

A normal paranoia? The emergence of distrust between parents of autistic children and public officials

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Abstract

This paper explores the development of distrust and paranoia among parents and carers of autistic children in their interactions with public officials charged with such children's diagnosis, education and care. The suspicion and distrust framework of Fein and Hilton (1994), and Kramer's typology of organisational paranoia (1998, 2001) are used to show how distrust impacts on client experiences. Antecedents of distrust are identified, and the 'normalcy' of paranoia in this context is demonstrated. These findings should permit public sector staff dealing with parents and carers of autistic children to address such perceptions and build trust where little seems to exist.

Key words: trust, distrust, public sector management, special educational needs

Introduction

This paper seeks to explore how distrust and paranoia are created among parents and carers of autistic children in their dealings with public officials involved in the child's diagnosis and care. Autism (and the less severe form identified as Asperger's syndrome) is a developmental disability that affects the individual for their entire life, impacting on their

ability to communicate with and relate to people around them. Individuals within the autism spectrum struggle with normal social interaction, have limited social imagination and poor social communication. These three elements, known as the 'triad of impairment' (NAS, 2009), can be accompanied by behavioural problems, learning disabilities and other conditions such as dyspraxia or attention deficit hyperactivity disorder. The degree and specific manifestations of autism will vary from child to child, and around one in 100 people in the UK have some form of autism (NAS, 2009). While there is no cure, specific therapies and interventions can have a positive impact on the child's future prospects.

To maximize the child's life chances, parents and carers seek access to specialist resources through the educational and healthcare system. At the same time, local authorities that provide these services are subject both to financial constraints and also to a variety of statutory requirements and guidelines in relation to meeting such children's needs – creating potential for tension between the two groups. This research seeks to 'unpick' this tension and explore how distrust and paranoia develop among parents and carers of autistic children in their dealings with local authority representatives and professionals. These groups can be construed, from Giddens (1990) as 'faceworkers' at access points in an 'abstract system' (systems that rely on the expert knowledge of members within a set regulatory framework) and towards whom great vigilance is often directed by clients in each and every interaction.

Concerns over low public trust in government and public administration have led many Western governments to modernize their public sectors, on the assumption that greater client satisfaction, and therefore trust, will result from better performing public services (Van de Walle and Bouckaert, 2003). This emphasis is reflected in academic articles which direct attention towards internally-oriented performance improvements for staff (e.g.

Gould-Williams, 2003; Albrechte & Travaglione, 2003; Heintzman and Marson, 2005). Less attention, however, has been directed towards the actions of such staff that underpin and contribute to loss of trust with their external audience.

Drawing on the typologies of suspicion – a proxy for distrust – elaborated by Fein and Hilton (1994) and the typology of organizational paranoia developed by Kramer (2001), this paper addresses the above research gap and explores evaluations of low trust by parents and carers of autistic children. The main focus is thus the relationship between the parent/carer and those in authority or at the coal face responsible for the child's health, care, education and welfare. These may include teachers, doctors, care workers, health and therapy specialists; they may be local officials or budget holders implementing their area of professional practice. While a diverse group, the various 'providers' of services for a child are often defined as a whole 'organization' or single entity in the eyes of the trustor.

In the context of the relationship between parent/carer and public officialdom, this paper has the following objectives: 1. to explore the extent to which parents of autistic children experience distrust; 2. to explore the factors that contribute to such feelings; and 3. to consider how distrust may move into the deeper form of suspicion, and at the extreme end, paranoia. The paper thus addresses a neglected area in the literature of relations of distrust through the research site of autistic children and their carers, and in so doing offers potential solutions for 'faceworkers' in the front line of delivering what is hoped to be a 'trustworthy' service.

Trust and the UK public sector

Trust has historically had a struggle for acceptance in business and management-related disciplines (Kern, 1998; Deakin and Wilkinson, 1998; Koehn, 1996; Flores and Solomon, 1998), although Mollering *et al* claim that in recent years “trust researchers constitute a very active and distinct academic community that is set to continue studying the role of trust” (2004: p557). Elsewhere, there is widespread acknowledgement of its importance, for example in the health care literature (Gilson, 2006; Hupcey and Miller, 2006), in which its presence is seen as key to the “development of health care relationships and ... vital for satisfactory patient outcomes” (Hupcey and Miller, 2006, p1133).

Anxiety is endemic within the (often unequal) patient/client and medical/public professional relationship, characterised by uncertainty, risk and vulnerability (Calnan *et al*, 2006; Calnan and Rowe, 2006; Pate *et al*, 2006). From Brown (2007), the extent of this anxiety varies in proportion to the level of risk and the degree of unpredictability. Risk and uncertainty are key elements of traditional conceptualisations of trust, in combination with reliance on another party whose behaviour is beyond one’s control and where there is potential for trust abuse (Zand, 1972). For example, in a healthcare setting, the patient depends on the medical professional to be competent and well-intentioned towards the patient, yet is unable to exercise vigilance or control over the professional’s conduct despite the high level of risk associated with being ill (Calnan and Rowe, 2006).

