Mainstreaming in Massachusetts

By Mark Vaughan & Ann Shearer

Centre for Studies on Integration in Education (CSIE) &
The Campaign for People with Mental Handicaps (CMH)

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How special education became ordinary in one state in America

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The Campaign for People with Mental Handicaps (CMH)

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Introduction

The last decade has seen something of a revolution in American provision for children with special educational needs. In 1975, the Federal Education of All Handicapped Children Act guaranteed for the first time that children and young people so defined should have access to a free and appropriate public education — and that this should be in the 'least restrictive environment possible', which means as near as possible to the place where children without handicaps are educated. So, while provision in the United States had lagged behind that in Britain — which brought the last of its handicapped children into the education system in 1971 — it then took a step ahead in its determination to build the maximum integration possible into its special education provision.

The Federal Law came into operation in 1978. Meanwhile, though, the state of Massachusetts had introduced its own special education law, which in some ways goes further than the Federal one. Chapter 766 came into effect in the school year 1974/5, so Massachusetts has now had exactly a decade in which to build, debate and refine a new way of meeting the special educational needs of some 14 per cent of its children and young people. It is this Massachusetts experience, rather than that of special education reform in the US as a whole, that this report is about.

And Massachusetts has something to celebrate. There have been difficulties and snags. There remain inequalities. One of the things that must strike any visitor is just how open and undefensive everyone is about these. But that Massachusetts has shown commitment to the principle of integrating its children and young people with special educational needs into the mainstream of educational life, there can be no doubt at all. There's no doubt either that the principle has widespread support. And the experience of just how it can be translated into practice has enormous value.

It is particularly important to any one concerned with special education in England and Wales at this time. The 1981 Education Act has been in operation for just two years. Local education authorities (LEAs) and parents are only just beginning to get accustomed to the complexity of its procedures. In all the hard work that has to go into these, the philosophy of integration that informs them can perhaps get dulled. LEAs have been slow to make a public commitment to it; parents often doubt whether it can 'work'.

We are in this country, though, beginning to confront this central issue in special educational provision. In July 1985, the Fish Report on Special Education in the Inner London Education Authority made an appraisal of services which is so far unique among English and Welsh education authorities. And it unequivocally challenged the continued segregation of up to five per cent of the authority's population into special, separate, schools.

The Fish report, "Equal Opportunities for All?" based its stand for integration on the ILEA's commitment to ending discrimination on grounds of race, sex and class and to providing equal opportunities for all its students. The report was in no doubt that the right place for the education of children with special needs was the place where they retain regular contact with their contemporaries. 'The potentially adverse effects of isolation and segregation, in whatever context, including comprehensive institutions, are now well known, including the risks to social competence and to the development of a positive self-identity'.

In Massachusetts, people believe that too. The difference is that they have been working to get beyond the rhetoric for a decade. What their efforts show is just how many people need to be involved in the effort — legislators and bureaucrats at every level, teachers and researchers, and above all, parents, their advocates and children themselves. And what they show, too, is just how rewarding and exciting the process of change can be.

MARK VAUGHAN and ANN SHEARER visited Massachusetts in May, 1985. They were very generously received by parents, schools, administrators and many others who took time out of their busy schedules to help them understand the Massachusetts experience of special education and its background. This is the place to thank them all for their help — especially Gunnar and Rosemary Dybwad.

It's the place, too, to record that responsibility for any errors of fact or emphasis rests with the authors: their informants certainly did their best to make sure we understood the complexities!

MARK VAUGHAN is coordinator of the **Centre for Studies on Integration in Education (CSIE),** which covers the whole range of special needs. The Centre, which is part of **The Spastics Society,** collects and disseminates information on integration in practice, and helps to raise parental, professional and political awareness of this and related issues.

ANN SHEARER is a founder member of the **Campaign for People with Mental Handicaps (CMH).** Her books include *Disability: Whose Handicap* (Blackwell, 1981) and *Living Independently* (Centre on Environment for the Handicapped, 1982).

What does the law say?

American Public Law and Massachusetts State Law.

P.L.94.142 A summary of the major rights and duties

General

In 1975, America passed the Federal Education of All Handicapped Children Act which is known as Public Law 94.142 and covers all states. In the State of Massachusetts, the law has its own local flavour and goes somewhat further, and is known as Chapter 766.

The Federal Act ensures that in all states handicapped children have available to them a free, appropriate, public education designed to meet their unique needs, and ensures that the rights of handicapped children and their parents or guardians are protected.

It covers all handicapped children aged three to 21 and guarantees a full programme of academic and related services for them.

Mainstreaming

Local education authorities in each of the 50 states are responsible for identifying, locating and educating children with special needs, and then providing for them in the least restrictive environment.

This means a child must be educated to the maximum extent appropriate with non-handicapped children. It must include non-academic and extra-curricular activities. The placement must be as close to the child's home as possible.

IEP

Each child must have an individualised educational plan (IEP) written for him or her, giving a profile of their needs together with specific ways in which goals and objectives will be reached over a one year period.

This IEP is decided on only after a Team Meeting which must include the parents, and child where appropriate. The IEP is not valid without the parent's consent which can be revoked at any time in the process. The IEP must be written within 30 days of it being determined that a child needs special education and related services.

Review

A review of the plan must take place at least once a year. Parents have the right to a full re-evaluation every three years. Parents have the right to refer their own child for an evaluation.

Testing

Parents have the right to have their child tested in non-discriminatory test material, in the usual mode of the child's communication.

Notices

Notice of an evaluation (or changes in placement and provision) must be given in the native language of the parent, unless it is clearly not feasible to do so.

Appeals

Parents have the right to an appeal or hearing if any of these rights are denied or if they are in dispute with the school or LEA. They also have the right to appeal to a higher body if the hearing finds against them.

Parents can request that a hearing be open to the public; they must receive a copy of all documents five days prior to the hearing; they have the right to present evidence, to confront, cross-examine and to compel witnesses to attend.

Access to reports

Parents have the right to see and obtain copies of all records and reports and to have confidentiality maintained.

Notification

Parents must be informed of all meetings early enough to ensure their opportunity to attend.

Where parents withold or revoke consent their child is still guaranteed all normal education services.

Where parents disagree with an evaluation of their child they have the right to a further independent evaluation at public expense.

In Massachusetts, under Chapter 766

All categories of handicap, such as mentally retarded, hard of hearing, speech impaired etc, which are listed in the Federal Law, are abolished and replaced by a system that classifies children with special needs according to the degree of time that they spend *out* of the ordinary classroom, receiving special provision. (This system is known as the Program Prototypes).

Evaluation by professionals of a child can only go ahead with the parent's written permission.

Parents can participate in all meetings of the Team where the IEP is being developed.

They may be accompanied or represented at these meetings by someone of their choice.

The parent, and a child aged 14 or older, have the right to meet with the Team Meeting chairperson prior to the actual meeting.

A student aged 18 or older may act on his or her own behalf.

Parents have the right to semi-annual progress reports.

Student rights under Chapter 766

At age 14+ students have:

The right to have a pre-evaluation meeting.

The right to be present at Team Meetings and to help write their own educational plan (under 14 they need permission from the chairperson).

The right to have language used at the Team

Meetings which is the same as that used at home.

The right to bring two people of their parents' choosing to the Team meeting (they could be friends of the student).

The right to have the evaluation completed within 30 school days after consent is given.

The right to have the evaluation completed within 30 school days after consent is given.
or all aspects of the educational plan.

The right to see all records which the school has on file.

The right to a copy of the IEP, on request.

The right to stay in their present programme while the evaluation process is going on, unless parents or the Special Education Director feel it is not in their best interests.

The right to progress reports semi-annually, if the student requests them. These must be sent to parents.

The right to an annual review of their IEP, their needs, and the appropriateness of their programme.

