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Milton, Damian (2010) *The identity of parent 'advocates' of autistic children: a discursive psychological examination of two in-depth interviews.* Project report. The Open University, Milton Keynes, UK (Unpublished)

The identity of parent 'advocates' of autistic children: a discursive psychological examination of two in-depth interviews.

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Abstract

This project aimed to examine the everyday talk of parent 'advocates' of autistic children, in the construction of their own self-identities. The project employed a discursive social psychological approach, in order to examine two semi-structured interviews with parent 'advocates', in terms of the interpretive repertoires employed, subject positions taken up, and any ideological dilemmas expressed. A number of repertoires, subject positions, and dilemmas were established within the texts, the most poignant being a 'militarised' repertoire, constructing a subject position of a 'fighter' in a 'battle zone', against a 'system' of professionals, ostensibly in place to help such families. In so doing, the discourses, presented an alternative explanation to the stress often reported in research regarding parents of autistic children, being located within the condition or behaviour of their autistic child; suggesting that further research is needed to explore the reasons behind this tension.

Introduction

Parenting is often thought of as one of the most rewarding and yet demanding roles an individual can undertake within their life. When a parent is told that their child has 'autism', this can have a major effect on their role within the family (Smith et al., 2007). This project explores the identities and sense of self that parents express, long after this change in their lives, at a point where the parent has begun to 'advocate' for others in a similar situation; and how this sense of self has developed through these changes, to be situated within such a relative position of strength.

Following on from the work of others (Duarte et al., 2005; Eisenhower et al., 2005; cited in Smith et al., 2007), Smith et al. (2007), utilising a cognitive social approach, found that parents of children on the autism spectrum reported higher levels of stress than parents of children with other forms of disability. Over a third of mothers were found to have elevated depression scores and mothers of adolescents had higher levels of anger. For mothers of

toddlers, low-levels of 'emotion-focused' coping strategies compared with 'problem-focused' were associated with good maternal well-being, regardless of the child's symptomatology. For mothers of adolescents, coping strategies were found to act as a 'buffer' against difficulties encountered when autistic symptoms were high. For Smith et al. (2007), this buffering effect reflected adaptations made by mothers of adolescents in coping with stress. These findings were further evidenced in survey research of Northern Irish parents by Cassidy et al. (2008) and of Japanese parents by Mori et al. (2009), where both studies found elevated levels of stress, and the breakdown of conjugal relationships.

Utilising a discursive approach, Rolfe (2008) found that teenage mothers presented a different narrative to dominant discourse; instead they were active in negotiating and constructing an alternative and subversive discourse concerning their own identities as mothers, carers and women. This project will also use such an approach to see if parents of autistic children also challenge dominant discourses concerning their parenting.

Utilising a qualitative discursive psychological approach, Landsman (2005) found that mothers of disabled children expressed a dilemma between two competing models of disability, 'medical' and 'social'. Traditional medical model discourse sees disability as residing within the individual. This model states that disabled people suffer a reduction in abilities due to a deficiency compared to the norm. In accord, the power to define and treat disabled people is held by the medical profession, positioning doctors and patients within highly constrained power relationships and social roles to perform. The social model of disability rejects the notion that disability is dependent upon individual impairment. Baynton (1997, cited in Landsman, 2005) conceptualised disability as part of a wider hierarchical system of norm/other:

"…social hierarchies rely upon culturally constructed and socially sanctioned notions of disability." (Baynton, 1997, cited in Landsman, 2005:125).

Landsman (2005) concluded that in seeking to improve opportunities for their child, parents initially complied with a 'medical model' discourse, yet over time in the process of providing meaning to their lives, increasingly drew upon 'social model' discourse and 'minority group models' of disability and rejected the medical model, or blended the two approaches in complex ways. Mothers exercised choice as to which experts to 'trust', although medical

experts were described as seeing such rejections as 'denial' or that 'patients should face reality'. The mothers in this study however, often declared themselves as the 'expert' instead.

This project will adopt a discursive social psychological perspective akin to the work of Rolfe (2008) and Landsman (2005); and thus does not frame these mothers as 'stressed' and potentially 'depressed' from the outset, yet as constructing and negotiating their self-identities through everyday purposeful 'talk'. This perspective can trace its roots to the seminal work of Potter and Wetherell (1987) who blended influences from linguistic analysis, Ethnomethodology (Garfinkel, 1967) and Poststructuralism (Foucault, cited in Hollway, 2007). This approach offers a challenge to the dominant academic discourse within social psychology of the cognitive approach, as adopted by Smith et al. (2007). The discursive psychologist Edley (2001, citd in Hollway, 2007) argued that identity was like a 'jelly that never sets' and highlighted social representations and practices that help to constitute unequal power relations. By utilising a discursive approach, the intended study will hope to shed light on the discursive resources drawn upon by 'parent advocates' and the actions performed in their 'talk', in terms of its constitutive functions in constructing social reality.