In the UK, public sector leaders are subject to an explicit competency standard of fostering mutual trust (Albrecht and Travaglione, 2003; Pate *et al*, 2006). They operate in a sector generally characterised by proxy indicators for trust that take the form of measurable targets and performance standards, complete with inspection regimes and sanctions for non-performance (Blackman *et al*, 2006). Such efforts are reflective of the modernisation efforts now pervasive across public services, and are deemed crucial in a transactional

environment that, while predicated on trust, takes place in the context of a service offering that is both difficult to measure and based on an asymmetry of information exchange. However, proxy indicators are criticised in particular for encumbering local authorities' abilities, and flexibility to react to and meet local needs (Lyons, 2006 in Blackman et al, 2006).

Proxy indicators for trust such as policy initiatives and their attendant statements, practices and procedures therefore bridge a knowledge gap on the part of clients concerning the quality of the service, but struggle more when it comes to assuring clients of the integrity of the 'sort of person' (Dasgupta, 1988) they are dealing with. These indicators form what Skinner *et al* (2004) describe as a 'pledge', necessary for the creation of trust, in setting expectations towards obligations or commitments that must be fulfilled. As such, they form part of the institutional framework (including rules, the legal system, social custom, professional qualifications and accreditation bodies) underpinning trustors' relationships with public sector bodies and their representatives, and form the basis for institution-based or institutional trust (Zucker, 1986; Giddens, 1990). This provides some degree of confidence in the behavior of unmonitored and unknown others, and therefore permits the general populace to place a degree of trust in strangers to act in its interests.

While proxy indicators can provide measurability of trust's cognitive aspects as a substitute for uninformed surveillance on the part of unqualified patients and clients, they cannot capture its affective elements. For many years, the trust literature has recognised the interaction between trust's cognitive and affective components (Lewis and Weigert, 1985; McAllister, 1995; Lewicki & Bunker, 1996; Ring, 1996; Brockner and Siegel, 1996; Husted, 1998). The cognitive components of trust focus on the rational aspects such as competence, reliability, justice and fairness, knowledge and the contractual or calculative elements of the

relationship. The affective bases for trust concern the relational components of goodwill, integrity, interpersonal skills, openness, motives, social norms, interpersonal care and concern, personal character and mutual identification (Zucker, 1986; McAllister, 1995; Lewicki and Bunker, 1996; Ring, 1996). In other words, the rational elements account for cognitive trust; the relational highlight its affective element. Each has a significant role to play in trust development, but while the rational aspects such as competence represent in most cases the necessary conditions for trust to occur, the affective components may be a more essential ingredient. As Lewis and Weigert point out, “the stronger the emotional content relative to the cognitive content, the less likely contrary behavior evidence will weaken the relationship” (Lewis and Weigert, 1985: 972). In fact, it is towards this aspect that clients and patients exercise great vigilance.

Accordingly, potentially trusting expectations upon entering into a relationship will be mediated via an interaction between trust’s cognitive, affective and institutional bases. The foregoing discussion has highlighted how: “trust based on the assumption of technical competence alone is *revisable*’ (Giddens 1994: 89). That the professional, therefore, is ‘kindly, concerned and trustworthy’ is crucial to inducing a deeper sense of trust (Scambler and Britten 2001: 58)” (Brown, 2007, p358). Repeated engagement enables the interaction of the cognitive, affective and institutional aspects thus forming a virtuous circle of trust creation or vicious circle of decline when trust building processes fail (Tubin & Levin-Rozalis, 2008).

Distrust, suspicion and paranoia

According to the nursing literature, loss of trust may be indicated by, for example, increased vigilance over care and medical professionals, increased stress on the part of trustors and

reductions in their physical health (Hupcey and Miller, 2006; pg 1133). In the general organisational literature, although much trust writing is concerned with defining trust and considering what builds trust, few articles deal explicitly with the creation of distrust. Those discussing breakdowns of trust recognize that: “trust is continually under negotiation, whether explicit and articulated or not. Trust in any relationship is built out of (and destroyed by) routine frustrations, promises and commitments” (Flores and Solomon, 1998: 223). It is with the small items, or everyday ‘trivia’ in the words of Flores and Solomon that this research is concerned to create an understanding of trust demise – routine difficulties and obstacles (deliberate, institutional, personal or accidental), perceptions of broken promises and commitments (whether tacitly held in custom and attitude or explicitly enshrined in legislation or rules), beliefs in the competence or otherwise of responsible others in the exercise of their professional practice or duties, broken expectations of one’s own future, or of the proper exercise of the role of others – these all have a role to play in the creation of distrust in this context.

