

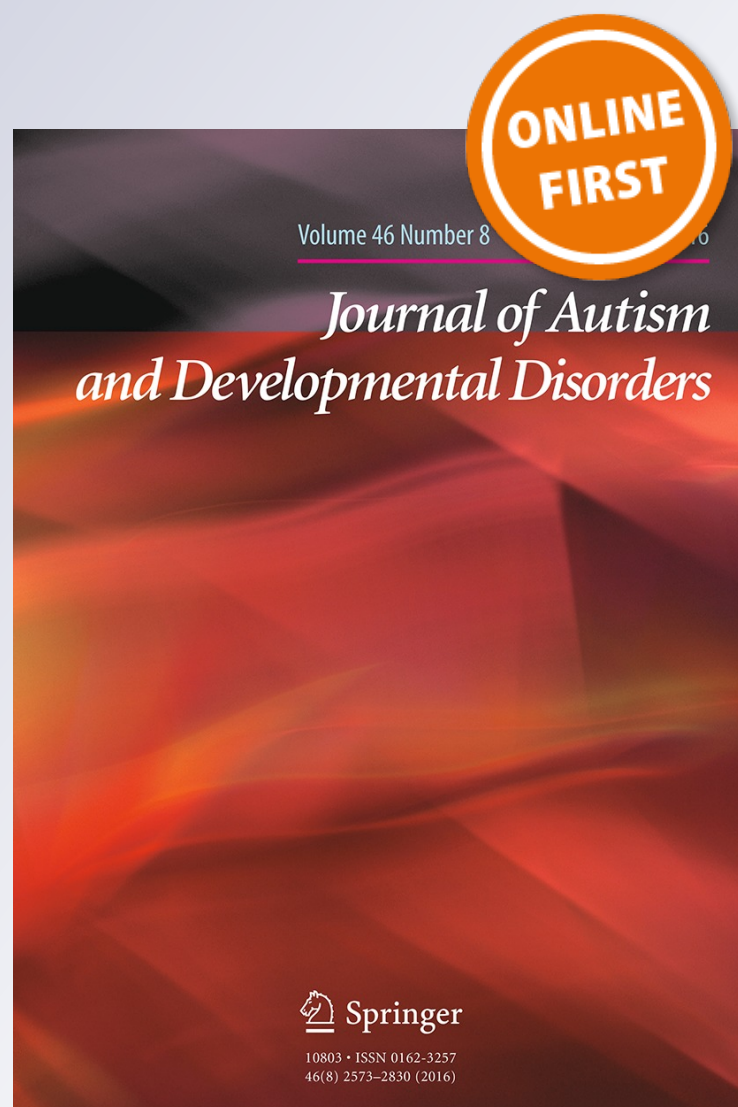
# *How Families Make Sense of Their Child's Behaviour When on an Autism Assessment and Diagnosis Waiting List*

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# How Families Make Sense of Their Child's Behaviour When on an Autism Assessment and Diagnosis Waiting List

Katie Denman<sup>1</sup>  · Cordet Smart<sup>1</sup> · Rudi Dallos<sup>1</sup> · Paula Levett<sup>2</sup>

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**Abstract** Families waiting for an Autism Spectrum Condition assessment often experience difficulties explaining, or making sense of, the referred young person's behaviour. Little is known about this sense making, or how clinicians might support this ambiguity. This paper explored finite details of how five families do 'sense-making' in conversations with each other, while on the waiting list for an ASC assessment. A Discursive Psychology analysis of these conversations found that sense making was affected by (1) an interactional pattern of interruptions impeding the progress of sense making narratives; (2) face saving to maintain positive identities and shared understanding; and (3) difficulties in word finding within sense making narratives. These practices challenged the production of a coherent family sense making narrative.

**Keywords** Autism spectrum disorder · Family · Systemic · Discourse analysis · Sense-making · Face saving

## Introduction

Families of a child diagnosed with autism can find themselves repeatedly explaining the child's behaviours to others, while still trying to understand behaviours themselves. These families can experience severe challenges in their daily lives (Gray 2001; Alvarez 1992; Neely et al. 2012; Solomon and Lawlor 2013). Where a child is high functioning or their behaviours don't fit easily within the classic diagnostic criteria for autism, explanations can be even more difficult (O'Reilly et al. 2015). These children are more likely to receive a later diagnosis (post 6 years; Jonsdottir et al. 2011) and to experience co-morbidity (Mazzone et al. 2012). Later diagnosis frequently means families receive less early support in 'making sense' of confusing behaviours. 'Making sense' can be considered as 'the ongoing retrospective development of plausible images that rationalise what people are doing' (Weick et al. 2005 p. 409). Further, families can be on the waiting list for a formal diagnosis for some considerable time in the UK (Karim et al. 2012). Whilst waiting, families still have to work to understand what is going on with their young person. Connolly and Gersch (2013) reported that parents find being on the waiting list for a diagnosis particularly stressful; that interventions, information and support is generally unavailable for these families; and that little is known about how families 'make sense' of their child's behaviour during this time. Yet, it is important for clinicians meeting families to know about their perspective in order to provide effective interventions (Lawless et al. 2008). Therefore, it is this problem of understanding how families make sense of their experiences while on the waiting list, that the current paper addresses.

Dallos and Draper (2005) emphasised how family sense making of experienced difficulties can be crucial for the

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wellbeing of all family members. Families can be understood as systems that produce and orientate to different difficulties in specific ways. For example, Crix et al. (2012) and Stuart et al. (2015) illustrated the difficulties for families of a young person with a diagnosis of Chronic Fatigue Syndrome (CFS) in managing discourses of illness and laziness, and the particular sensitivities for these families around mentioning or including psychological explanations in family sense making. Dale et al. (2006) also noted how parental sense making affects parenting. Thus, understanding sense making is essential to develop effective family support (Dale et al. 2006).

A systemic understanding of sense making, examining how families co-construct meanings, can enable clinicians to know where to begin in supporting families (Gale 2010; O'Reilly et al. 2015). Gale (2010) proposes a discursive approach is particularly suited to analysing families' co-construction of behaviours, allowing analysis of how family members use different discourses from society to perform different actions. For example, using different discourses to shift blame and protect family members (O'Reilly et al. 2015). How families interact and discuss these ideas can be crucial in shaping people's realities and offering the building blocks for the creation of meaning (Georgaca and Avdi 2012; Gale 2010). This systemic perspective informs the current paper. From this stance, clinical sense making is now explored, before expanding further on the socio-cultural positioning of family sense making.

