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A different head? - Parental agency and early intervention

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Abstract

This paper considers the agency and identity of parents of children with Down Syndrome within early intervention. It draws upon semi-structured, conversational interviews with nine parents, and the reflections of one of the authors upon their experiences within early intervention programmes. It considers how representations of the deficit-model permeate the participation of the parent in this process. It explores the multiple identities of the parents and links these to notions of parental participation within the current policy context of early intervention in England. The notion of parental agency is an implicit driver within the current early intervention programmes, yet it appears to be compromised by the nature of those programmes.

(6371 words)

Introduction

In this paper we focus on the ways in which parents of a child with Down syndrome may have their own agency and identity shaped by their experiences and contact with professionals delivering early intervention. The paper results from the first author's re-evaluation of his own agency within the early intervention process. This re-evaluation occurred as a consequence of engaging with the second author in an examination of interviews with the first author and nine other parents who were also involved in early interventions. In this paper we describe how this re-evaluation came about, and then go on to explore the changing nature of this agency. We begin by describing the disruption of parental identity as a consequence of a 'diagnosis' of Down syndrome, the policy drive that subsequently encourages parents to engage with early intervention support systems and professionals, and its impact upon their personal and public selves. We go on to consider the changing relationship that parents have with the professionals and the services they provide, looking in particular at the development of parent's ways of thinking about their children and their roles in their lives. We consider the degree to which these changes modify parental agency, and highlight the need to understand the consequences for those parents (and their children) whose agentive act is to not to engage with the process.

The paper presents the first author, Jonathan, as a parent of a child with Down syndrome, challenged by his experiences of parenting in the context of early intervention. The discussion includes how his perception of his parenting experiences has been framed by professional knowledge and power. These experiences have been influenced by a model of child development that refers to a 'typically developing' child which encourages a deficit view of the child and 'their' learning difficulties. Included amongst this discussion are accounts of other parents, and a more detailed analysis of the data, illustrating how professional knowledge may impact on parents and the ways in which they perceive and interact with their child with Down syndrome.This paper takes on the narrative form, with both authors presenting the data collected on parents perspectives, referring by name to each author and the parents. This seemed to be an appropriate way to present the interview data on parent perspectives, alongside the co-author's personal reflections, providing insights into parental agency and identity.

Jonathan's agency has changed as the research has progressed; he has become more aware of how the intervention process has affected his relationship with his son. This transition began

with questioning the nature and appropriacy of the early intervention activities he was being asked to carry out with his child at home, and ended with his recognition that his role as a father was to want to play, and to engage in spontaneous play, and that this was an effective way of 'being' with his son. It was clear, however, that the transition in relation to his behaviours with his son were echoed by a change in his relationship with the support services around his family.

Whilst reflecting upon Jonathan's personal experience of early intervention and the experiences with the data, we both recognised that his agency and identity as a parent has been influenced by professionals he has come into contact with. This has caused us to raise questions about the positioning of 'the parent' in relation to service providers, and their knowledge and power. The following questions emerged for us relating to how parental agency is facilitated in this process:

- Is it possible to empower parental agency when subjected to professional understandings of how to bring up a child with Down syndrome?
- Is it possible that parent agency is compromised if parents have to co-construct a vision of effective interaction between themselves and their child which is based on professional values?
- Is it possible that those who do not compromise their agency will struggle with current early support procedures?

From interviewing parents to exploring agency

As a result of Jonathan's experience as a parent, and reflective discussions between the two authors, an initial set of research questions relating to parents and their children's experiences of early intervention were created. The interview subjects were identified through four sources. A number of parents responded to a request for participants made through an international email list set up by a parent of a child with Down Syndrome, others responded to a message within the Down Syndrome News; two parents were known to Alice as they lived in the local community; and two parents were identified through another informal network of parents who are supported by a local Portage Service. Parents were selected on the basis of child age, so as to have access to perspectives at different points of the early intervention process. They were given a detailed outline of the study's aims at the outset and

were informed that they could withdraw at any point. One parent who initially volunteered chose not to be interviewed.

