

# Referrers Perceptions of the Autistic Presentation: A Content Analysis

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## Abstract

**Background:** No studies to date have explored the content of referrals into ASD services. Investigating this may improve the accuracy and speed with which adults with ASD can be identified. **Methods:** Twenty-one referral forms for autistic adults diagnosed by a specialist ASD service were analyzed using a content analysis. **Results:** Five main themes were identified in the data: “The Social Dilemma”, “Communication Disconnect”, “Attainment”, “Managing Uncertainty” and “Emotional Well-being and Mental Health”. **Conclusions:** The results brought novel insights into the nature of difficulties adults with ASD face according to referrers. The findings enhance professional understanding of the issues most likely to represent ASD. The results highlight the importance of developing additional screening tools and methodologies that can capture referrers concerns.

## Keywords

Autism, ASD, Adult, Assessment, Diagnostic, Thematic, Qualitative

## 1. Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition, defined by enduring deficits in social communication and interaction, as well as restrictive, repetitive interests and/or behaviours (American Psychiatric Association, 2013). ASD exists in approximately 1% of the general population; which equates to 700,000 individuals in the UK (Brugha et al., 2011). However, data published by the National Health Service (NHS) in the first 3 quarters of 2018-19 indicated fewer than 18,000 referrals for diagnostic assessment of ASD were made in the UK in that period (Community and Mental Health team, NHS Digital, 2019). Based on this number of referrals it is clear a significant proportion of adults with ASD remain unknown to specialist services. The gulf between the

number of people known versus unknown to specialist services is even more striking when diagnostic rates as low as 25% - 30% are factored in (Sheehan, 2018; Talari et al., 2017).

The challenge facing adult ASD services in the UK is not merely one of diagnostic sensitivity, but also one of capacity. Although there is limited data for comparison, research suggests the average waiting time for adults receiving diagnostic assessment is 162 days, with approximately 60% of adults waiting over the 119 day threshold adhered to by children's services (McKenzie et al., 2015). Specialist services are known to be burdened with diagnostic demand and adults awaiting assessment have frequently articulated dissatisfaction at lengthy waiting times and difficulties in accessing diagnostic pathways (Murphy et al., 2016; Taylor & Marrable, 2011).

Securing a diagnosis in the UK can therefore be a lengthy process resulting in a significant proportion of the adult autistic population remaining unidentified by specialist services. Identifying adults with ASD in a timely fashion is perhaps most challenging in those without a learning disability (Mazzone et al., 2012). This is a group often referred to as "*high functioning*", although they are known to experience difficulties with the development and maintenance of relationships, independent living, academic achievement and finding employment (Smith et al., 2012). Whilst presenting as having average to above average cognitive ability, these individuals still display poor adaptive skills because of core autism symptomatology (Hedley et al., 2017). Studies show that such "*high functioning*" adults are less likely to develop meaningful relationships because of impairments in social communication and are often either unemployed, underemployed or subject to workplace discrimination and have significantly lower psychosocial outcomes, when compared to neuro typical peers (Dijkhuis et al., 2017; Lin & Huang, 2019).

### 1.1. Pathway Development and Service Improvement

At present there are no definitive biomarkers for ASD to improve the accuracy or expediency of diagnostic assessments. Moreover, recent studies have identified significant limitations where established screening tools for ASD are concerned (Adamou, Jones, & Wetherhill, 2021; Jones, Johnson, Alty, & Adamou, 2021). Further screening tools and methodologies for the accurate and timely identification of people with ASD, are therefore required.

### 1.2. Qualitative Studies

Qualitative research is an umbrella term for research methodologies which describe and explain people's experiences, behaviours, communications and social environments (Corbin & Strauss, 1990). Qualitative research is an important means of gaining an insight into human behaviour by exploring and understanding the lived experiences of individuals (Willig, 2013). In this study qualitative methodology allows for the exploration of the perspectives of referrers in relation to their patients.

In the field of ASD qualitative research has generally been populated by experiences of children and their families (Phelps et al., 2009) with a smaller number of studies exploring the experiences of adults. Hurlbutt & Chalmers (2002) report that adults with ASD have their own “unique culture”, views of “support systems and self-worth” and can describe factors that can help “make a difference” to their care. A small body of research has focused on the experiences of clinician’s supporting adults with ASD. For example, Warfield et al. (2015) report clinician’s views that resourcing issues and a lack of awareness can hinder the care of adults with ASD. Crane et al. (2018) conducted one of the few qualitative studies exploring the perspectives of adults with ASD, parents and associated professionals. This study revealed multiple barriers to service user satisfaction related to; lack of awareness, a tendency for practitioners to focus on negative aspects of the condition, lack of rapport between service users and practitioners and inappropriateness of assessment tools. Nevertheless, to date no qualitative studies have explored accounts of referring professionals to ASD services.