This project aims to see how mothers within a marginalised positionality construct a discourse that navigates through the available competing public discourses of the 'medical' and 'social' models (Landsman, 2005) and how identities are built to the point of 'advocating' for other parents in a similar situation. Like Smith et al. (2007) this project will be related specifically to parents of autistic children; yet will concentrate on how they build subject positions from culturally available discursive repertoires in relation to their children, autism, professional intervention, and ultimately their own constructions of personal identit; leading to the following research question:

How is the identity of a 'parent advocate of an autistic child' expressed in everyday talk?

Methods

The methodology chosen for this project was two in-depth semi-structured interviews (lasting approximately thirty minutes each). The interview questions loosely followed an interview schedule (as outlined in appendix 1), with points raised by participants followed up

with questions to elicit greater depth of response. The participants were chosen based on them having the least potential risk of emotional stress or harm being caused by participating, hence, not only parents of adolescents, yet also those advising other parents on coping strategies as 'parent advocates'. The interviews adopted an open-ended format (see Appendix 1), allowing for flexibility of response and rich and detailed qualitative data to be produced regarding constructions of identity. The data was then analysed using key discursive conceptual tools to explore the positionality, meanings, constructions, and dilemmas that constitute the lived reality of being a 'parent advocate' of an autistic child.

The concept of 'interpretive repertoires' originated in the work of Gilbert and Mulkay (1984) and was later applied to social psychology by Potter and Wetherell (1987) to explain the common sense and contradictory ways people talk about and make sense of the world. 'Interpretive repertoires' are made up of a lexicon of common knowledge, ideas, terms and metaphors, drawn upon to build explanations, descriptions, accounts and arguments. For example, the 'medical' and 'social' models of disability referred to by Landsman (2005). This involves identifying key notions and themes expressed in discourse and in this case, regarding identity and 'subject positioning'. Identities, through the lens of discursive psychology are fluid and produced in discourse via culturally available categories utilised to define people.

Taking a mixture of 'top-down' approaches (Foucault, cited in Hollway, 2007) to examine the 'talk' produced by participants, and 'bottom-up' approaches (Edley, 2001) to explore the choice available and agency involved in the 'taking-up' of subject positions; this project endeavoured to analyse how participants position themselves in relation to autism, their child, their family, friends, community, professionals, parenthood and their own identities. In so doing, this project aimed to identify any 'ideological dilemmas' or contradictory 'repertoires' present in the use of these models or personal constructions expressed within the discourse produced. According to Billig et al. (1988), views are not fixed or consistently expressed and represent flexible rhetorical resources, often used in a contradictory way, for instance, using both 'medical' and 'social' models of disability to construct accounts.

'Parent advocates' were chosen to buffer against any harm coming to participants in discussing their views, as these parents are already very active on public internet forums, commenting about their lives and advising other parents regarding coping strategies.

Despite this caveat, the participants were asked to have emotional support from a friend or family on hand and the interviews took place in a quiet environment, agreed prior to participation. The participants were fully briefed and debriefed as to the nature of the project, involving prior written consent and advice regarding anonymity, the right not to answer questions or withdraw from the research and the usage of data. Both participants wished to have their own names used, and also wished to have a copy of the project forwarded to them upon completion. It was considered necessary however, to remove surnames and the names of children from the transcripts to protect privacy and any potential harm that could ensue from the participants being identified.

<u>Analysis</u>

Between the two interviews, a total of six interpretive repertoires were found to be in use (appendices 2 and 3). One of the repertoires employed by both participants was concerning children on the spectrum being 'different', rather than 'disordered'. These narratives utilised notions such as 'autistic strength', and evoked the social model of disability on many points (although this did provide a dilemma for the participants – see below).

"I would also put the word challenge in place of disability..." (Susy, appendix 2, line 193).

"I couldn't get my head around how two kids could be so different, yet get the same diagnosis, that made no sense to me..." (Claire, appendix 3, lines 31-32).

"I don't think that there is a bridge between the top of the autistic spectrum, to normal, or whatever normal is..." (Claire, appendix 3, lines 127-128).