In the initial phase of the study four parents of children with Down syndrome were interviewed, and the questions were related to their experiences of early intervention and the role of professionals. The first four interviews were with parents of three children with Down syndrome, three of whom were mothers and one of whom was a father. The children were aged between 3 and 4 years old, two were boys and one was a girl. One family lived in a suburban city area, and the other two families lived in rural settings. All were living in the south-east of England. Three were white British and one was Brazilian. The interviews were semi-structured, conversational and took place in the homes of the families and lasted for approximately one hour. Grounded theory (Strauss and Corbin, 1998) was used to analyse the interview transcripts; responses were categorised in relation to the recurring themes which emerged in the data. Open coding of the transcript data resulted in an initial break down into discrete parts, which could be closely examined and compared for similarities and differences. Subsequently, a process of Axial Coding was carried out. Using categories developed as a result of discussion and from the initial Open-coding process, categories built up, which the researchers cross-referenced, looking for relevant links between phenomena. Information was added from the categories, until they became saturated, and there was clear understanding of their meaning.

In order to find out more about specific issues that had emerged from the first four interviews, a second series of questions were devised. These were specifically around the parent's views on the nature of the child's learning experiences. Jonathan was the first parent to be interviewed, by an independent interviewer, as part of this second interview process. This allowed for his views to be contextualised within the initial analysis. A further five parents of children with Down syndrome were interviewed, by the same independent interviewer. These interviews were with five parents of five children with Down syndrome, all of them mothers, all white British. Four of the children were girls, aged 5-7, and two were boys, aged 2 and 4. All of the families were living in south England, but two of the families had moved from other parts of the UK where they had also received early intervention support. All the interviewees described themselves as living in rural or semi-rural settings. The second set of interviews were semi-structured, conversational, took place over the phone and lasted for approximately one hour. Grounded theory was again used to analyse the

transcripts of the interviews; responses were categorised according to the recurring themes which emerged in the data.

In the process of exploring this data, Jonathan came to ask questions about the nature of his agency and involvement with early intervention, leading to a re-visiting of the interview data to explore notions of agency and identity within it. The synergy of personal reflections and the interview data enabled the exploration of Jonathan's experiences of early intervention in a more 'personally challenging manner'. As such, his reflexive journey with both forms of 'data' permeates this paper. His personal experiences have been considered to be 'data' within this paper, alongside the interview data from the nine other parents of children with Down syndrome. The use of both forms of data has increased the reliability of the data relating to understanding parental experiences and the notion of parent agency. Alice has also been involved in the process of gathering and analysing data whilst engaging in reflective dialogue with Jonathan. This reflective dialogue, has involved both a comparative and a dialectical approach. In the analysis of the interviews, categories and concepts that emerged from the data were compared in order to discover their similarities. These conceptual groupings were set against Jonathan's personal experiences. The two forms of data were juxtaposed as valid subjects for exploration and explanations of behaviours and identities. At times this juxtaposition reinforced similarities in experience, and at others it highlighted a possible difference of interpretation, which required Jonathan to re-examine his own understandings of his experiences within early intervention.

The issue that triggered the consideration of agency and identity, in particular, was the realisation that the majority of the parents interviewed had developed professional roles through voluntary work or employment, which could be linked to their involvement with early intervention. Two of the parents had professional roles prior to the birth of their children (Louise was a speech and language therapist and Tricia was a nurse), however, the other parents had developed professional roles linked to young disabled children as a result of their experiences; Mary recently became a Portage Home Visitor, Kate has become a Makaton Facilitator and School Governor, Sue chose to go on a Hanen (language through play) training course, Rachel has become a campaigning partner to a trustee of a Down syndrome research charity, Catherine became Chair of her local playgroup and then a Rural Childcare Development Officer, Martha and Robert organised a borough wide Down Syndrome awareness week. This engagement with the professional identity echoed the changes which

Jonathan had undergone as he became involved in a number of early intervention projects and organisations. It was the prevalence of this professional connection as a theme within the research that raised the question about the impact of early intervention upon parental agency and identity.

