

MAKING INCLUSION WORK FOR CHILDREN WITH DOWN SYNDROME

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Summary — This article reports the findings from a survey of over 400 families, investigating their experiences of inclusive education in the United Kingdom. The findings indicate considerable variation in provision between different Local Education Authorities across the UK. The article details indications of good practice and appropriate provision as found in the survey results.

Keywords — *Down syndrome, education, inclusion, school-aged children*

Introduction

Over the last twelve months, the author has been collecting data from a sample of over 400 families whose children attend mainstream schools. Their experiences of inclusive education make fascinating reading and illustrate the point made in the Green Paper “Excellence for all children” that provision for children with very similar needs can vary widely from one area of the country to another. From the picture painted by the questionnaire responses, it is now possible to produce guidelines as to what successful inclusive practice should look like.

Models of support

Evidence suggests that a very significant proportion of children with Down syndrome could be placed successfully in a mainstream school. Research data, although still somewhat limited,^[1] indicates that such placements lead to academic as well as social gains and increase the chances of the child making local friendships that extend beyond the school day. These facts have led increasing numbers of parents to seek an inclusive placement for their child.

In some parts of the country^[2] over 80% of primary and 50% of secondary aged children are already included, although the picture is very different elsewhere.^[3] In all too many Local Education Authorities, parents still have to put up a fight to secure an adequately funded place in their local school. From the current sample of 315 parents who have succeeded in gaining a mainstream place for their child, 29% report difficulties with either the Local Education Authority or the school itself.

While a majority of children with Down syndrome are able to take part in at least some activities with little additional support, maximum benefit will only be obtained if the child has access to a classroom assistant or support teacher for much of their time in school. Further, tasks will need to be modified and adapted to ensure that they are relevant and appropriate.^[4]

While there clearly are students for whom only minimal support is required throughout the day, the practice is not generally recommended. All children benefit from some time without direct supervision, enabling them to gain in independence and mix socially with their peer group. On the other hand, it is not possible for a busy class teacher to deliver an appropriately flexible and

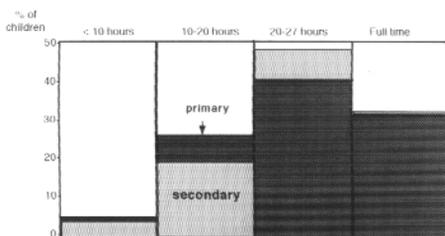


Fig.1. Hours of LSA support per week

differentiated curriculum on their own, without disadvantaging the rest of the class.

A nationwide survey recently carried out by the author indicates that the majority of children with Down syndrome in mainstream schools are supported by a learning support assistant for between 20 and 27 hours a week (Fig.1). Of the children in the survey sample, 58% at primary and 61% at secondary level were largely unsupported at dinner time, at break times and during assembly. A further 25% at primary and 18% at secondary level took part in lessons such as physical education, drama and music without support. However, only 2-3% were unsupported in more academic lessons.

Survey data confirm the view expressed by many parents that the level of support offered by an Local Education Authority has more to do with local policy or the anxieties of schools than with the needs of the individual child. Far too many Local Education Authorities operate a blanket policy which results in all children with Down syndrome being offered a standard package of support. As a consequence, those with lesser needs are frequently over-supported and are, as a direct consequence, less likely to become independent learners. Conversely, those who need more support may have to be transferred to a more specialised setting, against parental wishes, when problems could have been overcome in situ.

What is surprising is that the picture of support at primary and at secondary level is so similar, despite the fact that in most parts of the country the populations differ significantly. Responses from parents suggest that most children with Down syndrome can now find a place in a mainstream primary, as long as the family are persistent and shop around local schools. On the other hand,

in many Local Education Authorities, only the most able youngsters are gaining a secondary place.

Several parents in the survey have already accepted the inevitability of special schooling at 11, despite successful mainstream experience at primary level. Nevertheless, where less academically able students have transferred to the secondary sector, they appear to be doing just as well as those with more advanced levels of performance. What seems clear is that 'cognitive ability', whether measured by I.Q. tests or attainment, is a remarkably poor predictor of successful mainstream placement.

Working in a team

In organising support for the student with Down syndrome, the class teacher should aim to:

- Keep withdrawal to a minimum and give the child access to as much of the normal curriculum as possible.
- Encourage the child to become an independent learner.
- Foster co-operative working with other children in the class.
- Work directly with the children themselves, at least once a week, and ideally daily.

These objectives are best met where class teacher and support staff see themselves as a team,^[5] working flexibly to meet the needs of the whole class. As Lorenz notes,^[6] a learning support assistant who is always at hand and who prompts the child continually, or intervenes immediately the child is faced with a problem, will inhibit the development of independence.

Far better is a situation where the assistant offers support only when needed and works regularly with other students who require help. Although some parents become very agitated when they find some of their child's hours being used to assist other children, this approach is likely to be far more beneficial in the long term than continual one to one support. It frees the class teacher to work directly with the child and gives the child opportunities to work with other people.

