

*Original Research Study*

## **Disabled by the Discourse: Some Impacts of Normalising Mechanisms in Education and Society on the Lives of Disabled Children and their Families**

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### **Abstract**

*This paper challenges and explores some key effects of dominant discourses around disability that currently prevail in the New Zealand educational system and society through a consideration of one family's experiences. The workings and impacts of a medical/special education view of disability and difference are analysed using data based on interviews and documents from my Doctoral research. Excerpts of data are used to demonstrate ways in which individualised and deficit views of disability impact on the construction of the child and their family. The implications of this for disabled children's learning, participation and rights to an inclusive education are discussed.*

**Key Words:** Disability; discourse analysis; family experience; inclusive education

### **Introduction**

This paper presents data relating to my daughter Maggie Rose and our family. It is drawn from interviews with Tony (Maggie's Dad) and I (Maggie's Mum), my writing in the form of a journal article about our family's early childhood centre and early intervention experiences (Macartney, 2002), entries in Maggie's baby and 'Learning Story Books' and personal recollections. Family and early childhood centre narratives are juxtaposed with written documents from medical, and special education professionals and our recounted experiences of interactions with medical and special education personnel.

The data and analysis in this paper critique deficit discourses related to disability through this focus on medical and special education personnel, documents and practices and the experiences of one family with a disabled child. However, the critique of the use and impacts of normalising, deficit discourses is equally relevant to the attitudes and actions of many parents and teachers which influences the exclusion and/or inclusion of disabled children and their families in early childhood centres (Lyons, 2005; MacArthur, Purdue & Ballard, 2003; Macartney, 2007; Purdue, 2004). This is because individuals and groups in our society, including teachers and parents, draw from and contribute to the reproduction of dominant deficit discourses circulating in our society (Minister for Disability Issues, 2001; Purdue, 2004). Therefore, although this paper explores these issues in relation to medical and special education personnel, the critique is of the prevailing discourses in education and society that none of us are immune to.

### **Theoretical Perspectives and Methodology**

The research is underpinned by a view of disability as a social construct, expressed structurally and ideologically through a web of unequal, oppressive, and resistant to change, power relations (Barnes, Mercer & Shakespeare, 1999; Bogdan & Taylor, 1998; Fine, 1993; Oliver, 1990, 1996; Skrtic, 1991, 1995). My research incorporates several methodologies and theoretical perspectives. The research draws on an interpretivist theoretical perspective, which is based on a social constructionist epistemology (Burr, 1995; Crotty, 1998). An interpretivist perspective is interested in social life as it is constructed and experienced by individuals within their lived contexts (Ferguson & Ferguson, 1995). Researchers working within an interpretative paradigm use ethnographic, descriptive and narrative detail of people in their everyday contexts as the basis of their data collection, interpretation and analysis (Ferguson & Ferguson, 1995). The main theoretical and methodological framework for this research is discourse theory and analysis. I chose to use discourse theory and analysis because I am interested in the communication, production and influences of dominant beliefs, attitudes, and assumptions on family experiences and on how parents of disabled children construct their view of their child.

#### ***Discourse Theory and Analysis***

The purpose of using ‘discourse’ as a sensitising concept and tool for analysis in this research has been to explore the links between everyday life as it is experienced by families and the wider social context. Discourse theory is a useful tool for explaining and exploring social meanings, arrangements and power relations, and how they are socially, culturally and historically negotiated, contested and produced. Gee (1990) defines discourses as more than language, spoken or written. Discourses are both constitutive of and embedded in social, political and cultural practices (Gee, 1990; 2004; MacLure, 2003; Rogers, 2004). Discourses are expressed through language, behaviour, institutional arrangements and social practices. They are:

...ways of behaving, interacting, valuing, thinking, believing, speaking, and often writing that are accepted as instantiations of particular roles by specific *groups of people*, whether families of a certain sort, lawyers of a certain sort... They are always and everywhere *social*. Language, as well as literacy, is always and everywhere integrated with and relative to *social practices* constituting particular Discourses (Gee, 1990, p. 5). (Italics in original)

A key function of any discourse is not only what it includes but also what it excludes: “Discursive formulations provide rules of justification for what counts as knowledge within a particular context, and at the same time stipulate what does not count as knowledge in that context” (Edgar & Sedgewick, 2002, p. 117). Rather than only seeking to understand the meaning of the social world for participants as it exists: “discourse analysis endeavours to uncover the way in which it is produced...It examines how language constructs phenomena, not how it reflects and reveals it” (Phillips & Hardy, 2002, p. 6).

#### ***Discourse and the Sanctioning of Knowledge, ‘Truth’ and Power***

Foucault (1977, p. 49) describes discourses as “practices that systematically form the objects of which they speak.” According to Foucault (1980), there exists an interdependency between knowledge(s), ‘truth’, and power. Foucault (1980, p. 131) says:

Truth is a thing of this world. It is produced only by virtue of multiple forms of constraint. And it induces regular effects of power. Each society has its regime of truth, its 'general politics' of truth: that is, the type of discourse which it accepts and makes function as true; the mechanisms and instances which enable one to distinguish true and false statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who are charged with saying what counts as true.

Burr (1995) suggests that a key relationship between discourses and the exercise of power is that discourses function in ways that obscure the unequal power relations operating in society. The knowledge and 'truths' that particular discourses privilege and the power relations they maintain are taken for granted and accepted as 'natural' and a representation of a stable and fixed reality rather than as contestable and subjective versions of events and phenomena (Foucault, 1980).

