How parents build a case for Autism Spectrum Disorder during initial assessments: "We're fighting a losing battle"

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Abstract

Integral to the diagnosis of autism spectrum disorder (ASD) is the initial assessment through which the existence of a 'problem' is first ascertained. Despite this, there remains limited research on this early part of the diagnostic pathway. In this paper, we utilised conversation analysis to examine relevant issues in relation to the practitioner-family interactions that take place within this initial assessment context. Our findings illustrated that parents typically first raised the possibility of the presence of an ASD diagnosis through 'building a case', which professionals were then able to ratify or negate. Further, we found that the assessments unfolded sequentially and clinical decisions were typically reached through a distinctive pattern of interaction. These findings have important implications for clinical practice, including for the study of ASD assessments and diagnosis.

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Autism Spectrum Disorder (henceforth ASD) is described in the medical literature as a neurodevelopmental disorder characterised by impairments in communication, social interaction, and repetitive behaviour with rigid thinking styles (Karim et al., 2014). There has been a significant increase in the prevalence of ASD in recent years and this is an international concern with a growing research base (Bailey, 2008). Estimates of prevalence in the 1970s suggested that 20 in every 10,000 children were diagnosed with ASD (Wing & Gould, 1979), but recent estimates are nearer to at least 1 in every 100 children (Baird et al., 2006). On one hand, this has led to questions surrounding the meaning(s) and legitimacy of "ASD" as a construct being raised (O'Reilly, Karim, & Lester, 2015; Lester & Paulus, 2012), with the diagnostic criteria used being described by some as 'in flux' (Lester, Karim, & O'Reilly, 2014). More practically, it has led to increasing pressure on existing services for diagnosis and treatment (Ridge & Guerin 2011), within a health economic context which (in the developed world) emphasises resource efficiency within significant economic constraints.

When seeking a diagnosis for a health condition, access to knowledgeable and skilled professionals is viewed as essential, particularly as such diagnostic labels enable access to further services, intervention, and support. Interactions with gatekeepers, such as medical practitioners, therefore, become a central process that patients must negotiate. More specifically, diagnosing ASD is complex and time-consuming; it is also complicated by multiple factors, such as variation in clinical practice, the heterogeneity of presentations, and co-existing conditions (Karim et al., 2012). For families, there is typically a latency of around three and a half years between first contact with a professional and final diagnosis, with an

average of one year between families' first concerns and the point at which they initially raise these with a professional (Crane et al., 2015). Pre-diagnosis, parents report considerable variation in the extent to which services acknowledge their concerns, resulting in multiple visits to numerous professionals prior to eventual diagnosis (Goin-Kochel et al., 2006). Hence, the pathways that lead to diagnosis (and families' experiences of these) vary according to a range of individual, systemic, and contextual factors. Accordingly, and reflecting that parents often report high levels of stress (Crane et al., 2015) and negative experiences (Osborne & Reed, 2008) during the overall diagnostic process, there has been a recent increase in qualitative research focused on family perceptions of diagnosis. To date however, there has been little scrutiny of the processes that occur between the initial concerns raised by parents and the final diagnosis, particularly when opinions may differ between the various parties involved. Although this period has been recognised as significant for those going through assessment and diagnosis, and guidance is emerging for services (especially for adults). For example in the UK the Autism Act (2009) has provided some guidance in children, however this area needs ongoing development.

In this paper, we aim to provide a socially-oriented perspective on the complex and multifaceted issues surrounding diagnosis by presenting a conversation analysis of video-recorded discussions between diagnosticians and families during pre-diagnosis triage screening within UK child and adolescent mental health services (CAMHS). This specific service setting, which typically marks initial entry into specialist mental health services (Mash &Hunsley, 2005), provides a useful context in which to explore issues in relation to families' diagnostic journey because it tends to receive referrals of children with complex and frequently co-morbid profiles, where differential diagnosis may be drawn out and challenging (Parkin et al., 2003). Hence, families typically attend CAMHS triage assessments following

significant contact from a range of professionals, and at a point where unequivocal decisions are sought regarding whether to pursue a diagnosis of ASD.

During the assessment process, the child and family are questioned together (Antaki & O'Reilly 2014). Hence, it is what the families and practitioners say – that is, their *talk* – that is central to the process of initial assessment. Through talk, suggestions of ASD may be presented and responded to, with practitioners thereby displaying their judgements regarding whether to send a family for an official ASD diagnostic assessment. The centrality of verbal discussion to this process renders a qualitative focus on '*talk-in-interaction*'– that being the manner in which families and practitioners interactionally organise what they say and their responses to one another during these assessments – as apposite for this study. Conversation analysis (CA) thus provides a powerful framework for generating a user-focused perspective on issues surrounding diagnosis, particularly as there is growing recognition that the close study of communication practices that occur within service contexts may serve to enhance practice and care, and result in practical recommendations for clinicians (e.g., Heritage & Robinson, 2011; Parker & O'Reilly 2012; Stivers, 2002; Strong et al., 2008).