### Clinical Sense Making

Clinical 'sense making' of autism is largely guided by diagnostic manuals, and criteria for a diagnosis of autism has changed over the years (Baker 2013). Autism Spectrum Condition (ASC) is a relatively new diagnostic category that now incorporates a broad spectrum of individuals, with substantial differences in the level of difficulties experienced (Grinker and Cho 2013; Rutter 2011; Rutter et al. 1999). The publication of the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) categorises characteristics under the broader diagnostic term, Autism Spectrum Disorder, eliminating previous sub-categories [American Psychiatric Association (APA) 2013]. Within this paper the term Autism Spectrum *Condition* is used, to denote a more neutral and less stigmatising terminology rather than implying a 'disordered' person (Baron-Cohen et al. 2009).

Currently, ASC assessment and diagnosis is made on the basis of the presence of characteristic behaviours and the mechanism of causation is unknown (NICE 2011). Therefore, an ASC diagnosis often comes with an uncertain prognosis and ambiguity around treatment, due to a lack of

aetiological understanding (Punshon et al. 2009). It is frequently understood as a deficit and through a medical lens as a "neurodevelopmental and biologically based disorder" (Molloy and Vasil 2002; NICE 2011). There is substantial evidence for a genetic basis with strong heritability (NICE 2011). However, Hallmayar et al. (2011), in a large population based twin study, found that genetic susceptibility factors have been overestimated and proposed environmental factors need to be further explored. Historical formulations of ASC being relational and attributed to poor parenting, although now discredited (Alvarez 1992), still also seem to affect how families make sense of ASC (Walden 2012). Confusions can also occur as children diagnosed with ASC often present with difficulties similar to children with insecure attachment patterns (Moran 2010; McCulloch et al. 2013). However, the differences in the underlying aetiologies between ASC and attachment difficulties have been outlined (Rutter et al. 1999; Gindis 2008; Oppenheim et al. 2008; Moran 2010). It has also been argued that ASC can be regarded as a social construct; a diagnostic category that is shaped within a socio-cultural context of 'normalness' (Timmi 2004; Molloy and Vasil 2002); and an ambiguous disability, whereby the label is constructed by medical, media, cultural and family discourses (Avdi et al. 2000; Huws and Jones 2010; Grinker and Cho 2013). The social model of disability, including intellectual and sensory impairments, conceptualises disability as a social construct. The model rejects the idea that disability is an individual's problem and highlights how disability is a result of society not accommodating individuals' impairments (Lawthom and Goodley 2005). Thus clinical sense making is yet to offer clarity for understanding ASC and is arguably not the only valid way of sense making, leaving space for families to create their own meaning.

### Family Sense Making

Families have to negotiate not only clinical sense making discourses that they might have limited or incomplete access to, but also a range of media discourses. These include what Walden (2012) termed 'parent blaming discourses' such as the discredited 'MMR scare' and 'refrigerator mother' theories as suggestions for ASC aetiology. Further, families themselves can have their own 'family myths' (Ferreira 1965; Dallos 1991) that inform sense making. These might be, for example, that the sole cause of the problems in our family is that X is 'ill', or that 'we are all on the spectrum', developed through family stories sometimes repeated over generations. Family sense making may have different purposes: to 'face save' (Goffman 1955) or maintain positive outward identities (Solomon and Lawlor 2013); development of personal meanings; and

development of conjoint family sense making narratives, which are elaborated here.

Maintaining positive identities in the face of others is challenging, and families frequently experience severe problems and stigma in their daily lives from having a child diagnosed with ASC (Alvarez 1992; Gray 2001). Research suggests that women continue to struggle with discourses that account for behaviours as a lack of maternal affection (Walden 2012), and parents face challenges in explaining behaviours to others (Solomon and Lawlor 2013). For example, they have to deal with challenging behaviours such as a child of 6, 8, 12 or even 14 having a 'melt down' in the middle of the street due to a routine change or a siren passing by, or a child wandering off resulting in involvement with the police or other services (Solomon and Lawlor 2013). Solomon and Lawlor (2013) suggested that Goffman's concept of 'face saving' is particularly relevant here, in considering how families have to perform a particular face that is acceptable to specific communities. Goffman (1955) proposed that 'saving face' occurs in the event of 'face threatening' social situations, where a person can be embarrassed, or their identity is in some way compromised. Face saving, and Brown and Levinson's (1987) subsequent politeness principle, alludes to the social actions that particular utterances in conversations appear to have. 'Face Saving' is often used in Conversation Analysis and Discursive Psychology, and appears to offer an analytic tool for understanding how parents might manage family members' identities in conversations. Presenting positive identities seems to be the aim of many parents of children with disabilities (Heiman 2002). For those on a waiting list without a diagnostic label to refer to, which may offer some clarity, it might be even harder to understand what is going on and to present positive identities to others.

While enacting positive identities for family members to those outside of the family, family members simultaneously need to make sense of events for themselves. For parents at least, individual sense making is an ongoing and multidimensional process (Lester 2012), changing throughout the course of an ASC assessment and diagnosis (Russell and Norwich 2012). Parents may initially resist a diagnosis, and then, after a period of loss and assimilation, work to reposition ASC in a positive light, reconstructing ASC as predominantly a neurological difference (Russell and Norwich 2012). However, the use of diagnostic language as a sense making tool still creates dilemmas that parents post-diagnosis have to negotiate. In different contexts parents distance themselves and their child from being responsible, or being 'bad parents with naughty children' (Farrugia 2009; Lester and Paulus 2012; Sperry and Symons 2003). They reject diagnostic discourse to deter negative assumptions (Farrugia 2009), stigma (Uk Kim 2012) or fault being implied through pathology

(Bagatell 2007). This underscores the difficulties for families in maintaining an outwardly facing positive identity, even post diagnosis, but illustrates how the diagnosis can be a useful tool for accounting for non-normative events.

A central challenge in this sense making process appears to be in accessing accurate evidenced-based information, which O'Reilly et al. (2015) found is not always available for families even post diagnosis. There seems to be an assumption from many clinicians that families do not attempt to make sense of children's behaviours before a diagnosis of ASC has been given (Lester 2012). However, within systemic theory, family interactions are considered the foundation for sense making (Dallos and Draper 2005). Families discuss events and thus some form of conjoint sense making, even if not explicitly stated as such, must occur within the family on the waiting list. That is, if a child constantly wanders off, families will not wait for a diagnosis of autism before explaining this in some manner.

