

An investigation into the experiences of parents and head teachers involved in the integration of primary aged children with Down's syndrome into mainstream school

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This study details the results of an investigation into the experiences of parents and head teachers involved in the integration of primary aged children with Down's syndrome into mainstream schools. Ten families were involved in the study, each with a child who attended a mainstream primary school within Hampshire. Structured interviews were held with parents (mothers) of each of the ten children and nine of the head teachers in order to gain information about the process of integration and the experiences of those involved. The information elicited by means of these interviews was used to draw up a theoretical 'model of good practice' which might facilitate the integration of a pupil with special educational needs into a mainstream school.

Acknowledgements

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Introduction

In the United Kingdom the concept of integration in education began to be realised during the 1970's and this was reflected in legislation with the passing of the 1981 Education Act which stated that children with special educational needs were to be educated in ordinary schools whenever it was "educationally and economically viable". This was hailed as indicating a 'moral' commitment to the principle of integration and many parents of children with special educational needs were optimistic that, backed up by the research findings and predictions, they might reasonably expect that some of their children would be educated within the mainstream system.

Booth and Statham (1982) documented the experiences of several sets of parents as they attempted to gain places in mainstream school for their children, all of whom had Down's syndrome. Eventually unit provision was established (although not by the LEA) with the children spending part of their school day in mainstream classes. Parents expressed their delight at the progress made by their children, both academically and socially, and felt that the children benefited from being with those who were socially and linguistically more able.

Casey et al. (1989) carried out a longitudinal study examining the cognitive development and academic attainments of 36 children with Down's syndrome over a period of two years. Eighteen of these children attended mainstream schools and eighteen were in schools for children with moderate learning difficulties. The children in mainstream performed better on all the variables measured; comprehension, expressive language, numeracy, verbal fluency and drawing and showed a significantly greater gain in mental age.

Sloper et al. (1990) studied the progress of 117 children aged between six and 14 in different types of specialist and mainstream provision. They found that children in mainstream schools were likely to have the highest academic attainments, followed by those in units in mainstream schools, then those in schools for moderate learning difficulties, and those in schools for severe learning difficulties, even after the factor of the mental age of the children in the different types of schools was removed. The researchers found that staff in mainstream school placed more emphasis on academic skills in the curriculum, whereas those in special schools stressed self-help, socialization and language skills. Children in special schools were taught academic skills but their lower attainment levels may have been due to the differing importance placed on academic attainment (Lorenz et al., 1985).

Several other studies have been carried out which indicate that children with Down's syndrome can be educated within the mainstream, providing that teachers are made aware of the possible strengths and weaknesses that the child might have such that they can alter their teaching programme (Buckley and Wood, 1983; Duffen, 1976; Piertese and Treloar, 1981). However the majority of children with Down's syndrome in the UK continue to be educated within special schools and many parents find that considerable pressure is still placed upon them to accept a place in a special school for their child.

This study investigated the experiences of a group of parents who chose mainstream education for their child. Research

concentrated on the integration process from both the perspective of the parents and the head teachers involved.

Aim of the study

The aim of the study was to use the information gained from structured interviews with parents and head teachers who had experienced the integration of a child with Down's syndrome to produce a theoretical 'model of good practice' by which the process of integration could be facilitated.

Method of research

Ten children with Down's Syndrome who were in Year 1 or Year 2 of a mainstream school were selected for inclusion within the study.

Structured interviews were held with the mothers (no fathers were able to be present) of all ten children and nine of the head teachers.

Results

1. Amount of advice regarding school provision offered to parents and head teachers before child began school

In the early stages of the child's life, parents received advice from several agencies, the most common of which was Portage. Parents generally rated that help that they received as valuable but felt strongly that they had not had **enough** advice and support in the early years.

	PR	HV	PT	P	DS	FD	PH	ST	FY	SW
1		+	+	+	-	-	-	-	-	-
2		+	+	-	+	+	-	-	-	-
3		+	+	-	-	-	+	+	-	-
4		-	+	+	-	-	-	+	+	-
5		-	+	-	+	-	+	+	+	-
6		+	-	+	+	-	-	-	-	+
7		+	+	-	+	-	+	-	-	-
8		-	-	+	-	-	-	-	+	-
9		-	+	-	+	-	-	+	-	+
10		-	+	-	-	-	+	+	-	+
Total		5	8	4	5	1	4	5	3	3

Table 1. Personnel with whom parents had contact in the pre-school years.