### ***'Bio-power' or 'Bio-politics'***

Foucault (1977) saw the body as the primary site of the exercise of disciplinary power. He termed the expressions of power that began to emerge in the second half of the eighteenth century 'bio-power' or 'bio-politics'. Foucault (1977) linked bio-power to the development of a statistically based science of knowledge. Bio-power represented a new 'science of knowledge' whose focus was the experience of life. It created, utilised and was dependent on a new construct, that of the existence of a 'population' which could be measured, defined, classified, divided and controlled. The rise of the institution and discourse of medicine was central in the development of bio-politics and has had a major influence on the construction and experience of 'disability' (Tremain, 2005). A process and effect of bio-power has been the creation of the 'bodily conditions' of 'impairment' and 'disability'. This medicalised discourse of disability is based on a view of disability as a biological, pathological (abnormal) condition contained within individuals. Because of its status as a 'real' and identifiable pathological condition and its separation of the 'normal' and 'abnormal', 'the problem' of 'disability' or 'impairment' is believed to require 'expert', professional intervention and management. Perhaps the most significant process and effect of bio-power in regards to disability has been the separation and division of 'disabled' / 'not normal' and 'able' / 'normal' bodies (Tremain, 2002; 2005).

### ***The Social Construction and Uses of 'The Norm'***

The central classification that underpins medical/special education discourses and practices related to disability, and education is the notion of the 'norm'. The development and advancement of medical science and developmental psychology have constructed our cultural understandings and practices around notions related to the 'norm'. From a medical standpoint, disabled people are contrasted with the classifications of 'healthy', 'normal', 'fully participating' members of society and are 'found' lacking.

The concept of there being a set of norms, which are subsequently positioned as the ideal, requires the notion of the 'abnormal' or 'deviance' in the 'population'. The abnormal becomes anything that deviates from established norms. This development of the construct of statistically defined norms in relation to human attributes and behaviour and the acceptance that human traits and characteristics are universal, that they can and should be defined, measured and ranked in relation to established 'norms', has become accepted as part of the 'natural' order of things (Davis, 1997). Because the cultural knowledge produced

through dominant discourses is largely accepted as the 'truth', the assumptions, beliefs and politics underpinning that knowledge and its associated practices are mostly seen as unproblematic and not in need of scrutiny or challenge. Through this taken-for-granted acceptance of a medical, psychological and developmental 'regime of truth', the relationship between power, politics and discourse is obscured (Burr, 1995).

### **Disciplinary Mechanisms**

Foucault (1977, p. 138) suggests that modern bio-power is primarily exercised through a process of self discipline centred around what he described as a "micro-mechanics of power" which acts on and through the 'docile' body. People willingly scrutinise and conduct themselves through monitoring and regulating their own behaviour in relation to dominant classifications and constructs such as the existence of the normal, ideal individual in society. The particular disciplinary practices that Foucault (1977) outlined were surveillance, hierarchical observation, normalising judgements and the examination. These practices are briefly outlined below and are used to interpret my family's experiences of disability, inclusion and exclusion.

#### ***Surveillance, Self Regulation and Hierarchical Observation***

Foucault (1977) argues that the arrangement and 'government' of space is a key element of disciplinary practices associated with bio-power. He suggested that individuals monitor, regulate and modify their own behaviour in response to the knowledge that they may be under observation at any time. Allan (1999, p. 21) suggests that the 'disciplinary gaze' operating in educational contexts constructs disabled children "as objects of power and knowledge". She (Allan, 1999) further suggests that children with disabilities within mainstream education are the subjects of much greater scrutiny and surveillance, than their non-disabled peers. She gives the more constant supervision that children with disabilities often experience, such as the close presence of a teacher aide during classroom and break times, as an example of the closer scrutiny they are under (Allan, *ibid*). Social controls centered on surveillance within institutions such as schools and early childhood centres make it possible for children to be sorted into different types or kinds through recorded and informal observation, adult supervision, assessments and judgments by teachers, teacher aides, parents, visiting 'experts' and peers.

#### ***Normalising Judgments and the Examination***

The taken-for-granted acceptance and use of normalising judgements as the foundation of dominant developmental educational theory, practice and discourse has the effect of quantifying and highlighting individual differences, and defining anything outside of the 'norm' as pathological or problematic. The response to these 'problems' is to provide 'treatment', which is rationalised as a necessary and benevolent response to an individual's 'needs' (Graham, 2005). Children whose behaviour or characteristics fall outside of the norm are labelled as having 'special needs' and are seen as requiring a different education ('treatment') than their ('normal') peers as a result.

The 'examination' refers to the production, collection and storage of written documentations of difference or deviation from the norm (Foucault, 1977). It involves a set of professional practices that are familiar to many disabled children and their families. The examination involves surveillance - in the forms of written (hierarchical) observations, verbal accounts, tests, measurements and assessments by 'experts' - to quantify how a child or adult deviates from the norm. The examination has an objectifying effect that results in the person being

defined, labelled and treated as a 'case' more than as a 'person' (Foucault, 1977). These effects can include decisions and interventions that result in exclusionary practices in education. Allan (1999, p. 22) suggests that the examination and the documentation that accompanies it marks the 'disabled child' out:

...for perpetual surveillance throughout the remainder of his or her school career and beyond. Parents and professionals also come under scrutiny as part of the continuous review of the recorded child's needs. All are caught by a gaze which is always alert to the deviant.

Following is a presentation of excerpts of medical/special education, and family/early childhood centre perspectives related to Maggie-Rose. These excerpts are analysed using Foucault's (1977; 1980) theories regarding the workings and effects of discursive disciplinary mechanisms at the level of lived experience.

### ***Re-Presenting the Data***

I have juxtaposed and contrasted medical/special education narratives with family narratives using a 'split text' (Lather & Smithies, 1997). The text is divided into two columns, one medical/special educational, and the other family. Each column can be read as separate but related pieces of writing. Juxtaposing the data encourages the identification and exploration of differences and relationships between a medical/special education approach to disability and our family's views and experiences. Juxtaposing the data is intended to highlight the characteristics of each worldview and construction of disability, and is used as a strategy for examining the effects of different ways of understanding and responding to disability.