The right to have records protected and kept confidential. The only people allowed to see their records without their special permission are school officials, teachers who work with them, and certain State Department of Education people. Anyone else must have written permission from the student. (Under 14, or not in ninth grade, parent's permission must be given).

All the above rights apply, between the age of 18 and 22, plus the following:
The right to refer him/herself for an evaluation.
The right to refuse an evaluation.
The right to deny parents access to records and other information.
All parents' rights under Chapter 766 become students' rights upon reaching age 18.

Time Lines under Chapter 766

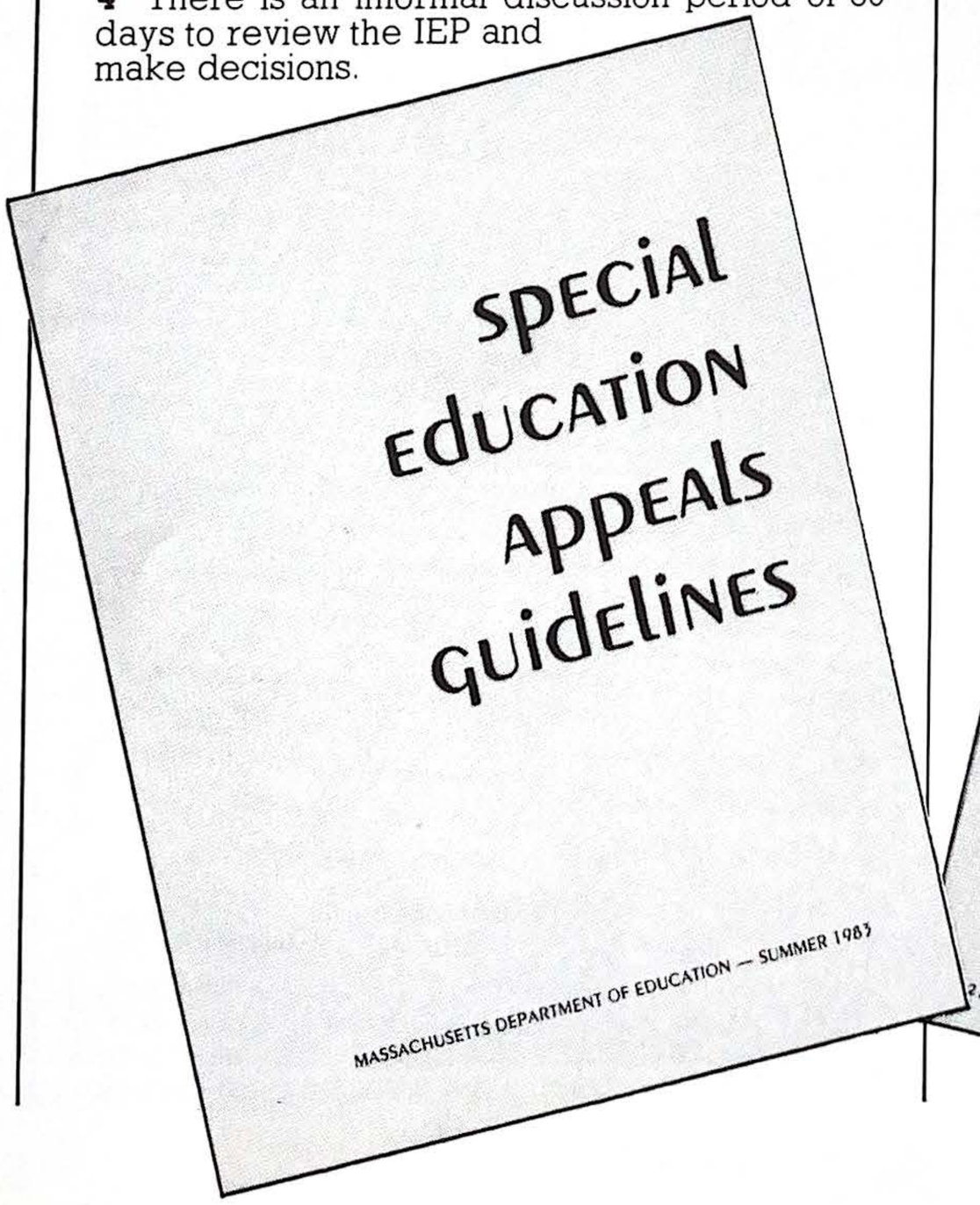
1 If someone besides the parent refers the child, notice must be sent to the parent within five days.
2 The evaluation must be completed within 30 school working days of the school receiving the parents' written consent.
3 Following the evaluation Team Meeting, the IEP must be sent to parents within ten days.
4 There is an informal discussion period of 30 days to review the IEP and
make decisions.
5 If the parent requests an independent evaluation, it must be completed within 30 days.
6 Following the completion of the independent evaluation and new Team Meeting, the parents must make their decision within 30 days.
7 After receipt of a rejection of the educational plan, the local school committee must send notice to Bureau of Special Education Appeals within five days.
8 After receipt of a rejection of the educational plan from school committee, the Bureau must send notice to both parties.
9 Upon receipt of a request for hearing (appeal), the hearing must be scheduled within 20 days by the Bureau.
10 Upon receipt of a request for a hearing, a decision will be given by the hearing officer within 45 days.
11 If a parent disagrees with the decision, they may appeal to the State Advisory Commission (SAC) within 15 days.
12 Following receipt of a request for appeal, the SAC must give a decision at the next monthly meeting, provided the request is received at least 15 days before the meeting.
13 If the parent disagrees with the SAC decision, they may appeal to the Superior Court within 30 days.

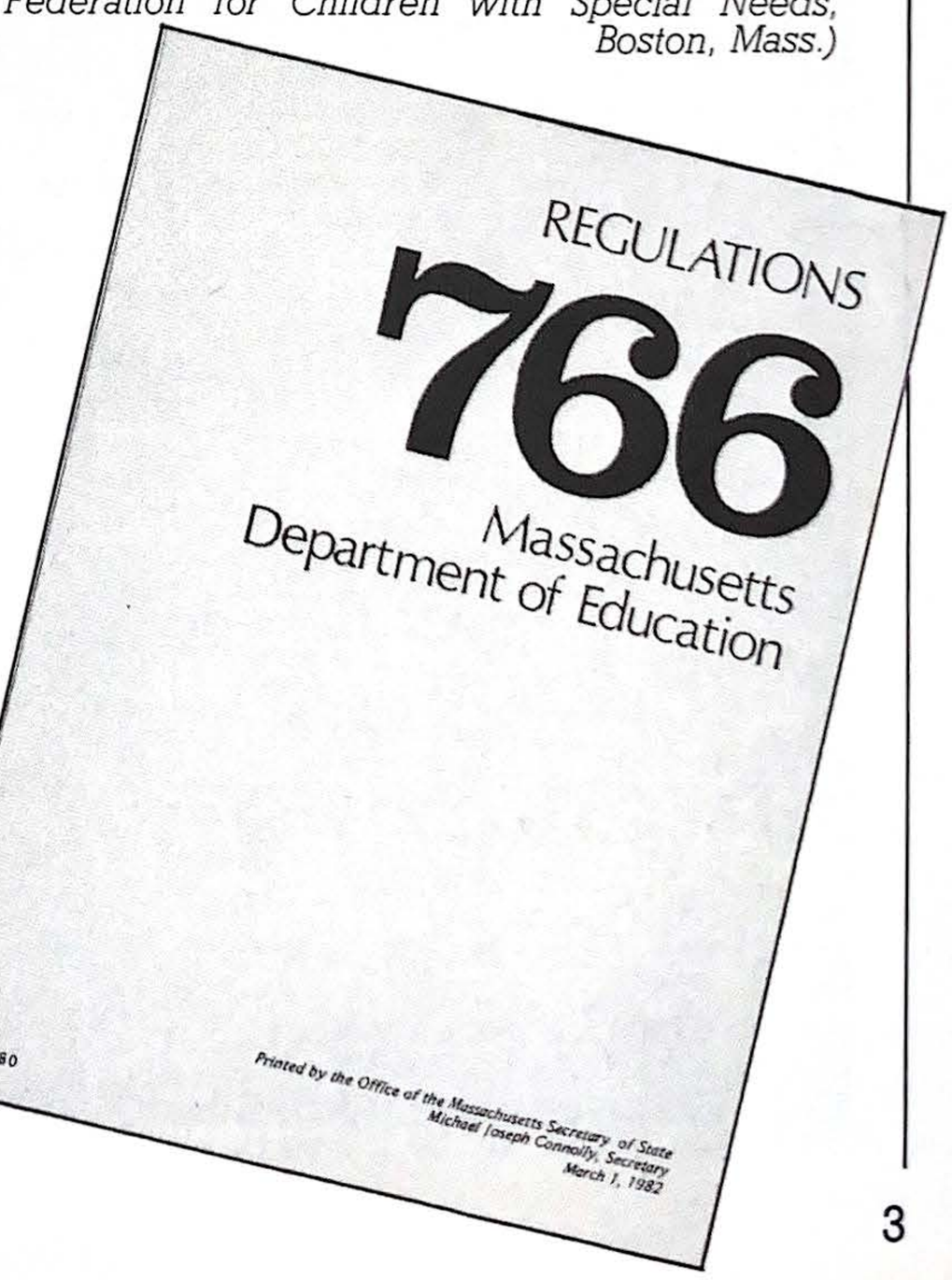
Section 504 The Civil Rights Law for People with Disabilities