Key to Table 1

- PR = Parent
- HV = Health Visitor
- PT = Portage Teacher
- P = Paediatrician
- DS = Down's Syndrome Association
- FD = Friends
- PH = Physiotherapist
- ST = Speech Therapist
- FY = Family (Other family with child with Down's Syndrome)
- SW = Social Worker

Most parents had encountered little obvious resistance to their decision to send their child to mainstream school although many felt that they had not been actively encouraged to do so.

Head teachers generally also felt unsupported in terms of both the adequacy and amount of advice that they were offered before the child entered their school.

Headteacher	None	Some	Lots	Background
1	+	-	-	-
2	-	+	-	-
3	+	-	-	-
4	-	+	-	+
5	-	-	-	+
6	+	-	-	-
7	-	+	-	-
8	-	+	-	-
9	-	-	+	-
Total	3	4	1	2

Table 2. Amount of advice received by head teacher before child entered school.

Headteacher	Adequate	Inadequate	Ambivalent
1	-	-	+
2	-	+	-
3	-	+	-
4	-	+	-
5	-	+	-
6	-	+	-
7	+	-	-
8	-	+	-
9	+	-	-
Total	2	6	1

Table 3. Headteachers' perceptions as to the adequacy of the advice received.

2. Amount and adequacy of support received once child began at school

Generally, the amount of advice and support received by parents since their child had entered school was rated as inadequate. Many of the mothers felt angry and hurt that they had received so little support, and also that much of what had been said to them had been negative, stressing difficulties and limitations that their child might experience.

Head teachers had received limited amounts of advice and support since the child had been in school. Six of the nine head teachers had received advice from the Sarah Duffen Centre but no other agency had provided an equivalent level of support. Had the centre not been in existence, head teachers would have received very little advice overall. Most of the head teachers interviewed reported that, apart from when they were approached by the Centre (usually at the request of the parents) they had had to ask for any support that they had received.

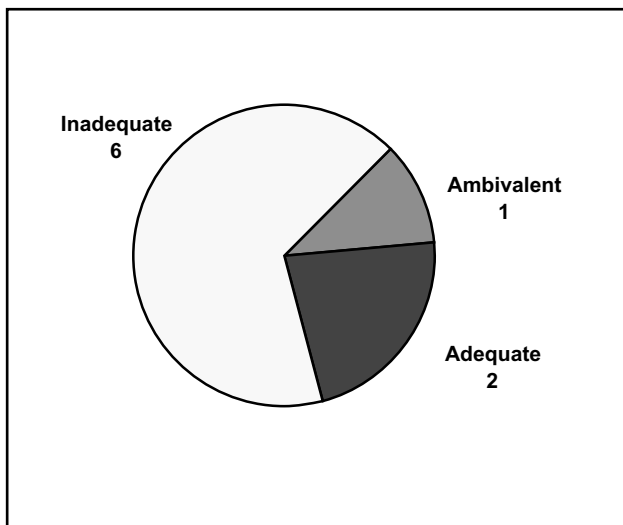


Figure 1. Adequacy of support received by headteachers.

3. Additional support allocated to the child in school

There was considerable variation in the amount of additional non-teaching assistant (NTA) support allocated to the pupils within school (between 19 and 32.5 hours). No simple correlation between the needs of the child and the amount of support offered existed. The level of support appeared to be more an indicator of the willingness and ability of the school and parents to fight for the needs of the child rather than being based on the absolute level of need.