CA is becoming increasingly recognised as an appropriate approach for examining social interaction and communication in ASD (O'Reilly, Lester, & Muskett, 2016). Nonetheless, within the scholarly literature there remains limited dialogue regarding the ways in which the constructions of ASD are actualised in practice (Lester & O'Reilly, 2016). However, a recent special issue in the *Journal of Autism and Developmental Disorders* focused on the value of CA, arguing for both the use of CA and showing how CA is crucial in understanding the experiences and practices of those diagnosed with ASD, their families and practitioners (O'Reilly et al., 2016). CA has been particularly pertinent to medical interactions (Solomon

et al., 2016), with important implications for the study of the diagnostic process whereby families, parents in particular, lay out their concerns for specialist working within mental health services. Thus, in this study, we took up these concerns and centred around analyses around the following research questions:

    i)   What features of talk are associated with presenting and dealing with a possible ASD diagnosis in the context of an initial assessment?

    ii)   In what ways do these features reflect broader issues in relation to the diagnosis of ASD and professional practice with families?

Method

Context and setting

The research utilised data taken from a sample of 28 opportunistically sampled families who attended their first assessment appointment at CAMHS, UK. Ethical approval was provided by the National Research Ethics Service (NRES), with a multi-stage process employed for ensuring consent and assent from participants. All data were pseudonymised with any person-identifying features removed from transcripts prior to analysis.

Each initial appointment typically lasted ninety minutes, generating a corpus of 42 hours of video recordings, all of which were used in this study. Participating families were seen by a minimum of two mental health professionals from a range of professional groups, including consultants, staff-grade and trainee child and adolescent psychiatrists, clinical psychologists, assistant psychologists, community psychiatric nurses (CPNs), learning disabilities nurses, occupational therapists, psychotherapists, medical students, and student nurses.

For this paper, the entire corpus was scoped and sessions in which ASD was verbally discussed as a possible diagnosis were sampled. This produced a final dataset of 10 sessions, each of a different family, for detailed analysis, including one female and nine males. The mean age was children was 9.9 years (contrasted with a mean of 11 years for the full data set), and ranged from 6 to 16 years.

Analysis approach

Broadly, CA is an inductive approach to the study of language use, with well-established quality criteria. Drawing on naturally-occurring data (i.e., audio- or video-recordings of interactions that occur in the 'real world' without researcher intervention), analysis focuses on the sequential turn-by-turn organization of interactions, thereby explicating how particular social activities play out through shared structures of talk (Hutchby & Wooffitt, 2008). A precept fundamental to CA is that any speaker's conversational turn simultaneously reveals their understanding of the prior turn (e.g., an answer demonstrates understanding of the prior turn as a question) and projects for a particular subsequent turn from the next speaker (e.g., a question opens a subsequent interactional slot for an answer). CA therefore produces accounts of interaction based around participants' moment-by-moment understandings of talk, interactions, and social contexts (Bolden & Robinson, 2011), through demonstrating how such understandings are shown on a turn-by-turn basis (Maynard & Clayman, 2003).

In this study, we drew upon CA to analyse the dataset. Within CA 'unmotivated' examination of data is encouraged. Thus, given the specific focus of our study, analysis was driven during the first pass of these data by the research questions, generating a collection of relevant forms of interactional sequence. Detailed transcription is required for this analytic approach. As

such, in this study, the standard CA Jefferson format was used (Jefferson 2004). In line with CA conventions, purposively extracted representative fragments of data and analysis are reported below to illustrate key findings arising across these data.

Findings

Key analytic findings were that: (1) parents tended to be the first to raise the possibility of an ASD diagnosis, which was verbally introduced and developed in a distinctive manner that we describe as 'building a case' for ASD; and (2) this case was then ultimately ratified or negated by practitioners, who as a consequence of the social organisation of these assessments were interactionally positioned to do so. In all cases parents were the first to raise or orient to the characteristics of ASD, either through presenting symptoms consistent with the diagnostic criteria for ASD (such as obsessive behaviour, literal thinking) or by actually using terms such as autism or Asperger's. In three cases the practitioner was the first to use the diagnostic term 'autism', but this was in response to the parents' prior work on building a case for ASD symptomology.