Section 504 of the Federal Rehabilitation Act, enacted in 1973, was the first civil rights law guaranteeing equal opportunity for more than 35 million handicapped Americans. It states that programmes receiving Federal funding are prohibited from discriminating against disabled people. This covers schools and colleges.

'No otherwise qualified handicapped individual shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under program or activity conducted by any Executive agency or by the United States Post Office.'

(This section on law has been adapted from: Federation for Children with Special Needs, Boston, Mass.)





What are the placement options?

The Federal law (P.L. 94.142) has a list of categories into which children with special educational needs are expected to be placed, similar to the English and Welsh list of 12 categories of handicap which were abolished with the implementation of the 1981 Education Act (on April 1 1983).

Massachusetts, however, has taken a different approach. The Program Prototypes introduced under its own law define the different placement options available to the evaluation team looking at an individual student's special needs. The goal, as with the Federal law, is to maintain students within the mainstream of education in 'the least restrictive environment' — the one nearest the ordinary classroom possible.

These are the Program Prototypes:

502.1 — Regular education programs with modifications
The student is assigned to a regular classroom. The IEP specifies slight changes in the regular education program and additional services which will be provided by the regular classroom teacher with materials and equipment provided by specialists. All aspects of the IEP are delivered in a regular public school facility.

502.2 — Regular education program with no more than 25 per cent time out
The student is assigned to a regular classroom and additional instruction is provided outside the classroom in individualised or small group situations. The student may not be removed from the regular education program more than 25 per cent of class time. Individualised and tutorial services are provided by specialists and/or Learning Center teachers and are designed to carry over into the regular classroom. All educational services are delivered in a regular public school facility.

502.3 — Regular education program with no more than 60 per cent time out
The student is assigned to a regular classroom, and additional instruction is provided outside the regular classroom up to 60 per cent of class time. Individualised, small group instruction is provided by specialists and/or Learning Center teachers. All educational services are delivered in a regular public school facility.

502.4 — Substantially separate program with more than 60 per cent time out
The student is assigned to an educational program which is separate from the regular school program. This special class is made up entirely of other students with similar special needs. Substantially separate programs are conducted by special education teachers with special training and certification. The student may participate in the regular education program up to 40 per cent of the time.

502.4(i) — Substantially separate program with more than 60 per cent time out
Operated in a facility other than a public school regular education facility, subject to approval by the Regional Review Board.

502.5 — Day school program
The student is placed in a special Chapter 766 approved day school program which offers special services which are not available within the public school system. The student returns home each night. Transportation is provided by the public school system.

502.6 — Residential school program
The student is placed in a twenty-four hour program in a Chapter 766 approved facility outside the public school system. The student lives at the facility. The public school system may pay in some cases for education-related services or cost share with other agencies or individuals.

502.7 — Home, Hospital, and Regional Adolescent Program
Special instructional services are provided to a student who has to remain at home or in a hospital for an extended period of time (14 to 60 days).

502.8 — Program for children 3 to 5 years old
Nursery school programs which serve pre-school children with mild to severe handicaps. Classes are organised according to needs and age. Parental involvement is an important part of this program.

502.9 — Diagnostic program
A diagnostic program consists of observations and assessments designed to define a student's special needs. A diagnostic program is provided when the assessments conducted by members of the Evaluation Team are so inconclusive that it is impossible to write an IEP. The student may be assigned to a diagnostic program for not more than eight weeks. The Evaluation Team meets again to write an IEP based on the findings made during the diagnostic program.

502.11 — Programs for students 16 through 21 years old
Students in need of special education who are 16 through 21 years old are eligible for programs within each of the program prototypes on the same basis as all other students. If no suitable program exists within a Program Prototype, the Evaluation Team must design a suitable program for the student.

The context of reform

The debate about who should have responsibility for the education of which children with differing special needs is hardly a new one in the United States, as elsewhere. From the 1950s on, it took place against a rather different background from the one in Britain. In the US there was a slow growth of special classes rather than of special schools; and very many children with different special education needs were effectively excluded from any sort of schooling at all.

Within a tradition where central Government involvement has been seen as something like an

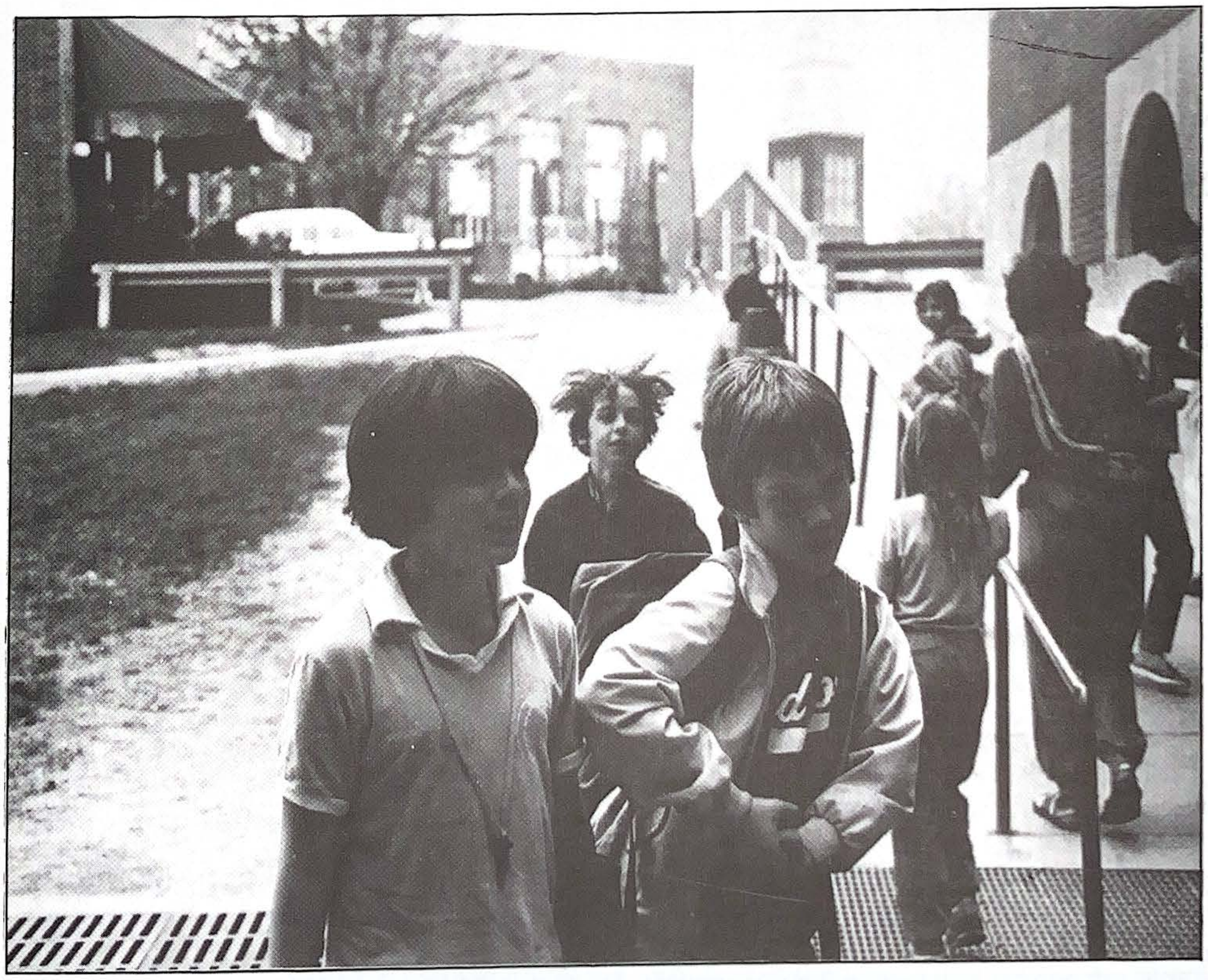
anathema, the Federal administration only gradually brought its own authority — and cash — to bear. Its first intervention, in 1957, brought federal money for research into special education and teacher training — but no funds for classrooms. That began to happen in 1965, with the Elementary and Secondary Education Act, which established a grant programme 'for the purpose of assisting the States in the initiation, expansion and improvement of programs and projects for the education of handicapped children'. The Education for the Handicapped Act followed five years later. But neither of these contained specific guidelines for State use of Federal grants.

