# Developing inclusive school communities: voices of parents of children with disabilities

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#### **Abstract**

Inclusive Education as outlined in the Education White Paper 6 is a response to the widespread social, economic and political changes in South Africa, as well as a means of establishing a caring, humane and egalitarian society. The introduction of this policy will, however, require extensive changes in education, as the focus shifts from learners' adjustment to the demands of the system, to the system's capability to accommodate all learners' needs as inclusively as possible. This means that the collaborative effort of every role-player in developing the new system is critical. For the effective implementation of inclusive education, education legislation and policy stress the role and responsibility of parents, viewing them as integral partners in developing a more inclusive system, where decision-making and the responsibility for outcomes are shared. Parent-school partnerships that allow parents to become active collaborators rather than passive observers of their children's education should therefore be fostered. Although this issue has been addressed in the international context, in South Africa relatively little research has been done into inclusive education from the perceptual and experiential viewpoint of parents of children with disabilities. An understanding of these parents' experiences could contribute to a richer description of the nature of inclusion, could ultimately inform the process of involving parents as partners in developing both an inclusive education system and community, and could better facilitate collaboration between parents and schools. This article presents the findings of the pilot phase of a research project that aimed to uncover and understand the experiences of parents of children with disabilities who are in mainstream classrooms in South Africa. In answer to the research question, the findings of this study suggest that inclusion is a continuous and ongoing process that requires the development of collaborative relationships and support for all the role-players involved.

Key words: inclusion, community, parent-school partnerships

## **Introduction and Background**

Since the emergence of the new democratic South Africa in 1994 there has been extensive educational policy development and subsequent legislation. The final education policy paper, Education White Paper 6: Special Needs Education, Building an inclusive education and training system (July 2001), provides a framework for developing an inclusive system that acknowledges and respects diversity in learners and enables education structures, systems and learning methodologies to meet the needs of all learners, not just those with disabilities. Implementing inclusive education in schools demands the interactive participation of all role-players, including teachers, managers, parents, learners and community members. Recent education legislation and policy in South Africa recognises the role and responsibility of parents and emphasises their participation. Parents are key informants of their children and can be a vital source of support for them and the school. Parents are viewed as integral partners in developing a more inclusive system, where decision-making and the responsibility for outcomes are shared. In this article, we argue that an understanding of parents' experiences could ultimately inform the process of involving parents as partners in developing both an inclusive education system and community, and could better facilitate collaboration between parents and schools, thereby contributing to a richer description of the nature of inclusion. The purpose of this article is therefore to describe the experiences and perceptions of parents of children with disabilities who are included in mainstream schools. This article further argues the importance of listening to parents' voices in order to inform the development of inclusive school communities and, more specifically, parent-school partnerships.

Inclusive education is a complex concept that cannot be narrowly defined or interpreted as placing children with disabilities in mainstream schools or providing special education supports. Its complexity is evident when in the current literature it is described as being synonymous with a process of reform and restructuring of the school as a whole, with the aim of ensuring that all learners can have access to, and are active participants in, a range of educational and social

opportunities to achieve the highest possible quality of life (Mittler, 2000: 2; Sands, Kozleski & French, 2000: 5). This challenge is met when the values of inclusion, community, collaboration, democracy and diversity are embraced by everybody, and when "all children and members of the community have a future of fulfilled human and community potential, security, belonging, and valued interdependence leading to meaningful contributions" (Coots, Bishop, Grenot-Scheyer & Falvey, 1995 in Sands et al., 2000:5). Therefore, an inclusive school is concerned with valuing diversity and caring for all its members, rather than focusing merely on assimilation and mainstream placement.

Inclusive school communities have the potential to serve as the context for the creation of a system of education, and ultimately a society that reflects an emotional sense of community, caring and belonging. According to the Centre for Studies on Inclusive Education (in Swain & Cook, 2001:187) "an inclusive school is community-based: it is not selective, exclusive or rejecting, but open, positive and diverse". A philosophy of positive valuation and celebration of difference underlies the theory and practice of inclusive education. An inclusive school is not only characterised by barrier-free and accessible buildings and grounds, but also by appropriate curricula, support systems, teaching methods and means of communication that are adapted to meet the diverse needs of all learners. In order to make such changes, however, a fundamental reworking of a school's culture and ethos is required, involving aspects such as norms, values and attitudes, specifically attitudes towards diversity and human relations in the school community and management.

In practice, the creation of inclusive school communities requires attending to the rights of all learners, shared responsibility among all school professionals, changing organisational structures to promote collaborative decision making and creative problem solving, and necessary changes in existing professional roles and school practices. These changes rely on the new ways that relationships are formed between all members of the school community while they learn to think, feel and be together in innovative ways, so that the rights of all learners are ultimately acknowledged. One such relationship that has received renewed attention in recent international publications, and that is essential for the implementation of inclusion, is the relationship between parents and the school community (Mittler, 2000:151-170; Garrick Duhaney & Salend, 2000; Grove & Fisher, 1999; Bennett, Lee & Lueke, 1998). In South Africa, the critical role that parents<sup>1</sup> are required to play in the education and development of learners has officially been recognised in new legislation and policies, such as the SA Schools

Act (1996), the National Plan of Action for Children (1996) and the White Paper 6 (2001). Even though the philosophy and values of inclusive education are embedded in our constitution and emphasised in all policy documents, and even though the role that parents of children with disabilities can play in implementing inclusive education is stressed, the perceptions and experiences of parents during this introductory phase of implementation have yet to be fully considered.

Listening to and attempting to describe parents' experiences is necessary for a number of related reasons. Parents, as a vital system in any school community, are valuable informants about their children and are able to provide information about the nature of their children's disabilities. Their experiences of including their children in mainstream schools continuously help to deepen their insight into their expectations of an inclusive school. In this manner they contribute to further clarifying what inclusive education is and what it is not, informing the nature and development of parent-school partnerships – a new type of relationship in schools. The resulting understanding is relevant to a systems view of human behaviour, which highlights the interaction and interdependence between the child, parent and school community. As early as 1974, Bronfenbrenner (in Garrick Duhaney & Salend, 2000) reported that intervention strategies that involve parents provided more gains for children than those that do not.