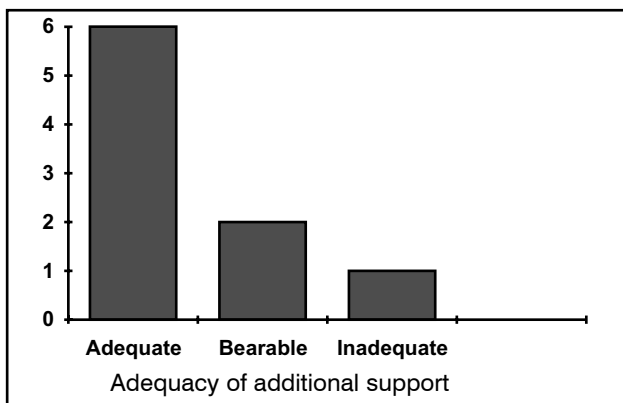


Figure 2: Additional support allocated to pupil in school.

Most of the parents were happy with the amount of support that had been eventually allocated to their child in school although many felt bitter that they had had to push for additional support rather than having it offered to them.

Most parents were happy with the way in which the support was used, but there were three mothers who expressed some anxieties. One mother felt that the NTA was used as a general classroom “dogsbody”, cutting paper and vacuuming etc, rather than working with her child. Two other mothers felt that their child worked on a 1:1 or apart from the class group too often. Mothers spoke of finding it difficult to voice any concerns and discuss anxieties as many felt that their children were somehow “on trial” and that any criticism they made might be taken as evidence that their child was not coping within mainstream education.

Head teachers generally felt the additional support allocated to the child to be adequate although some felt that the child needed additional specialised teaching which was not provided.

4. Contact between parents and school

The amount of contact that parents and school staff had before the child entered school varied considerably. In some cases, the child and parents made only those pre-school visits that would be made by any child about to begin school, whereas in other cases, special additional arrangements were made. This appears to depend very much on the ethos and attitude of the head teacher and school staff. In those schools in which the head teacher was determined that the child should be treated as normally as possible, few, if any, extra arrangements were made. However, in those schools in which the headteacher felt that there would be difficulties to overcome in integrating a child with special educational needs, additional arrangements were more likely to be made, in an attempt to reduce possible anxieties of staff and parents.

In the majority of cases, parents felt that they had had adequate pre-school contact, although two parents felt that they would have liked to have had more. The success of this pre-school contact appeared to depend upon the effectiveness of the communication between school and parents - if the amount of contact arose as a result of discussion and negotiation, parents and school staff appeared satisfied. If however, parents felt that the amount of contact had been imposed upon them, they were more likely to feel dissatisfied.

Both parents and head teachers generally felt that the amount of contact that they currently had at the time of interview was adequate. This contact was usually on an informal basis - as the child was dropped off or collected from school, although there were occasions, such as the annual review, when formal contact occurred.

Both parents and head teachers felt that regular and frequent contact was essential, although this need not be on a pre-arranged basis.

5. The role of the educational psychologist in integration

Parents found the role of the educational psychologist generally difficult to comprehend. Their main criticism was

that they felt uninvolved and ignored by the educational psychologist who they felt made decisions without consulting with them. Parents complained that the EP:

1. Did not inform them when they were coming in to school.
2. Could never be reached by telephone.
3. Rarely visited the school and, if they did so, often failed to give advice.
4. Assumed the parents had knowledge that they didn't have.

The general opinion was one of immense dissatisfaction with the EP and the feeling that they had contributed little in terms of support and advice.

The amount of contact that the school had with the educational psychologist varied considerably from termly to monthly visits. In some cases there was always some discussion as to the progress being made by the child with Down's syndrome whereas in other cases, the child was only discussed if specific need arose. Some head teachers feel that this contact was sufficient whilst others would have liked more. The majority of head teachers found what contact they had useful, even if they felt the amount that they had was inadequate.

Head teachers felt that there was a definite role for the EP in helping a child with special educational needs to integrate and outlined some of the areas in which they felt that the EP could offer assistance. Firstly, in guiding them through the legal obligations that had to be fulfilled in order to meet the needs of the child, such as giving guidance as to the frequency and content of progress reviews etc. Secondly, head teachers felt that they should be able to look to the EP for guidance as to teaching programmes and behaviour modification programmes (where necessary) that would be suitable for the child. Thirdly, schools felt that the EP should visit regularly in order to reassure school and parents that they were attempting to meet the needs of the child in the right way.