1. Parents' cases for ASD

Parents built a case to support their suggestion of the likelihood of an ASD classification in two ways. First, they offered a candidate diagnosis of ASD, which was carefully offered up for discussion with the professional. Second, they provided evidence for the possibility of ASD by outlining behaviours and characteristics that were synonymous with the criteria for the condition. Notably, these strategies were presented interchangeably and in an integrated

way. This meant that parents typically built a case for the problems presented by their child whilst packaging these as reflecting ASD.

a. Building a case by offering a candidate diagnosis

In healthcare consultations, it is common for parents to offer candidate suggestions regarding the nature of their child's condition. Whilst this implies that the nature of the visit is to seek treatment for a condition that is already potentially known by the family, Stivers (2002) demonstrated in medical settings that candidate diagnoses are often offered speculatively in a manner that lessens authority to any claim, thereby respecting the expertise of the doctor while raising a diagnosis as a possibility. Similarly, in the data analysed for this study, offerings of candidate ASD diagnoses by parents tended to be carefully constructed, and often reflected the contributions of others present in the room. Extract 1 illustrates this.

Extract 1: Family 16 (Prac = psychiatrist)

```
1   Mum        you know we don't know what's gonna ↓happen until
2              the as[sess]ment's happened
3   Prac          [yeah]
4   Mum        (0.21) an' I've but obviously I've I've you know
5              I've stated my con↓cerns for quite a ↑while now
6   Prac       um
7   Mum   →    an (0.40) it just it j- it just pops out at me as as
8         →    being very Aspergecy I mean I I wo (0.34)I wouldn't
9         →    wouldn't say he's Autistic in any ↓way shape or form
10             [in the sense that]
```

```
11   Nan                                                          [he

12         does show] some ((though))

13   Mum  →    YEAH HE DOES but the cleverness an you know that

14   Prac      um

15   Mum       you know 'e: (.) y- you put an Autisticthey're very

16             clever in it certain areas they they (  ) (an' then)

17             certain areas they struggle with

18   Prac      um

19   Mum       his is just (0.42) it is a social inter↓action and

20             he zones out and he's ↓very obsessive and he's very

21             anxious and

22   Prac      um

23   Mum       certain times a↓round people he doesn't want to be

24             around people he has to just has to zone off [again]

25   Prac                                                   [um]
```

In this extract, a parent suggested that their child may meet the criteria for Asperger's Syndrome, a now-obsolete diagnostic category used to refer to individuals who meet the diagnostic criteria for ASD but are considered high-functioning. Note, however, that this assertion was not delivered parsimoniously. Instead, an extended turn (lines 1 to 9) was built, which possesses several subtle features. On one hand, the parent played down aspects of her claim, for instance by providing a caveat in relation to her forthcoming suggestion (line 1), and in line 8 using the passive voice ('*it just pops out at me*' versus 'I think' or 'I believe that') and an informal variation of the diagnostic term ('Aspergecy'). On the other hand, the parent simultaneously strengthened the legitimacy of her case (lines 4-5) by commenting on the long-standing nature of her concerns. Hence, even in this apparently straightforward

presentation of opinions, the parent managed the delicate task of asserting a reasonable-sounding and influential argument when she, as a non-clinician, was not socially positioned to use diagnostic language.

In line 9, the parent then presented a contrast between the candidate diagnosis and being '*autistic*' (line 9). As with contrasts more generally in talk (c.f. Pomerantz 1986), this was presented within the somewhat unequivocal form of words '*in any way shape or form*' (line 9). While a diagnostician might challenge the appropriateness of such a contrast, in this clinical interaction it had a notable consequence: immediately following this strong formulation, another family member took the floor in overlap (line 11). Whilst this turn was not completed, the mother's subsequent expansive response highlighting '*cleverness*' in spite of the presence of recognisably clinical issues ('*obsessive*', '*anxious*') indicates that she received this as an emerging disagreement with her assertion in line 9. Such dynamic modification of the cases built by the parents when offering up candidate diagnoses was evident across the dataset, clearly reflecting the context-specificity of the 'version' of the child being presented.

For parents in these sessions, the delicate offering of a candidate diagnosis sometimes functioned as both an explanation for the atypical behaviour of their child, and also as a way of orienting to the perceived need for a concrete label. Extract 2 demonstrates this. Here, the candidate offering of ASD was presented within the first 16 minutes of the session:

Extract 2: Family 5 (Prac = Psychiatrist)

```
1    Mum         ↓an' it was like I mean it is Mrs C↓ooper ↓the SENCO
2                at the school is ↓b you kn↓ow basically (0.38) been
```

```
3              pushing us push (0.62) you know she's felt ↓Mandy's

4              autistic ↓for quite a while ↓now  (1.34) ↓but it's

5              just getting (0.27) the educational psycholo↓gist

6              (0.28) who's just ↓not

7    Dad       it's just gett↓ing

8    Mum       ↓well we feel like we're fighting a losing batt↓le

9              to be ↓ho[nest]

10   Dad        [↓one one] says it's ↓this one says it's ↓that one

11             says it's the ↓other and it's like nobo↓d[y's

12             ↓they're all] fighting to ↓make a decision ↓is my

13             op↓inion

14   Prac                                              [it's

15             diffic↓ult]I think it will be help↓ful to look at

16             everybody's ↓view and then then ↓make a decision
```