## Research design

# Purpose of the study

This article presents the findings of the South African pilot of a collaborative research project between inclusive education researchers of three South African universities and two American universities. The study aims to explore, understand and document the experiences and perceptions of parents of children with disabilities who are in mainstream schools in the Gauteng and Western Cape provinces of South Africa.

#### Method

We adopted Morse and Richards' (2002:2) explanation of the concept *method* as the "collection of research strategies and techniques based on theoretical assumptions that combine to form a particular approach to data and mode of analysis". The purpose of this study, and the type of data required to answer the question appropriately, demanded a qualitative approach, because we aimed to

achieve a deep understanding of how the participants of this study experienced the inclusion of their children in mainstream schools, of the meanings they attached to inclusive education and of how they interpreted what they experienced (Merriam, 2002:4; Leedy, 1997; Morse & Richards, 2002:28). Qualitative methods provide researchers with a certain kind of knowledge and with tools to organise and make sense of messy data. Morse and Richards (2002:10), however, stress the essential coherence between the research purpose, research question, the choice of method, data collection, data analysis and the way in which the theoretical outcome is judged. Based on these principles, we designed a basic interpretive qualitative study that focussed on understanding meaning that was mediated by a researcher as primary instrument. The strategy was inductive and the outcome of the study descriptive (Merriam, 2002:6). The emergent and collaborative nature of the design added a dimension of reflexivity and opportunities for multiple voices to be heard. It gave us the freedom to participate in the world of the individuals in order to learn from them and from each other, and enabled us to refine the research focus and strategy in process (Eloff, Engelbrecht, Swart & Oswald, 2002). We did, however, formulate a clear purpose and an appropriate data-management and analysis protocol at the outset (Morse & Richards, 2002:3), something especially necessary to enhance the research teamwork.

## Context and Sample

The unit of analysis of this study is parents of children with disabilities in mainstream schools in the Western Cape and Gauteng provinces of South Africa. We purposefully selected 15 parents as "information-rich cases" that would enable us to learn more about the focus of the study (Merriam, 1998:61). According to Spradley (in Morse and Richards, 2002:173), good informants are those that know the required information and that are willing and have the time to participate and share this information (Spradley in Morse & Richards, 2002:173). The more specific selection criteria included the following:

- (a) the child of the participants must have a disability,
- (b) the child must be included in a mainstream school, and
- (c) the child must have attended the school for at least one year to ensure that each participant had appropriate knowledge and experience of inclusive education.

Principals, district personnel and support groups identified the participants and they were then contacted telephonically to explain the project, obtain consent and arrange for the interviews, which was the chosen method of data collection.

We did not deliberately choose parents who were in favour of inclusive education, to allow for a range of experiences and understandings to emerge.<sup>2</sup>

The participants were the parents of children with a range of disabilities from urban schools. Other than one maternal grandmother, who was the child's primary caregiver, all the participants were the children's biological mothers. The children included 7 girls and 9 boys between the ages of 7 and 13 years. Thirteen of these children have been in mainstream schools since grade one, while three were in special education for a part of their school career. Table 1 provides a summary of the participants' children and the nature of the children's disability.

Table 1 The children of the participants of the study

Child <sup>3</sup>	Nature of child's disability	Placement information
I.1 Abbey <sup>4</sup> (Girl, 13 years)	Spina Bifida Mobility impaired, catheter	Grade 7 Special school grades 1 – 4 Mainstream since grade 5
I.2 Mary (Girl, 12 years)	Acquired brain injury Right-side affected, speech	Grade 6 Mainstream school grade 1 Special school grades 2 – 5 Mainstream since grade 5
I.3 David (Boy, 9 years)	Duchenne's Muscular Dystrophy	Grade 3 Mainstream since grade 1
I.4 Sean (Boy, 10 years)	Downs syndrome	Grade 2 Mainstream since grade 1
I.5 Bonita (Girl, 9 years)	Spina Bifida Shunt, incontinence	Grade 4
FG.1 <sup>5</sup> Annie (Girl, 8 years)	Trisomy 14 (MOSAIC), Brain damage, developmental delay, Hepatitis B	Grade 1
FG.1 John (Boy, 12 years)	Tourette's Syndrome Behavioral, social and learning problems	Grade 5 Mainstream since grade 1
FG.1 Jean (Girl, 9 years)	Spina Bifida Catheter, mobility, shunt	Grade 4 Mainstream since grade 1
FG.1 Frances (Girl, 11 years)	Growth impairment Memory impaired, learning problems	Grade 2
FG.1 Will (Boy, 11 years)	Specific learning problems	Grade 6

FG.1 Simon (Boy, 14 years)	Specific learning problems Visual impairment	Grade 7 (repeated grade 2)
FG.2 Lawrence (Boy, 8 years)	Downs Syndrome	Grade 1 Grade 2 for Life-skills
FG.2 Paul (Boy, 7 years)	Downs Syndrome	Grade 0
FG.2 Andrew (Boy, 13 years)	Downs Syndrome	Grade 4 Special school grade 1 Mainstream since repeating grade 1
FG.2 Audrey (Girl, 7 years)	Downs Syndrome	Grade 1
FG.2 Chris (Boy, 10 years)	Downs Syndrome	Grade 3

#### Data Collection

Data were collected by means of five unstructured, interactive individual interviews and two focus group interviews, participant observation and document analysis. These methods assisted us in acquiring a range of information about the parents' experiences of including their children in mainstream schools, as well as the nature of their children's disabilities (Krueger & Casey, 2000:24).

Unstructured, individual interviews were conducted with the parents of Abbey, Mary, David, Sean and Bonita (referred to as I.1 - I.5), in order to obtain their personal views and experiences as parents of children with disabilities included in mainstream schools (Kvale, 1996:105). They were familiar with the general subject matter before the interview was conducted. The participants were interviewed in the privacy of their own homes while their children were at school, each lasting one-and-a-half to two-hours and tape-recorded in preparation for analysis. The *grand tour* question of these interviews was, "Tell me about your experience of including your child who has a disability in a mainstream school." We, in our capacity as the researchers, encouraged the participants to tell their own story and asked an occasional question for clarification. We, however, also asked specific questions when the participant had finished speaking and hadn't volunteered all the information we required. This included information about the placement process, the kinds of things that had happened since the placement,

the adaptations and accommodations that the school had made for the child and the reactions of the child's peers and siblings.