6. Response to the integrated child

In the majority of cases, parents reported that their child was totally accepted by his or her peers. Head teachers tended to have some reservations about the level of acceptance shown to the child - mothers were more likely to report that their child had been totally accepted. Two head teachers acknowledged that the pupils in the class found some aspects of the child's behaviour difficult to cope with at times and also that their lack of competence in language (shared to a greater or lesser degree by all the children in the study) caused difficulties at times.

Both parents and head teachers commented on a tendency to "mollycoddle" the child with Down's syndrome. Whereas parents tended to regard this as evidence of their child's successful integration and acceptance by their peers, some head teachers felt that the child had not been accorded the respect that children usually showed their peers and was treated rather as a plaything. Two head teachers also commented on the tendency for adults in the school to mollycoddle the child and single him or her out for extra

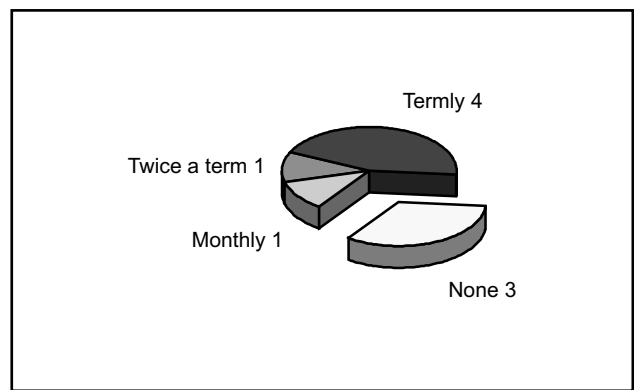


Figure 3. Amount of contact school has with EP.

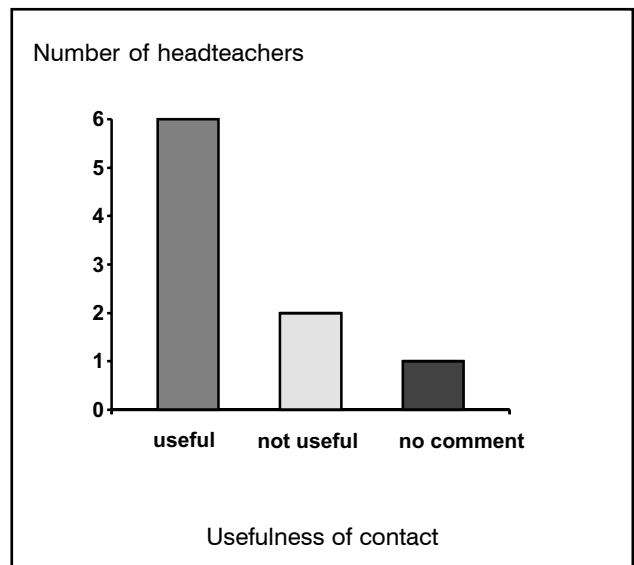


Figure 4. Usefulness of the contact with the EP.

attention, or make allowances for that child that would not be made for others. These head teachers felt that they had had to work hard to try to ensure that the child was treated in an equivalent manner to his or her peers, thus fulfilling the goals of integration as they perceived them.

Only two head teachers had had negative comments made by parents of other children and these had focussed upon the amount of time given to the child with Down's syndrome which parents perceived to be at the expense of their child.

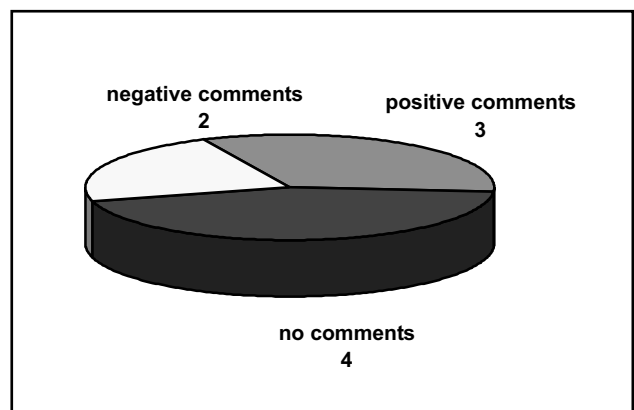


Figure 5. Parents' response to the integrated pupil.