For parents, the offering of a candidate diagnosis functioned as both an explanation for the atypical behaviour of their child, and also as a way of orienting to the need for a concrete label with which to acquire services. Unlike Extract 1, however, most noteworthy in this extract is that a third party reference was drawn upon to offer the candidate diagnosis, with similar delicacy being employed when offering up the possibility of autism through the phrasing *'she's felt'* (line 3), rather than 'she is certain' or 'she knows'. Through this third party claim, the notion of Mandy's ASD was carefully introduced as being the opinion of someone who holds authoritative knowledge on the subject (that is the Special Educational Needs Coordinator –SENCO – line 1). Importantly, it is this knowledgeable agent who was reported as '*pushing'* (line 3) the parents to explain Mandy's needs. By focusing on this kind

of language, the very notion of '*pushing*' was juxtaposed by the longevity of the process, with *'for a while now'* (line 4) implying an assertive position on the case.

Additionally, in this extract, both parents collaboratively built an account for Mandy's potential diagnosis that employed idiomatic formulations of the problem at hand. By using the idiom *'fighting a losing battle'* (line 7) and '*fighting to make a decision'* (line 11), the parents pointed to a complex process prior to the assessment. This point was grounded in the assertion that the educational psychologist was yet to be persuaded, with an implicit suggestion that the psychiatrist may facilitate resolution. Although the two parents worked together to offer up the possibility of ASD, the psychiatrist still held the ultimate epistemic rights to offer the specialist mental health service for the family, and promote or decline the probability of an ASD diagnosis. This epistemic right was oriented to in the uptake of the collaborative reports offered by the parents, as the psychiatrist responded in a fairly neutral format with '*look at everybody's view'* in order to *'then make a decision'* (line 14). The psychiatrist's turn thus neither validated nor rejected the candidate proposal offered by the parents. Ultimately, therefore, the notion of ASD remained fluid and negotiable as the assessment continued, while at this point it was 'on the table' as a possibility.

b. *Constructing the child's problems*

In our data, alongside the candidate diagnosis, parents frequently provided additional information, sometimes preceding the offered candidate diagnosis, to evidence their claims. This was mostly done as 'symptom' construction, with parents providing details regarding the child's behaviours. Importantly, they illuminated their child's behaviour as warranting

special attention in some way by indicating some problems within it (see Smith, 1978). This

is illustrated in Extracts 3 and 4.

Extract 3: Family 3 (Prac = Psychiatrist)

```
1    Prac        yeah a::nd er there is al↓so: s- something about how

2                Alex he ↓er ba- basic↓ally grown ↓up and (0.30) he

3                n- he likes certain ↓things to be in certain ↓way

4                ([at the] time)

5    Mum          [yeah]

6    Prac        ↑alri:ght ↑can ↓you tell ↓me about it ↓more

7    Mum         when he first went big ↓school um:: (.) he had this

8                obsession with (0.77) needing (0.74) what was it

9                five p↓ens three ↓pencils just and it was all I had

10               ↓to check his bag about ↑twenty ↓times before he'd

11               go out coz he used to ↓think somat ↓would be missing

12   Prac        >right<
```

In lines 1-3, the psychiatrist summarised Alex as displaying a particular behaviour, in this

case liking '*things to be in a certain way*' (line 3), which was based on the information

presented by the family. This initial formulation was produced with a significant degree of

hedging (lines 1-2), displaying the delicate nature of describing the child as implicitly

obsessive, a tendency positioned as central to ASD's behavioural profile (DSM-5; APA,

2013). Comparable delicateness when constructing an identity as 'problematic' or

'pathological' in some way has been demonstrated in other work (e.g., Lester & Paulus,

2012). In the next turn (line 5), the mother offered an unsolicited agreement with '*yeah*',

affirming the psychiatrist's formulation of the child's pathology. Notably, the uptake of this affirmation was seen when the psychiatrist posed an unprefaced question, eliciting additional information from the mother as a way of seeking further evidence for the child's problems. Conversely therefore, the parent's response following the psychiatrist's subsequent prompt explicitly evoked *'obsession'* (line 7). The mother responded with specific details about this obsession, further building up the case that Alex was indeed '*obsessive*'. Her use of specific numbers, such as '*five pens*' and '*three pencils*' (line 9), offered a certain preciseness to her knowledge of the child's behaviour, without which the child's normality could otherwise be maintained.