By 1970, the Children's Defense Fund estimated in its 1974 report *Children out of School in America,* nearly two million children between the ages of seven and 17 were not in school at all — a national average of 4.8 per cent of the school population which in ten states was as high as six per cent. By the school year of 1975/6, when The Education of All Handicapped Children Act was passed, it was officially estimated that eight million children needed special educational services, but that only half were being served in a way appropriate to their needs, while one million were not in school at all.

In Massachusetts, an early recognition of State responsibility for children with special educational needs came with the special commission set up in 1952 by the legislature, to investigate the training facilities available for children classified as mentally retarded. Three years later, (when there were estimated to be some 600 classes for 7,000 children classed as 'trainable' in public schools across the land), this commission was able to assert that society had a moral duty to educate children who were mentally retarded, and that what they needed were special classes and services. Further, it said that the education of these children was provided for in the State constitution and that 'negligence in planning a school program to meet their needs denies them an equal opportunity for education, the lack of which may cause them to become a burden to society rather than an asset'.

This early assertion of a constitutional right to education was dramatically echoed in the landmark court decision in the case brought by the Pennsylvania Association for Retarded Children against the Commonwealth of Pennsylvania in 1971, which found that the State, having undertaken to provide all its children with a free public education, could not deny access to that education to any mentally retarded child. But in Massachusetts by then, the main impetus for educational reform was coming from parents who were poor and belonged to minority groups, whose children were often inaccurately misdiagnosed as 'mentally retarded' and put into special, segregated classes where their needs weren't met. Between 1968 and 1970, a group of these parents, aided by a lawyer, demanded that Boston school department and the State Department of Education provide appropriate services for a small number of mis-classified children, and re-examine all children in special classes for 'the mentally retarded' — which at the time were the only public alternative to regular classrooms.

But as the debate gathered steam, it emerged that the question was not simply one of misdiagnosis of children from minority groups, but a far wider one which affected children with a whole variety of special needs, many of whom were excluded from school altogether. In 1970 (at about the time that England was passing the Education Act which finally brought children diagnosed as having 'severe mental handicaps' into the educational system and so creating a



• *The Pierce School, Brookline.*

new category of ENS(S) school from the 'junior training centre'), a Task Force on Children out of School, made up of concerned professionals and citizens, published *The Way we go to School: the Exclusion of Children in Boston.*

What this report showed was that very many children in Boston — and by implication across Massachusetts — were either excluded from school altogether or so misplaced as to be suffering from a *de facto* exclusion. It reckoned, for instance, that as many as 7,800 children whose first language was Spanish could be out of school altogether. It showed how little was known about the fate of children with severe physical handicaps, and that while there were some 3,000 in Boston's special classes for the mentally retarded, with another 1,000 on the waiting list, many of these children had been mis-diagnosed.

In its follow-up report *Suffer the Children: the politics of mental health in Massachusetts,* the Task Force, (which later became The Massachusetts Advocacy Center), brought more details. It showed, for instance, that of some 40,000 children reckoned to have severe emotional disturbances, only half were getting any special help at all; that 16,000 of the 30,000 estimated to have a mental handicap were getting no services; and that the appalling conditions in the State institutions where many severely handicapped children were living made many of such 'services' as did exist, a mockery.

Out of these beginnings, boosted by court action to obtain special services, came two strands which were to be important for the future of educational reform.

The first was the recognition among special interest groups of how much they had in common, and the welding of the Coalition for Special Education.

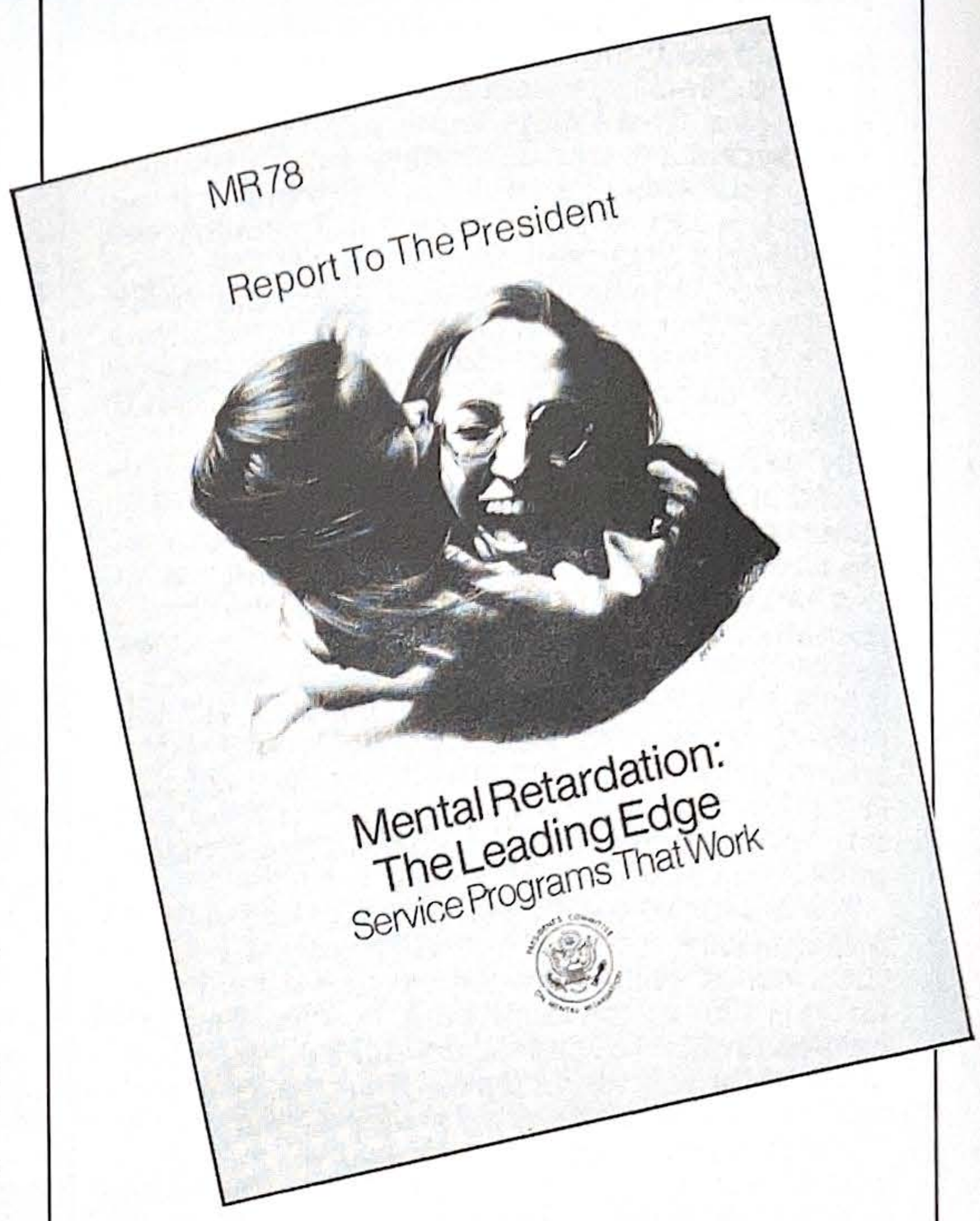
The second was a recognition by the State bureaucracy that it needed to give far higher priority to developing special educational services, and the beginnings of a refinement of assessment (evaluation) procedures and parental involvement which were to find full expression in Chapter 766.

