'Tell me about Katie'

Attitudes of mainstream 7-8 year olds to a peer with Down's syndrome

Barry Carpenter

Parent and Director of the Centre for the Study of Special Education, Westminster College, Oxford, U.K.

Using a case study of integration into a mainstream primary school for his daughter with Down's syndrome, the author seeks to explore the attitudinal development of her mainstream peers after a four-year period. As such, it is a first step, tentative piece of research, fraught with potential pitfalls. As Bines (1995) points out as a 'researcher [I am] inevitably part of the phenomenon being studied'.

Through scripts written by children aged 7-8 years about Katie, their peer with Down's syndrome, an analysis of the children's perceptions of and attitudes towards Katie was undertaken. The findings reveal significant insights on the part of the children, and an appreciation of the child for her abilities, not her disability.

The outcomes of the research are interpreted in terms of family empowerment within a community, following a positive period of interaction for the child with Down's syndrome in a neighbourhood mainstream school setting. A new paradigm, worthy of further exploration, is that of 'parent as researcher'.

Introduction

Our daughter, Katie, has Down's syndrome. After four years of partial integration in our village First School (4-8 year olds), Katie, like her peers, had to make the transfer to a Middle School. Our opinion, as her parents, was that these had been four very positive and fruitful years.

Academically, Katie had made good progress. She could read with interest and enthusiasm, and had attained Level 2 in the English National Curriculum. She had used some signing to support her expressive language: symbols had greatly stimulated her acquisition of words during the emergent literacy phase. She could write her first name independently, and could copy other basic words. She was confident with number bonds up to ten.

This evaluative study is a celebration of her very positive experience of integration into mainstream education - a testimony to the faith and dedication of all involved, from Katie herself, to her classmates, her teachers, her integration support teacher (IST), the local authority and her family. No child's education is a solitary achievement, but is the result of the energy and involvement of countless people; and Katie is no exception.

I am very aware that from the hard research perspective, this study is inadequate. There are no control comparisons made for a peer without learning difficulties. It is impossible to gauge the extent to which Katie's classmates were influenced by the thought that Sue (my wife) and I would read the letters, and edited their contributions accordingly. However, for all of us involved in the analysis for this article, what comes through the letters as a collection is the seeming spontaneity of the descriptions. The involvement of others besides myself in the evaluation of the letters will have minimised, I hope, any parental bias which might have influenced our conclusions.

However, it was not as an academic that I approached this study. As one of Katie's parents I am too involved for such a dispassionate approach. I came to it as a parent. There is a statement to be made here about the validity, and vitality, of parents' contributions to the on-going debates around integration. The effects of an integrative strategy are felt most strongly in the family. At the end of the day, professionals leave their offices and schools, but the family has to cope with the emotional fall-out from their child with learning difficulties if the strategy selected is not optimal. We, as families supporting our children, and intimately involved with them, also have a responsibility to the professionals to celebrate successes with them as well as bringing to their attention the points at which their strategies are foundering. The areas we may want to focus upon - for example, acceptance of our child by peers, behaviour and the opportunities they are given to function within their local community - are different, but complementary, to those more usually studied by professionals, and demand a more qualitative approach. Our advantage as parents, in observing our child's interaction in his/her various communities, is that we do not disturb the dynamics or behaviour of that community because we are part of it. The parental contribution is unique, cannot be replaced, and should not be effaced.

The collection and analysis of the data from this study inevitably drew on my experience as a researcher, but the skills required for basic evaluation are within reach of most

parents. The purpose of this research was important on a personal level. We wanted to identify the embedded attitudes of mainstream children who had had sustained shared learning with our daughter. What did their relationships with her mean to them? For, at the end of the day, it is the positiveness or otherwise of those attitudes that will determine the quality of life for Katie when she endeavours to achieve societal integration. When she takes up her rightful place as a citizen in her community, who will be her friends, her neighbours? Who will support her?

Background

Schools can create the conditions within which a strategy for integration can operate (Carpenter, 1994), but they cannot legislate for the attitudes which peers may adopt towards the child with Down's syndrome. The questions that we ask are as pertinent in adult as in child societies. Will the child be included in the various activities of his/her mainstream peers - both educational and social - or will s/he be ostracised? Will learning alongside their peers be ultimately enabling or disabling? And will children in mainstream schools treat them with friendship or contempt, as an equal or with condescension? Will the child's peers see the personality or the disability?