These issues were further evidenced in extract 4. Here, particular characteristics commonly associated with ASD were again presented in conversationally subtle ways, in this case with the child participating in the interaction. As in extract 2, in the below extract there was again evidence of differing opinions between speakers, thereby shaping the nature of the arguments that were presented.

Extract 4: Family 16 (Prac = Psychiatrist)

```
1   Mum       and he smiles ehh I went to call for somebody ((said
2             in a silly voice)) I said no
3   Child     I do go to [↓call]
4   Mum                  [yeah he know] he know he knows where he
5             knows his ↓areas where he's allowed to go and where
6             he's ↓not allowed to [go b]ut every now and a↓gain
7             we do [↓push]
8   Prac             [um}      [um] (.)
```

```
9              ok but it's [not sort of] consistent[it's not it's

10             not all the time]

11  Child                  [no but]

12                                     [sometimes I ca]ll

13             for ↓people

14  Mum        ↑no:: I wouldn't say it was con ↑ye:ah ↓no I

15             wouldn't say it was consi↓stent [but]

16  Prac                   [um]

17  Mum        (1.07)

18             but he gets very fru↓strated when he's out playing

19             with other children(0.36)um

20             (3.09)

21             his social circles are quite strained at ↓times

22             cause people don't understand

23  Prac       um::

24  Mum        how (.) lively he is
```

The extract above begins with a sequence primarily involving the mother and child in which there was debate about the extent to which he experiences social difficulties. During this stretch of interaction, the child made a strong counter-claim '*I do go to call*' (line 2), which was softened to '*sometimes I call*' following further contributions from both adults. The mother further clarified that these challenges were not '*consistent*', with the word '*but*' serving to mark the subsequent language as providing additional evidence of difficulties (lines 14-15). Prior to describing the child as becoming '*very frustrated*' and having '*social circles*' that are '*strained*', the mother paused (lines 17 and 20). Pauses, particularly those beyond 1.2 seconds, often point to delicateness in the talk (Pomerantz, 1984). This likely

reflects the dilemmatic issues generated in an interactional context wherein a child's

diagnosis is dependent upon descriptions of symptomology, yet aspects of such descriptions

are resisted by the child.

2. *Practitioner response to the presented case forASD*

Following the question-answer interactional structure of these assessment sessions, families

exclusively built cases for ASD following clinician-delivered questions. As with all question-

answer sequences, it was always the practitioner who was interactionally positioned to

evaluate, ratify, or resist the talk of the parents. Given that a diagnosis of ASD has been said

to cause negative reactions in parents (Osborne & Reed, 2008), it could be predicted that

practitioner responses would be delicately formulated; this appeared to be the case - although

not necessarily in the manner that might have been expected. When professional opinions

were delivered to positively evaluate the cases built by parents (i.e., that is, there is a

likelihood of ASD), this was done so in a fairly definitive and straightforward manner.

Conversely, when contradicting the possibility of ASD raised by parents, practitioner talk

reflected far more layers of social delicacy. These two possibilities are illustrated in extracts 5

and 6 respectively.

Extract 5: Family 24 (Prac = Psychiatrist)

```
1   Prac      So what we then do is try to fit it into (0.87) try
2             to explain the diagnosis (0.72) I think you're right
3             I think you know he does qualify for an autism
4   Mum       Yeah
5   Prac      diagnosis I mean there's no doubt about it
```

The extract, which followed a case for ASD being built by the parent, demonstrates that there was little difficulty in the practitioner delivering the probability of a diagnosis of '*autism*' (line 3). There are two further notable details in this turn. First, the psychiatrist did *not* offer confirmatory diagnosis, rather suggesting in a more softened manner that the child '*does qualify for an autism diagnosis*' (lines 3-5), before strengthening this assertion with the additional '*no doubt about it*' (line 5). Second, the offering of the probability of 'autism' was reflected back against the case that the mother herself presented during the session. By saying '*I think you're right*' (line 2), the outcome was positioned as a result of the evidence offered by the mother during the assessment, with the psychiatrist's diagnosis functioning as confirmation, rather than one of surprise or disagreement.

In contrast to extract 5, in the next extract the news that was delivered to the family was that the child did not qualify for an ASD diagnosis and this was evidently more challenging for the practitioners to deliver.