As the above discussion indicates, the development of trust and distrust is a history-dependent process, arising out of an informational, professional, institutional and social environment that creates and embeds expectations. A priori expectations characterise the start of the trust process with a-posteriori ruminations on experiences used as a point of comparison (Kramer, 1998: pg 252). The selected definition to capture this sees distrust as “confident, negative expectations regarding another’s conduct” (Lewicki *et al*, 1998; pg 129); with such negative expectations comprising the attribution of sinister intentions to the trusted other, feeling fearful of them, and acting to buffer oneself against their undesired conduct (*Op.Cit*). When trusting expectations are violated, then harmful motives are assumed: cynicism, wariness and scepticism characterise the encounter, reliance is reduced where possible, and vigilant appraisal of others’ action to discern concealed intentions and

motives is likely to result (Fein and Hilton, 1994; Lewicki *et al*, 1998). This latter act is symptomatic of a state of suspicion, in which the social perceiver “actively entertains multiple, plausibly rival, hypotheses about the motives or genuineness of a person’s behavior” (Fein, 1996, p1165, cited in Kramer, 2001, p3). Further, there is a belief “that the actor’s behavior may reflect a motive that the actor wants hidden from the target of his or her behavior” (Fein & Hilton, 1994, p169, cited in Kramer, 2001, p4).

This evolution of distrust, from unmet expectations through to vigilance and cynicism towards the trustee in a relationship, has been developed in the works of Fein and Hilton (1994) and Kramer (1998, 2001), who have investigated organizational distrust through the lens of suspicion in the former case, and paranoia in the latter.

Fein and Hilton (1994) set out a typology of suspicion, which underpins relations of distrust, based on three factors. Suspicious perceivers:

1. see situational cues in contextual information suggesting others might have ulterior motives;
2. have forewarnings others might be insincere or untrustworthy; and
3. have had their expectations of others violated.

As the distrustful, and potentially paranoid social perceiver conducts vigilant appraisal and finds corroboration of his or her worst fears, then a downward spiral of distrust and suspicion is engendered with negative coping responses confirming the emerging hypothesis that others are not to be trusted. Clients of health and public service professionals who continue to confirm rather than disconfirm this viewpoint may enter a state of ‘hypervigilant dysphoric rumination’ (Kramer, 2001; pg 29-31) in which social interactions are construed in highly personalised and unhappy (thus ‘dysphoric’) ways and to which the trustee directs

considerable, perhaps obsessive, attention. The sinister attribution bias, in which the distruster over-attributes a lack of trustworthiness to others, dominates all such interactions and individuals elaborate “trust-related ‘mental accounts,’ so that more cues from the environment tend to be coded as indicative of lack of trustworthiness and need for further vigilance” (Kramer, 2001; pg 31).

Paranoia becomes a possibility at this extreme end of distrust and can be defined as “a form of heightened and exaggerated distrust that encompasses an array of beliefs, including perceptions of being threatened, harmed, persecuted, mistreated, disparaged and so on, by malevolent others... These perceptions include suspicions that others are exploiting, harming or deceiving one, along with preoccupations and doubts regarding their loyalty or trustworthiness” (Kramer, 2001, p6). It is important to note here that while clinical psychology presumes paranoia to be located ‘inside the head’ of the social perceiver, social psychological theory pays more attention to paranoia’s social and situational origins. As Kramer (1998; pg 253-4) argues, paranoia is experienced mundanely by us all, and is better characterised as misplaced or exaggerated distrust. In certain situations it is an intentionally adaptive coping response to disturbing situations (eg walking down a lonely street on a dark night) rather than necessarily manifestations of disturbed individuals.

Kramer (1998; 2001) accounts for these social processes through the development of a typology of the antecedents of paranoia in organisational settings, characterised by four factors:

1. heightened perceptions of the evaluative scrutiny to which one is subject, particularly within hierarchical relationships where subordinates exercise greater vigilance over interactions;

2. perceived social destructiveness amongst paranoid individuals leading to and creating dysphoric self-consciousness;
3. social uncertainty and uncertainty about status, leading to the sinister attribution error e.g. a tendency towards enhanced feeling of paranoia among newcomers to the organisational situation and environment;
4. technologies that foster organizational paranoia e.g. the fragile trust between auditors and those they audit, reducing the (dis)trustor's perceptions of psychological safety.