Anastasia Vlachou (1995) reporting her research into teacher and peer attitudes towards the integration of students with Down's syndrome reflects on her own experience of such children. She recollects:

'Disabled children were not neighbourhood children ... they were targets of curiosity, pity and fear ... or of jokes' (1995, p. 109).

Ann Lewis has undertaken a major study which seeks to analyse critically 'Children's Understanding of Disability' (Lewis, 1995). She identifies that much of a child's understanding of disability comes from adults, and that many studies have shown that adults have a poor understanding of learning disability. This remains the situation even now, in spite of some powerful pieces of literature and media which have sought to combat the social barriers of discrimination (Bines, 1995; Mason & Reiser, 1994; McConkey, 1994). Lewis carefully monitored link integration projects between mainstream and special schools involving pupils with severe learning difficulties, and her findings powerfully illuminate the nature and quality of pupils' interactions. This study emphasised some earlier work (Lewis and Carpenter, 1990) which demonstrated how link projects can draw out pupils' communication skills, particularly in relation to discourse strategies.

Both Lewis (1995) and Vlachou (1995) demonstrated that interactive strategies with the pupils were by far the most effective way of revealing true attitudes and insights. In her earlier research Ann Lewis (1992) has articulated the validity and power of group child interviews as a research tool:

They were prompting one another with reference to things not known to the interviewer and this enabled individual children to amplify their responses ... the effectiveness may reflect the absence of the sorts of features (such highly specific questions, and questions rather than comments) which diminish the quality and quantity of children's talk in conversations with adults.' (1992, p. 415).

This child-centred open ended approach to eliciting information from children subsequently informed the data-collecting strategy employed in this research.

The rights of pupils with learning disabilities to an inclusive education has long been a subject of debate (Pearpoint et al., 1992; Slee, 1993; Stainback and Stainback 1992). Bird and Buckley (1994) have drawn readers' attention to the quality of learning experienced by children with Down's syndrome in mainstream settings, and the developmental advantages which ensued. Katie's experience, through a partial integration model, certainly corroborates this.

The case study

After considered debate, we decided on a partial integration approach (Jenkinson, 1993) to Katie's education. We felt that to expect the First School teaching staff to manage her very specialised educational programme (supported by alternative and augmentative communication approaches) on a full-time basis would pressurise an already demanding schedule.

Over the four-year period, Katie's attendance pattern at the First School was changed from afternoon-only to whole-day sessions as she grew in confidence. (On school days when time was divided between the Special and First schools, the IST provided transport between them.) Initially, her time in the First School was fully supported by a Nursery Nurse from her Special School. Later the IST took over Katie's supervision, covering half the time she spent at the First School. This was gradually reduced and, at the end of her four years at the First School, Katie was attending unsupported, with the IST making weekly visits to monitor her progress and offer advice to staff when required.

The integration of Katie's two educational experiences was orchestrated by the IST. She liaised between the Special and First Schools, ensuring that all Katie's teachers were involved in drawing up her Individual Education Programme targets and consulted about their implementation. A needs analysis was carried out to determine which subjects would be best taught (in the light of Katie's special requirements) by each institution. The shared record keeping was an important feature of this integrated learning programme (as it should be of any such programme). The IST organised an Integration Diary which kept us informed of Katie's progress at the First School, and formed a companion document to the Home Diary provided by her Special School.

The First School staff accepted the challenge to meet Katie's particular educational needs with enthusiasm. Encouraged by the staff of the special school, they became increasingly aware of the benefits of sharing responsibility for Katie's education. As their confidence in their ability to implement effective educational strategies, and to deal with her sometimes awkward behaviour, grew, they adopted innovative approaches to subjects, enabling her greater access to the First School curriculum. From participating in 'open' experiential areas such as Art, PE and Music, her academic experience was broadened to include Science and Technology and Information Technology. For her IT classes, the Special School were able to provide specialised programmes which helped not only Katie, but also other pupils with special educational needs at the First School.

Although, as with any integration strategy there were unforeseen setbacks, the overwhelming evidence mitigates for its success. As parents, we were delighted with the way the integration programme had been managed between the special and mainstream schools. We felt that Katie was getting the 'best of both worlds' and that her learning experience was broad and well-balanced. Her complex educational and social needs were being met by both settings in a way that neither school would have been able to manage in isolation.