Finally, sense making is also negotiated between family members, and a relational understanding is therefore crucial if clinicians are to be able to work from the family's perspective (Solomon and Lawlor 2013). Making sense of ASC prior to a diagnosis might be particularly challenging. Regardless of whether a child ultimately receives a diagnosis of autism, they will be displaying some symptoms of neurotypical difference which might affect patterns of family interaction and the achievement of shared understandings. This difference in interaction was illustrated using Conversation Analysis (a form of discourse analysis) by Pollock and Auburn (2013), who showed how a person with autism can be 'out of sync' in a particular interaction. Conversations included interruptions and hesitations indicating 'troubled' talk (Hayashi et al. 2013). Within Conversation Analysis, 'troubled' talk is not focused on what someone is saying. The trouble refers to a disruption in the progressivity or flow of the conversation (Hayashi et al. 2013). Crix et al. (2012) identified that such disruptions can have substantive effects on how families express shared understandings of medical concerns. In Conversation Analysis, speech is considered to operate in a turn by turn manner—person A speaks, then person B, etc. However, where this sequence is altered, such as person interrupting, speaking too early, or not responding, we can consider speakers to be misaligned, and there can be difficulties in establishing solidarity between them. These differences in conversation sequencing can also be described as having different social actions, such as marking points in conversations as being delicate, or face saving (Lerner 2004). Therefore the organisation of family conversations through turn taking seems to affect how families can express explanations for their difficulties (Crix et al. 2012; Gale 2010; Potter and Wetherell 1987; Stuart et al. 2015). In order to help to understand the difficulties that families experience in sense making so that clinicians can better support these

families, we sought here to examine how families over-come 'trouble' in sense making accounts of the behaviour of a child waiting for an ASC assessment. Specifically, the research question was: how do families overcome 'trouble' in building explanations of the focal child's behaviour when talking together? The objectives were:

- (1) To identify extracts from conversations between family members about the behaviour of the focal child that were troubled, which we termed 'troubled sense making practices';
- (2) To identify the sources in troubled family sense making practices; and
- (3) To identify the social actions present in troubled family sense making practices (such as face saving).

## Method

### Design

This study employed a cross-sectional design, where each family participated in one family interview. Prompts for family conversations were presented on a flip chart (Crix et al. 2012). Interview questions encouraged families to discuss how they understood the behaviour of their young member who was waiting for an ASC diagnosis, to provide conversational material that could then be subjected to detailed analysis using Discursive Psychology and Conversation Analysis. The questions were intended to be neutral and did not use the words 'ASC', 'autism' or 'Asperger's' as the children had not yet been given such diagnoses. This design did not produce naturalistic data, as families were talking for the purpose of the interview (Potter and Hepburn 2005). Yet, the flip chart design allowed interpersonal interaction and processes to be revealed without the researcher's additions. It is presumed that the conversations that occurred in the interviews would be similar to conversations that occurred outside of an interview situation (e.g. at home), based on theory underlying systemic approaches to therapy (Dallos and Draper 2005; Crix et al. 2012; Stuart et al. 2015).

### Stakeholder Involvement in the Research Process

The research was conducted by one Trainee Clinical Psychologist (KD), a clinical researcher and parent of a child with an ASC diagnosis (CS) and two Clinical Psychologists (RD and PL). This research team ensured the representation of both parents and clinicians throughout the research process. In addition, consultation was made with parents from a University Service Receiver and Carer Consultancy Group, who were specifically engaged in modifying the participant

information and ensuring neutral language was used. For example, interview questions were modified from asking about a child's 'difficulties', which parents considered negative phrasing, to asking about their 'referral to services'. Parents also provided input into recruitment through suggesting different modes of communication including the use of a phone call and recruitment from local support groups as well as waiting lists. Alongside KD, CS was heavily involved in the analysis of data, and some analysis was also done conjointly with a further parent of a child with an autism diagnosis and expertise in Conversation Analysis.

### Recruitment

Ethical approval was granted through UK National Health Service (NHS) and University Research Ethics Committees. The inclusion and exclusion criteria used for recruitment were as follows:

#### *Inclusion Criteria*

- Two or more family members participated in family interviews, including the caregiver who held parental responsibility for any children involved.
- Children aged between 6 and 18.
- The child or young person in the family had been referred and accepted onto an ASC assessment team waiting list.
- The child had been waiting for more than 1 month. This was an attempt not to overload the families, who may have received some information and input at the point of being placed on the waiting list.
- The child had been waiting for less than 22 months, to reduce the possibility of the child's assessment coinciding with the research.
- Children and young people who had received a separate mental health diagnosis were included in the study given that co-morbid difficulties are common.
- Adults were able and willing to comply with all study requirements.

#### *Exclusion Criteria*

- Children and young people who had already received a diagnosis of ASC through multiple assessments by a multi-disciplinary team as recommended by NICE (2011).<sup>1</sup>

<sup>1</sup> Currently in the UK a number of children who had previously been given a diagnostic label of ASC without a multiple assessment approach by a multi-disciplinary team are being re-assessed in line with the NICE (2011) guidelines, if there is a query about the diagnosis by parents or professionals.

- Families whereby the caregiver did not hold parental responsibility for the child or could not comply with all study requirements.

Participants were recruited from a UK ASC assessment team waiting list, commissioned to assess children between the ages of 6 and 18. Children aged below 6 were assessed in another service. An Assistant Psychologist, based in this team, identified all families who met the above criteria from the waiting list. They invited those families to take part by sending research information packs, including participant information sheets for adults and children aged 6–10 and 11–18. This older age group was selected to capture higher functioning children who might have experienced more challenging routes of referral. There is little evidence directly exploring this group, and less clarity in terms of how to support them. The sample were selected based on who, in clinical practice, is placed on the waiting list for ASC assessment, and so it was inclusive of those with co-morbidities, reflecting this client group.

KD also approached local ASC support groups to invite any families who met the inclusion criteria. Those who were interested from both routes were contacted to discuss participation in more detail and were given a further week to consider participating. Thirteen families initially agreed to be contacted but eight withdrew at a later stage. One family did not provide a reason for this. Five families withdrew due to logistical difficulties of finding time to complete the interview and stressful life events and two families withdrew due to having reservations about their child with suspected ASC taking part.

### Participants and Procedure

Five families took part in the study. All families described their ethnicity as White British. Demographic information was collected by the researcher before interviews commenced. All names are pseudonyms. There were two families in which three members of their family participated, including the focal child. These families have been termed 'triadic' families. There were three families in which two members participated, which have been termed 'dyadic' families.

Family 1: 'Tom' (aged 7, who was referred for an ASC assessment), his grandmother 'Sharon' (64) and grandfather 'Paul' (64)

Sharon and Paul described that Tom was 'classed as on the autism spectrum' since he was a baby by a Paediatrician but had not had a rigorous assessment. Sharon reported their social worker referred them for a re-assessment now Tom was 7. The family had been on the ASC assessment waiting list for 7 months.

Family 2: 'Sam' (aged 11, who was referred for an ASC assessment), his mother 'Carol' (48) and sister 'Lucy' (14)

Sam had been on the ASC assessment waiting list for just over 1 year. He was referred by his Paediatrician. Sam had a diagnosis of a Learning Disability and ADHD. Sam was adopted. Sam's adoptive brother (Ben) had recently been assessed for ASC and not been given a diagnosis. Both Carol's first partner (Sam's adoptive father) and her first partner's son from a previous relationship had been diagnosed with ASC. However none of these people have a genetic connection to Sam.