The dominant narrative that was found throughout the talk of both participants was that of an almost militarised nature. Both participants regularly used phrases such as 'being a fighter', or being 'in a battle zone'. This repertoire was usually employed when talking about negotiations with professional bodies regarding their children.

"...a lot of people can find me quite aggressive and (laughing)...because...umm...I don't tolerate fools. So...yeah...(laughing)...which I don't think is a bad thing really (laughing)..." (Susy, appendix 2, lines 37-38).

"...all I have to do is say my name, and everyone is sort of, running in all sorts of directions..." (Susy, appendix 2, lines 201-202).

"...the amount of fighting they have made us do is just completely unacceptable..." (Claire, appendix 3, lines 90-91).

"...we have had to fight every step of the way..." (Claire, appendix 3, line 172).

"...it has made me a fighter..." (Claire, appendix 3, line 190).

Other repertoires employed included: a sense of community felt between the participants and other parents of children on the autistic spectrum; a sense of being on a 'journey' or having changed through the experience of raising a child on the spectrum; seeing parents as 'experts' regarding the care of their own child; and a general lack of awareness amongst the general public leading to misperceptions regarding autism. Below are examples of each of these repertoires from the interviews:

"I have met lots of fascinating people that I otherwise wouldn't have met." (Susy, appendix 2, lines 51-52).

"...and I do see it as a community actually..." (Claire, appendix 3, line 147).

"...my opinion actually has changed a lot, I think that I have had four or five different opinions." (Claire, appendix 3, lines 116-117).

"...the people who aren't on the autistic spectrum, don't seem the slightest bit interested in adapting, and in trying to learn..." (Claire, appendix 3, lines 152-153).

When relaying the above repertoires, the participants took up several subject positions within them (see appendices 4 and 5). The first of which was to take up the position of being disabled or in some way related to the autism spectrum:

"I chose, to be able to step around that, and perhaps had choice, because the disability was different, although epilepsy and autism are to an extent relatable or can be relatable..." (Susy, appendix 4, lines 188-190).

"...she came up with the idea that maybe, that both we were on the autistic spectrum as well..." (Claire, appendix 5, lines 10-11).

Secondly, the participants positioned themselves as separate from parents of typical children and others in the general public, with the first participant positioning themselves and those they chose to socialise with as 'non-discriminatory':

"Everyone has challenges in life, and so if society wants to talk about disability and make it a negative thing, then well, let them..." (Susy, appendix 4, lines 194-195).

Working in tandem with the dominant 'militarised' interpretive repertoire, the participants positioned themselves in opposition to the 'system' of professionals, whose social role it was to help them and their families/children, although this also presented a dilemma for the participants (see below).

"Well, you know the difficulty with autism, is really, sort of...umm...having to deal with, fairly on mass with some of the very negative attitudes, approaches and bureaucratic stances..." (Susy, appendix 4, lines 74-75).

"...our major successes in general, have been, will have been winning (laughing)...umm...against the education authority..." (Claire, appendix 5, lines 92-93).

The participants also positioned themselves in regards to their families and partners, although in somewhat contrasting ways. The first participant 'Susy', positioned herself in opposition to her ex-partner, whilst the second participant 'Claire', positioned herself in terms of educating her family and working in partnership with her husband, often referring to herself as 'we'.

"...he found it difficult, if not impossible to understand the nature of his disability, and so how to deal with it, or anything like that..." (Susy, appendix 4, lines 97-98).

"...family...umm...I think I have begun to take little steps with them, explain it, umm...break them in gradually..." (Claire, appendix 5, lines 62-63).

The second participant, toward the end of the interview, positioned herself in comparison to other parents of children on the spectrum, some as being in a 'worse off' position than her, and seeing others as unnecessarily wanting to label their children. The first participant 'Susy', also positioned herself with other such parents, yet in a much less striking way.

"...she has had to fight, you know, even harder in some respects, and she is going to have to continue doing that, for a lifetime..." (Claire, appendix 5, lines 246-247).

"...people want to label their kids..." (Claire, appendix 5, line 274).

Finally, particularly the first participant, positioned themselves as being in a position of strength when navigating the difficulties they faced, due to a sense of an internal positive attitude to life:

"I think that it is this approach or attitude that has buffered me..." (Susy, appendix 4, lines 16-17).

In total, four potential ideological dilemmas were identified within the two discourses. Although both participants portrayed a 'social model of disability', with one even explicitly saying so, there was on occasion an underlying link made to some kind of fundamental difference inherent in the child, more akin to a 'medical model' view, although as Landsman (2005) points out, this may not be a contradictory use of repertoires, but a coherent building of a middle ground, a path between the two. There was also a narrative of an increasingly 'social model' outlook through experience:

"...having a positive attitude toward disability and disabled people, and umm...I believe in the social model of disability..." (Susy, appendix 6, lines 7-9).