While Kramer's typology is designed to apply to organisational environments, it offers a useful lens through which to explore the experiences of the parents of special needs children. Kramer points out that a hypervigilant state can be highly rational in certain situations: "distrust and suspicion are not always irrational. In highly competitive or political organizational environments, for example, an individual may have quite legitimate cause for suspicion and concern about others' trustworthiness. In such environments, the costs of misplaced trust can be quite costly - and sometimes even fatal - to one's career" (Kramer, 2001). Applied to our research context, it could be argued that these costs could equivalently relate to one's child's health, education and future life prospects.

Combining Fein and Hilton's typology of suspicion with Kramer's antecedents of paranoia, the following characteristics emerge. Distrust and suspicion are characterised by perceptions of ulterior motives and lack of sincerity in others as well as by failed expectations. Paranoia is characterised by more extreme forms such as hyper-vigilance and feelings of being under scrutiny, the sinister attribution error, negative feelings of social distinctiveness and lack of psychological safety – the latter manifest in particular by feelings of being under the gaze of significant others. This is summarised below:

Figure 1: Core antecedents of distrust and paranoia

| Suspicion/Distrust | Paranoia |
|---|------------------------------|
| Perceptions that others have ulterior motives | Hyper vigilance and feelings |
| Perceptions that others are insincere | of being under scrutiny |
| Failed expectations | Sinister attribution error |
| | Negative feelings of social |
| | distinctiveness |
| | Lack of psychological safety |
| | (under the gaze of |
| | significant others) |

These antecedents, synthesised from Fein and Hilton (1994) and Kramer (1998; 2001), underpin the paper's objectives and formed the basis of the current research.

Methodology

Data were gathered in 2005 in the Greater London area by means of in-depth, semi-structured interviews conducted with 16 parents of children aged between 4 and 16 who had been diagnosed with an autism spectrum disorder (ASD). The research adopted a social constructivist approach in that it explored how men and women give meaning to their experiences and how they make sense of their reality. The goal of constructivism is to understand the world of lived experience from the point of view of those who live it (Schwandt, 1998). It seeks to understand "how the seemingly 'objective' features, such as organizations and institutions, are constituted by subjective meanings of individuals and inter-subjective processes" (Eriksson and Kovalainen, 2008: 19). This, together with the

exploratory nature of the research (Yin, 1989), suggested qualitative techniques as the best strategy (Miles and Huberman, 1994). Interviews were therefore chosen as the methods of inquiry and were supplemented with informal observations and discussions with parents at support group meetings, outside the school gates and at activities organised for autistic children.

The NAS website was used to establish a sample. The first author made contact, via email, with the published leader of the local support groups, and either interviewed the leader or a person they recommended. Informed consent was obtained from all participants via an emailed letter outlining the study, its purpose and likely outputs, along with assurance of confidentiality (particularly important as some respondents were fearful of repercussions from being critical of their local authorities). Questions were deliberately open-ended and concerned the circumstances and emotions of diagnosis, key challenges faced in their negotiations with professionals, perceptions of success in these dealings, and experiences of empowerment or exclusion. Questions were orientated to understanding experiences of the relationship with professionals and the meaning attached to those experiences. Such qualitative data gathering techniques, and the resultant data “are fundamentally well suited for locating the meanings people place on the events, processes and structures of their lives: their ‘perceptions, assumptions, prejudgements, presuppositions’ (van Maanen, 1979) and for connecting those meanings to the social world around them” (Miles and Huberman, 1994: 10).

Data were gathered in the form of both written notes and tape recordings which were transcribed. Analysis involved reading and re-reading each of the accounts to uncover themes and patterns and arranging chunks of these accounts into coding categories under a multitude of themes, which were amalgamated into some 17 thematic areas. Analysis aimed

to “understand the patterns, the recurrences, the whys... the bedrock of inquiry is the researcher’s quest for ‘repeatable regularities’” (Miles and Huberman, 1984: 67). Such open data gathering and coding permits “a source of well-grounded rich descriptions and explanations of processes in identifiable local contexts” (Miles and Huberman, 1994: 1). The seven characteristics synthesised from Fein and Hilton’s and Kramer’s typologies guided but did not foreclose the data analysis. This follows Blumer’s (1954) notion of ‘sensitising concepts’ in which “a concept provides a set of general signposts for the researcher in his or her contact with a field of study. While the concept may become increasingly refined, it does not become reified such that it loses contact with the real world” (Bryman, 1993: 68).

Guided by these typologies, four themes emerged from the data:

1. emotions of anxiety and suspicion around diagnosis and provision;
2. impressions of the authorities as all-powerful;
3. parents feeling they are treated as undeserving;
4. feelings of being an outsider in the ‘normal’ world.

These themes are presented below.