Family 3: Mother 'Barbara' (47) and brother 'Phillip' (12) of 'Charlie' (aged 14, who was referred for an ASC assessment but did not participate)

Charlie had been on the ASC assessment waiting list for 3 years and was referred by a Learning Disability Nurse. Charlie had diagnoses of Downs Syndrome, Learning Disability and sensory processing difficulties.

Family 4: Mother 'Cheryl' (44) and father 'Richard' (48) of 'Peter' (aged 8 who was referred for an ASC assessment but did not participate)

Peter had been on the ASC assessment waiting list for 9 months, referred by a Paediatrician. Parents discussed how they had been trying to get a referral for an ASC assessment since Peter was aged 3. Parents had consulted a private Psychologist who had concluded Peter was displaying behaviour that would warrant an assessment of ASC. Peter had a diagnosis of auditory processing disorder.

Family 5: Mother 'Anne' (42) and grandfather 'Jim' (68) of 'William' (aged 10 who was referred for an ASC assessment but did not participate)

William had been on the waiting list for 18 months. A practitioner from Child and Adolescent Mental Health Services (CAMHS) and a Paediatrician had made separate referrals to the ASC assessment team. William's sister, Sarah (aged 18), had recently been given a diagnosis of ASC.

The families were invited to an interview by KD. The families were given an interview location choice of either the ASC assessment service building or a local community centre. Families 1, 3 and 5 chose to meet at the ASC assessment building. Family 2 chose to meet at a local library and Family 4 chose a local youth centre. A private room was used at each location. On the day of the interview the research was explained again to all family members and they were given a chance to read the information sheets. Participants were told that the research focus was on how families understand and make sense of their

child's behaviours before a diagnosis of ASC is made. KD explained that the interview questions would be presented to them on flip charts and although the researcher would be present in the room, sat out of sight, it was hoped the family would discuss the answers among themselves. KD explained that the questions were collated into three main areas. These were written on three separate pages, as listed below.

#### Page 1: Family background

Tell me about your family

- Describe each person.
- Describe what type of family you are.
- How are you all similar?
- How are you different?

#### Page 2: The referral

Talk about the referral to (name of ASC assessment service)

- Why have you been referred?
- What led up to it?
- What is your understanding as a family of what might be going on?
- Do you all see it the same way?
- What else could it be?
- How have you managed as a family?

#### Page 3: Other people

Professionals (teachers, General Practitioner [GP], paediatrician, social worker, educational psychologist), media, culture

- How do people view your family?
- What have you been told about what might be going on?
- What have you read?
- How has this had an impact on how you make sense of what is going on?

The family decided for themselves when to move to the next question page. It was suggested that the interview may take approximately 1 h and they therefore might spend 20 min on each section of questions. Consent was discussed on the phone before the family agreed to meet and written consent was given before the interview took place. Consent forms were required from all adults to consent for themselves and their children to take part. Children were also given a child friendly consent form adapted for their age (6–10, 11–18). Family interviews were video-taped in order to capture verbal and non-verbal communication. At

the end of the interview all family members were asked if they would like the opportunity to talk separately. This was a recommendation made by the Carer Consultative Group as they felt parents may not be able to talk openly in front of their child. Only a sibling from family 2 used this opportunity. The interview questions were not repeated. The sibling instead used the time to add information she felt she had been left out about the family dynamics.

#### Method of Analysis

A synthetic discourse analysis approach was used to interrogate the data, drawing on Discursive Psychology with tools from Conversation Analysis (Stuart et al. 2015; Crix et al. 2012; Lester and Paulus 2012; Wetherell 2007). Stuart et al. (2015) and Crix et al. (2012) showed how such an approach can usefully be applied to unpack how interactions work in families, and so this seemed appropriate to meet the aims of the current study. The main tools were drawn from Conversation Analysis. This is a rigorous analysis of the details of how conversations work. The sequences of conversations are analysed, and each utterance or conversation turn is considered to have a social action (such as requesting, informing or aligning), and can re-define the meaning of what was said before. Analysis and identification of conversation practices is underpinned by an extensive literature defining multiple forms of actions in talk (see, for example Sidnell and Stivers 2013; Heritage and Drew 1992; Hepburn and Wiggins 2007; Lerner 2004), and it is common practice to refer to this literature during analysis, enhancing credibility and rigour. We termed our approach to analysis synthetic, as we combined Conversation Analysis with systemic theory which emphasises how interactions within family contexts can have a substantive effect on how people experience their social worlds (Dallos and Draper 2005). Further Discursive Psychology was used, which elaborates on Conversation Analysis, to consider psychological phenomena that can be present in talk, such as how people discuss emotions (Edwards 1999) or manage crying (Hepburn and Potter 2007). These techniques were applied to illuminate how family relationships were played out as participants discussed questions related to their understandings of their family member on the waiting list for an ASC assessment.

The analytic procedure began with orthographic transcriptions of the interviews, and then repeated viewing of the videos and reading of the transcripts. Every point at which families appeared to begin to offer explanations for their child's behaviour, or 'make sense', was identified as an extract. For example, when they used terms such as 'because' or 'this is why'. This followed Hepburn and



Potter (2011), who note that this process of selection is subjective yet is common practice in Discursive Psychology. This produced 68 extracts. We subsequently identified 34 of these 68 extracts as involving ‘troubled’ talk (Hayashi et al. 2013), that is where turn taking was interrupted by hesitations, interruptions, or repair where people might restate what they were going to say in a different form. These included 12 extracts from triadic family interviews, and 22 from dyadic interviews, meeting our first research objective, to identify troubled sense making practices. These extracts were transcribed using Jeffersonian conventions (Jefferson 1984; see Table 1).

The social actions and sequences of the extracts were interrogated to examine how family members built explanations of the focal child’s behaviour between them. This involved firstly a detailed Conversation Analysis analysis of the interactions at a turn-by-turn level (Lerner 2004), identifying interactional sequences (Schegloff 2007) to illuminate ‘trouble sources’ present in sense making practices (Schegloff 2007) and meet objective 2. To address objective 3, the social actions that people were performing were focused on. Face saving was a particular feature within these transcripts, correlating with Solomon and Lawson’s (2013) earlier work, and the sequence analysis enabled clear identification of how this was achieved in the interactions.

**Credibility**

Bracketing interviews were engaged in, particularly for KD and CS who were more deeply involved with the analysis, and given CS’ personal connection. This involved reflections on personal experiences affecting the conduct, analysis and dissemination of the research (Rolls and Relf 2006). Diaries were also used by KD throughout the analytic process, and KD and CS both engaged in a group reflective session involving other researchers. To ensure rigor and credibility of the analysis, separate analysis was conducted of the extracts by KD and CS, and then discussed together, with co-authors, and presented blind at

Conversation Analysis data groups to encompass as many alternative positions on the analysis as possible.