Disturbing the "Possible Self"

Individuals have a conceptual system that organises a 'record of agentive encounters' (Bruner, 1996 p36) that can be related to the past and the future. As a parent, the possible self sees a future with the child that is based upon the childhood the parent has experienced and subsequent agentive encounters. However, as a parent of a child with Down syndrome this 'possible self 'is likely to be displaced as soon as the label is applied to the child, either before or after birth. Hornby (1995) records fathers talking about the initial trauma they experience following diagnosis of their child, while Bridle and Mann (2000) note being left 'feeling very inadequate and desperately in need of some direction' (Bridle and Mann 2000, p11.). The possible self of aspiration, confidence, and optimism gives ways to the opposite 'negative possible self', of hopelessness, uncertainty, and pessimism. Parents have not produced the perfect baby. They have produced something that experience identifies as 'other' (Goody, 1993). Goody also notes how parents are affected by the same social bias that operates against disability, with its links back to the nineteenth century: 'it tars all concerned with the same brush. In Dr Down's time, medical science looked for the *causes* of disability, and found them often in the parents.' (Goody, 1991, p.8)

The roots of this negative perspective of the child and parent identity attached to this can be identified as part of the '"constructed" self-system [that] is inner, private and suffused with affect', as well as in the manner in which the self 'extends outwards to the things and activities and places with which we become "ego-involved"' (Bruner 1996). Parents may find that both their personal and public sense of parent-self is compromised. Not only are their own expectations displaced, but people respond to both them and their child in a way that is quite different to the manner in which they respond when a typically developing baby is born. This confusion is likely to be self evident from the moment the news is delivered. Ordinarily, given the medical context of the birth or screening process in our culture, the first responses are framed by a medical view of the baby. Whether it be a mid-wife commenting on the baby as it is delivered, or the sudden silence that descends in the operating room or a blurted explanation from a nervous or disdainful Doctor, there is a long history of negative reactions from

professionals (Down's[1] Syndrome Association 2006). The reactions of friends, family and wider family are also often awkward. For example, as a consequence of there being a specific predictive test for this type of baby, many people have asked Jonathan; and many other parents that he knows, "So did you have a test?", and their responses have changed according to the answer that he and other parents have given them, and their view upon this answer. In addition, people typically struggle over whether to offer congratulations or commiserations on hearing the news; often feeling a need to reassure the parent that the child is 'lucky to have you as parents'.

Engaging with a Professional Perspective

It is in this state of flux that individuals begin to deal with the state support systems. Currently, in England, there is a policy shift towards a greater emphasis on early intervention programmes. The Department for Education and Science and the Department of Health have placed an increasing emphasis on the education of children with learning difficulties through partnership with parents and early intervention (DfES, 2004). This response was quantified by the Early Support Pilot Programme in September 2002, a £13 million pound initiative within a wider initiative of Sure Start programme for supporting children and families (Paige-Smith and Rix, 2006). Since 1997, the Sure Start Programme has been attempting to integrate family support such as health and early learning services and to provide high quality integrated care. In September 2006 there were 1,000 children's centres comprising about 500 Sure Start Local Programmes, 430 previous Neighbourhood Nurseries and 70 Early Excellence Centres (National Audit Office, 2006). Many authorities also provide a pre-school early intervention teaching programme, such as Portage, specifically for disabled children. There were 152 National Portage Association registered Portage services in England in 2004/5 with a total of 1194 Portage home visitors providing support for 5370 families through home visits and other related activities (Russell, 2005). In addition, every local authority provides a range of therapeutic services, such as Speech and Language and Physiotherapy, which may be delivered as part of the early intervention package.

These programmes generally recognise the need for child-centred, family-centred activities, however there is still a focus on 'activities' for children's' identified problems and 'deficits'. The notion of family-centred practice is built around the central, active role of parents and

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[1] In this paper the term Down syndrome is used instead of Down's syndrome. This term is increasingly used internationally. For example, after considerable discussion with parents and practitioners, it was adopted by the UK government when publishing the Developmental journal for babies and children with Down syndrome

family in the care of their children, and respect for the family's beliefs, values, cultural identity and ways of coping (Baird, 1997, Pearl, 1993*)*. It is suggested that parents need to have a sense of control over their family life and to recognise that effective intervention strategies result from their own actions, strengths and capabilities (Mahoney & Wheedon, 1997). The form and function of this early intervention can be seen as an example of social agency (Portes & Vadeboncoeur 2003) in action, as a process co-constructed by others through the expression of their own agency. Individual parents are agents, "impelled by self-generated intentions" (Bruner, 1996, p16); however the inner psychodynamics of their selfhood are institutionalized by cultures. We are party to a social agency which through engagement we constitute and out of which we are constituted.