Anxiety and suspicion around diagnosis and provision

All parents interviewed reported feelings of distrust towards public officials responsible for providing care and education for their child. While there was evidence that some parents understood the constraints under which local and health authority decisions were made, this understanding seemed to exacerbate rather than diminish feelings of distrust and underpinned the suspicion that the providers were motivated by financial considerations alone - and therefore did not have their child’s best interests at heart. Such attitudes and feelings, often supported by discourses of distrust in shared peer narratives as observed

informally by the lead researcher, frequently originated in uncertainty around diagnosis and subsequent experiences of unmet expectations regarding education and care provision.

Diagnosis of autism is to a large extent dependent on a complex interaction of disparate factors upon which different professionals do not always agree and where there is no structured system of support – no two autistic children will look the same. This means diagnosis is often characterised by high uncertainty and anxiety, and is subject to great variations across and within boroughs and counties – with no clear path visible to the recipients of these ‘services’. In this highly confusing stage, parents struggled to come to terms with a new uncertain identity. This confusion was often exacerbated by early ‘normality’ of the child who may have met early developmental milestones but where subsequent doubts arose from parents themselves or from other carers and health/educational professionals:

“it was so much pressure, umm, on my shoulders, one day you’re thinking he’s not autistic, because he’s just different than others, and the next day, oh my god he is, and just a constant roller coaster, and at the same time coping with the statement (of special educational needs – see below) and the educational psychologist, and speech therapist, and this constant thing, and trying to explain to the family what’s going on, family and friends, and how different that is, and everyone was saying ‘don’t worry, he’ll start to speak in sentences and that, and it will be fine and you can forget it all’, and obviously it didn’t happen.” (*Leader of a support group, non-NAS affiliated*)

Denial was often recalled as the first response – “I found it hard, at the early stages you don’t want to know” – and many respondents described prolonged grief as they sought to

come to terms with the 'loss' of the child they thought they had and struggled to accept the diagnosis. Subsequently, though, many respondents were disappointed to find no clearly specified route through the system and a large knowledge gap which public officials failed to fill.

"I was waiting for all these things to kick in and it doesn't, so I was going completely up the wall, it was just awful and no one was giving me any ideas about what to do"
(Leader of a support group, non-NAS affiliated).

"we were kind of left with ... OK they've given us this word, autism, what does it mean and you take it from there and it's up to you to go out and find out things, find out the possible treatment and education, nobody from any kind of profession has come along and said well this is what you do, this is what we can do. You have to find out yourself, I've never known anything like that" *(Leader of a support group, non-NAS affiliated).*

In fact, rather than offering advice and support, officials were often perceived as obstructive (one parent saw the role of the LEA as "not to suggest things") and parents described instead finding information on the internet, and turning to other parents and local groups for support.

Before an autistic child can receive any form of specialist education, they must subsequent to diagnosis hold a statement of special educational needs. This specifies the level and type of support they will require in an educational setting and should be legally binding. However, many parents find that much of what is written in a statement is not legally enforceable (deliberately worded so that schools can implement the recommendations 'flexibly')

according to one professional working in the area) and therefore may not necessarily be provided by the local authority. This creates a context for perceptions by parents of evasive tactics. One perceived tactic involved the frequent offering of mainstream provision (i.e. a place in a non-specialist school) under the 'inclusion agenda' – seen by parents as evidence of insincerity and a pretence at provision. As one group leader commented:

“It’s their line, they say to everybody ‘we can meet [your child’s] needs’ at mainstream schools, that’s what they say, they say that to every single parent, they never help, no control [for the parents] whatsoever”. (*Leader of NAS support group*)

“When you want something that fits into the educational provision list they’ve decided they’re going to provide, things will happen very fast and very efficiently. If not, you can flounder in a sort of a black hole, you know, not getting letters replied to, not getting phone calls returned”. (*Secretary of NAS support group*)

While the inclusion agenda has been particularly powerful in shaping attitudes and experiences on both sides, many parents felt this was an excuse not to provide expensive specialist provision for autistic and special needs children. In fact, only when mainstream school was seen to have failed, was specialist provision offered:

“They have to fail first, they have to be traumatised before it can change – and then it takes ages. They need evidence.” (*NAS branch officer*).

This effectively bars 'high functioning' autistic children, such as those suffering from the less debilitating 'aspergers syndrome' whom the criteria of the education authorities for special help often exclude:

“there is no provision for high functioning/aspergers. So either they go home with nothing, or they stay unsuitably in mainstream while the LEA engages in mind games with the parents.” (*NAS branch secretary*)

“When these children get to secondary, these poor children, having struggled through primary, how will they cope with secondary? They will fail, be bullied, have the confidence knocked out of them.” (*NAS branch officer*)

Anxiety over diagnosis and uncertainty over levels and nature of provision is thus a key characteristic of the relationship between parents/carers and public officials. This is exacerbated by perceptions of lack of support and deep suspicion as to the motives behind some of the decisions made. This supports other work on the relationship between patient/client and medical officials (Calnan et al, 2004; Calnan and Rowe, 2006; Pate, 2006) which suggests that uncertainty and feelings of vulnerability on the part of the client often characterise a loss of trust. In this respect, the data presented fits with the key antecedents of suspicion and distrust from Figure 1 (perceptions of insincerity and of ulterior motives regarding the offering of mainstream provision; unmet expectations regarding level of support and information provided). Moreover, the notion expressed that local authorities may seek to thwart the intentions of parents (that they set out *not* to suggest things) and that they have a perverse desire to cause difficulty and to harm (playing ‘mind games’ with parents) may be suggestive of a sinister attribution error identified as an antecedent of paranoia.