7. The attitude of the head teacher towards the idea of integration

Most head teachers had felt very positive about the idea of accepting the child with Down's syndrome into their school. Some of the head teachers admitted that they had assumed that full support would be provided and, realising now that this was not necessarily the case, felt that they would be more cautious another time. Having had the child in the school, most head teachers continued to feel positive and felt that there had been many benefits.

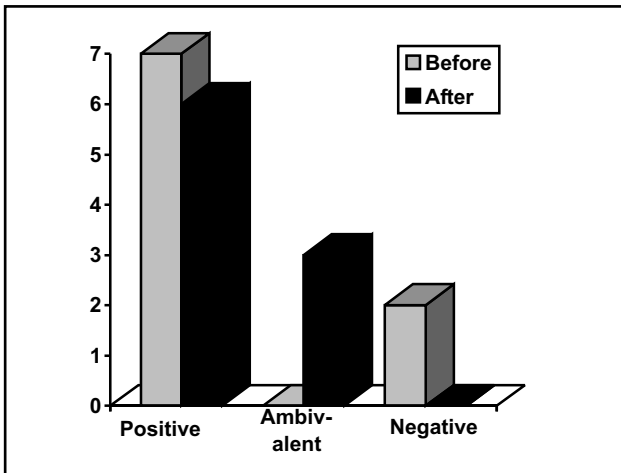


Figure 6. Head teachers feelings both before and after integration.

8. Parents' and head teachers' feelings as to the future of the child.

Generally parents felt that their child would remain in mainstream education, although some highlighted that there might be new difficulties to face as their child grew older. Most parents rated 'independence' and 'having a job' as their main aspirations for their child's future. Parents did not express a wish that their child should develop the same academic abilities as their peers but concentrated more upon basic self help and simple vocational skills. Head teachers were less certain than parents in feeling that mainstream education would be suitable for the child throughout their school career. They focussed on the increasing disparity that might arise between the abilities (social and academic) of the child with Down's syndrome and his or her peers.

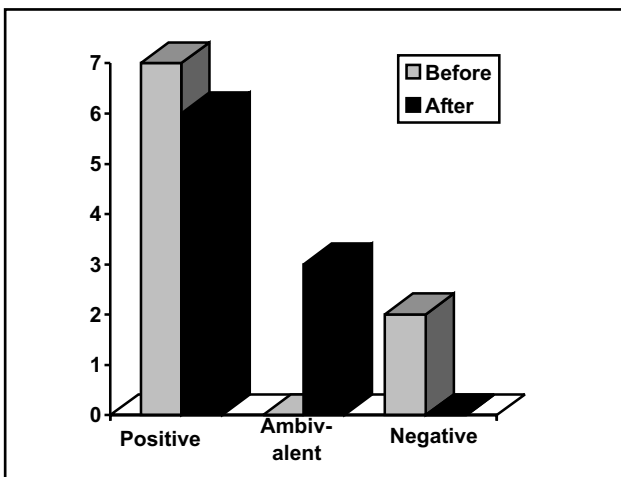


Figure 7. Head teachers' opinions as to the most appropriate future school placement for the child

Conclusions

Consolidating the above findings, it is possible to suggest a model of good practice:

Before the child begins school

Parents should receive comprehensive advice from an early stage. Those in the medical, educational and welfare professions should be honest with parents and provide them with fair predictions as to the difficulties that their child *might* experience and the abilities that their child *might* possess. Advice should be readily available for parents regarding choice of playgroup and school.

Head teachers and prospective class teachers should be encouraged to visit the child, both at home and in a playgroup or nursery setting, such that they become familiar with the child and have the opportunity to speak with the parents and the play-group or nursery staff about the child. Such pre-school liaison will help to alleviate the understandable anxieties that the class teacher might have in knowing that a child with special educational needs is to be entering his or her class.

The amount of support that the child is to receive in school should be clarified and in place *before* the child begins school. This reduces the tensions that arise from staff having to arrange cover so that the child is supported, or the child not being able to attend school until the support arrives, by which time the class has settled.