And Katie ... she adored school - both schools. She embraced the experience with pleasure, showing none of the distress which people mistakenly, in Katie's case at least, associate with integrated special/mainstream education.

The wider context for integration
Whilst schools can and do assume considerable responsibility for integrating children with significant learning difficulties, we must not forget that integration is a shared responsibility between home, school and the community. What social activities are available in the community which can be accessed by the child with Down's syndrome? What is the attitude of various community groups to receiving a child with Down's syndrome? What is their capacity to offer support? Do they expect the parent to be the supporter? (Not a totally satisfactory arrangement as it can impair the parent-child relationship - and sometimes the parent just needs a break!).

In addition to the time Katie spent in her local First School, she attended several groups in the village. These included our local church, where she joined a Sunday school class unsupported. In the dancing class she was greatly assisted by the fact that the other children had learned to sign, and would translate the dance teacher's instructions for Katie. The children also knew, almost instinctively, that Katie's dominant learning mode was visual and took time to demonstrate the steps to Katie. (In the dance shows, Katie's visual memory and recall was so good that she could lead others when they became stage-struck!)

Katie joined the Brownie pack in the village. Initially they asked for parent support while Katie settled into the group. They were also very interested in teaching the other children to sign, and asked for our assistance in doing this. Katie progressed through some 20 badges, went on a Brownie camp, and joined in all aspects of Brownie life. Often the very sensitive Brown Owl assigned a trainee leader to support Katie, but the leaders learned to identify potentially difficult situations and to organise support within their own resources.

Community involvement is an essential part of integration. We, as parents, must undertake an education role within the community. If we want that community to accept our children with Down's syndrome then we have to demonstrate positive, informed attitudes that can demystify traditional, ill-conceived attitudes towards children with Down's syndrome, and enable community members to establish meaningful contacts leading to full acceptance of the person with Down's syndrome in the community.

The study
Towards the end of Katie's time at the First School. I visited the class. These children had been with Katie throughout her four years. (The school were always very good at keeping Katie with her chronological group. Too many times we hear of Down's syndrome children kept in the reception class throughout their Infant School career, and this leads only to developmentally inappropriate management, and a repetitive curriculum experience that must be boring for the child.) I asked the children to, 'write about Katie as if you were telling a friend who had never met her'. Each child produced a letter: we did not discuss as a group their thoughts about Katie, so that each individual's responses were, within reason, their own thoughts.

The letters written by the Year 3 children leave the reader with a vivid portrait of Katie. It is obvious from the statements they have made that they knew Katie intimately, and the letters cover all aspects of this relationship from the practical details of her appearance, through her likes and dislikes to their apprehension of her personality. It is also notable that the great majority of statements are completely unrelated to her having Down's syndrome, as though it were a minor detail lost in the greater significance of her other characteristics.

There were 29 letters written by Katie's First School peers. Each letter amounted to a series of personal statements about a friend in the same class. We isolated the individual statements made within each letter. Where a sentence contained more than one statement (for example, 'nice and friendly') these were broken down into the constitutive elements. On occasions, contradictory statements were found within the same sentence, and these, too, were treated as separate statements. Within the letters there were a total of 271 separate statements, which, when rationalised by semantic content, gave 91 different statements. For example, 'smiling' and 'a smiling face' were considered to belong to the same group of statements. We found that the number of statements made per letter varied between 3 and 24.

Evaluation of data
In the following evaluation, the professional researcher will recognise that even with such basic material that was yielded by the letters, there would have been many other ways in which this data could have been treated. For example, further analysis could have led us to enquire how many statements from the different subcategories were present in each letter, and to assess statistically the significance or otherwise of the findings? However, we decided not to take the evaluation further than we have done. In offering this as one possible model of a pilot exercise for the 'parent as researcher' it is important that we acknowledge that valuable feedback can be made available to professionals from straightforward treatment of data, and that parents have limited resources - time being not the least of these.

The statements were separated into three categories: statements which concerned Katie's characteristics, i.e. non-reactive statements (see Table 1); statements which concerned both Katie and her peers' reaction to her, i.e. reactive statements (see Table 2); the third group of five statements were either too general to be useful ('lots of good things about her') or did not engage with the investigation ('I hope she enjoys her new home') (see Table 3).