The context of implementation

Although the main provisions of the Massachusetts special education act were echoed in the 1975 Federal Education of All Handicapped Children Act (Public Law 94.142, which came into force in 1978), implementation has not been without its difficulties.

Nationally, there were growing rumblings about a general 'crisis' in education which would be entirely recognisable to anyone following the education debate in England and Wales. There's a concern about increasing education expenditure and falling education standards, a harking back to the myth of a golden age when schools were disciplined, teachers dedicated, and pupils got on quietly with learning their three Rs. There's an official move towards the introduction of testing for basic educational attainment and a muttering among some right-wing American politicians that the country would be better off altogether if the national Department of Education was simply abolished.

Concern about special education has been swept into this debate — and there's some evidence as well of the difficulties of implementing the national law. In 1981, the Comptroller General of the USA reported to Congress on *Unanswered Questions on Educating Handicapped Children in Local Public Schools,* and found, based on a review of ten states, some signs of confusion. There was a lack of clarity about precisely which children should be eligible for special educational help (and so Federal funds);



• *A major report to the President describing successful service programmes across America which have increased opportunities for independent living for people with mental handicaps.*

there was often a failure to implement the strict requirements of Individual Education Plans; there weren't enough staff to monitor local education agencies; Federal evaluation of different States' performance was inadequate.

Among these rumblings came an official response which had nothing to do with trying to strengthen the Act and a lot with the opposite. In August 1982, the US Department of Education launched its proposals to amend the regulations under the Act in ways which might, as it claimed, have eased the financial and administrative burden, but would also have considerably weakened parents' rights.

This move, however, had the opposite effect from the one presumably intended; as one parent activist later said, 'they did us a big favour'. The 30,000 letters of protest that flooded into the Department of Education in Washington broke all records and simply showed — as did the huge numbers of protesting witnesses at regional hearings — the strength of support for the act, which was now focused in a new and effective way.

The proposed amendments to the regulations were dropped. But the story is not over yet. By April 1985, critical Reagan-watchers were citing the appointment of one Dr Eileen M. Gardner to the newly-created national Office of Educational Philosophy and Practice as one straw in the wind. She had made no secret of the philosophy and practice she would favour, having outlined both at some length in an essay published by the influential right-wing Heritage Foundation the previous year. As Federal involvement in education funding had risen, she argued, educational standards had fallen. The Education of All Handicapped Children Act had played its part in this decline, resting as it did on 'the questionable

assumption that the responsibility for retarded individuals is primarily society's, as a civil right, rather than the family's with the help of society'. Expenditure had become 'uncontrollable', while the effectiveness of the education that many handicapped children had once received had decreased and 'normal' children had been damaged as well.

Dr Gardner's solution was clear: dismantle the US Department of Education, give responsibility for providing special schools or self-contained classes back to families (aided by tax credits and education vouchers) and local communities and greatly restrict the number of children qualifying for special education at all.

There was something of a national outcry following Dr Gardner's appointment to her official position. She resigned after a matter of days.

That's not to say, though, that there isn't continued debate about the special education laws — and a burgeoning number of court cases which attempt to clarify entitlement as well. Are the costs of special education rocketing uncontrollably, unaffordably, and to the detriment of 'regular' education programmes? Is the return for the mountains of paperwork and complexity of administration an appropriate education for individual children with special needs, or simply a deflection of educational staff from their real educational job? Are parents' rights being honoured, or are they still unequal partners? Is the fundamental philosophy of the act — the education of children with special needs in the least restrictive environment possible — in danger of slipping away?

Ten years after Chapter 766 came into force, all these questions and more are still being debated in Massachusetts. But what is striking, is how hard it seems to be to find anyone closely involved with the special educational scene who would want radical changes in the law. The consensus seems firm: whatever the continuing hiccups and inadequacies, Chapter 766 has brought about a reform in the education of children with special needs which has wide and continuing support.

It's hard to imagine, perhaps, our own Department of Education authorising the mass issue of badges proclaiming 'Let's celebrate the 1981 Act' ten years after its implementation. But that's what the Massachusetts State Department of Special Education did for Chapter 766. And maybe it wouldn't have risked that either if people didn't feel that there was something to celebrate.

In a state-wide survey of attitudes to Chapter 766 in 1982, the Gallup Organisation found that:

- 95 per cent of every educator group asked agreed that handicapped children have as much right to a public school education as any other and 75 per cent that the quality of special education in public schools had improved over ten years
- Only three per cent of parents of younger children with special needs and seven per cent of older ones believed their children had not improved since receiving special education
- Fewer than 30 per cent of parents with children in regular education thought Chapter 766 should be narrowed
- Fewer than ten per cent of the general public with no children in public schools were unfavourable to the law.

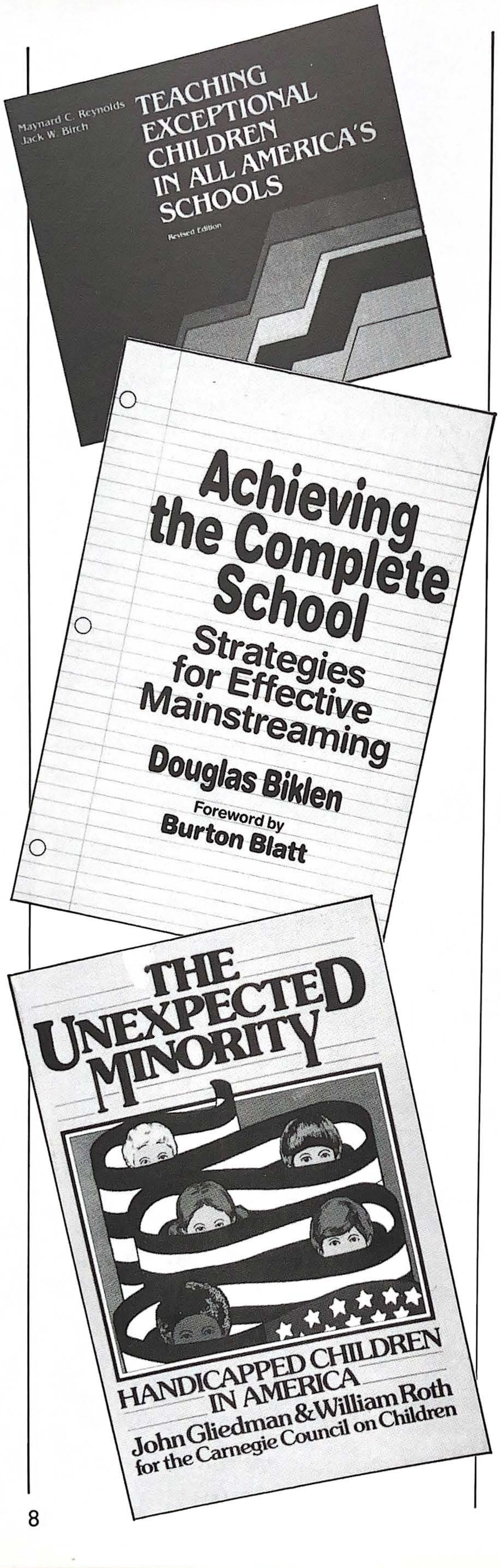
(Implementing Massachusetts' Special Education Law: A Statewide Assessment, Mass. Dept. of Education. 1982).