Extract 6: Family 22 (Prac 1 = Psychiatrist, Prac 2 = Clinical psychologist)

```
1   Prac 1    from the Asperger point of ↓view er (0.24) (I mean
2             it) children w who are on on (0.52) have (.) um sort
3             of Autistic like features (0.98) they really
4             struggle in terms of social interaction (0.60)um:
5             (.) they have very narrow interests (0.45) the:y um:
6             (0.25) they have >communication difficulties an<
7             (0.91) talking to him seeing him talking to you it
8             doesn't indicate any of that (0.49) he's very
```

```
9            ↓sociable he likes to interact he enjoy interaction

10           he enjoy attention (0.59)er: he's he's intelligent

11           (0.49) er in terms of you ↓know (0.68) how he can

12           get all these things =he doesn't have problems

13           making friends (0.44) which goes quite against the

14           diag↓nosis so I think we there is no (h)

15           developmentally e e it's a neurodevelopmental

16           con↓dition and should be present (0.30) right from a

17           very young age from three onwards an I couldn't pick

18           up anything (0.54) from (0.72) what you told m[e]

19  Mum              [um]

20  Prac 1   (0.43) that could have been in[dicative]

21  Prac 2                    [an he se]ems t[o make]

22  Prac 1                                   [(in that sense)]

23  Prac 2   (0.23) frie[nd]s

24  Prac 1            [um]

25  Mum      =yeah

26  Prac 2   =as well whi[ch is u]sually a (.) a sign to indicate

27           that actually maybe

28  Prac 1               [yeah]

29  Prac 2   (0.42) that (.) he doesn't (0.25) >necessarily have

30           social-communication difficulties like ASD type

31           ↓difficulties< (0.44) yeah
```

On examining the above extract, clear differences between the delivery of a 'no-diagnosis' versus a 'diagnosis' are apparent. First, the dysfluent turn within which this news was

delivered (by Practitioner 1, lines 1-17) was considerably longer than the comparable

delivery of news in Extract 5 (line 3). Here, Practitioner 1 provided a relatively long list of

tendencies of the child that were eventually packaged as going *'quite against the diagnosis'*

(line 12). Comparable evidence was not presented by the practitioner in extract 5. Second, the

mother's response of *'um'* (line 18) was both minimal and equivocal, which appeared to

occasion a second clinician (Practitioner 2) joining the sequence to deliver the 'no-diagnosis'

collaboratively, with both practitioners producing *'yeah'* towards the end of the extract in a

manner demonstrating agreement with one another's prior talk. Two practitioners were also

present in Extract 5, but here no such collaborative delivery of 'diagnosis' news was evident.

These differences imply that within this diagnostic context, it was more interpersonally and

socially problematic for a practitioner to deliver a 'no-diagnosis' as opposed to a diagnosis.

Discussion

In this study, CA was undertaken to examine triage assessments in UK CAMHS in which

ASD was raised as a possibility. Through the application of this micro-analytic approach, we

were able to interrogate the nuances of the interactions to explore unfolding discussion of

children's complex problems. The data revealed that parents, as opposed to practitioners,

were the first to raise ASD as a possible diagnosis, and that they did so using specific

discursive practices. Families built a case for ASD through the use of evidence of their

child's difficulties, whilst at the same time carefully hedging aspects of their argument

through the use of medical terminology. In this way, they demonstrated both an awareness of

the nuances implicit to the social interaction with the clinicians, whilst also appreciating the

complex and at times conflicting agendas that surround diagnostic processes. Practitioners

themselves were then positioned to ratify or contest the cases built by the parents, with the

manner in which this was accomplished again providing insight into the subtle complexities

of this service context. This use of medical terminology and characteristics that resonate with

ASD reflects the increasing knowledge within the wider social discourse about 'symptoms'

and behaviours commonly positioned as signalling ASD; this perhaps also points to the

growth in information technology that has facilitated accessibility to such materials (see also

Stafford et al., 2014). How such information is taken up and presented thus complicates the

diagnostic process.

There are a range of practical implications that can be highlighted within this study's

findings. First, families are indeed highly invested in the search for an understanding or

explanation of their child's behaviour, and parents of children with mental health concerns

may seek a non-blameworthy explanation for the child's behaviour, such as diagnosable

conditions or genetic explanations (O'Reilly & Lester, in press). Parents may feel that the

diagnostic process is long, experience negative responses from professionals, and become

dissatisfied with the length of this process (Crane et al., 2015; Sansosti et al., 2012). Although

previous research has suggested that the diagnosis of ASD can have a negative impact on

parents, likening it to a grieving process (Avdi et al., 2000), in our dataset it was the families

who argued for the presence of ASD. While the grieving process may take place following a

diagnosis, at the point of initial assessment the drive for an explanation seems to be the

parents' priority. This situation may also be a reflection of the increasing profile of ASD and

the possible reduction in associated social stigma, at least to some extent.