In particular, parents are engaged in a process that has been driven largely by those with a medical training. Between 2005-2006, for example, the co author was involved through his role as a parent and academic in the creation of a Down Syndrome Developmental Journal for parents of a new born child with Down syndrome in England (DfES, 2006). The production of this document, funded by the Department for Education and Skills and the Department of Health as a part of the early intervention support programme has been primarily driven by Psychologists and therapists. In keeping with recognition of the parental voice, parents were asked to evaluate and comment upon the journal throughout the process. The responses to this detailed tick list were by and large favourable; however, the discussions were framed by the initial aims and focus of the medical practitioners. Parents could only comment on the model that was presented to them.

This involvement with a 'tick list form of assessment', in itself set up a conflict for Jonathan, who through his experiences as an educationalist was, for example, aware of Carr's (2004) credit model of the developing child. Carr's model presents an alternative to the 'functional diagnostic model' located within early intervention programmes that has been found to create difficulties for parents and their children with Down Syndrome (Bridle and Man, 2000, Paige-Smith and Rix 2006). Dunn (2004) has also considered how the narrative credit-based assessment approach of learning stories is an alternative to the criterion-referenced developmental assessment approach, within the context of New Zealand early years settings. She evaluates the implementation of the narrative approach in early intervention and notes

discussed below (DfES, 2006). By removing the **'s**, the term suggests the syndrome belongs to those to whom the label is attached rather than to a long dead scientist.

how the approach can be misinterpreted; it is not about 'a happy story' but that it is about an important learning moment for a child: 'otherwise it is not useful in terms of a formative assessment in which scaffolds for learning are identified' (Dunn, 2004, p.125).

In carrying out Early Intervention, Jonathan came to question the way in which the medical developmental model can frame a parent's early interactions with their child and can be considered to represent a 'professional' perspective of the child. Within early intervention strategies both the child and to a certain extent, the parents are assessed in terms of their skills and resources, and this assessment process is used in defining support measures and support levels, by service providers. Here too the parent's possible self is compromised, even if that parent already understands the professional perspective.

Prior professional training did not prepare Louise, who was also a speech and language therapist, when she needed to deliver the early intervention programme with her child:

   I definitely have a different head on as a parent.

Jonathan did not consider himself to be prepared to deal with the medical, social and educational support processes set up for parents and their child with Down syndrome, either. He did not appreciate how pervasive the experience would be. Within a matter of weeks, his family's private life became part of an institutionalised, public space. Thousands of hours were to be spent in the company of professionals assessing his child, within the home and within institutional settings, or carrying out activities at their behest. A key part of his parental relationship with professionals was to describe experiences and understandings of his child and his child's developing characteristics. Like every other parent of a child with Down syndrome he had to tell his, and his family's, story over and over again. His 'record of agentive encounters' became a very public record.

Parents identity and professional knowledge
Parents commonly report a sense of powerlessness during the initial diagnosis and decision making process about their child, as they go from professional to professional. On average they will see ten different professionals and have more than 20 visits to professionals in a year (Sloper, 2004). The Guidance document 'Together from the Start' (2003, DfES, DoH) indicates 'how services may not effectively deliver care and support to children and families' through providing one case study example of a family with a 13 month old son who had 315

different service based appointments over nine months in 12 different locations (DfES, DoH, 2003). Jonathan's son saw at least 11 professionals subsequent to leaving hospital in his first year of his life. He had appointments at least twice a month throughout this time, and from the age of 6 months had a minimum of one home visit per week. According to Jonathan he felt that:

> The majority of these early visits did not serve any useful purpose either. They were precautionary. They were assessments to see if anything needed to be done, assessments driven by a professional understanding of the statistical likelihood of potential health issues. As a father I felt that all they achieved was to reassure us and professionals that this child, our child, was not what we came to understand he possibly could be. This is not to say we were not grateful. If our child had fallen on another side of the statistical divide we would have wished for all the support available. This is an example of the asymmetric mutual dependence that characterises the power relationship between us and the professionals, of course. As parents we are beholden to the professional, though it is through us that they gain access to our children. We book the appointments and turn up for the appointments because we believe it is the right thing to do. In many ways our only power is that without us they would have one less child to work with.