Advice to the school

Schools should also receive advice and support from those with knowledge and expertise both before and after the child begins school. Such advice might come from the EP, the occupational therapist, speech therapist or advisory teacher. Many of the head teacher's anxieties were not as to whether or not to accept the child into their school but as to whether they could meet the needs of that child whilst continuing to meet the needs of the others in the class. Many of these anxieties stem from inexperience and a lack of confidence, and these anxieties would be minimised if staff were able to share them with others and receive advice from outside professionals.

Once the child is in school

Both parents and school staff continue to need support once the child has begun school. Again, support and advice agencies should be on hand to answer questions, reassure parents and staff and provide advice. This support should be offered to schools on a regular basis and schools should be made aware as to whom they should contact if unexpected difficulties arise.

Support staff

Support staff should be clearly aware of their role and the way in which they are expected to give support to the child. Ideally parents should be involved in any discussion relating to the role of the support staff, but if this is not possible, they should be clearly informed as to the way in which the support staff will work with their child. This would help to alleviate misunderstandings or dissatisfaction.

Issues regarding the use of support staff should be on the agenda at every progress review, such that parents feel that they can voice any concerns in a supportive atmosphere.

Communication

There should be frequent communication between school and parents on both an informal and formal level. Parents should feel that their opinions are valued and heard and be kept fully informed as to the progress made by their child. The amount of formal communication that will take place should be made explicit at the start of the child's school career, although these arrangements should be flexible such that they can be adapted according to need. Schools should always inform parents when their child is to be seen by any professional from outside school, such as the educational psychologist or speech therapist.

Role of the educational psychologist

The role of the educational psychologist should be made explicit to parents. Parents should be notified in advance of any visit that the educational psychologist is to make to see their child and should also be made aware of any change of educational psychologist. They should also be involved in any decision making or discussion involving their child, or if this is not possible, be informed of it immediately following the event. Educational psychologists should avoid using jargon or assuming knowledge on the part of the parents. The issue of inaccessibility on the part of the educational psychologist needs also to be addressed.

The number and nature of the school visits made by the educational psychologist should be negotiated and understood by both educational psychologist and school. Depending upon the needs of the child, the child might be discussed, albeit briefly, at every meeting, or an arrangement made that the child will only be discussed when the school deem it necessary. Schools and parents should not be left with the impression that the child is being ignored.

Preparing others

Head teachers should consider carefully whether they wish to announce the child's arrival to the parents of the other children in advance. If they choose not to do so, it must be remembered that some parents might have anxieties about the effect that a child with such educational needs might have on the education of their child, and the staff should be prepared to explain in detail the level of support that the child would receive in order to alleviate such concerns.

Head teachers might also want to consider discussing the child with the *whole* school staff before the child begins school - including lunchtime supervisors, cleaning staff etc and emphasising the importance of treating the child as 'normally' as possible - disciplining where necessary and encouraging the child's independence, rather than being over protective or over attentive. Much of this will depend upon the ethos of the school and the approach which the head teacher and parents believe to be appropriate.

Aims of integration

The aims of the mainstream education for the child should also be clearly stated. If the main aim of the education is that of social development then this should be understood by both staff and parents. If the emphasis is on academic as well as social development then this also should be stated. In this way, all will be working with common aims and the progress made by the child can be realistically evaluated by parents and staff. If head teachers feel that the child is in mainstream school mainly to develop academic skills and are aware that

the gap between the pupils and his or her peers is increasing, they might feel that the placement is no longer suitable. Parents, however, might feel that their child is still developing in other skill areas and that therefore the placement is still entirely valid. Unless this is discussed and re-clarified at regular intervals, this might become an area of tension, particularly as the pupil gets older.

Conclusion

The study elicited much information relating to the process of integrating pupils with Down's syndrome into mainstream primary schools. Overall both parents and head teachers are committed to integration and feel that there are benefits for both the child concerned and those in the wider school community encompassing staff, other children and parents.

However the study highlighted inadequacies and dissatisfactions with the current 'system' which place strain on families and head teachers who are attempting to provide children with Down's syndrome with their entitlement to a mainstream education. Further research and appropriate action needs to be undertaken to ensure that children with special educational needs in mainstream schools have these needs appropriately met.

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