Authorities perceived as all-powerful

Respondents readily identified various public officials as holding power over them and were keen observers and interpreters of all their interactions and messages. The rationale for decisions made was seen to be overwhelmingly financially-based and outcomes as unsatisfactory for the child concerned. One husband and wife, for example, explained how their autistic son had been placed in a school for severely disabled children because it happened to be in the borough. One branch secretary commented:

“You find a school, you have to do all the legwork, you come along and say this is the right school for my child and then they say ‘no, we can provide this at this school’ because it doesn’t cost so much, that’s their line really..”

Those holding the purse strings at the top were seen as tough and driven by their own agendas. This was a repeated theme – public officials were viewed as insincere and untrustworthy in their professional judgements because financial motives were seen to underpin their actions. Respondents described them in emotive terms as “hard-boiled”, “inhuman”, “Machiavellian”, “not to be trusted” and with “hidden agendas” of saving money and protecting their professional authority. Parents used words such as “fight”, “battle” and even “devil incarnate” when referring to the local authorities and the effort to gain proper education for their children. One respondent observed: “there’s this sort of veneer that they appear to be involving you”, but as a branch secretary put it: “you don’t have choice, not without a battle.” In summary, one NAS branch leader stated:

“It’s snide, it’s underhand, the autistic parents I know tend to be up on things and it’s awful to be so condescended to. Yes, there is no money, but ... they don’t do things by the book.”

Often articulate and knowledgeable, a number of parents expressed little respect for many of the professionals responsible for their child's welfare. Even case workers, expected by parents to be on 'their side' in achieving the best for their child, were included in perceptions of incompetence and of underhand tactics:

“this anonymous ... person who was not an expert in autism, not a therapist, not a speech and language specialist, just an administrator who was given your case and told to keep you down... keep you off meeting them” (*Mother of an autistic boy, aged 7*).

From Kramer's antecedents of paranoia, heightened perceptions of evaluative scrutiny can be exacerbated within hierarchical relationships. What has emerged here, however, is an acknowledgement of a more fundamental power dynamic that may go beyond hierarchical positioning (that might for example exist between teacher and student, line manager and employee) to include the very significant consequences of control over decision making and control over the allocation of (education and welfare) resources. Perceptions that allocative criteria were overwhelmingly financially-based and the assignation of ulterior motives to this all powerful group may signify a lack of sincerity associated, from Figure 1, with suspicion and distrust. Furthermore, perceptions that public officials prevaricate over the reasons for some of the decisions made and practise avoidance strategies may be symptomatic of paranoia's sinister intent. This form of exaggerated distrust may be exacerbated by a power dynamic based on complete control (on the part of public officials) and lack of respect (on the part of parents). Elements of both distrust and paranoia thus emerged as key discourses among parents as they made sense of their experiences with public officials who had power over and were managing the welfare of their child.

‘Undeserving’ Parents

Parents and carers often claimed they were made to feel undeserving and that they were making unreasonable demands for their children. One NAS branch leader, echoing others, commented:

“I do get horrified, with some people it’s just taken for granted that all parents of autistic children are going to have demands that are unreasonable, they feel that parents are asking for what they shouldn’t have... yes that’s my feeling at the outset you will be unreasonable!”

Perceptions that, as parents, they were ‘undeserving’ of communication, consideration and support were also implicated in the interface with care providers in schools and nurseries – often seen as overprotective of their authority. One headmistress of a specialist school was described by an NAS branch secretary as “like a brick wall”. Similarly, the head of a special needs nursery, while popularly perceived by those in authority as “excellent”, was seen by parents as cold and defensive:

“She is very possessive and is afraid you’re criticising, and she says ‘this is what we do’. With [our son’s] headbanging, we thought we were doing her a favour telling her about it, and she dismissed it saying ‘oh, that’s what all autistic children do’.”