We created six subcategories with the data in Tables 1 and 2. Ranked right to left across the tables, the represent an increasing depth of personal relationship. To elucidate: any

Table 1. Statements made about Katie by her peers (non-reactive).

Physical appearance	Circumstantial information	General behaviour/ interaction	Contextual behaviour	Evaluation of activities	Activity preferences	Personality
She makes signs/Makaton by rubbing her hands (9) Small (little) girl for her age/Quite small even though older (5) Has long/blond hair (4) Blue eyes/chubby cheeks (3) Doesn't use her mouth as much as we do/can't talk very good/uses Makaton because she can't speak very well(3)	She's 8/has a birthday in July (6) She's been in school for 4 years (4) At Christmas brought a Makaton video/signed book (4) Goes dancing (4) We see them outside in the street (4) She was an oompaloompa last Christmas (4) Has a brother called Matthew (3) She goes to Blythe School (2) She visits on Wednesdays (1) Goes to Brownies (1)	She likes/is good at working with grown-ups (3) She has tantrums (3) Hard to work with/understand (3) Most of the time she is good (3) Is growing up really fast/is grown up (2) She likes John best (2) Good partner/shares things (2) Fiddles with everyone's hair (2) Hugs people/is cuddly (2) A bit naughty (2) Remembers please and thank you (1) She has invited people to her new school (1)	Fiddles/runs out/gets bored in assembly (5) Messes around in the toilet (1) Tidies the classroom (1) At home time jumps up and down and says 'Yes' (1) Wouldn't come from the corner when she was to dance (1) Sometimes she does not know where she is (1)	Good at writing her name/reading/ maths (5) Does good drawings/painting (4) Hard working/gets on with her work (3) Good at dancing/ remembers the dances (2) Good at making models with boxes (2) She has improved a lot (2) She has caught me/us up sometimes (2) Did things in the dance too early sometimes/a bit fast (2) When she works on her own she's a bit messy (1) At Brownies, tries hard with games (1) Good at sign language (1) Tries to sing our songs in assembly but has not heard them before (1) Good at all sorts of work (1)	Enjoys working with clay (2) Likes to paint (2) Likes doing science (2) Loves playing in the sandpit (1) Hates taking things (1) Always dressing up in the reception class (1) Loves 'Charlie and the Chocolate Factory' (1)	Nice/a nice character/nice to meet (21) Kind/sweet/ never horrible (8) Funny/fun to have around/to play with (7) Smiley face/ happy girl/enjoys herself (6) A bit bossy/likes her own way/is nicer when whe gets her way (6) Can be cheeky (5) Playful (3) Tries very hard (3) Just a little slow (3) Goes mad/silly sometimes (2) Helpful (2) Cheerful (1) A nuisance (1) A little pain sometimes (1) Doesn't take no for an answer (1) A bit fussy (1) Enthusiastic (1)
(1) 24	32	26	10	27	10	72
(2) 11.9%	15.9%	12.9%	5.0%	13.4%	5.0%	35.8%

(1) = number of statements in category
(2) = percentage of statements in category of total number of statements in Table 1 (rounded up/down to the nearest 0.1%)

Total number of statements in Table 1 = 201.
Total number of categories in Table 1 = 70.

Table 2. Statements made about Katie by her peers (reactive).

Physical appearance	Circumstantial information	General behaviour/ interaction	Contextual behaviour	Evaluation of activities	Activity preferences	Personality
I go to her parties/her parties are really nice (5) I went to her house (2) We exchanged presents (1)	I go to dancing/ Brownies with her (6) I like how she does her signs/moves her fingers (2)	Hard to communicate/ can't understand her signs (5) She lets me hold her hand (1) She lets me feed the guinea-pigs (1)		I had to help her (2) Is a nuisance when we do work (1) I like singing with her (1)		I think she's fun/nice to work with/play with (14) She's good at making me laugh/makes me happy (6) I like her a lot I enjoy her coming to the school/lovely to have her in our school (4) She has been loved by all round the school (3) Everyone looks after her/we won't let her be bullied (2) Everyone wants to sit next to her in assembly (1) I enjoyed her jolly face (1) A year has been long enough to be a real friend to Katie (1) It's a shame she's leaving, everybody will be very (x5) sad (1)
(1) 8	8	7		4		37
(2) 12.5%	12.5%	10.9%		6.3%		57.8%