### 1.3. The Current Study

The current study reports the findings of a content analysis of the textual accounts of referrers. Data was generated from referral forms for individuals who went on to receive a diagnosis of ASD. This exploratory research aims to understand what the content of clinician’s referrals can tell services about the difficulties and presentation of adults with ASD. The findings of this study might inform the development of future screening tools and methodologies which can improve the accuracy and expediency of diagnostic assessments.

## 2. Methods

### 2.1. Participants & Materials

The inclusion criterion for this study was adults over the age of 18 with diagnosis of ASD; without a global learning disability. All participants included in the study were diagnosed by the NHS South West Yorkshire Partnership Foundation Trust (SWYFT) Adult ASD service, which adheres to the National Institute for Health and Clinical Excellence guideline for diagnostic assessments (CG142). Therefore, all participants had received a diagnosis following assessment by trained specialists, using a combination of face-to-face interviews, developmental and personal histories from family members, validated diagnostic instruments and multi-disciplinary review.

All participant data was collected from referral forms and returned to the Service in a period covering two years. The forms prompt referrers to provide information they feel is relevant to describe the difficulties and presentation of the person they are referring. To have been accepted, all referrals must have been made by a healthcare professional (HCP) in the trust locality.

### 2.2. Procedure

Researchers reviewed all referral forms returned over the past two years which

resulted in a diagnosis of ASD. In total, 38 referral forms were identified, and these were jointly reviewed to determine which should be excluded due to insufficient information. 17 referral forms were excluded on the basis that they were blank or contained minimal textual data. A total of 21 referral forms were included for content analysis on the basis they provided sufficient textual data. Each referral had its textual data transcribed into an individual document. All personal identifiable information was removed during this process and pseudonyms were used for participants and referrers in the study (Table 1).

### Autistic Adults & Referrers

Table 1 contains referrer information and demographic information for the Autistic person being referred for assessment.

**Table 1.** Demographics of ASD adults and referrers.

Referrer Pseudonym	Referrer designation	Client Pseudonym	Age	Gender	Ethnicity	Existing Diagnosis
Dr M. Zayda	GP	Paul	20	Male	British Mixed	ADHD
Dr M. Smith	GP	Carl	23	Male	White/British	None
DR D. Caroll	GP	Fredrick	48	Male	White/British	None
Dr M. Smart	GP	Harriet	24	Female	White/British	None
Dr I. Syeed	GP	Julie	24	Female	White/British	None
Ms P. Reynolds	Occupational Therapist CMHT	Patrick	50	Male	White/British	Low Mood
Dr S Nabil	GP	Ricky	62	Male	British/Mixed	None
Dr S. Dylan	GP	Ursula	27	Female	Unknown	None
Dr S. Norton	GP	Barry	35	Male	White/British	Dyslexia and Dyspraxia
Dr T. Cobin	GP	Chloe	30	Female	Unknown	Low Mood
Dr H. Ellens	GP	Luke	37	Male	Unknown	None
Dr W. Rastling	GP	Stuart	39	Male	Unknown	None
Dr R. Finch	GP	Pamela	25	Female	White/British	None
Ms W. Wendell	Care-coordinator	Clark	29	Male	Unknown	Schizo-affective disorder
Dr G. Rogers	GP	Wendy	55	Female	White British	None
Dr L Aslam	GP	Betty	21	Female	Unknown	Dyslexia
Ms S Kirkstall	Mental health nurse	Sandra	21	Female	White/British	Dyslexia, dyscalculia, OCD
Dr P Crowther	GP	Donald	38	Male	Unknown	None
Dr M. Rivers	GP	Dean	42	Male	Unknown	None
Dr. R. Clandell	Clinical Psychologist	Aisha	41	Female	Asian, Asian British	Recurrent depressive disorder
Dr S. Tricker	GP	Penelope	25	Female	White British	Anxiety, depression, Personality disorder(s)

Age was normally distributed (Shapiro Wilks;  $W = 0.91$ ,  $p = 0.06$ ), mean = 36.1 (SD = 12.1); ranges 20 - 62. Male age normally distributed ( $W = 0.97$ ,  $p = 0.92$ ), mean = 38.6 (SD = 12.1). Female age not normally distributed ( $W = 0.74$ ,  $p = 0.003$ ). Median = 29.3 (Interquartile Range of 5.25).