**Analysis**

The analysis focused on how families have trouble building joint explanations of the behaviours of a child member who was on the waiting list for an assessment for ASC. The analysis section is reported in the style of Conversation Analysis, where it is standard practice to reference the analytic tools used within the analysis. Transcripts are provided with an abbreviated version of Jeffersonian transcription to maintain the details necessary to understand the analysis. A list of these Jeffersonian conventions is provided in Table 1.

From 68 extracts of sense making, 34 were identified that displayed what Hayashi et al. (2013) termed ‘troubled’ talk, or impediments in the conversation flow, immediately following the initiation of a behavioural explanation (objective 1). These practices were then interrogated to identify the trouble sources of these troubled sense making practices (objective 2). Sequences were then grouped together based on the different ways that trouble was displayed. In 10 of the 34 extracts, interactional trouble was created through interruptions by the focal child. In 3 further cases the trouble source was created through conversational diversions away from behaviour as a ‘problem’. These two practices were shorter in length than the remainder, and seemed to prematurely stop sense making narratives. In the remaining two reported practices, trouble sources were disagreements (12/34) and delicacy around the way that the word ‘autism’ was used (9/34).

To achieve objective 3 the social actions that families appeared to achieve through these ‘troubled’ practices were examined. We identified two main actions: face-saving of family members, which seemed to occur mostly where practices were closed down perhaps prematurely, and achieving ambiguous sense making which was apparent in the longer episodes.

**Table 1** Jeffersonian transcription conventions Originally developed by Gail Jefferson. Based on notations found in Jefferson (1984) and Wooffitt (2005)

|                   |   |
|-------------------|---|
| →                 | Lines in the extract pertinent to the point being made        |
| [                 | The beginning of overlapping talk                             |
| :                 | Lengthening sound of previous word                            |
| (())              | Words within show non-verbal activities                       |
| Hhhh              | Substantial breathing out                                     |
| <u>Underlined</u> | Stress or emphasis  |
| d-                | A sharp cut-off of the prior sound or word                    |
| (0.3)             | Number in brackets indicates a time gap in tenths of a second |
| =                 | No silence between two utterances                             |

## Where Sense Making was Stopped: Face Saving in Sense Making Practices

'Interruptions' and 'diversion' practices are explained first, and seemed to be part of the interactional patterns of these families. These practices seemed to do face saving work for family members that repaired difficulties in the interacting of family members, and maintained a positive 'face' for all of those present.

### Interruptions as Trouble Sources

In triadic families, when the child on the ASC waiting list was present, 10 of the 34 sense-making sequences were interrupted by the child, which created and interactional trouble source and temporarily changed the sense making trajectory. 7 of these sequences were interrupted by the focal child repeating a word that was spoken. This seemed to lead others to 'face save' a potential misalignment with the conversation by this child. This is exemplified in Extract 1 (lines 2, 5 and 10), where the '[' indicates where speakers start to talk in overlap with each other. Prior to the extract, Sharon (grandmother) was talking about who had impacted on Tom's (focal child) referral for an ASC assessment.

Extract 1: Family 1 (Sharon—grandmother; Paul—grandfather; Tom—focal child)

03.29  
 1 Sharon : then all the fami[ly  
 2 → Tom: [they all not good  
 3 Sharon: all the fami[ly um some help, some understands [don't they  
 4 Paul: [yeah  
 5 → Tom: [when they are um the family still in bed but they are  
 6 these three family were all in bed  
 7 Paul: Ok mate  
 8 Sharon: ((laughs)) yeah the fami[ly um all helps and understands  
 9 don't they  
 10 → Tom: [they get up shortly  
 11 Paul: yeah  
 03.50

23.03  
 1 → Carol: and even the whole kind of I think I've wrestled probably with  
 2 why that you know why does Sam do that and I need  
 3 t[o change my expectations  
 4 Lucy: [but you can't ask that because its [its there isn't a reason behind  
 5 it of as to  
 6 → Sam: [expectations? Mrs Smith has  
 7 expectations  
 8 Carol: she does and she expects you to behave in a certain way.  
 9 a[nd  
 10 Sam: [Mrs Bullen doesn't  
 11 → Carol: and you're fantastic in school, you do do that, don't you, you behave  
 12 in a really good way [in school  
 13 Lucy: [yeah  
 23.28

was spoken by Sharon (lines 1, 3 and 8). Tom was playing with a dollhouse and repeated the word family applying it to the family figures he had 'put to bed' in the dollhouse. Sharon seemed to imply with her self-initiated repair<sup>2</sup> from 'all the family' to 'some understands' on line 3 that not all family members understand Tom in the same way. However, after Tom's interruption creates a 'trouble source' that leads Sharon to simplify her talk. She states that, 'the family all helps and understands' on line 8. This seems to simplify the discussion by deleting the possible introduction of the different perspectives that other family members might have, which her earlier use of the term 'some of the family', seemed to indicate was coming. This repair may have acted as a face saving technique for the family in response to a trouble source<sup>3</sup> that some family members don't understand (Ferencik 2005), therefore interrupting possible alternative sense-making from other family members. Further, it illustrates how interruptions might also reduce the complexity of narratives expressed by families.

Extract 2 provides a similar example of how sense-making of Sam's (focal child) behaviour by Carol (mother, on lines 1–3) was inhibited as a result of interruptions from Lucy (sister) and Sam. Again the child's interruption was by repeating a word that was spoken (line 6).

Extract 2: Family 2 (Carol—mother; Lucy—sister; Sam—focal child)

Extract 1 illustrates how interruptions from Tom impacted on Sharon's ability to talk about how people understand Tom. Tom interrupted at frequent points when the word 'family'

<sup>2</sup> When a speaker initiates repair in their own talk to re-establish progressivity.

<sup>3</sup> A topic of difficulty, characterised by repairs.

Firstly, Carol tentatively initiates a sense making statement, seen in how she hedges this with 'kind of I think'. This type of hedging can be used to avoid face threatening acts (Brown and Levinson 1987). Carol spoke indirectly about making sense of Sam's behaviour, requiring the listener to make inferences about what she is saying, shown by her use of the phrase 'you know' (Laserna et al. 2014). Sam attempted to clarify what Carol meant by 'expectations' on lines 6 and 7 by contextualising the word in a school setting. This seems to function to divert the conversation away from sense-making to discussing school. Thus Carol appeared to skilfully encourage participation in conversation by all family members, but in turn this practice and the prior interruptions (trouble source), impeded the development of family sense making narratives.