The two focus group interviews consisted of five participants each. The one interview was conducted at a school at a time that suited all the parents, and the other took place after a monthly regional meeting of the Downs Syndrome Association. The latter is what is typically referred to as a 'piggyback' focus group, because participants gathered for another purpose and were therefore available for the interview (Krueger & Casey, 2000: 75). (The one group was therefore more homogeneous in terms of the type of disability than the other.) The researchers developed an interview schedule that guided these interviews. The focus question of the schedule was: *Tell us about your experiences as parents with regard to your child's inclusion in a mainstream classroom and school* ... As group facilitators the researchers introduced the questions and ensured that every participant had the opportunity to participate in the conversation, and also stayed on the topic (Krueger & Casey, 2000: 9). These interviews were also tape-recorded and transcribed

The secondary data sources included documents as well as field notes of our participant observation. Documents that were analysed as supportive data included a biographical questionnaire about the child and the family, and in some instances copies of relevant reports. The different types of field notes used in the study included expanded field notes of our observations during the interviews, as well as fieldwork journals that contained reflections about the data and emerging themes during data collection and analysis. Both these types of field notes were also supportive of the interview data.

## Data-analysis

Data-analysis is the process of obtaining sense from the data (Merriam, 1998:178). The data of this study were analysed in process, which involved continuously organising and refining units of meaning. The constant comparative method developed by Glaser and Strauss (1967; in Merriam, 1998:159; Morse & Richards, 2002) was employed to analyse the data of this inquiry. We read the first interview as a whole, while we made notes of the most striking aspects related to the purpose of the study in the margins. In this way, we compared one unit of information with the next and identified recurring regularities in the data. Before proceeding to the next transcript, we reviewed margin notes and consolidated them. We followed this process with all the interviews while, at the same time,

we remained open to new insights. After working through the entire corpus of data, we constructed themes by grouping those comments or units that seemed to belong together. The regularities became the themes into which we sorted the succeeding items. We continued with this process until a point of saturation was reached (Krueger & Casey, 2002:26).

The questionnaires and field notes, as supportive data sources, were mainly analysed to describe the participants, establish the nature of the children's disabilities and to confirm the main themes. For these purposes the constant comparative method of analysis was also implemented.

### Validity and reliability

Research should be rigorous and credible. The achievement of reliability involves ascertaining whether the results are consistent with the data and not that the same results be obtained should the study be replicated. Closely related to this is the achievement of internal validity, which questions how research findings match reality. Strategies to enhance reliability and internal validity included the following processes: the use of appropriate sampling techniques, pre-testing the interview schedule, a comparison of researchers' analyses, the building of a trail of evidence, working within a research team and the use of member checks (Eloff, Engelbrecht, Kozleski, Oswald, Swart & Yssel, 2002; Silverman, 2001:229; Morse & Richards, 2002).

#### Themes and sub-themes

The results of this study indicate that the participants experience the inclusion of their children in a mainstream school as a dynamic process that impacts on all the role players and that, therefore, requires the development of collaborative relationships and support for everyone involved. The remainder of this section describes each of the identified themes and sub-themes in greater detail. Although these themes and sub-themes appeared to be mutually exclusive, clear relationships seemed to exist between all of them.

## Placement process and concerns

The focus of this theme is the process these families underwent in making decisions about the most appropriate school placement for their child as well as the actual placement process after the decision had been made. The most striking aspect

of this data was that the situation of every child, and therefore of every parent, was unique.

At the time of the study, the time these children had been in mainstream education ranged between one and seven years. Some were at special schools for part of their school career before they were eventually included in a mainstream school, while others were purposefully already included in their pre-school years in order to prepare them for their school years. While some of these parents could choose between special and mainstream education, other parents, due to limited educational provision, finances and information, did not really have any other choice than to place their children in the mainstream. The placement decisions parents made therefore varied from "mainstreaming by default", to integration, where the option of placement elsewhere was still open *if the child did not succeed in adjusting to the school system*, to successful inclusion, where the parents and the school successfully learned to accommodate the child together.

A significant theme in this research is the **parents' motivation** for placing their child with a disability in a mainstream school. Parents consistently referred to their desire to raise their children as "normally" as possible - to learn *of* the world *in* the world. Two of the parents whose children were initially in special education explained their motivation in these words:

"What does she do if she stays there until she is in matric and she is brought up like that? Then she leaves and she must suddenly *cope with the real world?* And I just felt that I would prefer it if we went through the traumas now, that she can learn now how to 'cope'..." (I.1, 134 – 138 own italicisation).

"Because, *I cannot hide my child away*, she must learn...it does not help if we keep her locked up for eighteen years and then all of a sudden I say to her, there's the world, now you must find a place for yourself (I.2, 167 – 170 own italicisation).

These parents were of the opinion that their children had to learn to manage the demands of society in a school that would not ostracize, pity or exclude them (I.1, 480-482, 787 - 789; L.2, 303 - 304; I.4, 273 - 275), but that would accept them as individuals, and give them the opportunity to develop their own potential at their own tempo in their own unique way:

"He must be a pupil of this school and he must work hard. And if there's rules that he must obey them like all the other kids, he must also do that. *Don't let him be there for the sake of him being there* ... there is your chair, sit down and keep quiet ..." (FG.2, 501 – 506 own italicisation).

At the same time, some parents also wanted to influence society's views on disability: "We did the right thing, because the world must see them" (I.2, 526). These parents felt that their children had the right to have a place in society, to attend the same neighbourhood school with friends and to participate in the same community activities:

"And that's actually where we need to start, is at the ... in our environment, our neighbours, our community, our church ... And why shouldn't they be included? They've got a right, just as ... Just like ... yes. But it's the past. We sit with the burden of the past, that people put their kid in an institution and nowadays we don't do that anymore" (FG.2, 812–817; see FG.1, 591-592).

In the cases where parents could make a choice, the **process of placement** took place in a different way, due to the unique circumstances of every child. A prominent theme that emerged was that some children were unconditionally admitted to mainstream schools, while others were initially 'admitted' for a trial period:

"Look, they naturally said to us that there is a three month trial period *to see* whether she can become part of the group or not. ... You know, even though I went into it with so much faith that it is going to work, you know, you are half holding back, you are now not sure if it is going to work or not" (I.1, 270 – 278, own italicisation).