### 2.3. Analysis

A content analysis approach was used following Bengtsson's (2016) four stage model. The inductive process allowed researchers to search and identify categories and sub-categories manifested within textual data. To ensure familiarisation with data, researchers individually read and then re-read each transcript. The data was then decontextualised as lines were coded for potential meaning units (stage 1). The original text was then re-read alongside the coded data. This process of recontextualization ensured that all aspects of the textual accounts were covered and allowed for extraneous data to be removed (stage 2). To establish reliability and objectivity, researchers conducted individual analysis at stages 1 and 2. Stage 3 was conducted collaboratively, with researchers reviewing data, to confer, merge and define final operationalising categories and sub-categories (stage 3). Agreement between coders at this stage was high and demonstrated inter-rater reliability ( $K = 0.823$ ,  $p < 0.001$ ). This process was hierarchical in nature as smaller units were merged into larger categories. At stage 4 the data was presented in a narrative representing the categories and sub-categories which were identified during the analysis.

## 3. Results

Data extracted from referral forms presented commonalities and variation in referrer's perceptions of the difficulties experienced by adults who received a diagnosis of ASD. Five main categories emerged from the data: "*The Social Dilemma*", "*Communication Disconnect*", "*Attainment*", "*Managing Uncertainty*" and "*Emotional Well-being and Mental Health*".

### 3.1. Theme One: The Social Dilemma

Clinicians frequently referred to social challenges experienced by autistic adults. The nature of the challenge in this theme is represented by the dilemma of feeling detached and isolated from the social world, whilst simultaneously choosing to withdraw from it.

#### 3.1.1. Detachment

Use of the word "*detached*" occurred frequently in referrals when describing patient's experiences of feeling different and separate from wider society.

Dr Aslam describes this issue in relation to his patient Betty, stating she "*does not belong*" within her peer group or in wider society. Occupational Therapist, Ms Reynolds described a similar situation for Patrick who considers himself "*detached from social groups and feels different from others*" and in the case of Carl, Dr Smith commented that he had been "*an outsider at school*".

Social detachment had the effect of making autistic adults not feel "*at ease with other people*" and this sense of disconnection lead to some finding it "*difficult to trust people*" (Dr. Norton, in relation to Barry). For Luke, it was a source of distress for which they were seeking resolution. As Dr Ellen commented he was "*fed up with being alone*" and wanted "*to learn to relate to other*

*people and form relationships”.*

Adults with ASD frequently held external attributions to account for their sense of detachment. For example, as Ms Wendell (Care Coordinator) explained in relation to Clark:

*“He has concerns about people adversely impacting on him and that people struggle to understand him, which reduces his social contact [...] he finds it difficult to trust people as they do not understand his autistic behaviours”.*

Similarly, Dr Rivers described that Dean *“feels detached”* due to *“lack of support and understanding”* and Dr Smart adds that Harriet feels *“it would be helpful if work understood her difficulties and was able to take these into account”*. Referrers therefore frequently articulated their patient’s beliefs that the cause of their detachment was situated externally.

### **3.1.2. Isolation**

Whereas detachment represented a neutral expression of disconnection from wider society attributed to the external world, autistic adults also frequently reported having experiences of isolation situated in their internal worlds.

A majority of referrers disclosed that their patients had very limited social circles, lacked a close group of friends, or had no friends at all:

*“Wendy does not have a close group of people who are her friends”, “her social relationships are less fluent than she perceives those around her to have”.* (Dr Rodgers)

Dr Zayda commented of Paul that he *“made no friends at University, due to social difficulties”* and that *“he does not see friends, apart from online”*. Similarly, Dr Nabil explained that Ricky displays *“difficulties communicating with others, has no friends, and is very isolated”*.

For some patients forging new relationships, as well as maintaining and managing existing ones, was a significant problem. In the case of Penelope, Dr Tricker disclosed she *“struggles to make friends [...] she similarly struggled at school and used to sit alone by herself”*.

Dr Smith further reported that problems with forging relationships had left Carl feeling *“like an outsider”* and like he *“doesn’t fit in”* compared to other people. Another GP, Dr Carroll, reported that his patient Fredrick did *“not feel part of a group”*. Dr Carroll described the impact of this isolation on his patient’s self-esteem writing that he felt a *“failure”*.

Isolation was most profound in the descriptions of patients’ functioning in larger social settings and most referrers reported that individuals were prone to *“struggling in groups”* which they found to be a *“stressful”* experience.