### 'Labelling Behaviour as a Problem' as a Trouble Source

In the interruption sequences, interruptions lead to simplifications or topic changes in conversations. However, in a further set of 3 sequences, diversions were related not to an interruption, but instead to a reframing of the sense making, that seemed to avoid identifying behaviours as problematic. Suggesting behaviour was a problem seemed to be the trouble source here. This appeared to display sensitivity to levels of understanding within the family, and be another strategy for building positive identities. This is illustrated in Extract 3.

Extract 3: Family 5 (Anne—mother; Jim—grandfather)

|       |       |  |
|-------|-------|--|
| 23.14 |       |  |
| 1     | Jim:  | what is your understanding as a family of what might be going on, well   |
| 2     |       | I think I understand <u>now</u> [what's going on                         |
| 3     | Anne: | [d- yeah   |
| 4     | Anne: | yeah   |
| 5     | Jim:  | two children who have <u>developmental</u> problems and they behave      |
| 6     |       | in an <u>entirely</u> different way than one would <u>expect</u>         |
| 7     |       | (0.3)  |
| 8     | Anne: | <u>Hhh</u>   |
| 9     | Jim:  | in most [in that sense   |
| 10    | Anne: | [not <u>entirely</u> differ[rent they=                                   |
| 11    | Jim:  | [we:ll   |
| 12 →  | Anne: | =basically I think what I've got is two children who who                 |
| 13    |       | have who are <u>not neurotypical</u> they have <u>neurodevelopmental</u> |
| 14    |       | <u>difference</u>  |
| 23.40 |       |  |

Extract 3 illustrates how problem focused sense-making was reformulated in interaction between two members of a family. Jim's (grandfather) sense-making on lines 5–6 was responded to by Anne (mother) as though it was dispreferred<sup>4</sup> or something she did not agree with. This was

<sup>4</sup> A less favourable turn, turns that are against what is expected or a turn that is contentious. These are characterised by delays and hedges in speech.

shown by a delay after Jim's turn and an emphasised out breath by Anne (lines 8 and 9; Heritage 1983). Anne deleted that her children 'behave in an entirely different way' in her reformulation on lines 12–14, perhaps to face save her children. This seemed to alter sense-making. Jim attempted to continue with his dispreferred turn with an elongated 'well' on line 11 but discontinued to let Anne take the floor. The use of 'well' in conversation has been suggested by Owen (1981) to act as a face saver before something confrontational is presented or to maintain politeness (Brown and Levinson 1987). In these sequences it seemed important that difficulties in the families were reframed in positive ways, and this was achieved by reframing words that other family members had used. Families in these practices seemed to moderate each other's behaviours. However, in some instances, disagreements were more marked, and were themselves the trouble source, rather than categorising behaviour as challenging being the trouble source.

### Negotiating Understandings in Sense Making

#### *Disagreements as Trouble Sources*

Where the trouble source was an interruption, or a labelling behaviour as a problem, these trouble sources were more rapidly addressed through aligning with the interruption, or diverting/reframing explanations. However, where disagreement itself was the trouble source this took longer to resolve, but seemed to lead to more cohesive sense making

narratives. 12 extracts made up this collection. The sequences included an account of the child's behaviour, which at least one family member then contested (trouble source). Use of specific examples of experiences of the behaviour were then included, which appeared to be accepted by another family member with the phrase 'that's true'. An example is illustrated in extract 4, where Lucy describes Joe, another child in the family who is not

present, as dominant. Sam repeated the word 'dominant' to apply it to himself and Lucy and Carol disagreed about whether Sam is or is not dominant, in lines 5 and 7.

Extract 4: Family 2 (Carol—mother; Lucy—sister; Sam—focal child)

17.26  
 1 Lucy: he's quite dominant and manipulative  
 2 u[m]  
 3 Sam: [ar- am I dominant?  
 4 (0.4)  
 5 → Lucy: no ((laughs))  
 6 (0.6)  
 7 → Carol: [yes  
 8 Sam: [I'm obsessive I'm obsessed with stuff Mum  
 9 Carol: yes in- yes [you are dominant Sam  
 10 Lucy: [yes but not  
 11 Sam: I can upset  
 12 Lucy: yes but not  
 13 Carol: probably not meaning to [be  
 14 Lucy: [but not over cos cos Joe'll  
 15 wangle his way in there like you know like get in people's iPads  
 16 and get in [things by being=  
 17 Carol: [hes very charismatic  
 18 Lucy: =really sweet and charming an-and lovely um so he wins people  
 19 over like that whereas Sam is a bit [like want things my way  
 20 → Carol: [your behaviour has  
 21 dominated every single thing this morning since you got out of bed  
 22 yes  
 23 Sam: yeah you sent me [you said we had to stay in our room [wh- we wh-  
 24 we were in there for about two hours  
 25 → Lucy: [yes  
 26 → Lucy: [that's true  
 27 his behaviour is dominant  
 28 → Carol: but I think that was particular mood this morning sometimes it's  
 29 not always  
 18.15

preference structure (Schegloff 2007) for Lucy to agree, which she does with her statement in lines 26–27 'that's true his behaviour is dominant'. These longer examples, which are not diverted or interrupted as in other examples, appear then to allow more discussion of behaviours.

Extract 4 illustrates how Carol contests Lucy's disagreement that Sam is dominant in line 7. However, Sam in line 11 then provides an example of his behaviour. In lines 12 and 13, Carol and Lucy excuse Sam from being labelled in such an extreme way, and then continue to discuss Joe. In line 19 Lucy moves to say something about Sam, but is interrupted by Carol who then gives a specific example of how Sam's behaviour is dominating, which Sam then affiliates with in lines 23 and 24. This creates a strong

Families provided specific examples of behaviour, as in this case, that more than one family member agree with and seem to be highly persuasive and an effective way of overcoming the trouble source.

Extract 5 provides another example, although the order of the example and the 'that's true' statement is slightly altered.

Extract 5: Family 3 (Barbara—mother; Phillip—brother)

43.17  
 1 Barbara: people like get obsessive about something or you know the kind of  
 2 things that you'd see in autism (1.9) so that's not unusual [I spose I  
 3 spose if he'd been in a mainstream school it might be different  
 4 mighten it  
 5 Phillip: [sometimes  
 6 → Phillip: yeah sometimes like normal people can get obsessive with stuff like  
 7 Barbara: well that's true  
 8 Phillip: because one of my mates is obsessed with this one song and he just  
 9 plays it over and over and over again  
 10 → Barbara: yeah so it's not just with autism then  
 43.53

In Extract 5 on line 6, Phillip (brother) contested Barbara's (mother) formulation that people with ASC get 'obsessive about something' in relation to making sense of Charlie, her son. Phillip seemed to contest this idea perhaps to face save Charlie and people with ASC in general. This led Barbara to use the phrase 'that's true' (line 7). Phillip then presents an example in lines 8–9, which seems to persuade Barbara to change her perspective in line 10. This practice, then, seems to illustrate how families might be able to influence and change each other's interpretations and understandings of autism, further, that disagreement as a trouble source in some cases at least, might subsequently enable more developed narratives to emerge.