In some schools, particularly in the secondary sector, young people with Down syndrome are increasingly being supported by more than one assistant. This can work well where communication is good and support staff are placed in settings where their particular skills can be used to best effect. This approach, while still relatively uncommon, has several advantages:

- a) it avoids the unnaturally close relationship which sometimes develops between child and assistant,
- b) it allows cover to be arranged more readily if one assistant is ill or on a training course, and
- c) it avoids the trauma caused to a child whose support assistant leaves.

In the author's survey, virtually all primary aged pupils were being supported by one assistant. However, in the secondary sector, 32% had two or three assistants, while 19% were being supported by different assistants in different subject areas. Lee and Henkhuzens, in their study of ten inclusive secondary schools from five different Local Education Authorities,^[7] recommended the attachment of support assistants to subject departments as:

- a) It enables learning support assistants to become familiar with the subject area and the way in which each topic will be approached.
- b) It allows the assistants to feel more confident in their ability to support students appropriately, particularly where it is possible to place assistants in subject areas where they already have confidence, expertise or interest.
- c) It increases opportunities for assistants and subject staff to work together to produce a bank of appropriate materials.

The role of support staff

When support staff are used, be they teachers or support assistants, it is important that all concerned are clear about their role [8]. They should be there, primarily, to assist the child, although they also have a part to play in supporting the class or subject teacher. Many of the roles can be car-

ried out equally well by teachers or support assistants. However, schools must ensure that staff without teaching qualifications are not asked to plan work or teach students on a withdrawal basis unless they are under the direct supervision of the class teacher. On the other hand, using teachers for general in-class support may be a poor use of scarce resources.^[9]

One key aim of support, particularly at secondary level, must be to increase students' independence and progressively reduce their need for adult assistance. An adult accompanying a primary aged child around the school building is accepted as fairly normal practice. However, adults do not generally follow secondary aged students from one class to the next. Where support is required, this is best provided by peers. By encouraging other students to become involved it may be possible to overcome some of the problems of social isolation experienced by many young people with Down syndrome as they approach adolescence.

Involving the class teacher

In primary schools where there is more than one child receiving support, changing the support assistant, as well as the teacher, when the child moves classes can be a useful strategy, although one that is rarely used. Not only does this encourage the new teacher to take a personal interest in the child with Down syndrome, instead of relying on the assistant who already knows the child, but it prevents assistant and child becoming too close.

Where a learning support assistant is able to remain with the same teacher, rather than the same child, joint working practices can be developed over time to the benefit of all. However, in many schools this is not possible as their funding only permits them to employ one support assistant. Nevertheless, there is still a lot that can be done to prevent difficulties, when a school is aware of the potential pitfalls of over-dependence.

An assistant who has worked almost exclusively with the same child for a long time may be reluctant to let go and may be unwilling to work with other children in the class, even if this is in the target child's best interest. While parents and pro-

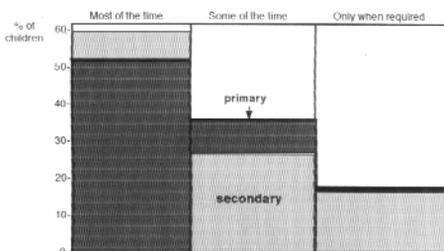


Fig.2. Direct involvement of support assistant

professionals should undoubtedly be fighting to maintain an adequate level of support for every child with Down syndrome, they should be equally vigilant and object just as strongly where children are being over-supported.

According to parents, in more than half of the schools sampled, the child's support assistant sits next to them for most of the time, occasionally or never working with other children in the class (Fig.2). Survey data indicate that in 28% of cases, primary aged children with Down syndrome are taught by their class teacher less than once a week. In the secondary sector this rises to 53%, with subject teachers all too often having little direct involvement in the child's educational programme (Fig.3).

At primary level, almost all direct teaching is carried out by support assistants. Yet we know that over half the learning support assistants involved have no formal qualifications, nor have they received any training in the teaching of children with Down syndrome. At secondary level students are likely to be taught either by a support assistant or by a support teacher without particular subject expertise. Hopefully, as teachers get more confident in teaching students with Down syndrome

and learn to work more flexibly with support staff, the picture will change.

Support for support staff

Most schools, quite rightly, emphasise the need to provide an adequate level of support for the child. However, they often fail to recognise or acknowledge the support needs of their staff. Questionnaire responses suggest that 69% of the primary and 81% of the secondary schools in the survey receive no input from an Local Education Authority advisory service. Of those that do, only 11% of primary and 7% of secondary schools see an advisory teacher more than once a term.

Even where outside help is available, parents and teachers should insist that time is provided for support assistants and teachers to plan their work. Special Educational Needs Co-ordinators, whose responsibility it is to manage the support staff, should ensure that they are given sufficient time away from their normal teaching duties to carry out this essential function.