*“Harriet is not in contact with any friends, she found it difficult and particularly stressful in group situations where she struggled to understand chit-chat and how to behave”* (Dr. Smart).

Isolation also stemmed from experiences of more overt forms of marginalisation. For example, Dr Rodgers reports Wendy’s experience of *“difficulties with colleagues and workplace bullying”* and Dr Smart similarly explained that *“Har-*

riet left her first University course due to bullying”.

### 3.1.3. Avoidance

Juxtaposed with reports of isolation and detachment were those relating to people who actively avoided or limited social contact in its various forms.

Avoidance was demonstrated primarily by the Autistic individual removing themselves from social engagements and environments. As Dr Rastling reported of Stuart he “*avoids interaction, stays in his room [...] and prefers to be alone*”.

In the case of Clark, Ms Wendell (Care Coordinator) explained: “*he misunderstands responses and people struggle to understand him—so he reduces his social contact*”. Likewise, Dr Finch documented that “*Pamela avoids social interaction, staying in her room, at home, rather than go out*” and Wendy is reported to be “*quiet in social situations and finds it difficult to initiate conversations—due to this, she occasionally would prefer to be isolated rather than in a social setting*”

Referrers frequently described the physical distancing which was employed in order to achieve avoidance. As Ms Kirkstall (Mental Health Nurse) wrote Sandra “*has to be a fair distance from others*” and that she “*withdraws and hides*” from others and the social world. Ms Wendell (Care Coordinator) also reports that Cark “*doesn't like to leave the house*” and Dr Clandell explains Aisha's behaviour by stating that she “*described herself as a loner*” who “*prefers to self-isolate*”.

## 3.2. Theme 2: Communication Disconnect

Referrers described a range of issues within Autistic communication styles resulting in unfulfilling or negative social interaction experiences. The difficulties described in terms of communication centred on various forms of disconnect between communicator and recipient. As a result, autistic adults were frequently documented to struggle in “*initiating*” and “*sustaining*” interactions.

### 3.2.1. Misreading the Exchange

Referrers described the autistic adult's inability to detect and “*read peoples emotions*” and “*body language*” appropriately, or to understand “*intentions*”. Several referrers described individuals finding “*social interaction overly complex*” and “*confusing*” which was frequently attributed to an inability to read the “*hard to understand intentions*” of others (Dr Smart describing Harriet). Occupational Therapist, Ms Reynolds also refers to this issue:

“*Patrick needs time to process information/He finds small talk complicated and struggles when people express their emotions [...] he finds it difficult to understand peoples thoughts*”.

In Patrick's view “*computers are easier to understand*” than humans who are “*difficult to read*”. This inability to read the thoughts and subtle nuances of others directly affected the conversational flow. For example, Barry is described as being overly dominant within conversation by Dr Norton:

“*Barry tends to over-talk [...] he dominates conversation as a coping mechan-*



*ism to alleviate the stress of the situation. He only knows he is talking too much—or dominating conversation, if someone tells him”.*

By comparison, some struggled to detect “*when to speak*” or “*initiate*” conversation. Ms Reynolds (O.T.) disclosed that Patrick only “*answers questions but does not start a conversation himself*”.

Several referrers described specific aspects of the communication process that their patients struggled to interpret. In the case of Harriet, Dr Smart explained “*she finds body language difficult to read*”, adding she “*is unable to tell when someone is bored or switching off*”. Consequently, “*her partner will always do the communicating for both of them*”.

Dr. Dylan explained that his patient (Ursula) did not know what to say next or when to detect cues to allow someone else to speak: “*she struggles to keep the conversation going, and doesn’t always understand when others want to speak*”. In the case of Julie, Dr Syeed explained that her difficulties were most acute in group settings where she could not decipher how to attend to the various participants in the conversation:

*“She has trouble interpreting social communication expectations and ‘what is expected’ in a social group and if she is supposed to speak or respond to chat directed at her [...] in group situations she struggles to understand chit-chat”.* He further explained that she cannot read the flow of conversation or when she is required to contribute:

*“Julie is unsure when to interject and has trouble making natural flow of conversation, e.g., talks too much or not at all. She cannot judge when the conversation has ended, so may walk away half way through”.*

Dr Dylan also describes Ursula’s difficulty in reading the emotional subtext:

*“She cannot tell when people are joking, she struggles to understand what people mean [...] constantly asking her partner if everything is okay, as she is unable to read between the lines.”*

An inability to “*read between the lines*” was frequently reported alongside difficulties detecting jokes and sarcasm within conversation. This was something which often caused individuals frustration and “*paranoia*”:

*“Harriet struggles with workplace ‘banter’, she does not understand sarcasm or innuendo and finds it extremely hard to interpret what is serious and what is banter. There have been many occasions of ‘paranoia’ trying to work out if someone is insulting her or making a joke” (Dr Smart).*

### **3.2.2. Inappropriate Responding**

The inability to appropriately read the social exchange affected the person’s ability to respond. Referrals frequently captured this difficulty as Dr Smart reported:

*“Harriet cannot understand how people may feel angry after certain events [...] she has trouble reading people’s emotions based on expression or behaviour, e.g., if they are happy, sad, angry etc. and therefore does not respond appropriately or sympathetically if needed”.*

Individuals were often described as appearing “*cold*” and “*uncaring*” in their



communication. As Dr Zayda explains, Paul “*is often seen as aloof or distant by peers*”. Dr Smith further commented that Carl can “*say hurtful things, without meaning to be hurtful*”, “*he doesn’t learn from situations that went badly, [...] his thinking is black and white*” and Paul “*appears rude at times, making cutting remarks, but not aware they may be upsetting*” (Dr Zayda)

Dr Tricker reported that Penelope was often informed she does not respond appropriately: “*Penelope thinks she is being friendly and supportive, but people tell her she is being impolite*”.

The inability to respond appropriately was frequently attributed to individuals having a lack of spontaneity or flexibility within the social interaction. Consequently, they had not been able to master basic “*small talk*”. As Dr Smart described, “*on rare occasions when Harriet does start talking, she can give her whole life history in 10 minutes and can scare people away*”. Similarly, Ms Reynolds (OT) explains that Patrick “*can exchange pleasantries but lacks spontaneous conversational skills*”.

### 3.2.3. Unintended Consequences

Most referrers described some unintended and negative consequences following their patients’ interactions with others. Referrers described the discrepancy between individual’s expectations and perceptions of their actions versus the eventual outcome.

For example, referrers frequently described “*inappropriate*” behaviour when their patients conversed with others and described them as being unaware when they have made an inappropriate remark or comment. Individuals were frequently reported to have displayed behaviour considered “*inappropriate*”, “*impolite*” and “*emotionless*” within conversation:

“*Paul never initiates conversation or arrangements and is unsure how to [...] he cannot make casual conversation and is often seen as aloof or distant by peers*” (Dr Zayda). When Paul does interact with others he is often described as “*rude*”, making “*cutting remarks*” which he is unaware of. Autistic adults were therefore often perceived to be “*rude*”. As Dr Smith commented, Carl “*feels his thinking is black and white [...] he can say hurtful things without meaning to be hurtful*”.

This gulf between the Autistic persons perception of the communication exchange with that of the receivers experience was mirrored in referrers personal reflections. Words such as “*aloof*”, “*awkward*” and “*impolite*” were frequently used to describe how patients appeared in clinic. Moreover, several referrers reflected on an uncomfortable or “*awkward consultation*” experience.

Elsewhere, referrers frequently described “*inappropriate*” behaviour when their patients conversed with others and described them as being unaware when they have made inappropriate remarks or comments. Individuals were reported to display behaviours considered typically inappropriate to others, appearing “*impolite*” and “*emotionless*” within conversation and displaying limitations in the ability to express empathic behaviour. Comparatively, this often went unno-

ticed by Autistic individuals, who did not recognise behaviour as “*rude*”.

Despite a propensity to offend or merely misjudge the situation it was apparent this was not the individual’s intention. As Dr Syeed explained, Julie “*accidentally makes rude and off topic remarks and is confused when this is pointed out*”. Similarly, Miss W. Wendell (Care-coordinator) stated that Clark’s “*topics of conversation can be inappropriate, and he misunderstands people’s responses*”.

In another example Dr Tricker reported that Penelope “*thinks she is being friendly and supportive, but people tell her she is being impolite*” and Dr Ellens describes that “*people can misread Luke*”, “*they often think he has said something impolite—or that he is annoyed, when he isn’t*”.

### 3.3. Theme 3: Attainment

Most referrals articulated the struggles and unfulfilled potential of Autistic individuals within education, the workplace, and the social arena.

#### 3.3.1. Education

A significant number of referrers disclosed the struggle of Autistic individuals in educational settings. The contributing factors included managing social interactions, increased stress levels due to pressures of task demands and requirements and an inability to adapting to change whilst attending further educational institutes.