Who is eligible for special education?

'This act is designed to remedy past inadequacies and inequities by defining the needs of children requiring special education in a broad and flexible manner, leaving it to state agencies to provide more detailed definitions which recognise that such children have a variety of characteristics and needs, all of which must be considered if the educational potential of each child is to be realised . . .'
(**Regulations 766,** Massachusetts Department of Education, 1981 edition).

'The law specifically abjures the use of categorical labels that stigmatise children. In the past, such labels were all the diagnostic process yielded. In contrast, Chapter 766 requires that a multi-discipline Core Evaluation Team assess each child's special needs and then prepare an appropriate individual educational plan. Along with instructional services, like tutoring in reading, a plan may include counselling, physical therapy, or psychotherapy for the child and/or the parents.

With the emphasis on labelling removed, 766 opens the way for a dramatic expansion of eligibility for special services. The law takes the radical step of dealing with all children in actual or potential educational risk. Thus if a child is in danger at midyear of not being promoted, or indeed fails, he or she can be referred for services. Similarly, four other groups might be referred: students suspended for more than five days in a quarter; those absent more than 15 days in a quarter without a medical excuse; those who demonstrate distinct learning or behaviour changes after an illness; those considered delinquent.'
(*Engendering Change in Special Education Practices* by Milton Budoff, **Harvard Educational Review,** Vol. 45, No. 4, November 1975)



In 1974-75, the first year of operation of Massachusetts' Chapter 766, some 81,000 children, or 6.7 per cent of the public (State) school population, were receiving special education. A decade later, the figure was over 130,000 and the proportion over 14 per cent — compared with a national estimate that 12 per cent of children and young people have special educational needs. The official reckoning of the State Department of Education is that, given the overall decline in school rolls, the numbers receiving special education will either fall or remain constant over the next five years. In other words, pretty well all Massachusetts children and young people between the ages of three and 21 with special educational needs have been identified.

But just because this state law is such an ambitious one, questions remain. Who exactly qualifies for special education? The law and regulations are deliberately vague: the only answer is 'any child reckoned to need it'. And for what do they qualify? Under the regulations, the official answer is 'everything which is required to be provided to a child in need of special education pursuant to the individual education plan for such child'. So there are two areas of debate and one common question: What constitutes a special educational need, what services can a child expect — and is there a limit to either or both in the real world of financial constraint, fallible human judgement and uncertainty about how best to help children learn?

The debate and the questions are national ones — though in Massachusetts they have their own special tinge because Chapter 766, unlike other US education laws, has abolished the practice of labelling by handicap, replacing it with a system of 'Program Prototype' (see page 4).

Who needs special education?

Political critics of the national special education scene can point to one particular statistic to press their case: between 1977 and 1983, the number of children defined as having 'learning disabilities' rose nation-wide by 119 per cent — and that means one million children. Though the number of children classified as 'mentally retarded' fell sharply over the same period, the critics don't see this as an indication that the national law has enabled better identification of children with special educational needs or even as a sign that labelling is becoming more positive. What they see is that regular teachers are increasingly opting out of their responsibilities to the children who used to receive remedial help within the regular system, and that education administrations are colluding with them so that they can qualify for more federal aid.

The huge expansion in the numbers of children filed under the catch-all head of 'learning disabled' has its educational critics as well. By August 1984, James J. Callagher, director of child development at the University of North Carolina and a former associate commissioner of education at the US office of education, was expressing some 'Unthinkable Thoughts' in the journal *The Exceptional Parent*. The number of children with 'learning disabilities', he reckoned, could be estimated as anything between 800,000 and eight million; the label had become 'a moving boundary line of special education and prevalence figures to an uncertain ceiling with no reasonable demarcation line in evidence'. This mattered educationally: he questioned whether the 'pull-out' strategy of withdrawing children so defined to resource rooms was really what they needed, when research suggested something far more comprehensive and intensive; he raised questions about what precisely should be offered

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In Massachusetts, a major independent evaluation of Chapter 766 conducted for the State Department of Education (here called 'the Huron Institute study' for the sake of shorthand) found that these concerns were already lively, five years after the act came into force. The researchers found that some ordinary classroom teachers were complaining that students with emotional or behavioural disabilities were 'malingering' and didn't need special education at all; a Gallup poll found a sizeable minority of its different respondents favoured some narrowing of the act. The Huron Institute found that the vagueness about what precisely constituted a special educational need was leading to quite some local variations in interpretation of the act and in what students were offered.

'In a community that defines special education needs liberally and is philosophically committed to the least restrictive environment provision,' it said 'a diversity of program options exists to provide a diversity of services for individuals, to assist in matching services to individual needs and to adjust the services delivered on the basis of student progress. Conversely, other communities, similar in many ways to those described above, may cling to a more rigid definition of special needs. Students with needs comparable to those provided for in other communities may receive relatively little service or may be removed from the mainstream of regular education for out-of-district placements'.

By 1985, it was becoming clear that the definition of who has special educational needs was depending not just on local philosophies but on cash as well. There seemed to be a general agreement among both advocates and administrators that as funding for *regular* education becomes tighter — and so, for instance, the size of regular classes increases — there's a tendency to classify children who would hitherto simply have received remedial help as in need of special education. (We look at this in detail later, under Integration).

Meanwhile, it seems worth underlining the Huron Institute's main conclusion on definitions of eligibility: 'Although we recognise that special education needs are not defined clearly in the law or regulations, we recommend no tighter definition. The study staff suggests that the current limited flexibility is more useful than any attempt at definition beyond the current requirements of the regulations. In fact, most experts in special education believe that inadequate criteria exist for defining special needs. We do not accept the argument that failure to categorise or to define special education according to the type of services available, in itself, need lead to inequity or to charges inappropriate to special education. We believe that the regulation requirements for referral, evaluation, identification of needs, development of a plan and placement, properly applied, offer sufficient safeguards within a flexible framework, both for students needing special education and for school systems'.

How far should entitlement go?

American children with special educational needs are entitled to a 'free, appropriate public education'. But what is 'appropriate'? What services can children draw on to enable them to remain in the least restrictive educational setting possible? And what are the limits of provision for a particular child?

By 1985, there was a whole pile of attempts to clarify these sorts of questions through the courts, and a mass of material for court cases to come. So far, few cases have reached the US Supreme Court, but two that have, give something of the flavour of the debate. In *Board of Education vs. Rowley* (1982), the first case under the national law to be heard by that court, it was ruled that a deaf child who was already doing well in a regular classroom was *not* entitled to a sign-language interpreter. But the Court did emphasise that individual decisions must be made for each child and re-emphasised the principles of the national act — that children with special needs have the right to a free public education, in the mainstream if possible, and to an individual education plan drawn up with the involvement of parents. In 1984, the Supreme Court ruled, in *Tatro vs. Texas,* that a child who needed clean intermittent catheterisation *was* entitled to have this provided under the law, as an educational service.