(Mother of autistic boy, aged 6)

Across many accounts, parents recounted experiences of lack of consideration, of being dismissed and seen as an unequal partner in their child’s care – often made to feel ‘undeserving’ of the specialist care and education requested or received. This created

uncertainty and anxiety over the nature of interactions with officials and, as the quote below suggests, a 'hyper-vigilance' over how these interactions should take place:

"I have to pick my time of day or what my emotional state was before I rang [responsible authorities] otherwise I'd end up laughing down the phone or crying down the phone and it just achieves nothing" (*Mother of autistic son aged 7*).

The perceptions by parents that they are seen as undeserving of special consideration for their child and that their knowledge and potential contribution is disparaged may well, from Figure 1, fall into the category which identifies heightened perceptions of evaluative scrutiny and negative feelings of social distinctiveness as key antecedents of paranoia. This is not to say that such feelings are misplaced. As Kramer (2001) points out, a hypervigilant state may well be a rational response in certain contexts. In this respect, the attentiveness exhibited by the mother in the above quote towards the circumstances of her proposed conversation with public officials may be symptomatic of a reasonable and judicious, rather than obsessive or irrational, coping approach.

Suddenly you are an outsider

To have an autistic child in the family was confirmed by all of the parents and carers who took part in this research as precipitating great emotional stress. A key cause, while not directly related to the relationship between parents and public officials but significant in the broader context of parent's lives, concerned feelings of alienation and separation from 'normal' society:

“Exclusion from society, from the education system, yes and that’s a pretty huge frustration” (*NAS branch leader*).

Another branch leader referred to parents who “can’t carry on, they have nervous breakdowns and I was the only one left standing for a while!” A branch secretary commented further:

“people are quite nervous about actually leaving home, I mean most of our families have never been on a proper holiday simply because they’re not confident enough to take the children somewhere where they don’t know ... my son’s behaviour can be quite embarrassing and difficult, and because he doesn’t look like he’s disabled, people just think he’s a naughty child and why the hell is she letting him get away with that, dreadful parenting.”

Everyday activities such as social events, supermarket shopping, bus journeys and family holidays presented considerable challenges to families. One parent described the limits of her participation at friends’ parties:

“I’d be stuck in the telly room with him (autistic son) without a drink, I was bitter, really bitter and I used to say to my friends ‘I’m fine, yes I’m fine in here’, although I’d much rather be with the adults, but now we just don’t go, we go on our own, or we take it in turns ... I was very jealous of those who do family things and we can’t, we’re just very restricted” (*NAS group leader*).

While another describes attendance at a birthday party with her son thus:

“he was just... charging around flapping his arms, trampling on people ... so I had to take him away early, under my arm, screaming and kicking and biting me ... I didn't know what to do” (*Mother of autistic son, aged 7*)

Experiences of exclusion not only had a material consequence in terms of lack of involvement in mainstream activities, but had a strong affective dimension as parents referred to feelings of bitterness, frustration, fear and embarrassment. The common narrative of isolation among this group of parents may well have profound implications for how parents made sense of their relationship with public officials and exacerbate the negative feelings (e.g. of suspicion, distrust) around the management of their child's autistic condition.

Conclusion

This paper set out to explore how distrust and paranoia are created among parents and carers of autistic children in their dealings with public officials involved in diagnosis and care. Specifically, it explored the extent to which the former group experience affective dimensions of distrust, the factors that contribute to such feelings and how distrust may move into the extreme form of paranoia. This often emotionally fraught parental and familial context coupled with a highly regulated framework of provision has potential to create a rich research site given that, from Kramer, “the fundamental properties of a substance or object are often revealed through exposure to extreme conditions” (Janoff-Bulman, 1992: p4, in Kramer, 2001, p5). He therefore argues that by studying the conditions under which presumptive trust unravels, a better appreciation is gained of the necessary and sufficient conditions for its resilience.

The paper addressed an identified research gap on manifestations of dimensions of distrust and has made a contribution to the field in the following ways. Firstly, at a general level, it has highlighted the significance of cognitive, affective and institutional components not just in understandings of trust (Tubin and Levin-Rozalis, 2008) but as contributory factors to antecedents and dynamics of distrust and paranoia. These components often overlap. Thus, an institutional framework of regulated education and care provision in conditions of financial scarcity, and joined with proxy (cognitive) performance indicators can put pressures on providers, and go on to create tension, uncertainty and negative affect among parents and carers. These dynamics and their interrelationships emerge from and are key to making sense of parents' and carers' accounts.

