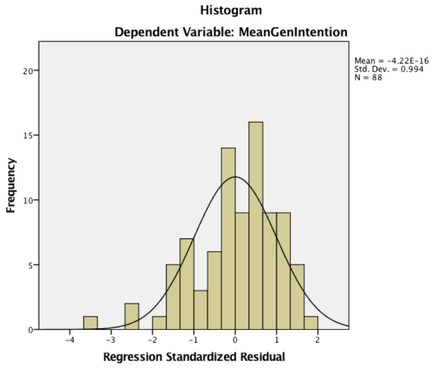
a. Dependent Variable: MeanGenIntention

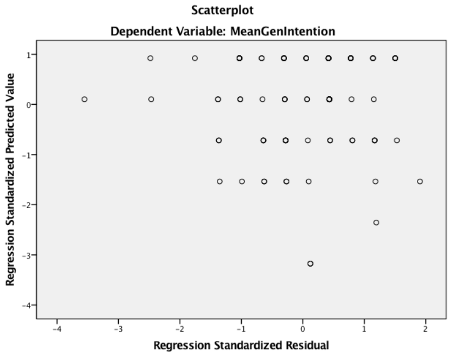
b. Predictors: (Constant), Overall I think that carrying out interventions for mental health difficulties for someone with Asperger's or high functioning autism is... - Good:Bad

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	3.195	.485		6.589	.000
	Overall I think that carrying out interventions for mental health difficulties for someone with Asperger's or high functioning autism is... - Good:Bad	.346	.081	.419	4.279	.000

a. Dependent Variable: MeanGenIntention


Histogram
Dependent Variable: MeanGenIntention
Mean = -4.22E-16
Std. Dev. = 0.994
N = 88
Frequency
20
15
10
5
0
-4
-3
-2
-1
0
1
2
Regression Standardized Residual


Scatterplot
Dependent Variable: MeanGenIntention
Regression Standardized Predicted Value
1
0
-1
-2
-3
-4
-4
-3
-2
-1
0
1
2
Regression Standardized Residual

Appendix T

Content analysis Qualitative Question

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