*Trouble with the Word 'Autism'*

A final trouble making source that we identified in sense making practices (9/34) was that the word 'autism' was implied, rather than directly stated. The word 'autism' and related words were used less in triadic families (only 6 out of the 28 sense-making sequences that referred directly to

and rather than say autism, seems to repair what she was going to say to state: 'we've looked up about it haven't we'. The conversation slot for the word autism is then changed so that she is able to use the word 'it' instead. This seems to provide some level of ambiguity. The tag question,<sup>5</sup> 'haven't we' that comes at the end of her utterance seems to prefer an agreement from Paul, and to seek a level of solidarity from him. This is supported by a non-verbal exchange of nodding, and followed by a long lapse<sup>6</sup> in the conversation. All of these features seem to indicate some difficulty in how to express or use the term autism, indeed, whether they even should use the term autism within this context.

The majority of events when 'autism' was implied but not spoken were in dyadic families (8 of the 9 total sequences in this collection). It appeared the speaker was treating the listener as knowing ASC was the topic though it was not named. However, diagnostic language was used in sense-making sequences. This is illustrated in extract 7.

Extract 7: Family 4 (Cheryl—mother; Richard—father)

28.53  
 1 Richard: yeah so all those sort of sensory things um then there was the  
 2 (3.2) you know sort of flapping flailing (2.0) he was doing (1.9)  
 3 I mean we became aware of this because of the amount of you  
 4 know as things went on (0.9) the research that was done (1.8)  
 5 Cheryl: how do you mean?  
 6 → Richard: (1.9) well you know us= us looking into it about [and  
 7 Cheryl: [yeah so  
 8 the more we looked the more he fit[ted  
 9 Richard: [the more we looked the more  
 10 → we thought well this [this=  
 11 Cheryl: [yeah  
 12 → Richard: =is a were sort of narrowing down here on something and  
 13 (2.0)  
 14 Cheryl: ye[ah  
 15 Richard: [you know we we we've come to a conclusion which of  
 16 course is not verified without doing the raft of tests (0.7)  
 29.48

autism). In extract 6, Sharon started her turn by reading out the interview prompt 'media'.

Extract 6: Family 1 (Sharon—grandmother; Paul—grandfather)

03.07  
 1 Sharon: media we've looked up (0.3) [we've looked up about it haven't we  
 2 Sharon: [((looks to Paul who nods))  
 3 (5.0)  
 03.17

Extract 7 provides a further example where the word 'autism' is omitted. Throughout extract 8, it appeared both Cheryl and Richard were referring to ASC as a conclusion of sense-making for their child without naming it. This is

Extract 6 illustrates how the word 'autism' was possibly replaced with 'it' implying a shared meaning in the family. In line 1, Sharon paused after the phrase 'we've looked up'

<sup>5</sup> An exit device at the end of a completed turn which enables another speaker to take a turn (e.g. 'we've looked up about it, *haven't we?*').

<sup>6</sup> An extended silence between two speakers, at a place where a speaker could commence a turn.

shown by Richard's use of 'it' on line 6, 'this' on line 10 and 'something' line 12, which was not elaborated on by Cheryl. Richard also used the phrase 'you know' three times in this extract (on lines 2, 3–4 and 6) suggesting he is referring to a shared meaning and asking Cheryl to make inferences about what he is saying (Laserna et al. 2014). Richard ended by saying their 'conclusion is not verified without the raft of tests', which perhaps suggests why 'autism' is not named in this extract (this was also seen in family 5). Nevertheless the lack of a meaningful word or phrase to explain behaviours was clearly a trouble source within these family interactions.

## Discussion

This study, based on five family interviews, identified difficulties that families can have in making sense together of the behaviour of a young member on the waiting list for an assessment of ASC. We identified 34 of 68 sense making practices that were difficult for families, identified 4 different forms of trouble sources—(interruptions by the focal child, problematizing behaviour, disagreements, and not using the word autism). The social actions associated with these trouble sources were largely related to face saving; and displaying understanding. Face saving occurred at 2 levels: in terms of ensuring all family members could take part in the conversation; and secondly in terms of managing positive identities. Thus 'troubled' sense making did not necessarily mean families had a poor understanding of ASC or were not attempting to make sense of difficulties (Lester 2012). Rather, relationship focussed actions, such as face-saving, were also managed when families collaboratively produced sense making narratives. Here we examine the implications of each of these findings.

First, face saving to repair interactions where the focal child interrupted conversations or produced divergent themes seemed to characterise these family interactions. So, in the same way that Stuart et al. (2015) identified particular delicacies in families where a young person had CFS around discussing psychological explanations, the families in the current study could be characterised as displaying a particular interactional pattern around managing interruptions and diversions. These interactions therefore seemed to prioritise the moderation of shared narratives to develop shared understandings. For clinicians trying to assess and develop understandings with families, then, consideration might need to be made that such systemic contexts might inhibit the development of complex narratives. Clinicians may wish to focus on developing narratives that use simple language and can be used by all family members; or clinicians could be a vehicle through

which families can hold these challenging conversations, keeping the conversation on track whilst at the same time allowing face saving to be heard by all family members.

Second, it was also noticed that family members worked to 'reframe' problem focused talk to reposition the child in a positive light, as suggested by Russell and Norwich (2012). Reframing is a technique used in systemic family therapy to create alternative, non-blaming discourses and previous research has highlighted its use in parent and therapist interactions to reframe behaviour of children with ASC (Lester and Paulus 2012). It is interesting that family members also perform this action during sense-making together, without a clinician guiding this interaction.

Third, where disagreements were the trouble source in the interaction (i.e. contradictions were treated by family members as trouble, creating hesitations and repair/rephrasing), longer sequences followed that in fact seemed to lead to greater solidarity in family members. An important outcome of this point is that the focus on how the interactions between family members worked enabled the identification of this nuanced distinction, suggesting a careful listening to how families discuss problems might be useful for the design of therapeutic interaction. This supports the prior work of Crix et al. (2012) and Stuart et al. (2015).