(1) = number of statements in category
(2) = percentage of statements in category of total number of statements in Table 2 (rounded up/down to the nearest 0.1%)

Total number of statements in Table 2 = 64
Total number of categories in Table 2 = 21

of the observations about Katie's physical appearance could have been made by a stranger within the first few minutes of being introduced to her, while the observations about her personality could have been made only by people who had known her for some time and therefore suggest that there has been significant personal interaction. As readers may appreciate, it was sometimes difficult to allocate statements, as there are the inevitable degrees of overlap between the subcategories.

I do not propose to comment on Columns 1, 2 or 3. Apart from giving the reader contextual information about Katie, they are not indicative of a deep relationship, although they would be important if we were considering the predominance of certain kinds of statement within each letter. As pointed out above, a stranger could have made the observations in Column 1. Columns 2 and 3, also, do not contain evidence of much more than a basic locational relationship; the information imparted about age, family members, etc., is common currency on the childhood conversational exchange.

Column 4 contains highly contextualised statements about Katie's behaviour. These represent only 5% of the total responses in Table 1, although over half of these are about Katie's behaviour in assembly. That these, sometimes individual, incidents have been worthy of particular mention says as much about the contributor's personal list of 'do's and 'do not''s, although they are behavioural specifics of which the more general forms can be found in the succeeding columns. It would be interesting to know, although impossible to ascertain, why these occasions are so memorable. Is it that they are evidence of a more general unpredictability in Katie's behaviour which the children have not learned to articulate as a generic difference? Or do they perhaps elicit an unexpected response from those in positions of responsibility?

In Column 5, however, the comments have become more engaged with Katie as a person. The commentators are interested in Katie's skills. A very high proportion (85.2%) of the statements are positive. What criteria are her peers using in making their evaluations? Are they saying that they think she is good at the subjects by class standards, or have they

made allowances for her learning difficulties and measured her achievements by other standards and expectations? Two comments ('She has improved a lot' and 'She has caught me/us up sometimes') suggest that this could be the case, although they could have been made from the writers' individual perspectives.

The statements in Column 6, again, represent an increase of personal involvement from the previous column. The writers have moved a step beyond the dispassionate observational stance. They know Katie well enough to predict her personal preference in certain situations. Katie comes across, even in these few comments, as a person of very strong opinions and feelings - an impression which is bourn out in the final column.

The final column, comprising statements about Katie's personality, accounts for an enormous 35.8% of statements in this table. (The next largest category, 'Circumstantial information', contains 15.9%.) Of course, there is some extent to which the categories drawn up are arbitrary, but this would seem to indicate that it is Katie's personality which, of her personal characteristics, has made the greatest impression on her peers, and that this is what they value her for over and above those falling into other categories. Not all the statements are positive ('a nuisance'; can be a little pain sometimes') but this is as likely to be evidence of a lack of empathy between two personalities as anything else. As with any child, one commentator's 'nuisance' will be another's 'doesn't take no for an answer'.

It is Column 7 which can be said to display the evidence of the success of Katie's integration, that her peers interact with her personality, not her disability. There are no standards other than universal standards which can be applied in assessment of personality; there is no room for allowances to be made. The majority of her peers' statements testify to her sense of fun and mischief, her courage and her stubbornness, her enthusiasm and her kindness.

This table divides the reactive statements made by her classmates (those which explicitly implicate the child making them as well as Katie) into similar categories to those in Table 1. Column 1 testifies to the observable facts of childhood association. They may or may not indicate that there is friendship involved, although the idea of 'exchanging presents' suggests that the children's own wills were in play. The statements contained in Column 2 also suggest no particular friendship.

Column 3 indicates a minor level of engagement and some of the children's responses to it: the difficulty in communication is obviously a problem for the children who commented on it; however, in the reaction there is also, we felt, an underlying sense that their frustration indicated a desire to communicate. Such statements did not place the responsibility for non-communication with Katie, as did some of those made in the previous table. In the second and third statements in this column, there is some sense of privilege felt by the children that Katie accepted them enough to extend friendship to them or allow theirs in return. This would suggest, once again, that the children seek to meet Katie as a person, and that their response to her is not prescribed or deemed insurmountable by her disabilities.