The school principal played a major part in the admission of all these children. He usually first had an interview with the parent/s and in some cases also with the child. Before admission, parents provided the principal with as much information as possible and also discussed specific concerns. The majority of the parents were especially concerned about their children's acceptance from peers and teachers and were also concerned about whether their children would be able to cope with the work tempo and work pressure.

Not one of these parents took the decision of school placement for their children lightly. They described the consideration as a "difficult decision" (I.2, 787-789)

and a "gamble"(I.1, 41-43, 168, 649) "... because you can either make or break your child by forcing him into such a situation" (I.2, 787 – 789). These parents' typical fears are clearly expressed by the following parent:

"I think the main worry when you put your child in inclusive education is, how are the teachers going to cope, how is he going to cope, your own child? Is he going to cope, is he going to be happy? And what are the other children going to do with this child in school?" (FG.2, 350 - 353).

After placing their children in mainstream education, at least a year later some of these parents still experienced anxiety and concern about the decision. During one of the focus group interviews, two parents stated that, "as a parent you worry a lot and you question yourself as to your doing the right thing" (FG.2, 464 - 466) "And, ja, you'll never know if you are doing the right thing or not" (FG.2, 375 - 376).

The impact of inclusion on parents and siblings

Inclusion impacted on parents and siblings in a variety of ways, demanding their involvement and commitment, as well as supportive relationships between the parents and the school. In addition, a further characteristic of the inclusion process is the parents' feelings of uncertainty about the future of their children's lives.

It became evident that the placement of a child with a disability in a mainstream school does not guarantee inclusion. The education of this child, especially as it relates to the inclusion of the child, places specific demands on parents. The inclusion process demands **involvement and (extra) dedication and commitment** from parents. A parent expresses the hard reality as follows:

"I think parents must also not expect that this child is going to be made a fuss of. But that is sometimes just what they expect. Do they want their child to be protected in a safe situation or do they want their child to learn to..., I think a parent must be reasonably level-headed about this ... can you, do you see your way clear to help your child adapt in a normal situation? Because I do not think it is going to be successful if the parent is not involved. And you can only be involved if you make a commitment. So yes, I would say commitment is certainly the most important thing. You cannot think, 'okay the school must now just simply do it' and leave the child to it. That is not going to work" (I.1, 657 – 668)

The commitment that is required from parents comprises involvement and extra sacrifices. In this regard, one of the parents states that, "we as parents have to walk the extra mile" (I.1, 692). This affects them financially, socially and emotionally. These parents were all responsible for bearing the costs of extra help, such as physiotherapy, speech therapy and occupational therapy, as well as extra classes, which in some cases took place during school times, but mostly after school (I.1, 452 - 454; FG.1; FG.2; I.4,19 - 20). There were also parents who could not afford this extra help/assistance so their children had to manage without it (FG.1, 446 – 447).

The responsibilities and input of these parents also had an impact on the social and emotional welfare of the whole family. One of the parents explained that, "Where previously we could do more things together, we now do therapy together ... socially, you also withdraw yourself. We are so busy, then comes the weekend, then I do not want to see people, I just want to rest, I just want time for myself" (I.2, 838 – 839, 876 – 879). In addition, parents are continuously enveloped in processing and facilitating feelings and experiences of the disability. This does not only include their own feelings and experiences, but also those of their child, and those of their child's brothers and sisters, grandparents, teachers and the broader community. Nonetheless, parents seem to reformulate the situation. They deliver a very strong plea to society to look beyond the 'burden' of living with a child with a disability and rather to recognise the uniqueness of their child, (as the case would be with any other child), as well as the enrichment the child brings into the families' lives.

For everybody the process of inclusion was a learning process. It was interesting how frequently the parents made use of the words *learning* and *process*. One parent explained the process in this way: "So, there are answers, but these are the answers that we need to work through, what people need to learn, what you must learn to make life for her as normal as possible" (I.1, 438 - 441). They sometimes had to learn to manage the inclusion process from day-to-day and step-by-step (I.3, 81 - 82; I.1, 745 - 747). These searches for answers were not always easy (I.2, 246) and were often painful (I.1, 520 - 521). All these parents actually established a clear image of commitment and perseverance, and decided that they would not "just lie down flat" (I.4, 183) but that they would learn from the situation and make the best of it.

The participants in this study referred to specific **supportive relationships and strategies** that they learned to make use of in the process of including their

children in order to support this inclusion. These strategies must be viewed in conjunction with parents' educational objectives for their children. These objectives included socialisation, self-reliance and independence, and thus related to normalisation. One of their first strategies was to prepare the child for the placement (I.1, p. 23-24). This preparation included placement in Grade 0 at the chosen mainstream school so that the child could gradually become familiar with the school, spiritual preparation and physical orientation of the school terrain. At the same time, the majority of the parents informed the principal and the teachers as comprehensively as possible about the child's disability.

One of the strongest themes that emerged during the course of this investigation was the importance of parents actively working together on the development of a mutual, supportive, open relationship with the school and the teachers. The school's willingness to accept the child does not ensure that all teachers will have positive attitudes. Therefore, parents were in agreement that "... the most important thing is the teacher and parent relationship ... to get the Headmaster on your side ... and ... the school must know you are there for them" (FG.2, 429 - 440).

These parents learned from experience that regular, honest communication and a problem-solving approach promoted the welfare of everyone involved with the child. The majority of parents were of the opinion that it was parents' responsibility to keep abreast of the progress and adaptation of their child at all times, and to find out how and where they could be of assistance, because, in the words of one of the parents, "it is ultimately in the interest of the child" (FG.1). Ways in which the parents communicated with the school included the following: a notebook for communication (FG.1, 400 - 401, 502), seeing the teacher regularly at the school (FG.1, 382 - 384), attending parents' evenings (FG.1; 15, 234), writing a letter or phoning (FG.1, 457 - 462; 1.2, 100 - 100, informing new teachers about the child's learning needs and attending regular group discussions with therapists and the teacher (FG.2, 100 - 100).