Although non-contact time is provided in over half of secondary schools, when teachers and assistants can discuss their respective roles and responsibilities, only a third of primary support assistants are given paid planning time. Undoubtedly some will stay behind after school, or give up their lunch break, to discuss the needs of the children they support. However, it seems unreasonable for schools to take advantage of the goodwill of such poorly paid staff. The solution lies in the hands of Local Education Authorities who should recognise the importance of planning and build it into the provision on the child's statement.

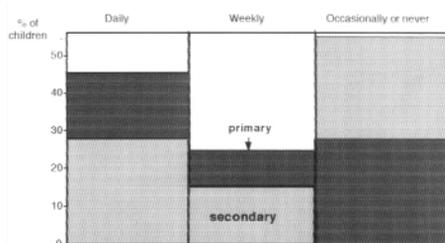


Fig.3. Direct teaching by class of subject teacher

Accessing the curriculum

In the primary school, there is generally little choice for the class teacher, other than to involve the child in normal classroom activities or alternatively, to ask the support assistant to work with them individually or in a small group. At secondary level there are many more possible options. Survey findings suggest that most secondary aged students with Down syndrome are taught in mixed ability classes for at least part of the week,

with or without additional support, and in lower sets or withdrawal groups for the remaining lessons.

Over a third of the students receive some additional in-class support from a learning support teacher in maths or english, while around half are withdrawn for individual or small group help at least once a week. Although most students with Down syndrome spend some time in bottom sets, one young man has been placed in the third of four sets, to avoid the disaffected and troublesome pupils often found in lower achieving groups. This is particularly pertinent for students with Down syndrome who frequently mimic the behaviour of their peers.

As Lee and Henkhuzens [7] note:

If you have a group of pupils with learning difficulties (and maybe associated behavioural difficulties) all together, there are no positive role models available, the teacher may be the only source of ideas and information, and the group may be perceived as difficult to teach.

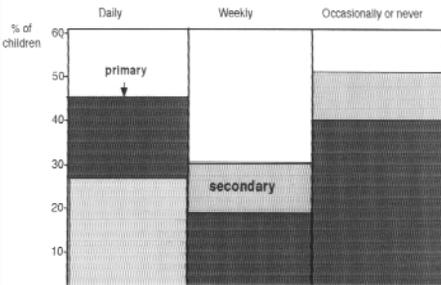


Fig.4. Frequency of withdrawal

At primary level most children take part in the same lessons as their peers. However, 60% are withdrawn on a regular basis by their support assistant, a speech therapist or a support teacher for individual or small group work. This figure falls to 50% for students at secondary level, with more focussed help being offered in-class (Fig.4).

While anecdotal evidence indicates that children with Down syndrome experience considerably more difficulty in maths than in reading, more time appears to be devoted to literacy related

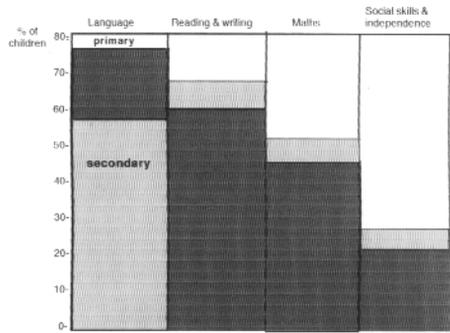


Fig.5. Focus of withdrawal

withdrawal than to maths (Fig.5). Although more than three quarters of primary aged students are withdrawn for language related work, this falls to less than half in the secondary sector, with more emphasis being placed on social skills and independence training.

Support from speech and language therapy services is also reduced significantly at secondary transfer, with 68% of secondary students receiving no speech therapy input as compared with 33% of primary aged children. However, even at primary level, only 29% of children see a therapist more than once a term, despite the major language problems experienced by most children with Down syndrome and the acknowledged need for support staff to be trained and supported in their language development work.

None of the primary aged students in the study were disapplied from the National Curriculum, although a small percentage of those in secondary schools were disapplied from modern languages. In some schools, the provision of a Learning Support option at Key Stage 4, allows additional time to be given to basic skills or complementary studies. In others, students in their final years are provided with an individualised curriculum containing both academic and vocational elements.

Conclusions

Data from over 300 questionnaires, followed up by discussions with parents and teachers, show quite clearly that successful inclusive education for many children with Down syndrome is a reality both at primary and at secondary level. Yet for

others, mainstream placement appears to be offering little in terms of skilled teaching or peer group interaction. While adequate levels of resourcing are clearly important, greater attention needs to be focussed on the way in which support is used.

The key factors for successful inclusion appear to be:

1. A positive attitude of the school as a whole to the disabled child.
2. A flexible approach to the use of support staff.
3. Ownership by the class teacher of the child's learning programme.
4. Good communication between the school and the parents.
5. Support for the school from Local Education Authority services.

If these are in place, there is no reason why the majority of children with Down syndrome could not attend their local school and benefit both socially and academically from an inclusive placement both at primary and at secondary level.

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Further reading

Experiences of inclusion for Children with Down's Syndrome, a report detailing the research upon which this article is based, is available from The Down's Syndrome Association, 155 Mitcham Road, London, SW17 9PG, England

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