Secondly, we have drawn on Fein and Hilton (1994)'s typology of distrust and suspicion, and Kramer's (2001) antecedents of paranoia to produce a synthesis (Figure 1) of key antecedents of distrust and paranoia. These have been used as a framework through which to evaluate data on levels of distrust emerging from respondents' accounts. In this respect, we have seen how distrust, in the form of perceptions of ulterior motives, lack of sincerity and failed expectations, is endemic among this particular group. Both distrust and paranoia can be identified through the themes that emerged from the data namely the experience of anxiety and suspicion around diagnosis and provision, the perception that authorities are all-powerful, the perception that parents are undeserving and the experience of marginalisation and exclusion. Thus, parents and carers experience insecurity and uncertainty during the diagnostic process; perceive ulterior and insincere motives in public officials such as a desire to save money and to defend a professional status; feel under scrutiny and see themselves positioned and denigrated as 'undeserving'; and are vigilant towards and attribute negative or sinister intentions to those with whom they interact. The paper thus throws empirical weight behind current conceptualisations of dimensions of

distrust and paranoia (Kramer, 2001; Fein and Hilton, 1994) captured within the synthesis presented in Figure 1.

Thirdly, we have drawn on the data to further develop the synthesis and to strengthen the link between paranoia and distrust. Following Kramer (2001), paranoia can be seen as an extreme form of distrust. Thus, from our data, perceptions of ulterior motives and lack of sincerity can translate into sinister intent. Failed expectations can precipitate a hypervigilant state. We have additionally identified power dynamics as a key factor in developments of distrust and these dynamics may well go beyond the significance of hierarchical relationships identified by Kramer's account. Thus, consequences of lack of control over decision making as well as strong feelings of upward disrespect may 'tip the balance' and assist in paranoia's affective uptake. Moreover, dismissive attitudes towards those in a powerless position may precipitate negative feelings of social distinctiveness. Across the board, we have seen that these feelings may be intensified by common experiences of being 'on the outside'. We can therefore develop our synthesis to include power imbalances and isolationism as further possible precursors of paranoia and factors that may well assist in the translation from distrust. The paper thus develops current conceptualisations of distrust and paranoia (Kramer, 2001; Fein and Hilton, 1994) and assists in a refined and emergent synthesis of their work.

Finally, the paper throws further light on the 'normalcy' of a paranoid response. As Kramer (2001) points out, the costs of misplaced trust in highly competitive or political environments make suspicion, concern and distrustful behaviour legitimate. In the present context, the future welfare of one's child is at risk if one trusts too much. Paranoia, then, can be seen to be a logical, appropriate and functional response. As Kramer argues, "people tend to be vigilant social information processors when the benefits of trust are perceived to be

significant and/or the costs of trust mistakes steep. Stated another way, when social perceivers construe the consequences to be substantial, they are willing to pay necessary attention to other's behaviour" (Kramer, 2001: pg 5).

In the context of the present study, there is no single 'system' in place for dealing with autism across the UK in its health, social and educational elements. In the complex interplay between institutional frameworks, regulatory regimes, financial constraints and the emotions of parents and carers, paranoia – rather than an individualised dysfunctional and excessive reaction – can accordingly be the most appropriate (and in some ways 'normal') response. This supports Kramer's view of a need for conceptualisation that can incorporate paranoia as a continuum of distrust rather than as separate categorization.

This has implications for providers of care in this context. Brown (2007) identifies the 'behind-the-scenes institutions that shape communication and decision-making is as perhaps the most crucial for trust creation: "These generate information about how people are treated by others (Brockner and Siegel, 1996) and create expectations about the values driving the behaviour of others, so influencing judgements about motivations and intentions" (Brown, 2007: pg 361). The parents enter the 'relationship' at first expecting a streamlined integrated system of care and support. Such expectations are breached, and they come to feel very much on the outside of a culture of communication on the inside that leaves them on the receiving end of a set of assumptions dictating their treatment as undeserving and focused on keeping them and their demands in their place. The values ascribed to them in, in their minds quite reasonable requests for help and services, are negatively infused with the notion that they are overly demanding.

Public sector staff need to start by asking themselves what, if any, are their prejudgements concerning the motivations, intentions and entitlements of the parents and children? What, in the arrangement, resourcing and incentives structure of their institution shapes attitudes towards, solutions available for and treatment of such parents? How do their own assumptions and behaviour, and that of others above and around them, and in other fields of these parents' supposed sources of support, impact on communication, information provision and decision-making? Do they understand the profound sense of exclusion, isolation and anxiety felt by these parents, such that they truly feel they, in every interaction, 'walk in their shoes'?

And could they become heroes rather than villains? To put this in final context, one support group leader related a funny story of wanting to run a story in her newsletter of a good thing social services had done for them – “this put social services into a complete panic, and in the end they asked us not to run it”! Heroes are possible, and this perhaps should be the aim of more public sector staff than is currently the case, as this final quotation reminds us:

“at a time in my life where I thought I was just being a really bad parent suddenly [the professional] appeared and ... she just basically swept me off my feet and just said ‘look, we will take care of this, you get yourself together’ and I needed somebody to do that”. (Mother of autistic son, aged 7)

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