Parents also shared specific supportive strategies that were beneficial to their child's progress. On a daily basis, after school, all the parents helped their children with homework and this usually took them longer to complete than it did their peers. In some cases, parents had to repeat class work for the sake of consolidation, or had to assist their children with catching up with work that they could not complete in class (FG.2, 1052 – 1056; I.1; I.2). A few of the parents supported the teacher in the classroom so that she had time to work with their children

individually. One was a trained teacher who adapted her child's class work and set his tests for two consecutive years (FG.2, 323 – 327, 1007 – 1049, 1197 - 1206). Another parent appointed a classroom assistant at her own cost to help the child in the class (FG.2, 287 - 300), while another drove to the school at least once a day to help her child up the stairs and to carry her school case up and down (I.1, 244-246, 356-398). Not all the parents could afford these forms of support and had to get by with homework support only.

These support strategies did not work in all situations. In cases where teachers professed to be positive, but actually displayed passive resistance towards including the child, parents felt disempowered: "... if she's make-believe positive ... if she's like that, then you don't know how to react to that as a parent" (FG.2, 487 – 496, 509 – 513; also see FG.1, 322 - 323). This perceived power relationship paralysed some parents, but others viewed it as a challenge to empower these teachers. These latter parents approached the teachers' resistance and aggression with an attitude of understanding and empathy. They displayed an understanding of the fact that teachers do not necessarily possess suitable training and knowledge to deal with disabilities in a classroom and that, on top of this, they had to work with large classes (FG.2, 642 – 672, 733 – 739; FG.1, 304 - 306). In virtually all these cases, it was the mothers especially who played a very strong role as advocate for their child (FG.1, 714; I.1, 356-398; I.2; I.3; FG.2), taking the lead in the placement decision process, in support of the child and in communication with the school, albeit of the opinion that both parents had to agree on the first two of these (I.1; I2, 269 –270).

It was also significant that the majority of these parents shared a special relationship with the children in tune with their needs and progress and offering personal support where necessary. It was sometimes necessary for parents to work through difficult situations that the child had experienced, with the child. These situations included derogatory remarks made by friends and failures that the child experienced in the class. Parents were then required to encourage them when they became despondent (I.1, pp. 6 & 7, 468 - 472). In general, these parents had to go out of their way to nurture friendships with the peer group, by informing other parents about their child's disability and by making a special effort when children came to visit, because, as one of the parents stated, their children with a disability, "are in other ways just like any other child".

Whether it is the start of a new school year or the arrival of a new teacher, , the onset of every one of the child's development phases causes parents to experience

uncertainties about the future once again. Besides the abovementioned uncertainty parents experience about the permanence of their child's placement, parents are also especially concerned about the selection of a high school that will be prepared to accommodate their child. Over and above immediate concerns, parents are also concerned about their children's welfare when they themselves are no longer there. Parents who are able to afford it, already start to make financial provision for the child's future (I.2), while others make arrangements with family to care and provide for their child if it should become necessary (FG.1, 147 – 150).

Even though it was not a strong theme in relation to the research question, most of the parents referred to the impact that the inclusion of their child with the disability had on **siblings**, for whom the inclusion process was also one of adjustment. Initially some of the siblings felt embarrassed because they overheard the comments made by others at school and they did not always know how to answer the questions they were asked by the other children. However, as one parent reported, all that was required was a bit of information: "Just needed that bit of information, just how to deal with that situation, and then I realised the reason why she has become so quiet because everyone is coming to ask her now 'What is wrong with your sister?'" (I.1, 1082-1085). Where both the child with a disability and the sibling attended the same school, the latter frequently fulfilled a supportive role and accepted responsibilities for tasks that the latter could not perform independently. According to one parent, "...you've got to ask the brother to help with everything. He's got to help him undress at school for after school ... and sometimes he doesn't want to do it all the time." (FG.2, 1310-1313).

#### The role of the school

In various ways, the school played a crucial part in the inclusion of each of these children. The parents made specific mention of the role and attitude of not only the principal, but also the teachers and the peer group, the manner in which their child was accommodated and supported in the school, and the reactions of the broader school community.

The **principal** played a significant part in each of these children's placements. The majority of parents experienced considerable resistance from school principals before their child was eventually placed by an accommodating principal (FG.2, 792-801). The principal was usually the first contact person at a school and, in some cases, unequivocally stated that children with disabilities were not admitted.

The reasons given by these principals were related to issues such as the training of teachers, class sizes, inaccessible school buildings and other parents' and teachers' reactions. It therefore appears that these principals did not know exactly what inclusive education is.

This attitude was in direct contrast with the principal's attitude and role at the school where the children were eventually placed. One of the salient characteristics of the school that promoted inclusion was the principal's philosophy that all children belonged in the school. One of the principals addressed one of the parents in this manner: "Mrs. Brown, even if your child must come with a 'nappy' or 'kimby', you bring her. She belongs here" (I.5, 153 – 155; FG.1, 75 - 76). Parents also made mention of principals' invitational and accepting attitude from the first day of meeting (I.1, 113-114; I.2, 106 - 107). They said that these principals also displayed "an understanding for these children" (I.1, 409) and that they were prepared to make adjustments to accommodate the children with disabilities (FG.2, 601 - 639; I.1, 411 - 437; I.4, 504). Generally, parents experienced that the school principals were aware of their child's circumstances in the classroom (FG.1, 457 – 460) and that they monitored their child's progress. These qualities in principals facilitated communication with the school, because the principals were accessible (I.2, 287 – 292; FG.1, 463) and frequently assumed the role of facilitator and mediator between teachers and parents (I.2, 287 – 292; FG.1, 463). It therefore appears that the school principal played a significant role in the changing of attitudes and practices of accommodating children with disabilities in mainstream classrooms (I.1, 491 – 492).

Parents were in agreement that the **teacher's disposition and support** was fundamental in the successful inclusion of their children. It was significant that parents had diverse experiences with teachers, even from the same school. The inclusion of these learners was a first experience for all the teachers. Consequently, everybody was initially uncertain and doubted their ability to implement inclusion. Certain teachers were positive and accepted responsibility for their own learning. Others kept up a positive front, but did not make any adaptations in the class. In contrast, some other teachers were openly negative initially, but underwent a change in attitude during the course of time. A few other teachers remained negative.