The excerpts are presented chronologically. The text is divided into three sections that cover consecutive periods of time in the life of our family. These periods are: 'Introducing Maggie Rose', 'Diagnosis', and 'Early Childhood Education'. Each section is followed by a discussion that 'disrupts' the text through contextualising, examining and interpreting the data in terms of the various ways of viewing and positioning Maggie and our family, and identifying disciplinary mechanisms and the effects of these on our family. The discussion of each section involves a critical consideration of:

- A developmental discourse/'regime of truth' through an examination of its effects;
- The negative positioning and subjugation of a disabled child and her family through the use of 'expert' status and power-knowledge by medical and special education professionals;
- Practices of classifying, assessing, and labelling children with disabilities and what these processes might achieve; and
- Possibilities for resisting and challenging deficit views of disability.

### **Introducing Maggie-Rose**

The medical/special education column contains no text in the first section 'Introducing Maggie Rose'. This has the effect of the reader initially having nothing to contrast our family story with. This format is intended to be a visual mirror of our family's process of getting to know and learn about Maggie before she was 'officially diagnosed' as being 'disabled'. The family narrative stands alone as the introduction to Maggie and, it is hoped, that in some small way, the reader 'gets to know her', as we did, without any (overt) medical/special education intervention, interpretation or labels.

<p><b>Medical/Special Education</b></p>	<p><b>Family Narratives</b></p> <p><i>Excerpts from Maggie's Baby Book</i></p> <p><b>11 weeks:</b> Smiling quite a lot – mainly to herself! Is starting to notice her hands which she raises up to her face like she's drinking from a jug. At one week old Maggie-Rose drank from a sherry glass because she hadn't quite worked out what breasts were for – perhaps she remembers. Maggie-Rose is extremely kissable and we can't imagine life without her lovely presence. She's very inquisitive in a crowd e.g. a café, party, with visitors etc... Weighs 10lbs!</p> <p><b>14 weeks:</b> Maggie is vocalising heaps – she likes to blow bubbles and has discovered that she can move the objects on her 'hanging frame' with her hands. She especially likes her felt toy which is a little white cloud with a smiley face and 6 ribbons hanging from it. Maggie goes to sleep at 8pmish and wakes between 3-4.30am. Goes back down till 7-8am – mum and dad are very impressed! Her raising her hand to her mouth is definitely an attempt to get her thumb into her mouth. She seems to enjoy the practise which is momentarily successful every now and then. Has got a ticklish neck!</p> <p><b>19 weeks:</b> Maggie-Rose and I (Mum) went on an aeroplane to Wellington. Maggie smiled during take-off and was fine on the flight. In Wellington Maggie met Aunty Sharon, Uncle Stephen, Aunty Deborah, Uncle Peter, cousin Immie, Granddad (Birdie), her Great Grandparents, and heaps of great aunties and uncles and cousins. She saw Nanny again too and had five days of non-stop cuddles! Maggie especially loved Frank (Great Granddad) who held her in his one good arm while they looked into each others eyes and talked – Granddad was much more animated with Maggie than any of the adults in the room – good taste!!</p> <p><b>5 months:</b> Maggie has an ABR hearing test on Friday as we have been concerned about her hearing for a couple of months now. Lately Maggie has been falling in love with soft toys and teddies – she's a real snuggler! Maggie has normal hearing in her right ear and a 50% loss in her left one. May not be permanent and won't affect her language acquisition or comprehension Yeh!! A great relief for B &amp; T.</p> <p><b>6 months:</b> Maggie is almost 6 months old – had her first solids today – about 1 tsp of pureed kumara – very enjoyable. Maggie has finally got that thumb into her mouth! She is a thumb chewer rather than sucker and either thumb will do!</p> <p><b>7 months:</b> Maggie-Rose is as delightful as ever – very into blowing bubbles and raspberries – loves the elephant mobile she got from the Horwoods for Christmas – 4 elephants with bells on – she reaches up and whacks the elephants, delighting in the movement and sound, she also talks to them in excited tones.</p>
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<p>going until she was 3 – 4 weeks old. After that weight gains have been steady and have taken off recently with a marked increase in weight so that now Maggie is quite obese. This is accentuated by her short limbs and short length...</p> <p>She did not smile until 9 weeks old and this was only occasional, more smiles came at 12 weeks of age, but she has been slow in her social development, not interacting with other people and not showing a great deal of eye regard even to her parents.... She is not able to hold her head up when prone and she is certainly not sitting, she does not support her weight when held upright...</p> <p>Maggie shows significant delay in her development, motor, social and cognitive development. She is also short, she needs further investigations..."</p>	<p>you very much.”</p> <p><i>We talked in our interview with N1 about the question marks that arose over Maggie’s development and her future:</i></p> <p><b>B.</b> And so, did you, like after Maggie Rose, after we went to the paediatrician, did you feel differently about her?</p> <p><b>T.</b> No, because I, like you, when we went away to Hanmer, we sort of had that epiphany the next day, it was just like, well, nothing’s changed. I do feel – I shared that feeling. But it was just, the question marks, there were just suddenly a million question marks that weren’t there before—maybe they kind of were there before, but if Maggie Rose had been “normal” those question marks wouldn’t be there. So it just sort of adds a whole layer of doubt.</p> <p><b>Int.</b> A different layer. Did you feel differently once you’d been to the paediatrician?</p> <p><b>B.</b> Ummm, I don’t think I felt – I didn’t feel differently towards Maggie, but I think that in some ways nothing had changed and in some ways everything had changed. And it was to do with, I suppose in some ways, sort of like having to share her more, having her being the...</p> <p><b>T.</b> The subject.</p> <p><b>B.</b> Yeah, the subject, or the object of other people’s interest and intervention and all of that sort of thing. It made me feel a bit tired...</p> <p><b>T.</b> And we both knew, because of our work, you know, because I had worked in mental health, how badly the world treats people with disabilities. So immediately as well as all those questions about what she’s going to be like when she’s 21, was “How’s the world going to treat her?” and being aware of the crap the world deals out towards people with disabilities. That sort of adds some anxiety that you don’t necessarily...</p> <p><b>Int.</b> – that you wouldn’t have had otherwise.</p>
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<sup>1</sup> The interviewer was a Masters student who I asked to interview Tony and I as part of the research. She interviewed us on one occasion, preparing her own interview guide after viewing the interview guides that I had previously prepared and used for the second participating family in this study.