Second, patient satisfaction is intrinsically linked with the communication with a professional

and the manner in which the diagnosis is disclosed (Crane et al., 2015). Specifically, our

study illustrates how discussion around a possible diagnosis of ASD supports the supposition

that families view the confirmation of the presentation of ASD as a positive outcome. Typically practitioners did not raise the possibility of a diagnosis of ASD outside of the existing framing of symptoms presented by the parents, and in those cases where it was suggested as possible, it was positively received. Evidence of this assumption is reinforced by the need for practitioners to have longer discussions when refuting the diagnosis in an attempt to justify their positions, as noted in our study's findings. Although our study included only one specific service context, which may not reflect other contexts where young children with mental health concerns are assessed, the salient points raised by these findings may be useful when considering other assessment situations. Indeed, our data were limited to the initial interaction and therefore does not demonstrate the eventual long-term outcomes of the whole diagnostic process. However, the use of naturally occurring data has a number of strengths for use in an exploratory context, as it enables identification of novel or counter-intuitive phenomena that may have otherwise been overlooked.

Third, highly ecologically valid findings, such as those we report here, have the potential to change practice. CA allows the analyst to examine the interaction in a way whereby they might provide professionals with clarity regarding 'what matters' to parents, as well as offer conversational strategies to convey this 'what matters'. The increased awareness of the interactional processes around diagnosis is important for enhancing clinical practice through the recognition and management of such conversational devices. Clinical professionals should, therefore, be mindful of the stake that parents have when attending assessments, as well as the subtle and overt ways in which they present their case in situ, and how this might reflect complex and ambivalent responses to the diagnostic process. A key issue for future professionally-relevant research, then, is to broaden understandings of the range of responses that parents may have to the diagnostic process across service contexts and at different points

in the diagnostic pathway. In doing so, it may be possible to identify more appropriate means of supporting families through this complex, and at times arduous, set of processes. Future research can then examine a range of contexts, through CA and other methods to flesh out the details of the phenomena sketched in our study.

References

American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders* (5thedition). Washington, DC: Author

Antaki C and O'Reilly M (2014) Either/or questions in child psychiatric assessments: The effect of the seriousness and order of the alternatives. *Discourse Studies* 16: 327-345.

Avdi E Griffin C and Brough S (2000) Parents' constructions of the 'problem' during assessment and diagnosis of their child for an autistic spectrum disorder. *Journal of Health Psychology* 5(2): 241-254.

Bailey A (2008) Autism as a global challenge. *Autism Research* 1: 145-146.

Baird G., Siminoff E Pickles A Chandler S Loucas T Meldrum D and Charman T (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: The Special Needs and Autism Project (SNAP). *The Lancet,* 368(9531): 210-215.

Bolden G & Robinson J (2011) Soliciting accounts with *why*-interrogatives in conversation. *Journal of Communication* 61: 94-119.

Center for Disease Control and Prevention (2014) Prevalence of Autism Spectrum Disorder among children aged 8 years - Autism and Developmental Disabilities monitoring network, 11 sites, United States, 2010. *MMWR* 63(2): 1-21.

Crane L Chester J Goddard L Henry L and Hill E (2015) Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism,* doi: 10.1177/1362361315573636

Eyal G Hart B Onculer E Oren N and Ross N (2010) *The Autism Matrix: The Social Origins of the Autism Epidemic*. Cambridge: Polity Press.

Gernsbacher MA Dawson M and Goldsmith H (2005) Three reasons not to believe

in an autism epidemic. *Current Directions in Psychological Science, 14(2),* 55-58.

Goin-Kochel R Mackintosh V and Myers B (2006) How many doctors does it take to make an autism spectrum diagnosis? *Autism* 10:439-451

Hugenholtz M Bröer C and van Daalen (2009) Apprehensive parents: A qualitative study of parents seeking immediate primary car for their children. *British Journal of General Practice* March:173-179.

Heritage J & Robinson J (2011) 'Some' versus 'any' medical issues: encouraging patients to reveal their unmet concerns. In: C Antaki (Ed.), *Applied Conversation Analysis: Intervention and Change in Institutional Talk.* Hampshire: Palgrave MacMillan, pp: 15-31

Hutchby I and Woffitt R (2008) *Conversation Analysis* (2nd Edition). Cambridge: Polity.

Jefferson G (2004) Glossary of transcript symbols with an introduction. In: G Lerner (Ed.), *Conversation Analysis: Studies from the First Generation*. Amsterdam: John Benjamins Publishing Company, pp. 13-23

Jefferson G (1986) Notes on latency in overlap onset. *Human Studies* 9:153-183.

Karim K Ali A and O'Reilly M (2014) *A Practical Guide to Mental health Problems in Children with Autistic Spectrum Disorder: "It's not just their autism!* London: JKP.

Karim K Cook L and O'Reilly M (2012) Diagnosing Autistic Spectrum Disorder in the age of austerity. *Child: Care, Health and Development* 40(1): 115-123

Lester J N Karim K and O'Reilly M (2014) "Autism itself actually isn't a disability": Negotiating a 'normal' versus 'abnormal' autistic identity. *Communication & Medicine*, *11*(2): 139-152.