With regard to the positive teachers, who were willing to accept responsibility for their own learning, one of the parents made the following statement: "When the teacher is positive ... as a mother I don't worry so much" (FG.2, 469 - 470).

She explained her inner peace in the following way: "The first day of school the Grade 1 teacher said to me I mustn't worry because she's got all the stuff on the internet and her husband bought her some books on inclusive education, so she was very well prepared" (FG.2, 887 – 891). The parents were of the opinion that teachers do not need to know everything from the start, "but you need to be prepared to learn ..." (I.1, 445). Teachers who were prepared to learn and change their practices in order to better accommodate the child were, amongst other things, prepared to accept the advice and help of parents and other professional people (I.3, 875 – 878, 902 – 908; FG.2, 330 – 340; FG.2, 488 – 491; FG.2, 629, 994). These teachers usually read everything about the children in their personal files (I.3, 273) or allowed parents to come to school in order to keep up with the child's progress at school (I.5, 160 - 172). They also shared this information with other teachers.

There were parents who, during the process of inclusion, also had experiences with teachers, "who were not interested ... and ... not really in the mood for extra hassles" (I.4, 483 - 484, 395 - 396). Such teachers usually did not make any effort to obtain information about the child, were not prepared to see parents except at parent evenings, provided no feedback about progress, except by means of the usual reports and left the child, "... to get on with it on his own" (I.4, 269 - 273). A few of the teachers were not prepared to accommodate the child or to make any adaptations at all.

The **peer groups** of these children were largely supportive, in one case a parent stating that "the children help her a lot" (I.2, 562). For example, they helped to pack and carry bags and suitcases (I.1, 499; I.2, 146 - 147, 583 - 592; I.4, 131), to draw straight lines (I.2, 562 - 563) and write down homework (FG.2, 1097 - 1101). In most cases this support developed naturally, but in one a "buddy" system was created in the class where children took turns with the above-mentioned tasks (FG.2, 1113 - 1136). This small group of peers were very proud because they taught the friend with Downs syndrome to walk down the stairs (FG.2, 1459 - 1463). Some parents were of the opinion that the other children no longer noticed the disability because they learned to adapt to it (I.2, 260 - 264; I.4).

Despite this apparent support and acceptance from their peer group, children with disabilities occasionally had disturbing experiences with individuals from within it. There were occasions when they were ridiculed (FG.1, 113 - 118, 676) and teased (I.5, 207 - 226, 671; I.3, 957), because they were different. In two separate cases, for example, a member of the child's peer group applied a lot of

pressure on the rest of the group by purposefully and openly excluding the child with the disability during group work. One of the parents described one of these incidents and her child's reaction as follows: "And then this one says, ag yuck, not with Abbey, you do not want to lend Abbey's stuff, you do not want to talk to her... and then the children laugh... and that upsets Abbey dreadfully..." (I.1, 592 – 610; also I.2, 157). In some cases, parents and teachers intervened and spoke to the child's friends and then such an incident did not occur again. Nevertheless, parents seem to possess wisdom in this regard and this is consistent with their reasons for including their children in the mainstream, namely, "They do say things and you feel like you want to cry and you, you don't know what to do, you're so helpless, but that's always going to be there ..." (FG.2, 1301 – 1303).

The majority of the parents referred to **specific adaptations and support** in the school and classroom that were or could be effective to address the unique needs of the child. These adaptations were specifically concerned with needs related to incontinence, work tempo and academic, physical and social skills. Parents suggested the following strategies:

- Adapt the curriculum In one case, a child with Downs syndrome was with
  the Grade One class for the first half of the day for Literacy, but spent the rest
  of the day with his peer group in Grade Two for Life Skills (FG.2, 60 62, 269
   278). In another case, the themes of the Grade Four curriculum were
  simplified, printed in a large letter type and illustrated with pictures to address
  the learner's needs. Due to the fact that this child also struggles with figures,
  he is, in contrast to other pupils also allowed to use a pocket calculator when
  they do mathematics (FG.2, 973).
- Make provision for more time or adapt the task requirements. As is apparent later on, a very strong theme that emerged was related to children's problem with the work tempo in class. These children get tired quickly and struggle to complete work in class. Consequently they have to catch up work at home in the afternoons in addition to completing homework. For this reason parents make several suggestions. These include that children be provided with more time for tests or exams (I.3, 674 679; I.2, 315 316; I.3, 674 679), that the volume of work be reduced if the child demonstrates that he knows the work, that another child's class work be photocopied if the child experiences problems with writing down the work in class (parents are prepared to pay) (I.2, 306, 416), that essays are typed instead of written (I.2, 419 427), and that children with a speech defect be provided with more time for oral work.
- Adapt bathrooms A number of these children experience problems with incontinence but learned to deal with them independently. In one case, a

bathroom was adapted to meet the child's needs and to ensure privacy. The child had her own key for the bathroom and made use of it every break in order to prevent embarrassment in class (1.1, 235 - 243).

• Be patient and adaptable - Sometimes it is necessary to stop and to listen, to wait if a child is slower than others, and to repeat work that they do not understand immediately (I.3, 372, 762).

All parents agreed that inclusion can work if the necessary adaptations are made and that, despite a few problems, it is worthwhile. It is evident that for inclusion to succeed every role-player must be prepared to learn and to make adaptations so that many more children than just the child with the disability are ultimately able to benefit.

The reaction of the other parents and the broader school community towards including children within disabilities in mainstream schools was a theme that many parents referred to. Most did not experience resistance from other parents who "were very much at ease with the situation" (I.2, 535 – 536; I.3, 480 - 481). At the same time, however, they did not receive support, because, in one parent's words, "you're part of the school community, but actually you're still on your own" (1.2, 6-7). Some took the initiative to speak to the other parents about their child and about inclusion, one speaking at a parents' evening and telling other parents about her child (I.1), while another held an information day to inform parents and other children about Downs syndrome (FG.2). In the child's residential vicinity, where people know the child, the majority of parents experienced that both adults and children accepted their child. Their children do, for example, go to neighbouring friends' parties and other children do invite them to play (I.4, 562 – 572; FG.1; FG.2). This accepting response is, however, in direct contrast to the reaction of the wider community that does not know the child personally. Parents experience that people stare (FG.2, 357), make comments (FG.1) or avoid making direct contact by talking to the parent and not to the child (I.2, 178). In addition, these parents were completely unaware of other parents in the same school who also had a child with a disability. The majority indicated that they had a need to talk to other parents in similar situations, but that any such support group must be neither too formal nor demanding.