As most of the parents who were interviewed commented, their position made them want to take everything that is on offer, 'just in case'. Louise said:

> But you kind of do it because you think "Well if it does help at all then you've got to give him the best chance", if that makes sense.

It would seem that there was a generalised parental belief in the role of professionals and the knowledge that they have. For example, none of the parents rejected support from a professional, and some referred to them as supportive friends. This continuing reliance upon the service, or the individual providing it, occurred despite repeated or extreme negative experiences with professionals. The parents refer to confrontations that occurred around low quality services or a lack of a particular service, such as speech therapy. All of the interviewees made comments that demonstrated that they had stood up to professionals or lost respect for at least one of them. Catherine said:

I definitely, definitely, have lost practically all my faith and trust in them. I feel they all need to be watched carefully. I find it exhausting, just the thought of it, because I wouldn't set myself up for that, I like to respect people, I like to like people.

Many parents reported the development of a confrontational possible self. This may be considered to be more significant for the parents of older children who could be considered to have a 'confrontational self' as a key identity. As Tricia explained:

I never used to shout and scream at people before, but now I've had to, I've learned that you have to.

The Impact of the Professional Perspective upon a Parent's Thinking
Out of the first wave of parental, agentive, experiences of early intervention grows an understanding of their role as parents within the early intervention process. As parents they not only have to deliver the intervention to the best of their ability but they also have to 'police' the professionals who are assisting in this delivery. Nonetheless, there is still rarely a question about the value of carrying out an activity that the child cannot complete. Mary said:

You can bang on and on and on and on at her on a particular activity and she wouldn't do it until she was ready to. But it's very difficult to say would she have done it anyway if we didn't… I suspect she wouldn't have done… I think the input made all the difference… I'm sure.

All but one of the parents identified everyday contexts as the primary influence in their child's learning, yet parents did not tend to view the effectiveness of their early intervention interactions with their child according to how much the child enjoys themselves, but by the degree to which they are learning in relation to targets. This acceptance of the professional way of thinking suggests that the parent-self has engaged with the professional mindset in such a way as to effect the nature of their agency. Rachel said:

The Portage checklist is my Bible, and I even got a scoring grid off Jane as well…. Yes, oh yes, we worked hand in glove.

Parents, for example, come to discuss characteristics of their child in terms of development and readiness, as opposed to personal interests and likes. Kate, for example, described her daughter's dislike of stereotypically male toys in the following way:

There are things like, if you're looking at toy things, with Chloe some of the stuff she just wasn't developmentally ready for. So we've had to put them to one side. Things like doing, building car tracks and getting cars to go around, doing that sort of imaginative play.

Jonathan found himself caught up in this change of self too. In many ways he came to judge the effectiveness of his parenting by the time and effort he gave to the Early Intervention, and the degree to which his son achieved the targets set for him. He often had to struggle with waves of self doubt, which grew out of the responsibility of achieving the targets that would demonstrate the progress of both his son and himself. Other parents also talked about a sense of failure, and guilt, as well as the way in which their focus is upon what will be achieved. Louise summarised it well:

I'm always looking at what he'll be like when he's 3 rather than worry what he's like when he's 1½.

Through this emphasis upon targets the focus shifts from an 'appreciation of the present' to 'what can be achieved in the future?'.

The thing that I resent about the whole business of Nick's infancy/babyhood is that I never actually took the time to just play with him like a baby. I always thought OK, the most important thing to do was stimulating him, ok, have him sitting up... instead of just bloody enjoying it. (Bridle & Mann p13)

Jonathan and the other parents in the study may be considered to have experienced a shift in their thinking. They:

- see themselves as needing to 'police' or oversee the professionals;
- relate to their children through a developmental model of the child;
- shift their focus from the child's present self to their possible future self

Does the Change in Mindset Empower Parent Agency?