In Massachusetts by 1979/81, the Huron Institute found, there had been a dramatic increase in the number and type of such 'related services' and personnel available to students with special educational needs — including speech, occupational and physio-therapists, guidance and family counsellors, psychologists and psychometrists, social workers and nurses. But, as it also found, 'whether the need for such services is educationally related and who should provide those services, often becomes the focus of controversies between local school systems, parents and other agencies'.

By 1985, the issue was still being debated — and further to be complicated, perhaps, by a recent court decision that the Massachusetts law went beyond the national one to provide for not just an 'appropriate' public education for children with special needs but the 'best possible' one.

Even on the narrower standard, as one education administrator puts it, is what is seen as 'appropriate' in rich suburban Brookline the same as what's seen as 'appropriate' in poor, inner-city Boston? What children get very often depends on what their parents expect for them — and though the rich parents who try to insist that skiing holidays or French teachers actually born in France are properly called 'educational services' may be at the horror-story end of anecdote, his general point is clear enough. More seriously, one of the major issues that concerns the parents who approach the Federation for Children with Special Needs in Boston, according to its director, Martha Ziegler, is precisely the lack of support services that most people would see as far more essential; the Federation is currently campaigning to get a better deal from health services in particular.

One of the major flaws in Chapter 766, according to Milton Budoff, who directs the Cambridge, Massachusetts-based Research Institute for Educational Problems, and was himself active in getting the Massachusetts law passed, was its failure to build in an insistence that health and welfare services and others like them maintained their efforts for children with special educational needs. And although Massachusetts has its own particular set of relationships between education and other administrations, there are lessons there for anyone trying to build special education reform.

What happened in Massachusetts, crudely put, was that as Chapter 766 put a whole range of new duties on education agencies, other public bodies — like the departments of mental health, public health, welfare and rehabilitation — seized the opportunity to move out of provision for children and young people and either leave as much as they could to education or try to charge for the services they provided.

The result at one level is that it becomes harder for individual children to get the supporting ser-

vices they need. At another level, the result is that the whole debate about the cost of special educational services can get skewed. This can be most clearly seen where the complaints — and the mythology — about 'run-away costs' are sharpest: in the placement of children in private day, and more especially residential, schools.

There's no doubt, as Milton Budoff has shown in his own research, that the first parents to use the new act appeals system were very often those of 'high social status' who wanted to get a publicly-funded private education for their child. (*Due Process in Special Education* by Milton Budoff and Alan Orenstein, Brookline Books, Cambridge, Mass. 1982). There's not much doubt that in the early years of the law, when large numbers of children with severe handicaps were effectively being brought into education for the first time, public school systems weren't always geared to meet their needs; or that for some children and some families, a residential placement is still needed in 1985. But there's no doubt either that with the cost of a private residential place running at $40,000 a year or more, or ten times that of the average for special education, the provision of boarding education for just one or two children can make a hugely disproportionate dent in a local education budget.

Yet those placements continue to be made. The important point seems to be that Massachusetts is trying not to concede that what a child may receive has to have a financial ceiling. Instead, it is trying to hold to the principle of the act: that their entitlement is to 'everything which is required to be provided pursuant to the individual education plan'.

Just how that principle works out, though, clearly depends on a number of factors. It depends on the implementation and monitoring of the law. It depends on funding. And it depends on the balance of power between parents and their advocates and the school systems.

Implementing the law

When it came to drawing up the regulations for Chapter 766, this wasn't seen as a job for the bureaucracy. Some 100 people were involved: citizens and representatives of their organisations, local school administrators, representatives of professional organisations and unions, and members of the State bureaucracy.

The chairman of their taskforces was Gunnar Dybwad, professor of human development at Brandeis University, himself a former director of the National Association of Retarded Citizens. 'We were aiming,' he says, 'at introducing a new concept — of not just parent participation, but parental responsibility, with due consideration for the concerns of the teachers. And we were aiming to do this in a manner which was not unduly threatening to the administrators.

'It worked, because we were blessed by a State education bureaucracy which was strongly in favour of the spirit of the law. But of course we had to be mindful of the feelings of the local school committees and administrators, who traditionally have enjoyed an unusual independence'.

State-wide

Of all the states in the US, the one with perhaps the strongest tradition of local educational autonomy is Massachusetts. With no fewer than 427 separate local education authorities for its total population of about 5.7m, it's not surprising, perhaps, that the Huron Institute found, some five years into Chapter 766's operation, that 'the primary theme of State/local relations is local resentment of an involvement of a state agency in the affairs of school districts accustomed to local control of education.'

'We don't need the act — we're doing it already' seemed then to be a fairly common cry from local education authorities across the State. But local memories, the Institute noted, didn't always match local realities. There was at least some indication, it reckoned, that the new monitoring role of the Massachusetts State Division of Special Education had had something to do with improved compliance with the law.

Just how far are school districts complying with the law's aspirations a decade after it came into effect? There are stories of time-lines missed and individual education plans not honoured. There are still widespread complaints from the schools' side about the amount of paperwork the act entails. The Huron Institute noted that these complaints tended to be from people who had least to do with the paperwork themselves. And as Martha Ziegler of the Federation for Children with Special Needs crisply points out, there was never any paperwork needed to exclude a child from school before the act was passed. Parents who approach the Federation emphasise most the inadequate working of the complaints system, as well as the lack of supportive services.

Sometimes lack of compliance with the law can be system-wide. In 1976, the Massachusetts Advocacy Center took the Boston school district to court in the first class action for non-compliance, and the district (with a school population of 63,000 of whom 17 per cent are thought to have special educational needs) has still not been discharged by the court. By 1982, the monitor appointed by the court to oversee how the district was performing its ordered tasks found continuing shortcomings. Vacant special education positions had not been filled; peripatetic special staff and aides were not being used as intended; although the roles and procedures of the evaluation team had been well-clarified, the mandated procedures and policies manual was still far from complete, and neither was the time-table for educational reviews and re-evaluations. By 1985, the court monitor had been replaced by internal monitoring within the district. The Massachusetts Advocacy Center continues to watch the situation

and return to court as necessary; a particular recent concern was transport, sometimes so inadequate that children have been left untended on the street.

There are also concerns for particular groups of children and young people with special educational needs. The State Division of Special Education, in 1985, is particularly worried about two groups that it feels are not as well served as they should be: those with severe emotional disturbances and those who need the bi-lingual education for which there is a dearth of teachers.

The Massachusetts Advocacy Center's major concern is that some young people, particularly those aged between 18 and 22, are being excluded from education altogether as a 'disciplinary' measure. 'When you do an individual education plan,' says Stephen Bing, the Center's director, 'what you do to reduce the incidence of misbehaviour ought be built in; the ultimate goal is to have that true for every kid. There are no figures, but we know there is exclusion. And it is damaging to kids to lose even one day'.

He is also concerned about three other groups. The first are those who are black, or whose first language is not English: they, he reckons, are disproportionately to be found in the most restrictive placements, and are dramatically under represented in the (good) private schools. The second are the children and young people characterised as 'profoundly emotionally disturbed', who make up some 900 admissions to State psychiatric hospitals each year, staying for an average of 40 days. The third group are placed by social services in 'group residential placements' of between 12 and 20, with education on site. There are 3,500 of these young people, mostly adolescent and mostly categorised as 'difficult' or 'disturbed', in places run by private enterprises under contract to the State. The hon: s, says Stephen Bing, display many of the negative characteristics of institutions; and their educational programmes are inadequately monitored.

The main official task of monitoring Chapter 766 falls to the state Division of Special Education, whose budget more than doubled between 1973 and 1974 to enable it to take on the completely new active role that the law demanded in place of its traditional non-intervention. The Division has bureaus to cover institutional schools, management, programme audit and assistance, programme development and evaluation and special education appeals. Under it are six Regional Education Centers, which must visit and evaluate public and private schools and produce a corrective action plan if needed, administer and if necessary withhold federal and State funding, and deal with individual cases and complaints.