For example, Dr Zayda disclosed that Paul had attended university but

*“He had to leave due to struggling to cope [...] he was unable to comprehend the consequences of his actions—like poor attendance, leading to leaving university, despite tutors meeting with parents and family.”*

Ms Reynolds (Occupational Therapist) commented that her patient Patrick “*did not find education choices easy [...] he went to mainstream school but felt detached from peers and not happy*”. In the case of Harriet it was reported that she had to “*take a year from college due to stress and difficulty in attending*” and also left her first university course “*due to being bullied*”.

Dr Smart reported that for Harriet managing change, the pressures of the social environment and workload became untenable:

*“She was unable to cope with changes to schedule or any additional social interaction [...] she struggles with group work in school, whilst at university she felt unable to communicate with peers she was working with and to work at their pace”.*

Similarly, Dr Sayeed reports that Julie required “*a lot of help and support from school*” “*She stayed at home during University; otherwise she would not have been able to cope*”.

#### 3.3.2. Employment Issues

Approximately half of referrers described an inability of Autistic individuals to maintain employment. For individuals not currently employed, referrers reported particular difficulties with “*changes at short notice*”, being “*overwhelmed by*

tasks” and an inability to adequately “interact with colleagues”.

Dr Crowther cited that Donald found his “job role challenging” due to his inflexibility. Specifically, he “couldn’t cope with working as an apprentice, as he wanted to do things in a different order”. In this instance Donald felt “paranoia and stress [...] he broke down and had to call his wife to ask what to do next”.

In the case of Wendy, Dr Rogers reported that she was unable to effectively manage her workload:

“While working, if she finds she has more than 50 emails in her inbox this becomes stressful and needs to be addressed to bring the number back down to 50.”

For a number of referrals a significant issue was gaining employment. Dr Zayda suggested that Paul “is unable to obtain employment due to behaviours, beliefs and difficulties with communication.” Similarly, Ms P. Reynolds (O.T) comments that much of Patrick’s “employment history consists of many training schemes” but that he was “unable to then maintain a worker role at part time level.”

### 3.3.3. Attaining and Maintaining Relationships

Referrers consistently documented the manner in which Autistic individuals struggled to attain and maintain relationships. This included forging new friendships, as well as maintaining and managing older ones.

There were consistent reports of Autistic individuals having “no friends” or “few friends” across referrals. Moreover, those that were able to develop friendships often reported difficulties “maintaining” them. Some Autistic individuals reported not understanding friendships and “misunderstanding” whether someone actually was their friend.

For example: Dr Zayda commented that Paul, “was unable to make friends, due to social difficulties” when at university and Dr Crowther explained that Donald “struggles with friendship and struggled at work with talking to colleagues and clients”.

A large majority of referrals described individuals struggling to develop and maintain romantic relationships. Dr Carroll reported that Fredrick had “one failed marriage” due to his rigid and inflexible behaviour. Dr Carroll cites that Fredrick’s ex-wife considered him “robotic and emotionless”. Another referrer, Dr Rastling described the difficulties his patient experienced with his partner as a result of his social communication difficulties. Specifically, that he was perceived as “cold” and “acted like his girlfriend didn’t matter”.

Occupational Therapist, Ms Reynolds described her patients desire to live up to his perception of societal norms by reporting that he had taken the decision to have children in the hope he would “present as normal”.

## 3.4. Theme 4: Managing Uncertainty

The desire to have a highly structured environment and predictable routine was reported in the majority of referrals. In all referrals where uncertainty or change

to individuals' lives was reported this often resulted in heightened anxiety and distress.

### 3.4.1. Routinized Behaviours

A majority of referrals disclosed the highly routinized daily living that was a part of their Autistic patients' lives.

As Dr Dylan cites in relation to Ursula, "*she likes to have structure*" and "*likes things a certain way*". In reporting Ursula's childhood Dr Dylan reported that she liked to have "*dolls lined up the same each time*". In another example, Dr Smart described Harriet's extremely "*rigid behaviours related to food*". He described her as having "*limited safe foods*" and that she had previously "*felt food was not safe without her mom and dad*".

In the case of Aisha, Dr Clandell states: "*she had rigid routines she is compelled to follow and finds change overwhelming. She becomes fixated on tasks and has to go from start to finish the 'proper' way*".

Disruptions to these routines frequently lead to episodes of emotional distress: Julie "*becomes highly distressed*" if change is introduced to her everyday routine; "*she finds new situations stressful and overwhelming and needs advance notice of any changes to routine*" (Dr Syeed).

Similarly, Dr Ticker explains that "*if Penelope's day does not go as planned, she is unable to cope and will retreat back to her room/house*".