The parents' experience of inclusive education is consistently shared through the filter of their own child's experience. Therefore, it is also important to acknowledge the impact that the process of inclusion has on the child with the disability.

The emotional and social impact of inclusion on the learner with the disability

These parents wanted their children to lead lives that were as normal as possible and were therefore prepared to act as advocates for them. Due to the fact that the move toward inclusive education is a new movement in South Africa, parents began the process with the knowledge that "their child (must) walk the road in order to help another child" (I.2, 13 – 14). The process placed specific demands on the parents but the demands it placed on their children were even greater, notably those related to **adjustment processes that the child went through,** the **unique challenges of inclusion** and **friendships.** 

In the beginning, all children went through an **adjustment period**, with experiences unique to the nature of the disability, the child's personality and the nature of the school context. One child with cerebral palsy and a resulting speech defect had initially struggled in the mainstream context, because she worked very slowly and struggled to express herself comprehensibly. In the beginning, until the teachers acquired suitable strategies, they were not able to understand her very well and this resulted in a lot of tension at home and at school (I.2, 109 - 138). Also, in the other cases, the school first had to get to know the needs of the child, before they could create a learning environment in which the child could adjust easily. It seems as if a few things had to go wrong initially so that everybody could learn to manage the situation more efficiently.

A very interesting theme was the exceptional **determination and self-perception** of these children. According to their parents, they did not view themselves as being 'disabled' (I.2, 122; I.3; I.4). Significant aspects of their determination included, amongst other things, their purposeful attempts to participate in extramural activities. A few, for example, participated in activities such as the Eistedfodd, entrepreneurs' markets (I.2, 123, 140 – 142), mini-cricket, school concerts and swimming (FG.2, 220 – 232). Other significant aspects of their determination included their ability to stand their ground where necessary, their attempt and will to function independently and their capacity to accept responsibility for their limitations. They also had the ability to defend themselves when they felt offended and people did not consider their limitations (I.1, 223 – 224). The mother of a child with muscular dystrophy, for example, stated that, "He speaks his mind" (I.3, 394 – 395, 953). When friends become impatient because he can no longer kick the ball as well as they can, as a result of his degenerative condition he says, "I am not made of porcelain" (I.3, 402 – 407). He explains that although his muscles work differently from theirs (948), he can still kick and play with them. He also stood up in front of the whole class and explained what muscular dystrophy is and what awaits him (I.3, 440 - 445). He also knows when he must rest and says it very discretely when it becomes necessary (I.3, 239). These children therefore appeared to possess a will to be independent and to do things for themselves (I.2, 666 - 668; I.5, 186). They displayed resilience to the demands that inclusion places on them.

Even though every child's situation is unique and even though experiences cannot be generalised, these children still experience similar **challenges** related to school in one form or another, including the pressure that is placed on them to achieve, the fast tempo of work, fatigue, mobility limitations and the extra support that they require during and after school. Although these challenges have been discussed separately, their interaction cannot be underestimated.

All these children experienced *pressure* to achieve to a greater or lesser degree. Parents were realistic about these pressures and made remarks like, "He has to feel the pressure and he has to deal with it ..." (FG.2, 394 - 395), but they also realised that too much pressure can result in their child becoming bewildered (I.3, 801 - 802). A parent of a child with Downs syndrome was concerned about this aspect of things and with regard to her own child stated that:

"Every year has become more of a challenge having Chris in mainstream inclusive education and especially this year the standard set is very high, the pressure is high, the volume of work is high. We try to keep him doing as much as what the other kids do, but find that there's a lot of things that he just can't cope with" (FG.2, 82 - 88).

It is common that these children tire easily from the physical effort of schoolwork and that they are not able to play and work at the *same tempo* as the others in the class (I.3, 725 - 727, 78; I.1, 282 - 285; I.2, 134; FG.2, 1149; FG.1, 179 - 181, 183). This causes them to fall behind in class with the result that they sometimes have to sit for hours after school to catch up outstanding work and to complete homework. Then their work is not always neat and they also make unnecessary errors in the process (I3, 686 - 695). Parents were of the opinion that, consequently, they did not have any time for playing because they sit "here for hours and hours and hours..." (I.2, 134; I.1, 542).

The *limited mobility* of many of these children also placed high demands on them, especially in negotiating stairs (I.3, 344, 499, 508) but, as one parent

remarked, they had to live with it. A few of these children fell easily (I.3, 250; I.1, 247 – 248) and therefore had to be careful all the time, and most walked slowly while moving from one class to another so had to learn to accept help from others and to process embarrassing situations when they did fall in front of others.

Another challenge that also had an impact on virtually all these children was the **demands that all the extra support** they received during and after school placed on them. This included extra learning support classes (I.1, 318; FG.1, 429 - 437), speech therapy, occupational therapy and/or physiotherapy (I.4, 202; FG.2, 533 – 543) and elocution classes (I.2). Even though this extra input is utilised as developmental and learning support, it requires time and effort.

One of the parents' greatest considerations for placing their children in mainstream education is social in nature. Although the children's experience of their peer groups was generally positive, not all the children formed good **friendships** that easily. As one parent described it:

She is friendly with everybody and everybody is friendly with her. You understand - friendly. But to have an intimate friend, build an intimate friendship is very difficult for her (I.1, 579 - 581) ... they come once... even at school I can see a distance (I.1, 887 - 888) ... She is just missing that intimate friend (I.1, 1167).

There are cases where socialisation is part of the problematic nature of the disability. In one case, for example, the child is withdrawn and does not socialise easily (FG.1, 172) while, in another case, a boy with Tourette's syndrome manipulates children and as a result they do not want to play with him (FG.1, 49-51, 317).

Nevertheless, some children make good friends after a period of time (FG.2, 190-192; I.3, 930-931; FG.1, 250). One child, who was initially in a special school, especially benefited from the mainstream placement. His mother stated that, "...the normality of the situation is that he's got friends in our street that's in the same class, you know. Oh it's so wonderful, in his own environment ... he's learning from them and the same friends in Church are the same friends at school and that's so wonderful" (FG.2, 589 – 594).