"...my son can be very tiring..." (Susy, appendix 6, lines 46-47).

"...a label like autism is like a signpost to get help for that person or that child, or it should be a signpost, it shouldn't be a label to define who they are..." (Claire, appendix 7, lines 311-313).

A significant dilemma was occasionally noted, largely due to the participants positioning themselves against professionals and the 'system', as they were presented with the dilemma of 'having to work' with said professionals, or 'fight' to find those deemed appropriate and autism aware:

"I had to arrange an array of specialists and legal people..." (Susy, appendix 6, line 114).

"...there are a load of wankers out there who don't know what they are talking about..." (Susy, appendix 6, lines 178-179).

"I know all about judicial reviews, do you know what I mean though? I've got this mind of information, that, about, you know, the law, that no parent should have to know..." (Claire, appendix 7, lines 186-188).

At one point in her discourse, it seemed that the first participant 'Susy', was presented with a dilemma regarding what she called the 'discipline spectrum' with regards to parenting ideology. A difference in this regard seemed to cause a split between her and her ex-partner and also a minor questioning of her own methods:

"I am actually not with my son's father now, and...umm...not being with him, has been the biggest help, although in one way, not, with this constant battle, battle, with discipline...umm...along the discipline spectrum..." (Susy, appendix 6, lines 171-173).

Another dilemma also seemed to be presented by the second participant 'Claire', whose self-narrative charted a course through those thought to be 'worse off' than her, for having children with more 'severe difficulties', and a negative positioning of some other parents, constructed as wanting to manipulate service providers, and 'label their children'. This narrative was set against a backdrop of professionals questioning the severity and/or the diagnosis, of her children:

"I sometimes feel that I don't have the right to moan about things…" (Claire, appendix 7, line 267).

<u>Discussion</u>

By applying the analytical tools of discursive social psychology, in reviewing the two interviews, six interpretive repertoires were identified: the disability or difference debate; a 'militarised' lexicon utilised to explain interactions with professional service providers; a sense of 'community'; a sense of change and accomplishing a 'journey'; and lastly, commenting on a lack of awareness and misperceptions on behalf of the general public (appendices 2 and 3). Related to these repertoires, were the taking up of six subject positions: positioning oneself as disabled, or as related to the autistic spectrum; as a non-discriminatory person and different to 'typical people'; as in constant 'battle' with professionals and the 'system' of public service provision; toward one's partner or family, and as from a position of personal 'inner' strength (appendices 4 and 5).

Despite differences between the two participants regarding family and relationship history, and the resultant narratives regarding these differences, the most striking similarity and theme running through both narratives, was the self-identity of a 'fighter', battling against an unforgiving 'system'. Professionals are constructed as having a lack of knowledge, and at worst deliberately making the lives of people on the autistic spectrum and their parents' lives worse. This 'battle' also led to the greatest ideological dilemma within the discourse, that of having to work with the very professionals, that have been perceived in such a negative light. Dilemmas were also found regarding diagnosis and severity, and parental discipline (appendices 6 and 7).

The findings of this project clearly indicate that both the parents in question had experienced high levels of stress, with one having a breakdown of their relationship with their partner. It was also found that the participants had learnt to handle this stress, rather than acquiring 'coping strategies' per se; however, this change may have more to do with a change in perception and ideology regarding the autistic spectrum. At first glance, the findings would seem to support those of Smith et al. (2007), Cassidy et al. (2008), and Mori et al. (2009), yet these studies suggested that the stress experienced by parents was due to the detrimental effects on family life of the child's autism itself. Neither parent even mentioned their children having 'challenging behaviours' and this factor hardly appeared in

the discourse. This may have been due to the participants being biased by responding in a way that they thought the interviewer wanted to hear (as they were aware that the research interviewer had a diagnosis of an ASD). It may also be the case however, that living with the 'symptoms' of autism, is less stressful than is often reported. The repertoires employed by the participants, presented familial stress as increasing due to differences in parenting ideology between parents; and primarily through the lack of awareness, and obstacles to progression, perceived by the participants regarding professional services designed to 'support' such parents. Although the participants echoed Landsman's (2005) finding that parents had to choose which professionals to trust, the participants in this study presented a far stronger narrative of 'fighting' such service providers, which may well indicate a lack of understanding amongst professionals regarding autism, in comparison to other conditions. This would suggest a wider political and sociological issue, as the services put in place to help, seem to cause these families more damage than any other factor. Indeed, 'fighting' this 'system' seemed to have become a focal point in the accounts of both participants, and a large source of self-pride in their constructions of self-identity.