A major part of early intervention programmes is assisting parents in their development as teachers or co-interventionists (Sayers, Cowden & Sherrill, 2002, Kaiser, Hancock, & Hester, 1998, Bronfenbrenner, 1974). Particularly important is the way in which services generate more effective interactions between parents and their children (Mahoney & Wheedon, 1997). For example, professionals will teach parents to talk to children in short sentences or to turn everyday activities into physical therapy opportunities or to react to certain behaviours with set responses. At the same time parents are informed of the centrality of play. Buckley and

Bird (1995), for example, talk about "setting up situations designed to enable the child to learn through play or exploration" (p2). All the parents recognised the importance of play, but equally recognised that mixing play and therapy was not easy. There are a number of studies that have shown that overly-directive parental interaction can result from practices taught by early intervention professionals (Mahoney 1988). Jonathan was certainly guilty at times of forcing his child to carry out activities that his son was not interested in, in a manner which was the opposite of playful; in a manner he would never have adopted with his other child. Similar observations were made by a number of other parents too. Kate said:

> As soon as you try and get her to do something that she's not sure about, and that she feels she going to fail at, then she doesn't want to do that. We have lots of conflict on those.

All parents recognised that activities were a site for conflict. All the parents identified the child's disinterest in certain activities and the potential tension that this causes. Some saw it as necessary to minimise the issue, others to overcome it in someway. Rachel said:

> She has to be continually pulled back to the job at hand.

A number of different strategies were used by the parents, such as greater flexibility to achieve a goal, or the identification of a new means of carrying out an activity. On other occasions the parents expressed how they had to decide to put aside an activity, sometimes with a view to returning to it at a later date and perhaps discussing it with a professional; hence maintaining a commitment to the aims of early intervention. The only parent, who gave up on a particular set of activities, felt she could do so because her child was carrying them out in another setting.

Out of this conflict situation, parents appear to develop strategies of how to cope by rationalising their approach to the activities and their child's response. Jonathan found that he increasingly saw the professionals as an occasional sounding board. He reflects on his experiences with professionals:

> Their physical presence was not a day to day experience for my child. However, being with the professional became a matter of course. In the early days, it had seemed important to be prepared for their visits, to be able to demonstrate that things had been achieved. But this need began to subside. As parents, we became used to not hitting targets, and not carrying out activities as often as we would wish. We also found that we spoke the same language. We shared a discourse with the professional. Over the months of tick lists, form filling and

target setting we had come to understand the language of early intervention and child support. The sessions became much more of a discussion between equals, and then gradually a discussion with someone who was supporting us and our child.

Conclusion

The parents in this study could be considered to gain a knowledge base that supports their child's learning. Jonathan found that in his relations and discussions with professionals he operated within the parameters of the professionals, and engaged with their ways of thinking. This echoes a long understood premise within Disability Studies:

> The more readily one adopts the disabled identity the smoother the process of dealing with professionals and other agents of rehabilitation. (Liggett 1988 p270)

This study involved people who have maintained and developed links with professional ways of working. In so doing they have developed socially valued agency that will help them to gain access to limited support resources. The experiences of those interviewed for this paper as well as the co-author's reflections would suggest that being an 'effective' parent requires incorporating professional values. In particular, even though Jonathan was involved in the creation of an early intervention programme, he recognises that his parental agency and identity had to be compromised in order for him to be an effective partner for the professionals and so maximise support for his child. This approach within 'family centred practice' presents a new dynamic in relation to the concept of parent participation and parent partnership. Within this conceptual framework the parent must become an ad hoc professional, whether they like it or not.

By directly involving parents in the development and implementation of programmes to support their child, parents feel more in control of the situation and the skills they require to carry out interventions. Parents are also more likely to feel that their relationship with professionals is improved (Dillenburger, Keenan, Gallagher & McElhinney 2002). However, even though notions of autonomy and parental control are seen as key to effective family-based early intervention practice, it seems that some processes required for the implementation of early intervention may conflict with parent agency.

These findings are based upon a small sample, who represent a limited perspective. These interviewees have engaged with the early intervention process and the professional identity.

Many other individuals may struggle to engage with this professional mindset. Further research needs to examine the views of parents from a wider range of backgrounds, in particular those parents who choose not to compromise their agentive experiences or are not able to engage with the social agency which places so much emphasis upon early intervention. Given this emphasis, research needs to consider whether parents struggle to access support opportunities unless they incorporate or acknowledge professional values within their parent-self and utilise these values when expressing their agency.

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