### 3.4.2. Inability to Adapt to Change

Individuals were frequently reported to have displayed an inability to adapt to changes in daily life. Spontaneous changes to the daily environment, or introduction of spontaneous tasks at the workplace were considered sources of stress; causing possible "*panic*", "*rage*" and "*meltdowns*".

In one example Dr Carroll described the difficulties Fredrick experiences in planning his journey:

*"Traffic diversion causes problems...he has to go over possible routes in that eventuality and becomes uneasy when he does not know the diverted route"*.

Similarly, "*Sandra feels tense and anxious when things don't go to plan [...] she does not like change to her safe spaces.*" (Ms Kirkstall, Mental Health Nurse) and Dr Norton explains that Barry "*is cautious trying new things and he finds change quite stressful*".

In another example Dr Syeed described Julie's inability to accommodate changes to her routine at University: "*if university classes are rescheduled she becomes agitated and distressed which prevents her from attending*".

Changes of routine or unexpected circumstances were therefore a major issue leading to increased stress and anxiety in adults with autism.

## 3.5. Theme 5: Emotional Wellbeing and Mental Health

Across referrals there were reports of challenges to Autistic individual's mental health and emotional well-being. There was frequent reference to formal comor-

bid diagnoses but also mention of broader experiences of emotional distress. For some these experiences underpinned severe behavioural disturbances.

### 3.5.1. Psychiatric Co-Morbidities

Psychiatric co-morbidities were frequently reported by referrers. Just less than half of individuals referred also had a history of depression or reported ongoing depressive symptomology. Other forms of psychiatric comorbidity included that of one individual who was reported to have experienced “*paranoid and psychotic thoughts*” and who had a diagnosis of “*schizoaffective disorder*”.

### 3.5.2. Emotional Distress

Even where there was not a formal diagnosis of a psychiatric comorbidity, all referrers reported some experiences of “*emotional distress*” on behalf of their patients. For example, in describing Julie, Dr Syeed reported that she experiences “*deep distress*” around uncertainty and finds some situations “*overwhelming, extremely difficult and stressful*”. In another referral Ms P. Reynolds (OT) reported that her patient “*struggles with his feelings*” and in “*dealing with high emotions*”.

### 3.5.3. Behavioural Disturbances

As a way of managing these feelings of emotional distress referrers reported that individuals would often become angry and have “*outbursts*”.

Dr Smith referred to Carl’s “outburst”:

“*[He becomes] easily frustrated, [he has] extreme bursts of anger [...] punches walls/becomes agitated and frustrated in social situations*”.

Other referrers described these outbursts in a similar fashion. Dr Smart reports that his patient Harriet experiences “*bursts of anger*” typified by “*screaming*”. Other referrers described their patients attempts to hurt themselves. Ms Wendell (Care Coordinator) reports her patient has self-harmed in the past. Similarly, Dr Finch reported that Pamela is prone to “*cutting herself*” when she feels overwhelmed.

## 4. Discussion

This qualitative analysis of the textual accounts of referrers exposed a variety of issues, which corroborated with the current diagnostic framework, but also expanded upon pre-existing knowledge and understandings of ASD. Referrer’s descriptions of adults with ASD provided novel insights, extending beyond broad diagnostic typology (American Psychiatric Association, 2013) to represent specific deficits in domains of social interaction, communication, restrictive/repetitive interests and behaviours; as well as broader implications for quality of life and psychosocial outcomes.

The theme of *Social Dilemma* encapsulated referrer’s perception of the autistic adult’s alienation from wider society and lack of inclusion within formal and informal social settings. This theme articulated the layered and multi-directional nature of social difficulties experienced by adults with ASD through sub themes

of “*detachment*”, “*isolation*” and “*avoidance*”. Whereas some referrers communicated autistic adults’ experiences of “*detachment*” and the feelings of being an “*outsider*”-largely attributed to external factors such as “*lack of understanding*” and “*support*” from wider society, other referrers reported on the autistic adults internalised feelings of isolation due to past experiences of marginalization and difficulties in forging meaningful relationships. The social dilemma experienced by autistic adults was most prevalent in the sub-theme of *avoidance*, in which many referrers communicated their patient’s feelings of isolation and rejection but juxtaposed this with their contrary self-isolationist behaviours and social distancing practises. Inclusion was therefore interpreted differently for individuals. Where some adults with ASD were seeking acceptance from wider society, referrals also encompassed those who wanted to be included but on their own terms, as well as those who wanted to be included but simultaneously withdrew from society.