The findings of this project echoed the findings of Landsman (2005), in that the participants presented a discourse of change and being on a 'journey', however, this was a different process for each participant, due to differing early experiences of autism within the family, with the second participant 'Claire' experiencing a larger change in perceptions. Although both participants did, to some extent, blend together elements of the social and medical models of disability, the emphasis of both parents presented a largely social account. This may not actually represent an ideological dilemma however, as the participants presented coherent arguments regarding the reasoning behind their own approaches to their children. As Landsman (2005) suggested though, the parents took on board more of the social model viewpoint through time. The participants also echoed Landsman's (2005) finding of a discourse of the 'parent as expert', however, the participants highlighted that this was in regard to their own children and not other people's, despite offering advice to other parents as 'advocates'. It is important to note here though, that neither parent used the phrase 'advocate' at any point in the interviews, and that this represents my own construction and not that of the participants. In contrast, the participants saw themselves as part of wider parental or 'autistic' community. In presenting such 'rebellious' and 'independent' narratives, the participants both challenged the dominant discourse of parents of disabled children being stressed and depressed due to the physical/emotional ramifications of the

child's disability itself. Both parents constructed a similar subversive discourse, mirroring the rejection of negative self-identification found with the young mothers in Rolfe's (2008) study.

It is important to note that my own experiences as an adult on the autism spectrum, and father of an autistic child, may have biased the interpretations made of the data. I have also self-identified as a 'social critic', yet interestingly, this is largely due to growing up in society with such an autistic perspective, and not my experiences as a parent. I have not constructed a self-identity of fighting professionals in order to gain access to 'better services' and instead relied more on friends, family, and my own abilities to meet my child's needs. This difference could be due to my son coming to live with me at the age of four, so many of the 'battles' had already been fought, or potentially a gender difference in perceptions regarding parenting and/or service providers.

A potential difficulty was that the participants may have 'couched' their responses in order to not cause offense to me personally, although on the plus side, a good rapport was built with participants, as I was perceived as genuine and unthreatening. Although some of the material covered brought up traumatic events from the participant's past, this rapport helped both participant and researcher to feel at ease. The questions elicited in-depth responses, without much prompting involved, although the experiences of advising other parents could have been explored in more depth, and the final two questions were considered in hindsight to contain double meanings and could have been split into separate questions, that would have been easier to comprehend and answer (appendix 1).

The findings of this project were highly illuminating regarding parental social positioning, highlighting a frustrating ideological power differential between themselves and professionals involved in the care of their children (Foucault, cited in Hollway, 2007). The analytical tools of discursive social psychology proved highly useful in highlighting these issues; however, the dilemmas found may have been imposed upon the data, due to *a priori* methodological assumptions. The participants presented largely coherent arguments and views, and the contradictory nature of discourse may have been overemphasised by Billig et al. (1988). The apparent dilemmas that were found, could also have been viewed from a social psychoanalytic perspective, particularly, the narrative of the second participant 'Claire', who expressed a difficulty in navigating a path between a perception of other

parents essentially 'faking' their child's problems, and professionals questioning the needs of her own children. It was considered in this instance however, that the discursive approach illuminated the narratives, with the concept of subject positioning being particularly useful. This research found a significant discourse concerning negotiations between parents and professionals, future research could look into the reasons behind these problems in greater depth. For instance, it was felt that this could be due to professionals primarily utilising a 'medical' model discourse, ostensibly in opposition to those used by parents to describe their children as 'different' and not 'disordered', however, further research could look at this possibility in more depth. Also, an interesting issue regarding parenting ideology was found, where the added factor of having a child on the spectrum, led to tensions in a participant's relationship. Future research could also look into how ideologies of parental discipline affect the perceptions, actions toward, and care of people on the autism spectrum.

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When did you first recognise that your child was on the autistic spectrum, and how did you initially feel as a parent?

It what ways (if any) does being a parent of a child on the spectrum, affect how others see you?

What have been the major difficulties and major successes that you have experienced as a parent of a child on the autistic spectrum?

How would you describe the autistic spectrum in general?

How would you describe the effect that your child's autism has had on your life, and how has this changed since you first recognised the condition in your child?

What led you to advising other parents on the internet, and how would you describe the role you perform in this regard.

Is there anything else that you would like to add at this stage?