In Column 5, there is some evidence in the first two statements of the impatience which people with learning disabilities inevitably meet with. They communicate a sense that the child feels him/herself held back by Katie and a sense of resentment. However, these comprise only 4.6% of the responses in this table.

As with Table 1 the overwhelming majority of statements (56.9%) refer to a relationship between personalities. Many of the statements testify to an emotional involvement. The statements celebrate Katie as a personality, the children making them, and the meeting of personalities in friendship. Some of the statements refer to what her friends offer Katie ('We won't let her be bullied') and others to what she offers them ('She's good at making me laugh/makes me happy').

Table 3. Statements too general to fit into the above categories.

General statements
She's handicapped (1)
Is Down's syndrome but she's also just a normal person (1)
Lots of good things about her (1)
I hope she enjoys her new home (1)
I know a lot about Katie (1)
I will pray for her every night (1)

But, analysis aside, the impression given is that Katie has received an enormous amount of love and support from her classmates.

I shall defer my comments on Table 3 to the discussion following. All are general comments and, as such, did not fit into the analysis. However, amid the statements of good will, are two of the most disturbing statements that can be made about a child with disabilities, whose implications are alarming by very reason of their generality: 'She's handicapped' and '[She has] Down's syndrome, but she's also just a normal person'.

Discussion of the case study

As I have said above, we consider these letters testify to the success of Katie's integration. Her classmates have given us a portrait of a child of indomitable, loving and vital personality, whose personal contribution to their individual lives is valued (in most cases!), not of a child whose primary identifier is that she has Down's syndrome. Even if the children had been affected by the fact that we would read their letters, this would not have merited the enthusiasm, contained within many of the reactive statements and the intimations that 'everyone' wants to sit next to her in assembly and looks after her. For us, perhaps the following is one of the most touching statements: 'It's a shame she's leaving, everyone will be very, very, very, very, very sad.'

There are perennial questions about what can be said to constitute integration. Does the concept incorporate perceived equality? If so, equality on what terms? Is the protective attitude that Katie's peers display towards her enabling or disenabling? Is it condescending or caring? The answers must lie, surely, in the intimacy of relationship, the extent to which the friendships are reciprocal, mutually supportive

and valued by both children. Many of the statements about Katie's personality in both Tables 1 and 2 would seem to suggest that there is real friendship.

There are only two statements which make direct reference to Katie's learning difficulties/Down's syndrome. Both are disturbing for the same reason. The stark statement, 'She's handicapped' evades categorisation but invades all categories with its limiting 'catch all' reference. Instead of allowing Katie to reach out to those around her, it stands to imprison her with preconceived prejudices and expectations. The second statement, it could be argued, redresses the balance, but to argue this way is miss the point. That the child concerned has discarded the statement fed to her (presumably by an adult) and evaluated Katie on his/her own terms is encouraging, and says much for the ways of seeing encouraged by the school; however, not all children are as independent in their thinking and such a label might have remained an unquestioned indicator of 'otherness'.

There are other statements in the table, such as the references to Katie's signing, slowness ('just a little slow') and her physical appearance ('Small/little girl for her age') which would indicate to an adult the possible source of Katie's disabilities. However, children of this age have not usually learnt to categorise in such a way. There was a great interest in Katie's signing. In a large proportion of statements it seemed to feature as an added attraction in the descriptions of Katie; for others it was a barrier.

Integration into school life, and into their peer group, is an issue for every child at some level. 'Integration' is a celebration of uniqueness between individuals in a society. It is a creation of space - emotional, spiritual, practical - into which an individual can grow. The concept organises a pattern of behaviour from others which should be a response to which every child, every adult, has a right. Katie's schools - both her First School and her Special School - have helped her celebrate her own uniqueness; and the letters from her peers also indicate, we feel, that she has helped them celebrate theirs.