### *Classifying, Labelling and Pathologising*

The paediatrician's letter reads as a chronicle of Maggie's perceived 'deficits' and is replete with markers of the particular ways in which she is deemed to be different from 'normally' developing children. Through the process of the examination and documentation, Maggie is objectified as a 'case'. Maggie's positive qualities and achievements are absent in the observation and examination and, when present, have been reinscribed as deficits. One example of this re-inscription process was the paediatrician's statement that Maggie was "quite obese". At the time we took Maggie to the paediatrician, breast milk was her sole source of nutrition. I had never considered, or believed, it was possible for a fully breastfed infant to be 'obese'. As the paediatrician pointed out, Maggie (and I) took a while to establish successful breastfeeding. Working hard on and succeeding in getting Maggie established with breast feeding was one of my first challenges and triumphs as a mother. As a result I was very proud of Maggie's ability to feed from my breasts, thrive and grow into what I believed was a chubby, healthy baby. I also experienced breastfeeding as the major process through which Maggie and I engaged in loving, mutual interactions. My experience and sense of achievement as a mother and Maggie's beauty and good health were silenced and marginalised through the paediatrician's 'expert' opinion and disciplinary 'gaze'.

At the time, I also felt affronted by the paediatrician's repeated statements about Maggie's "short stature" and limbs. At the time I couldn't see why her height should be relevant and of such significance to him that he felt he needed to refer to it at all, let alone in almost every paragraph. This noticing and focusing on Maggie's size and stature can be viewed as a 'normalising judgement' involving comparing and marking out perceived deviations from the 'norm'. Once these 'deviations from the norm' are spoken into existence, the child can be categorised and separated as 'other', a 'case', and in need of "further investigations".

Several months later, after a number of tests at the hospital, the paediatrician suggested that Maggie have an MRI scan to look at her brain activity. At this point Tony and I began to question why we were going to hospital for all of these tests when Maggie obviously wasn't sick, and therefore, in need of a cure. We realised that what we wanted was to let Maggie's development unfold 'naturally' without medical interventions or opinions influencing her future and how other people judged her and her capabilities. We became resistant to a medical gaze and view of our child. Even though we had 'doubts' or questions about Maggie's future, we preferred living with uncertainty to regular exposure to deficit medical labels, opinions, predictions and 'truths'. At that point we stopped going to the hospital for tests and we stopped looking for a label.

### **Early Childhood Education**

We checked out three early intervention services before choosing one for Maggie and our family. In the process of choosing an early intervention service we met with an EI social worker. A comment from this social worker that stuck in our minds was: "We get 110% out of our children". I think that this was given as a reason for choosing that service (see Macartney, 2002, for more discussion on this and our experiences):

We didn't want to get 110% out of Maggie Rose. We wanted to help her evolving sense of self to emerge and unfold, to keep getting to know her and to help her reach her potential in ways that responded to what felt right and comfortable for her. The 110% approach we felt was too pushy and disrespectful. Maggie's efforts to communicate were very subtle and she seemed to us to have quite a fragile sense of herself and the world. We didn't want to 'lose her' in an effort to maximise the speed of her

development. We were more interested in valuing and respecting who she was than in trying to make her fit as close to the ‘normal’ developmental path and time frame as possible...

One reason we chose playcentre was because of the high level of input and involvement we could have as a family into what was happening for Maggie Rose. We also wanted other parents and children within our community to get to know her...

The early intervention team changed at this point and so did their approach to Maggie. The EI people almost exclusively visit the centre, where Maggie is much quieter and more reserved than at home. They ask lots of questions each time they come about what Maggie is and isn’t doing. We (the ESW and myself) find ourselves trying to convince the EI people that she is ‘doing well’ in relation to what they are interested in. It is a situation where we feel defensive, always responding to their agenda and there is sometimes little relationship between what we are trying to achieve and what they are interested in...

We are interested in responding to and building on Maggie’s interests and supporting her and others to develop relationships with her. We see this as the path to her development, being accepted, and being influential in the centre. Their approach focuses more on deficits relating to what she “should” be doing next, rather than valuing the learning that we can see taking place and building on that...

We want to know what is happening for our child in the centre. Sometimes people from outside will come in and do assessments that we have not discussed or given permission for, or behave in ways that we don’t think are okay. For example, not introducing themselves to Maggie or telling her why they are there and what they would like to do. Or they try to get information from her that is already available through asking a centre adult or us. The result is that her play is unnecessarily interrupted. Sometimes what they want to know relates to a developmental checklist or other information that either we don’t see as necessary or is not the focus of what we are trying to achieve.