Overall, referrers communicated the autistic adult’s experiences of social exclusion and disconnectedness from wider society and peers. Inclusivity is considered important in encouraging feelings of acceptance within communities; however, many referrers described the contrary feelings of rejection and otherness in their patients. Such findings corroborate previous literature referencing loneliness and isolation (Hickey et al., 2018), and experiences of marginalisation and bullying within the ASD community (Chou et al., 2020; O’Connor et al., 2019).

Further analysis of referral forms revealed the theme of *Communication Disconnect*, which emphasized the disconnected nature of communication between the autistic adult and neuro-typical recipient. *Communication Disconnect* extends previous literature pertaining to autistic adults’ communication deficits (Cummins et al., 2020; Müller et al., 2008) by offering a novel interpretation of difficulties experienced; emphasizing sub themes of *Misreading the Exchange*, *Inappropriate Responding* and *Unintended Consequences*, to describe various forms of disconnect experienced between the autistic communicator and recipient. Disconnection within conversation was largely attributed to the autistic adult’s inability to accurately interpret subtext, body language, and expressions. This often resulted in misreading of exchanges and was further exacerbated by the autistic adult’s inappropriate behaviours as a response to inaccurate interpretations of conversations. Negative descriptors were typically used by referrers to describe how their patients were viewed by others. Autistic adults were repeatedly described as “*rude*”, “*impolite*” and “*awkward*” across referral forms; however as demonstrated in the sub theme of *Unintended Consequences* this was often not the intention, as autistic adults frequently reported being unaware of their behaviours until this was explained to them. Considering this, referrers also documented that other people were similarly misreading the intentions of their patients.

The theme of *Managing Uncertainty* presented evidence of restrictive, repetitive behaviours (RRB’s) amongst autistic adults; with an interesting distinction

pertaining to the subtypes of RRB's reported by referrers (American Psychiatric Association, 2013). Specifically, insistence of sameness and inability to manage and adapt to change was frequently described throughout referral forms. Many referrers described the autistic adults need for a highly structured environment and predictable routines, making *routinized behaviours* a major part of their everyday lives. Therefore, spontaneous changes and uncertainty to regular routines were met with resistance and were a source of stress and anxiety. The finding of this study therefore supports the relatively limited body of literature that has studied restrictive/repetitive behaviours in adulthood (Barrett et al., 2018; Chowdhury et al., 2010), compared to that of adolescence or childhood (Leekam et al., 2007; Richler et al., 2007).

Further themes outlined by this study included *Attainment* and *Emotional Wellbeing and Mental Health*, which reinforce existing understandings of poor psychosocial outcomes and quality of life in autistic adults (Lin & Huang, 2019). Referrers frequently documented poor outcomes for autistic adults within education, employment and in managing their relationships. This corroborates with existing research which demonstrates that autistic adults are less likely to develop meaningful relationships and to be either unemployed, underemployed or subject to workplace discrimination (Dijkhuis et al., 2017). The theme of *Emotional Wellbeing and Mental Health* documented the prevalence of psychiatric comorbidities across referrals, and occurrences of emotional distress and behavioural disturbances. Previous literature has estimated 70% - 80% of adults with the condition will experience at least one comorbid psychiatric disorder; with depression and anxiety being most common (Cage et al., 2018; Charlot et al., 2008). Studies show that individuals with ASD experience increased depression compared to neuro-typical controls, with higher functioning autistic individuals experiencing highest rates of depression (Hudson et al., 2019). This is supported by the current study, in which a large majority of referrers documented instances of anxiety, "low mood" or depression in adults referred for diagnosis.

## 5. Limitations

As a qualitative enquiry this study cannot assert the universality of its findings to the general population of adults with ASD. Nevertheless, the aim of this study was to provide an insight into the perceptions of referrers rather than to make generalisations concerning this population. A further limitation might be that clinician's referrals are necessarily shaped by their own pre-existing knowledge and experience of ASD. Nevertheless, referrers did provide extensive descriptive accounts for the people they referred yielding rich and important information which brought novel insights into perceptions of the autistic presentation.

## 6. Conclusion

Inappropriate referrals to Autism services deplete precious resources (Murphy et al., 2011; Rutherford et al., 2016). Most presently, 50% of those who access di-



agnostic pathways do not have ASD (Murphy et al., 2011). Until now, no research has explored the content of referrals and the perceptions of referrers to understand which descriptions are most likely to represent a person with ASD. In view of limitations regarding existing assessment measures, novel screening and assessment tools are required which can more appropriately capture the ASD profile. The findings from the current study might form a basis for the development of such a screening tool.

## Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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