Conclusion

The Education Reform Act, 1988, establishes as a principle that the curriculum should prepare pupils 'for the opportunities, responsibilities and experiences of adult life'. Educators have a duty to prepare all children for life together in their community. When all of our school-based educational forms of integration have long since passed what remains for all adults is societal integration - a life of living together in our community. However lofty the goal may seem, to create a harmonious society based on equality of opportunity must remain a priority for all concerned with developing positive attitudes in children. Effective citizenship for all of our children should be our endeavour, and shared learning is a medium by which, and through which, we can nurture the attitudinal growth and development of all our children.

Quality in parental involvement remains a vexed issue, and several researchers are seeking to evolve effective models (Hornby, 1989; Mittler and Mittler, 1994). Some are articulating the cause of 'parental empowerment' (Dempsey, 1993). All share the goal of improving the quality of parents (and families) interactions with the variety of personnel linked to a child with a disability. All suggest that a diverse repertoire of involvement strategies will be needed to ac-

commodate the obvious differences that exist between all families (Hornby, 1995). None have suggested that some parents may wish to act as the researcher; to gain their own insights into their child and family needs through investigation and enquiry which will illuminate the patterns of interaction. For some parents this may generate some insightful answers to the deep and vexing questions they often have, and which some professionals find perplexing and are unable to resolve.

It is hoped that the value of this first-step research exercise for parents is clearly demonstrated, for it is they who are the first, the last and the sustained educators of their child. And if that child happens to have Down's syndrome, it is the parents who will support them into effective citizenship in their community. The significant influence of other citizens is recognised, and the positive, or negative, attitudes of those citizens could make or break the quality of community-based opportunities for the person with Down's syndrome. Our responsibility as parents is indeed great.

References

Bines, H. (1995). Risk, Routine and Reward: Confronting Personal and Social Constructs in Research on Special Educational Needs. In P. Clough and L. Barton (eds) *Making Difficulties: Research and the Construction of Special Educational Needs.* London: Paul Chapman.

Buckley, S. and Bird, G. (1994), *Meeting the Educational Needs of Children with Down's syndrome: A Handbook for Teachers*, Portsmouth: University of Portsmouth.

Carpenter, B. (1994). Shared learning: the developing practice of integration for children with severe learning difficulties, *European Journal of Special Educational Needs,* 9, 2, 182-9

Dempsey, I. (1994). The Measurement of Parental Empowerment. In M. Arthur, R. Conway and P.J. Foreman (eds) *Quality and Equality in Intellectual Disability.* Newcastle, NSW: ASSID.

Hornby, G. (1989). A Model for Parent Participation, *British Journal of Special Education* 16 (4), 161-2.

Hornby, G. (1995). *Working with Parents of Children with Special Needs.* London: Cassell.

Jenkinson, J. (1993). Integration of students with severe and multiple learning difficulties, *European Journal of Special Needs Education,* 8, 3, 320-35

Lewis, A. (1992). Group Child Interviews as a Research Tool, *British Educational Research Journal*, 18 (4), 413-21.

Lewis, A. (1995). *Children's Understanding of Disability.* London: Routledge.

Lewis, A. and Carpenter, B. (1990). Discourse in an Integrated School Setting between Six- and Seven-Year-Old Non-Handicapped Children and Peers with Severe Learning Difficulties. In W.I. Fraser (ed.) *Key Issues in Mental Retardation.* London: Routledge.

Maron, M. and Reiser, R. (1994). *Altogether Better*. London: Comic Relief/Charity Projects.

McConkey, R. (ed.) (1994). *Innovations in Educating Communities about Learning Disabilities.* Chorley, Lancs.: Lisieux Hall.

Mittler, P. and Mittler, H. (1994). *Innovations in Family Support for People with Learning Disabilities.* Chorley, Lancs.: Lisieux hall.

Pearpoint, J., Forest, M. and Snow, J. (1992). *Strategies to Make Inclusion Work.* Toronto: Inclusion Press.

Slee, R. (1993). *Is there a Desk with my Name on It? The Politics of Integration.* London: Falmer Press.

Stainback, S. and Stainback, W. (1992), *Curriculum Considerations in Inclusive Classrooms*, Baltimore: Paul M. Brookes.

Vlachou, A. (1995). Images and the Construction of Identities in a Research Context. In P. Clough and L. Barton (eds) *Making Difficulties: Research and the Construction of Special Educational Needs*. London: Paul Chapman.

Address for correspondence:

Barry Carpenter,
Westminster College,
Oxford OX2 9AT.
U.K.