<p><b>Early Intervention/Special Education Narratives</b></p> <p><i>Excerpts from ‘Observation Guidelines for Development’ given to us by the Early Intervention Teacher:</i></p> <p><u>Sensori-motor Development</u></p> <p>Physical appearance</p> <ul style="list-style-type: none"> <li>• Is there anything unusual about the child’s body?</li> <li>• When plotted on a chart, are the child’s height and weight appropriate for age?”</li> </ul>	<p><b>Stories recorded at home in Maggie’s Learning Story Book</b></p> <p><b>Maggie 3.8 years</b></p> <p>“First day back at the centre after the holidays today. Maggie said: “Can I help you make the playdough?” before we left home this morning! She enjoys tipping cups of flour and salt in as well as mixing it up now. I’m teaching her the recipe! She got into making prints in the dough with her chin, saying: “Maggie made a chin print!” laughing and giggling and then doing it again. Elliot made dough ‘scones’ and Maggie liked: “The sugar on top” (flour).</p>
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<p>Motor activity</p> <ul style="list-style-type: none"> <li>• Is the child able to get from one play area to another alone?</li> <li>• Does the child appear to move more or less often than other children?</li> <li>• Are there any motor skills that the child seems to avoid?"</li> </ul> <p>Muscle Tone</p> <ul style="list-style-type: none"> <li>• Do body parts on the right and left side look and move the same?</li> <li>• Does the child assume a wide variety of positions?</li> <li>• Does the child look co-ordinated when moving from one position to another?"</li> </ul> <p>Sitting</p> <ul style="list-style-type: none"> <li>• Does the child need to be held in sitting?</li> <li>• Is the child able to hold the head up?</li> <li>• Is the child able to freely turn the head? (to both sides, up and down?)</li> <li>• Is the back rounded or straight?</li> <li>• Can the child bring the hands together in front of the body?</li> <li>• Can the child use the arms and hands to play with toys in sitting?</li> <li>• Does the child turn the upper body to reach for or watch objects, keeping the lower body stationary?</li> <li>• Is the child able to cross the centre of the body with the arms when reaching for a toy?"</li> </ul> <p><u>Social-Emotional Development</u></p> <p>Characteristics of dramatic play in relation to emotional development</p> <p>A. Structure of Play</p> <ul style="list-style-type: none"> <li>• To what degree is there continuity and logical sequence versus fragmented thought presented in the child's play?</li> <li>• To what degree is there a linkage or recognition of past, present, and future?</li> </ul>	<p>Elliot, Maggie and I went outside, we walked over to the shingle pit, which is a favourite of Maggie's at the moment. Maggie enjoyed making a "bell tower", "sprinkling the stones" and, of course, eating them. She asked to play: "Goldilocks and the Three Bears" before morning tea, but we had left our run too late." (Written by Mum-Supervisor)</p> <p><b>Maggie 4.3 years</b></p> <p>"...Mary read 'Goldilocks' to Isaac and Maggie. Maggie likes holding the Duplo Goldilocks and following the story. She put Goldilocks in the places during the story (e.g. the big bed, the middle sized bed etc.). Isaac helped make the Duplo stairs for Goldilocks to climb up and down." (Mary, Education Support Worker)</p> <p><b>Maggie 4.4 years</b></p> <p>"What a busy day! Maggie enjoyed using the little oven at the playdough table and called it "the Griller". She liked opening and shutting the door and cooking bowls of porridge for the 3 bears. Sasha joined in too and we had the Duplo Goldilocks story." (Mary)</p> <p>"We have been working on a production of Goldilocks and the Three Bears. Today we listened to the story on a tape of Maggie's – she had a Big smile when the story began and at the end she said: "Thanks for doing Goldilocks and the three bears!" Maggie tried on the bear costume (t-shirt with bear face) and said: "I'm a bear! I'm a bear!" She continued saying this through most of the session. We had a bear hunt later and Maggie was the bear which we found at the end of the hunt. She chased all the bear hunters away, saying "I'm a bear!" very loud." (Mary)</p> <p>"Jasmine and Sasha were dressing up and Maggie and Mary (ESW) walked over. Mary put a purple cape with gold trim on Maggie. Maggie looked in the mirror and said: "Goldilocks". She stood looking at herself in the mirror and I asked her if she'd like her face painted – she nodded. She</p>
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<ul style="list-style-type: none"> <li>To what extent does the child's play demonstrate rigid or inflexible thought patterns?</li> </ul> <p>B. Content of play</p> <p>What are the dominant themes of the child's play?</p> <ol style="list-style-type: none"> <li>Dependency</li> <li>Loss</li> <li>Power/control</li> <li>Fear/anxiety</li> <li>Self-image</li> </ol> <p>Does the child recognise the boundaries between reality and fantasy?</p> <p><b>Maggie 4.6 years</b></p> <p><i>EI teacher and Speech Language Therapist visited today. They suggested that we focus on the things below before their next visit:</i></p> <ul style="list-style-type: none"> <li>Sequence play – dramatic play e.g. bathing dolls etc. using words like First, Then, Next,</li> <li>Activities @ kai table and collage table to encourage interaction with one other child. Being at the tables mean the children are at the same height therefore Maggie is equal</li> <li>Maggie initiating change of activity – clear the activity away and wait for Maggie to choose a new one. (Mary)</li> </ul>	<p>nodded “yes” to being Goldilocks. Later Maggie was searching the dress-ups with Ellen (teacher). She found the bear shirts and then reached up for the ‘Goldilocks’ puppet on a high shelf and said: “Hello myself!” (Mary)</p> <p><b>Maggie 4.9 years</b></p> <p>“Maggie was in the dress-up area. She said: “Listen to the heartbeat” and was looking around for the stethoscope. She found it, put it on and said: “Doctor Maggie” while looking in the mirror. Mary asked: “What does your heart sound like?” Maggie said: “Boom-chicka, boom-chicka, boom-boom-boom!” Mary brought the rubber drum over and played the rhythm of the words. After a while Maggie copied. Maggie was reaching her hands up high towards where some beads were stored. Mary asked if she would like some help to get them down. Maggie said: “Ask a grown up.” We walked outside, Mary asked if Maggie wanted to walk onto the ‘stage’ (set of wooden steps and cubes). Maggie did and said: “We went to the house of three bears”. Mary asked what we did there and Maggie replied: “And Goldilocks sat down.” Maggie enjoyed retelling the story with Mary (filling in words and what happened next). Later Maggie chose the magnetic Goldilocks story and put pictures on the board with Isaac while Mary told the story.” (Mary)</p>
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The ways that Maggie Rose, the centre adults, Maggie's family and the special education personnel are positioned and position themselves and the effects of these positionings can be highlighted and explored through examining this data.