Lester J N and O'Reilly M (in press) Repositioning disability in the discourse of our times: A study of the everyday lives of children with autism. In: G Noblit& W Pink (Eds.), *Education, Equity, and Economy*. Springer.

Lester J and Paulus T (2012) Performative acts of autism. *Discourse and Society* 23(3): 259-273.

Lord C Rutter M & Le Couteur A (1994) Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders,* 24: 659–685

Marvin R and Pianta R (1996). Mother's reactions to their child's diagnosis: Relations with security attachment. *Journal of Clinical Child Psychology* 25: 436-445

Mash E and Hunsley (2005) Special section: Developing guidelines for the evidence-based assessment of child and adolescent disorders. *Journal of Child and Adolescent Psychology* 34(3): 362-379.

Maynard D and Clayman S (2003) Ethnomethodology and conversation analysis. In: L Reynolds and N Herman-Kinney (Eds.), *Handbook of Symbolic Interactionism*. US: Altamira press, pp. 173-202

O'Reilly M Karim K Stafford V and Hutchby V (2014) Identifying the interactional processes in the first assessments in child mental health. *Child and Adolescent Mental Health:* doi: 10.1111/camh.12077

O'Reilly M Karim K and Lester J N (2015) Should autism be classified as a mental illness/disability? Evidence from empirical work. In: M. O'Reilly & Lester, J. N. (Eds.), *The Palgrave handbook of child mental health: Discourse and conversation studies*, London, UK: Palgrave-Macmillan, pp. 252-271.

O'Reilly M and Lester J (in press) Building a case for good parenting in a family therapy systemic environment: Resisting blame and accounting for children's behaviour. *Journal of Family Therapy*

Osborne L and Reed P (2008). Parents' perceptions of communication with professionals

during the diagnosis of autism. *Autism 12:* 309-324

Parker N and O'Reilly M (2012) 'Gossiping' as a social action in family therapy: The pseudo-absence and pseudo-presence of children. *Discourse Studies* 14(4): 457-475.

Parkin A Frake C and Davison I (2003) A triage clinic in a Child and Adolescent Mental Health Service. *Child and Adolescent Mental Health* 8(4): 177- 183

Pomerantz A (1986) Extreme case formulations: A way of legitimizing claims. *Human Studies,* 9(2-3): 219-229.

Pomerantz A (1984). Agreeing and disagreeing with assessments: Some features of preferred/dispreferred turn shapes. In\; J Atkinson and J Heritage, (Eds.), *Structures of Social Action: Studies in Conversation Analysis*. Cambridge: Cambridge University Press, pp. 57 – 101

Ridge K and Guerin S (2011) Irish clinicians' views of interventions for children with autistic spectrum disorders. *Autism* 15(2): 239-252.

Sansosti F Lavik K and Sansosti J (2012) Family experiences through the autism diagnostic process. *Focus on Autism and Other Developmental Disabilities 27(2): 81-92*

Schegloff E (1999). Discourse, pragmatics, conversation, analysis. *Discourse Studies* 1(4): 405-435.

Shaney D Reid G and Evans B (2008) How parents seek help for children with mental health problems. *Adm Policy and Mental Health* 35:135-146.

Silva L and Schalock M (2012). Autism parenting stress index: Initial psychometric evidence. *Journal of Autism and Developmental Disorders* 42: 566-574.

Simonoff E Pickles A Charman T Chandler S Loucas T and Baird G (2008)

Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry* 47(8): 921-929.

Smith D (1978) 'K is mentally ill': The anatomy of a factual account. *Sociology* 12: 23-53.

Stivers T (2002) Presenting the problem in pediatric encounters: "symptoms only" versus "candidate diagnosis" presentations. *Health Communication* 14(3): 299-338.

Strong T Busch R and Couture S (2008). Conversational evidence in therapeutic dialogue. *Journal of Marital and Family Therapy* 34(3): 388-405.

ten Have P (2001) Lay diagnosis in interaction. *Text 21(1/2):* 251-260.

Wachtel K and Carter A (2008). Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism* 12(5): 575-594.

Wiggins L Baio J and Rice C (2006). Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Developmental and BehavioralPediatrics*27(2 Suppl): S79-S87

Wing L and Gould J (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders* 9(1): 11-29.

Wolpert M and Fredman G (1994). Modelling the referral pathway to mental health services for children. *Association if Child Psychology and Psychiatry: Newsletter* 16: 283-288

Ziolkowska J (2009) Positions in doctors' questions during psychiatric interviews. *Qualitative Health Research* 19(11): 1621-1631.