Fourth, where the young person was not present, it was easier for families to express a greater level of description of the behaviours that they had witnessed and experienced. However in these accounts families still seemed to be 'grasping for words', potentially highlighting how a diagnosis might help to provide accounts for people, and might highlight a gap that a label would easily fill. On the other hand, these labels can change the ways that people act and interact with others (see Scheff's [1974] labelling theory). Labels might provide useful frameworks for families to understand why they approach the world differently and relinquish previously held negative perceptions of behaviours (Sharp and Lewis 2013; Sperry and Symons 2003). Avdi et al. (2000) suggested drawing on diagnostic discourse can ease sense-making for parents. Certainly the families from the current study did find it difficult at times to explain behaviour without having terminology to do so. However, children with an ASC label may be taught differently at school (Eikeseth and Lovaas 1992) and the label can produce new confusions about a sense of self (Sharp and Lewis 2013). O'Reilly et al. (2015) suggest that what is most important post diagnosis is clear and understandable information for families to help to manage these confusions. The current study extends this by suggesting that families waiting for an assessment might also benefit from having more information and early discussions with clinicians as Connolly and Gersch (2013) have argued, which can be in itself an intervention. Providing early support in

managing sense making conversation might help families to more easily express information, whilst also providing intervention for families whilst on the waiting list for assessments for long periods.

The findings further provide a starting point for clinicians to help to understand the multiple social effects influencing how families are able to take up and use information that they are offered. This would help clinicians to keep the families' perspective in mind when discussing how to understand behaviour. Firstly, it seems clear that families' abilities to understand are affected by both family practices and concern for maintaining a positive face, as well as difficulties in formulating explanations and sense making. Therefore it is important to consider how the development of conjoint family narratives around behaviours within a family could perhaps be compromised, or altered by a different interactional pattern of interruptions within conversations. This might affect the progress of developing a shared narrative. Further, whilst sense making, there appears to be some considerable work done by family members to develop explanations that are sensitive to the different understandings of other family members in the room, which seem to be corrected if they 'go too far' in describing events negatively. This links with studies suggesting parents experience a dilemma when accounting for behaviour whilst also relinquishing stigma and blame (Bagatell 2007; Farrugia 2009; Lester and Paulus 2012). The delicacy around using the word 'autism' perhaps indicates the pre-diagnosis period families were at in their assessment and diagnosis journey (Russell and Norwich 2012). It perhaps reflects they were in an early stage of assimilating an ASC diagnosis into their language, whilst being in a period of uncertainty and ambiguity where a diagnosis and label had not yet been confirmed. Therefore, resisting the word could also face-save the speaker. Alternatively, this could also be considered as awareness by family members of the power imbalances between clinicians diagnosing the child and families. Perhaps families did not want to step outside of their own 'epistemic domain', or knowledge of ASC, too much and make assumptions before it is confirmed. This may have been an impact of KD's presence in family interviews. Nevertheless, it provides an insight into how families may be able to share their understandings of behaviour with clinicians and an area that clinicians might focus on, in modelling and discussing with clients what it is like to be comfortable with uncertainty.

### Limitations and Future Research

This study was based on only five families, so generalisation is questionable, however, within Discursive Psychology, a balance needs to be struck between having a large

enough sample size, but not having so much that linguistic detail cannot emerge (Potter and Wetherell 1987). The focus was also on language use, rather than the people generating the language and therefore a large amount of linguistic sequences emerge from relatively few people (Potter and Wetherell 1987).

Additionally, the sample was not homogenous, the age of the children varied, and this may impact on the time that families may have spent 'sense making' prior to the research (Dale et al. 2006). Further, triadic and dyadic families were included; and only triadic families involved the children who had been referred for an ASC assessment. Further research could expand on the present study by involving more triadic families to further include children's voices. However, including both types of families meant comparisons could be made on whether similar patterns of talk emerge when the child is or isn't present. One challenge, impacting on the sample size and non-homogenous sample, was recruiting participants. In particular, parents do not often discuss the possible diagnosis in front of their child (Ruiz-Calzada et al. 2012), which could explain why there were more dyadic families that took part. Additionally, pragmatic difficulties impacted on how many of the family members took part in the interviews and therefore, it was difficult to get a whole family picture. However, family therapists no longer insist whole families are needed to keep a systemic stance; rather one can work systemically with parts of the family system, keeping the wider family in mind, which is what was done through the interview questions (Dallos and Stedmon 2006). It is also notable that this sampling approach, though including variation, is reflective of the real world people who are on the waiting list for an assessment of autism. This includes children of different ages, and indeed children with co-morbid difficulties, and so the findings are likely to be relevant to the actual daily practice of clinicians.

An alternative perspective from this paper could highlight how children with suspected ASC interact within the family, as the main 'symptoms' of ASC are seen within interactions with others. It has been suggested in previous research that children with suspected ASC often do not make the inferences expected (Ochs et al. 2004). This poses a difficulty within families when politeness techniques are used to make sense of difficult behaviours. Indirect, tentative and ambiguous sense-making, requiring the listener to make inferences, perhaps impacts on how the child is able to express themselves in conversation. This perhaps highlights an area for future exploration in how children with difficulties in social communication engage in sense-making about themselves within a family context.

Furthermore, this study did not draw on naturalistic data. Free-flowing talk was possibly impeded on in these families by getting the interview done, perhaps influencing face

saving. Further research could draw on more naturalistic family talk of sense-making of children's behaviours pre-diagnosis to see if face saving techniques were also revealed outside of a family interview situation. However, this type of data is perhaps difficult to procure. Additionally, further research could recruit families before they have been accepted onto a waiting list.

The current study has only focussed on White British families. This perhaps not only highlights a limitation of this study, but also reflects which families are more likely to be referred to an ASC assessment (Slade 2014). Culture plays a big part in how families make sense of child's behaviours (Uk Kim 2012) and further research could explore how sense-making is done in interaction of families within different cultures. It has also been suggested that the discursive study of language would vary across different cultures and throughout history (Hu and Cao 2011; Laserna et al. 2014) and therefore, it is important to contextualise this study within the current historic and cultural context.

Through an inductive process, Conversation Analysis highlighted that 'troubled' sense-making did not mean families had a poor understanding of ASC. Rather, relationship focussed actions, such as face-saving, are simultaneously managed in family talk. This adds to the ASC and systemic literature and has implications for clinicians completing ASC assessments and supporting individuals and their families before and after a diagnosis is given. Considering the findings, it is recommended that clinicians remain aware that hesitations or difficulties expressing meanings in family talk could be related either to attempts to represent family members positively, or attempts to offer explanations that are congruent with different levels of understanding in the room. Additionally, clinicians may model how to be comfortable with ambiguity and uncertainty and model how families can develop simplistic narratives that all family members might be able to repeat and use as resources in discussions. It is also suggested the findings could be used to provide more information to families on waiting lists, and where possible, reduce waiting times for assessment.

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the design, interpretation of analysis and helped draft the manuscript; RD participated in the design of the study and helped draft the manuscript, PL assisted with conceiving the study and participated in its design and coordination of recruitment. All authors read and approved the final manuscript.

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