### Are the ‘Experts’ there to Create, Maintain or Fix ‘The Problem’?

The special education staff positioned themselves as ‘experts’ in relation to knowledge about ‘normal’ child development and how to support the development and learning of a ‘disabled’/‘abnormal’ child’. The developmental assessment checklists that we were given were based on normalising judgements in the form of pre-determined markers for ‘normal’ and ‘abnormal’ appearance, behaviour and development. The developmental markers in these checklists and the assumption that an assessor could know a child through answering the questions indicates a belief that universalised, developmental approaches to learning and assessment are valid, scientific, objective and value neutral.

The official purpose or intention of developmental assessment methods is to provide teachers and others with information that they can use to develop ‘appropriate’ interventions to support the child’s ‘progress’. The early intervention is intended to ameliorate or fix the child’s ‘problem’, to ‘close the gap’, and the information in the checklist is supposed to give the ‘experts’ the information about the child that they need to do this. But this contention does not stand up to scrutiny because many of the developmental indicators lead to marking out differences, rather than to intervening or ‘fixing’ the ‘problem’. For example, why should how a child looks in comparison to ‘normal’ children be relevant to educational intervention? Should and how can early intervention change a child’s physical appearance? And, why would establishing whether a child moved more or less often than “other children” be relevant if the purpose of the assessment was about intervening in the teaching and learning process? The outcome of using a developmental checklist is to develop a profile of a child by comparing them to what is deemed ‘normal’. It is a process of classifying and labelling using and documenting normalising judgements. The logical outcome of this process is to define a child who does not conform to the norms as ‘other’, deficient and lacking.

### ***The Myth and Effects of ‘Objectivity’***

The developmental checklist approach takes it for granted that children’s behaviours or characteristics should and can be accurately and universally pre-defined and objectively measured. Part of the claim to objectivity is a belief in the moral, cultural and value neutrality of the contents and processes of assessment. This claim to the scientific, objective and value neutral status of developmental approaches to assessment and intervention is open to critique through considering the effects of this knowledge, or ‘regime of truth’.

For example, can a teacher or special educationalist ‘know’ how to ‘objectively’ assess whether a child’s play ‘presents’: “continuity and logical sequence versus fragmented thought”? “Continuity and logical sequence” and “fragmented thought” are subjective categories that communicate a particular worldview and orientation in relation to how people should think and behave. “Continuity”, “logic” and “sequence” of thought are used as criteria for ‘good’ (normal) thinking and are privileged against “fragmented thought”. Consider this criterion in relation to Maggie-Rose and her use and love of books, stories, acting and her imagination. A rational, logical, sequential orientation to thinking actually requires a negative value judgement or a narrowing of what is deemed acceptable, productive of learning or relevant in her play and thinking. Maggie uses her book world (for example, Goldilocks and the Three Bears) as a way of making sense of, participating in and developing theories about her lived experience. From a special education perspective, this strategy is unlikely to be recognised, positively valued or understood. Using the pre-determined developmental checklist given to us by the early intervention teacher, Maggie’s way of constructing and communicating understandings of the world could easily be used as evidence of difficulties in recognising “the boundaries” between “fantasy” and “reality”. One of the ways Maggie has been described by a ‘special needs teacher’ is as having a “rich inner world”. This “world” is seen as ‘other’ and as a barrier to her engaging in ‘reality’ and is interpreted as her being ‘off the topic’.

### ***An Emphasis on the ‘Whole Child’ Within a Social Context***

In contrast with the individual and de-contextualised approach of the special education staff, at the early childhood centre we used narrative assessment methods that began with each child’s strengths, interests and participation and positioned them within a learning community and in relation with others. The approaches of the early intervention staff were

very much at odds with those of the parents and Supervisor of the centre. At the centre, the stories, photos, and examples of the children's artwork in their Learning Story Books were used as a starting place for planning the curriculum, programme and environment. The Learning Story Books were also intended to be a celebration of each child's interests, learning and achievements. They were living, changing documents that belonged to the children and their families. Rather than beginning with a textbook or checklist for knowledge about children's learning and development, we saw ourselves as parents and teachers as the 'experts' on the children in our care. Our methods and orientation also communicated a belief that the children were 'experts' about themselves. The suggestions from the EI staff that we focus on "dramatic play" and feed in the concepts of 'first', 'then', 'next', 'last' seem an impoverished and banal response to Maggie's newly developing interest in stories and pretending and the pleasure, skills, dispositions, friendships and learning that she was gaining from her interest.

Our response to Maggie's developing interest was to find a favourite story of hers (Goldilocks and the Three Bears) and to provide lots of opportunities for all of the children in the centre to explore the story together through the provision of resources, the planning of events, activities and occasions that would encourage and respond to this exploration and learning. We would find out about what learning was taking place through observing, documenting and discussing what was happening and we would use this information to further plan in response to the learning we believed was occurring. This approach positioned the children and adults in the centre as both 'experts' and 'learners'. Maggie was positioned as a competent learner and member of a community of learners. The early intervention staff came to be viewed as not relevant and an interruption to our way of working and of viewing Maggie-Rose.