In summary, the themes and sub-themes identified in this study demonstrate that the experiences of parents with children with disabilities in mainstream schools

are multifaceted and complex. This is evident in their variety of experiences of inclusion, including finding suitable placement for their children in mainstream schools, family involvement and commitment, establishing interactions and connections with principals, teachers and peers, as well as awareness of their child's adjustment and unique challenges during the inclusion process.

#### Discussion and Recommendations

The purpose of this article was to describe the experiences of a group of parents with children with disabilities in mainstream classes, with a view to understanding their perceptions of inclusion and the process of its implementation and, more specifically, to understand what they have learned about the inclusion of children with disabilities in mainstream schools. In the simultaneous process of data collection and analysis it became evident that it was first necessary to gain an in-depth understanding of the parents as 'partners' and their conceptualisation of inclusion before pursuing parent-school partnerships. In the literature on true partnerships between schools and families, it is clear that, like any close relationship, a true partnership, "... implies mutual respect based on a willingness to learn from one another, a sense of common purpose, a sharing of information and decision making and, some would add, a sharing of feelings" (Mittler, 2000:158). Nonetheless, the findings of this study about what parents perceive inclusion to be, contribute towards a broader understanding of the concept and directly inform the collaborative nature of parent-school partnerships.

The data obtained in this study compellingly reinforce the notion that implementing inclusive education is complex and multidimensional, and that it involves more than just placement. The participants repeatedly emphasised that inclusion is a process that is continuous and ongoing and that, especially during this beginning phase of implementation, it necessitates one step to be taken at a time. This process of parents including their children in mainstream schools culminates in a 'learning journey' for families, schools and communities and this is not always easy or pleasant, but is a time of both intra- and interpersonal discovery. As a broader philosophy and practice, inclusive education extends beyond the walls of the school into the community and fundamentally into society.

For the duration of parents' narratives it was evident that their experiences involved becoming aware of and actively constructing relationships with all the people with whom their child came into contact, such as principals, teachers, peers, other parents, support personnel and other professionals. It is significant that

neither the parents nor the teachers had received any training in working with each other. In the past, this co-operation has not been necessary as the education system was designed in such a manner that parents, as their children's primary caregivers, were given little recognition and were allowed little participation in decision making focused on their children's inclusion in learning programmes on the one hand and the governance of schools on the other hand (Department of Education, 1997:38).

Parents found relationships that were characterised by values of openness, honesty, mutual respect and genuineness to be most fulfilling. In some cases, these values were also those inherent in the school's ethos and this assisted in supporting the relationships between the parents and the school personnel. Relationships of this nature are essential for meaningful and effective collaboration between parents, and schools consistently identify them as a critical element in an effective response to diversity and in the implementation of inclusive education (Sands, et al. 2000:26; Lipsky & Gartner, 1996: 780). Collaboration can be described as a creative partnership between all role-players. In this partnership all members are of equal importance and are expected to continuously contribute their expertise in a collegial and trusting manner towards the achievement of a shared goal (Swart & Pettipher, 2000). In the context of inclusive education, true collaboration "erases boundaries" between families and schools to create seamless partnerships that work towards creating solutions aimed at the improvement of the implementation of inclusive education. According to Ferguson and Kozleski (2000: 11), the parents and families of children with disabilities contribute to the culture of school communities by bringing an understanding of the broader community and developmental needs and strengths of their children to the learning environment that can inform all school- and curriculum activities. As has been the case in other studies (Grove & Fisher, 1999), the parents involved in this study were active in creating and shaping the culture and meaning of inclusion within their different school sites.

Throughout this study, the parents reminded us of a fundamental ingredient in inclusive schools – the ingredient of support. They reminded us that one can only describe a school as being fully inclusive if emotional, social and educational support is available for all systems involved (e.g. schools, classrooms, teachers, parents etc), in order to support the learner, both directly and indirectly. This conceptualisation and understanding of support is what the parents and their children attempted to generate and develop when they decided to make their children part of mainstream society. Many made this decision with the knowledge

that support systems still needed to be developed in South African schools. However, through their active engagement with the existing education system they began to shape the nature of support required for implementing inclusive education. Ultimately, in order to support the learner, other systems, such as those consisting of teachers, peers, parents and other professionals, must be supported. The needed support can vary from information about disabilities, inclusion education and the adaptation of the curriculum to additional human resources such as teacher aids. Teacher-, and in some cases, parent education, that is contextualised and on-going, is also a necessary form of support. At the same time, child-to-child support is also necessary in inclusive communities. This can either be formal, including activities such as peer tutoring and buddy systems, or informal, including helping children with carrying their suitcases up and down staircases or assisting them in writing down their homework.

To conclude, in this beginning phase of the journey towards inclusive education in South Africa, the parents who participated in this study emphasised the *creative* and *indispensable* role they play and need to play in *establishing and defining inclusive school communities*. They are in favour of schools and communities that do not just 'tolerate' their children, but that respect them and accept and value their contributions. An essential aspect of feeling included is feeling valued. These parents believe that all people must work towards creating caring and supportive learning communities that provide a unique and enduring sense of identity, belonging and place for all people.

#### **Endnotes**

- The concept 'parents' is used in the broadest sense to include legal guardians as well as primary caregivers such as grandparents (SA Schools Act 84 of 1996).
- The aim of the pilot phase was broad and attempted to learn from parents who experienced mainstream placement. We acknowledge that a large group of parents in South Africa are disempowered and uninformed about their rights and their children's rights and opportunities and regard it as a barrier to implementation. They were not purposefully selected in the pilot phase because it was not the primary focus of the study. The first theme identified a group of parents that did not have a choice with regards to placement of their child, often referred to as 'mainstreaming by default'. This theme should be further investigated during the next phase of the study. The next phase of this research will hopefully empower these parents to voice their experiences.

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<sup>&</sup>lt;sup>3</sup> Pseudonyms were used to protect participants and their children

<sup>&</sup>lt;sup>4</sup> The code I.1 indicates participant of individual interview number 1

<sup>&</sup>lt;sup>5</sup> The code FG.1 indicates participant of focus group interview number 1

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