### ***Resistance***

Through recognising and refusing to accept a normalising discourse in our approach to Maggie's learning in her early childhood setting, we were able to marginalise the dominant discourse and therefore limit its negative effects on Maggie's learning and participation in her home and early childhood centre environment. Our ability to resist a deficit positioning of Maggie was dependent on having consciously developed an understanding of the assumptions, beliefs and knowledge underlying a normalising, deficit discourse and the negative implications of that knowledge. We then used that understanding to resist and reject mechanisms that would classify Maggie as special/deficient and translate into separate approaches to teaching and learning that led to a limiting of possibilities, and to practices that excluded her from the opportunities for learning and participation enjoyed by her 'typical' peers.

As a family, we have struggled to accept the involvement/interference of medical, and special education professionals in our lives because of the discourse this approach uses to construct 'reality'. However, the net of power is cast wide and the involvement of special education services is compulsory if we want access to funding for education support workers or teacher aides. Our aspirations and voices as a family and Maggie's voice have largely been ignored, marginalised or reinterpreted by those adults who draw from deficit and developmental views of disability and education.

### **Conclusion**

In this paper I have argued that a view of 'disabled' children as 'special' and 'other' leads to a restriction of their opportunities for participation and learning. To challenge dominant and

limiting discourses around disability and difference, early childhood teachers and teacher educators must first be alert to the workings of power and discrimination in society in general, and in early childhood settings in particular (Dahlberg & Moss, 2005; Dunn, 2004; Dunn & Barry, 2004; MacArthur, Dight & Purdue, 2000; Lyons, 2005; MacArthur, Purdue & Ballard, 2003; Mac Naughton, 2005).

The New Zealand early childhood curriculum document, *Te Whaariki* (Ministry of Education, 1996), curriculum support documents such as *Kei Tua o te Pae* (Ministry of Education, 2005) and *Te Reo Taataki* (Ministry of Education, 2000) and some of the recent New Zealand research and writing in the 'inclusive' assessment area (Cullen, Williamson & Lepper, 2003; 2005; 2006) do not include or adequately address a critique of normalising discourses and their impacts as critical when discussing and describing 'inclusive' approaches to early childhood education. Although the intention of much of this work is to include disabled children by emphasising the narrative approaches now typically adopted in New Zealand early childhood settings, much of the language and discourse underpinning this work continues to construct disability as a 'problem' of deviation from the norm that is contained within individuals who require 'specialist intervention' (Lyons, 2005; Purdue, 2004).

The effects of the tensions and disjuncture between developmental and narrative approaches to learning and assessment are underestimated when it is assumed that if the two systems of early intervention and early childhood centres work together using a narrative approach, inclusive education will be the 'natural' result. In contrast to a view of inclusion being about acknowledging and advocating for human rights, the focus remains on the assessment of individual children who 'have' "special needs". This focus on the individual through positioning disabled children as 'special' and in 'need' ignores and obscures the unequal power relations that are operating and the impacts of these (Fleer & Robbins, 2004; Purdue, 2004). I suggest that this contributes to the maintenance and reproduction of deficit/normalising discourses and approaches in education and does little to challenge the discourses underlying the power relations that these rely on.

Used critically, *Te Whaariki* can provide a framework for an inclusive pedagogy in early childhood education environments (Dunn, 2004; Dunn & Barry, 2004). The socio-cultural and ecological approaches that underpin *Te Whaariki* are in opposition to developmental, deficit discourses that compare, separate and individualise children as 'special', 'not normal' and 'other', and treat them differently as a consequence. It is the responsibility of those of us who work in early childhood settings to find ways of recognising the workings and effects of normalising/deficit discourses and to create settings where all participants are positively valued and treated with respect.

## References

- Allan, J. (1999). *Actively seeking inclusion: Pupils with special needs in mainstream schools*. London: Falmer Press.
- Barnes, C., Mercer, G. & Shakespeare, T. (1999). *Exploring disability: A sociological introduction*. Cambridge, UK: Polity Press.
- Bogdan, R. & Taylor, S.J. (1998). *Introduction to qualitative research* (3<sup>rd</sup> ed.). New York: Teachers College Press.
- Burr, V. (1995). *An introduction to social constructionism*. London: Routledge.

- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Sydney: Allen & Unwin.
- Cullen, J., Lepper, C. & Williamson, D. (2003). Professional development to support collaborative assessment. *Early education*, 33, 19-28.
- Cullen, J. Lepper, C. & Williamson, D. (2005). Exploring narrative assessment to promote empowerment of educators and parents of children with special educational needs. Paper presented at the International Special Education Conference, 'Inclusion: Celebrating diversity?' Glasgow, Scotland: Inclusive and Supportive Education Congress. Retrieved February 2008 from: [http://www.isec2005.org.uk/isec/abstracts/papers\\_c/cullen\\_j.shtml](http://www.isec2005.org.uk/isec/abstracts/papers_c/cullen_j.shtml)
- Cullen, J., Lepper, C. & Williamson, D. (2006). Checklists to narratives in special education: Learning stories used for early childhood teaching. *Australian Journal of Early Childhood*, 3(2), 20-30.
- Dahlberg, G. & Moss, P. (2005). *Ethics and politics in early childhood education*. London: RoutledgeFalmer.
- Davis, L. (1997). Constructing Normalcy. In L. Davis (Ed.), *The disability studies reader* (pp. 9-28). New York: Routledge.
- Drinkwater, C. (2005). Supported living and the production of individuals In S. Tremain (Ed.) *Foucault and the government of disability* (pp. 229-244). USA: The University of Michigan Press.
- Dunn, L. (2004) Developmental assessment and learning stories in inclusive early intervention programmes: Two constructs in one context. *New Zealand Research in Early Childhood Education*. 7, 119-128.
- Dunn, L. & Barry, S. (2004). *Inclusive assessment for children with early intervention support: Final report to the Ministry of Education*. Wellington: Learning Media.
- Edgar, A., & Sedgewick, P. (2002). *Key concepts in cultural theory*. London: Routledge.
- Ferguson, P., & Ferguson, D. (1995). The interpretivist view of special education and disability: The value of telling stories. In T. Skrtic (Ed.), *Disability & democracy: Reconstructing (special) education for postmodernity*, (pp. 104-121). Colorado, USA: Love Publishing Company.
- Fine, M. (1993). (Ap)parent involvement: Reflections on parents, power, and urban public schools. *Teachers College Record*, 94, 682-729.
- Fleer, M. & Robbins, J. (2004). Beyond ticking the boxes: From individual developmental domains to a sociocultural framework for observing young children. *New Zealand Research in Early Childhood Education*, 7, 23-39.
- Foucault, M. (1977). *Discipline and punish: The birth of the prison (2<sup>nd</sup> ed.)* Translation copyright: Alan Sheridan. New York: Vintage Books, Random House.
- Foucault, M. (1980). Truth & power. In C. Gordon (Ed.). *Michel Foucault Power Knowledge: Selected interviews and other writings 1972 – 1977*. The Harvester Press Limited: Great Britain.
- Gee, J. (1990). *Social linguistics and literacies: Ideology in discourses*. London: The Falmer Press.



- Gee, J. (2004). Discourse analysis: What makes it critical? In R. Rogers (Ed.), *An introduction to critical discourse analysis in education*. New Jersey, USA: Lawrence Erlbaum Associates.
- Graham, L. (2005). *The incidental "other": A Foucaultian interrogation of educational policy effects*. Paper presented at the AERA Conference, 11-15 April 2005, Montreal.
- Lather, P., & Smithies, C. (1997). *Troubling the angels: Women living with HIV/AIDS*. USA: Westview Press.
- Lyons, L. (2005). A place for everybody? Challenges in providing inclusive early childhood education for children with disability in Aotearoa/New Zealand. *The First Years/Nga Tau Tua Tahi: New Zealand Journal of Infant and Toddler Education*, 7(1), 16-20.
- MacArthur, J., Dight, A. & Purdue, K. (2000). "Not so special": Values and practices in early childhood education for children with disabilities. *Early Education*, 24, 17 – 27.
- MacArthur, J., Purdue, K. & Ballard, K. (2003). Competent and confident children? Te Whaariki and the inclusion of children with disabilities in early childhood education. In J. Nuttall (Ed.), *Weaving Te Whaariki: Aotearoa New Zealand's early childhood curriculum document in theory and in practice* (pp. 131-160). Wellington: New Zealand Council for Educational Research.
- Macartney, B. (2002). Maggie-rose: A parent's story. *The First Years/Nga Tau Tua Tahi: New Zealand Journal of Infant and Toddler Education*, 4(2), 29-31.
- Macartney, B. (2007). What is normal and why does it matter? Disabling discourses in education and society. *Critical Literacy: Theories and practices journal*, 1 (2), 29-41. Retrieved January 20, 2008 from World Wide Web:<http://www.criticalliteracy.org.uk/journal/table2.html>
- MacLure, M. (2003). *Discourse in educational and social research*. Berkshire, England: Open University Press.
- Mac Naughton, G. (2005). *Doing Foucault in early childhood studies: Applying poststructural ideas*. London: Routledge.
- Minister for Disability Issues. (2001). *The New Zealand disability strategy: Making a world of difference*. Wellington: Ministry of Health.
- Ministry of Education. (1996). *Te Whaariki: Early childhood curriculum. He whaariki matauranga mo nga mokopuna o Aotearoa*. Wellington: Learning Media.
- Ministry of Education. (2000). *Including everyone/Te re taataki: Meeting special education needs in early childhood*. Wellington: Learning Media.
- Ministry of Education. (2005). *Kei tua o te pae: Assessment for learning: Early childhood exemplars. Inclusive assessment (book 9)*. Wellington: Learning media.
- Oliver, M. (1990). *The politics of disablement*. New York: St Martin's Press.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. London: Macmillan Press Ltd.
- Phillips, N., & Hardy, C. (2002). *Discourse analysis: Investigating processes of social construction*. California, USA: Sage Publications.

- Purdue, K. (2004). *Inclusion and exclusion in early childhood education: Three case studies*. Thesis submitted for Doctor of Philosophy. Dunedin: University of Otago.
- Rogers, R. (2004). An introduction to critical discourse analysis in education. In R. Rogers (Ed.), *An introduction to critical discourse analysis in education*. New Jersey, USA: Lawrence Erlbaum Associates.
- Skrtic, T. (1991). *Behind special education: A critical analysis of professional culture and school organization*. Colorado, USA: Love Publishing Company.
- Skrtic, T. (1995). Power/knowledge and pragmatism. In T. Skrtic (Ed.), *Disability & democracy: Reconstructing (special) education for postmodernity* (pp. 25-62). New York: Teachers College Press.
- Tremain, S. (2002). On the subject of impairment. In M. Corker & T. Shakespeare, (Eds.), *Disability/Postmodernity: Embodying disability theory* (pp. 32-47). New York: Continuum.
- Tremain, S. (2005). Foucault, governmentality, and critical disability theory: An introduction. In S. Tremain (Ed) *Foucault and the government of disability* (pp. 1-24). USA: University of Michigan Press.
- Yates, S. (2005). Truth, power and ethics in care services for people with learning difficulties. In S. Tremain (Ed.) *Foucault and the government of disability* (pp. 65-77). USA: The University of Michigan Press.

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