The Greater Boston Regional Center is responsible for doing these things for 47 school districts and over a third of all the students with special needs in the state. The team there are fairly satisfied that children with special needs have been identified; the real issue is rather one of how appropriately they are placed and that, as they say, results from the constant tension between needs and funds. The other tension is between what the team is supposed to do and the time and resources available to do it in. There used to be 25 of them; now there are 12, to cope with the same or even increasing numbers of children. This means that one member of staff is responsible for eight or nine communities; it means that there simply isn't the possibility of the detailed working with a district over two or three years which has proved most effective in the past. It means too that individual cases may not always be attended to as speedily as they should be. 'The pending file', as the team leader Pamela Kaufmann says frankly, 'is a problem'.

'We'll get it right' says Stephen Bing, 'but it needs organisations like ours to push'. Certainly there seems no shortage of energy for the sort of 'external' monitoring of the law that is also important to its success.

For individual children, their parents and their advocates there is not just the opportunity of the appeals system built into the act and the ultimate recourse to the courts, but also the Federation for Children with Special Needs, which came together specifically to press for the law and has been working to make it effective ever since. There are a variety of publicly-supported advocacy agencies, like the Developmental Disabilities Law Center, which play their part.

The class action suit brought by the Massachusetts Advocacy Center against Boston School District is an example of group advocacy in action. But that is not a route that the agency would often take; as Stephen Bing says, 'our concern is to get government institutions to obey the law; from the court, you get a statement that they

should, and it's expensive and time-consuming'. So the Center does its own monitoring and reporting, makes its quiet administrative negotiations; builds and trains a network of child advocates, and goes to court when it feels it has to. And in all its work, it draws on a constituency which is maybe quite distinct in the way it crosses political, racial, and class divides. Just because of this, says Stephen Bing, 'Special education is the easiest thing to defend'.

The teacher's view

Most commonly, special education teachers in Massachusetts have a training in both regular education and special education, although some, who work with what's known as 'low incidence' conditions like visual impairment, are trained solely in their specialisation. The Massachusetts Teachers Association (MTA) represents both regular and special teachers. Its written material on Chapter 766 which is designed to inform its members — and often supported by state or federal funds — has been positive. *'766: Questions, answers and cases'*, for instance, starts explicitly from three assumptions: that Massachusetts towns and cities are 'trying to move forward in good faith'; that the processes of Chapter 766 should be adhered to in spirit as well as in letter, and that teachers should be provided with the time, resources and support to which the law entitles them.

Fred Andelmann is head of MTA's division of profession development, and has been closely involved with Chapter 766 from the start. How does he feel it's going?

"The apprehensions of teachers about support and funding have proven very accurate. There have been stages with Chapter 766. At first, there was active resistance and anxiety, and some fear of change, some of it well-founded. Then there was a vigourous, well-supported attempt to get it working. Now the mood is one of indifference, reflected in the level of funding and support.

Because of the financial problems, the whole system becomes even more strained. There is a resurgence of concern among teachers about how they are supposed to work. As education programmes have been cut, there have been compromises in special education: kids who should be in it aren't. But as classes are getting bigger in general education, there is also an increased tendency to refer to special education. And as special classes get larger, it becomes more difficult to do special education.

The first regulations were a lot more prescriptive than subsequent revisions. For example, in the first ones, there could only be eight children in a self-contained class without entitling a teacher to instructional aid. Then that became 10, or 12 if the Department of Education approved. There have been other compromises, on training for teachers, for instance. We've tried hard, but people have looked the other way. When has there ever been enough attention paid to ensuring that everybody knows what the system is and what it's meant to do?

We need better co-ordination between general and special education. One of the problems is that when a kid is the property of the special and general education systems, it becomes very hard for all involved to deal with the bureaucracies. The view of teachers has never been fully respected at State or national level — though special educators are listened to more. General teachers feel: "It is the special education system that determines what modifications in my programmes are going to be".

To the special educator, every youngster is different: "I know more about kids than I do about subjects". But special educators work with a small number of kids. The general teacher will say: "If I had as few kids as you . . .". So there is a continued, if friendly, tension.

In theory, special education teachers should spend as much time consulting and working with kids in regular settings as they do outside them. But this has been cut back as special education has become overloaded. We find that when a child with mild or moderate needs is assigned to a regular programme there is often no more assistance to the teacher than being told what to do. So it is important to let teachers know that often they are asked to implement an individual education plan that is not fully or appropriately funded. We often advise teachers that the best thing to do for themselves and parents — who have often already experienced considerable frustration — is to go to the parents and say: "This is what the school says, but I don't have the resources".

Severely handicapped children? We have teachers who have told us of children with spina bifida in a wheelchair who are doubly incontinent and said: "Don't expect me to change diapers without help". Often there is no help. So good sense must prevail. You must have adults who know what they are doing. It is right to expect teachers to teach and not to be nursemaids — though I myself feel that this sort of integration would be absolutely alright if there were welfare assistants.

How to close the gap between what the law designed and what is actually being done? We need to increase the capacity of the general education system to work more effectively with all kids. In theory, laws like this are designed to facilitate a gentle movement back and forth between general and special education, not to plunge people into the clutches of bureaucracy.

But that doesn't happen. The disputes and disagreements resolution is terribly clumsy. The forms are a nightmare: special education is crushed with the burden of paperwork. The timelines are attractive but almost never adhered to. An overly prescriptive law — as this is — almost invites litigation and disputes on the little issues. This was an attempt to introduce a people-proof system — you can't! But it's only when you have it on paper that there's some basis for redress.

We need more money for schools. But not just money. We need in-service training and information and to insist on a way of looking at children that requires you to look at goals and then honestly at present capacities — funds, people, leadership and administration. We need more teacher preparation. And we need some common sense.

But on the whole, kids are a lot better off than before. Some school districts have always cared very much about handicapped kids. But I'm absolutely convinced that without the law most schools would either have special education programmes in basements or stairwells or no programmes at all. On that basis alone, there is no question that the law is a success. In the last analysis, I'd settle for timely enforcement of existing regulations".

The administrator's view

John M. Cullinane has been director of pupil services in the wealthy Boston suburb of Newton for 15 years and is now approaching retirement. His brief includes the administration of special education programmes for some 1,300 of the district's 10,000 pupils.

In September 1975, he wrote a swingeing critique of Chapter 766's aspirations for the *Boston Globe*. Much of what was good in the law, he said, had long been standard practice. What it added was a huge increase in bureaucracy and paperwork — with an ill-written 'core evaluation manual' that the schools hated, 107 pages of regulations, and 73 forms requiring 36 signatures for each child evaluated. What it did not add was proper funding: it was 'the first educational reform ever to be financed by bake sales', whose heraldic device might well be 'a naked taxpayer on a field of empty wallets'. It created an adversarial relationship that discriminated against the schools and would probably widen the gap between rich and poor.

How does he feel ten years on?

"A backlash is developing — some of it the result of private enterprise's response to entrepreneurial opportunities. People are beginning to say "We want to help the handicapped, but this is ridiculous, parents should do more themselves". So there are issues of control and limits which are hard to manage. My own feeling is that children with a handicap do need the help of society — but that doctrinaire views about means-testing are ridiculout when it costs $40,000 a year for a private special school place and parents who may not have their child at home at all get tax relief for them.

The great majority of Newton's children with special needs are in the mainstream, either with people helping them in the regular class (between five and ten per cent), or taking them out for help up to 25 per cent of their time (about 70 per cent). My feeling is that the first is the preferred model. But the feeling of some parents is "Take the child out and work a magic on him" — which the professionals have encouraged; the special education mystique is still here to haunt us. My question to parents is: "When he's out, what's he missing?". We have got the resource to put aids into the regular classroom if we cut down on high-cost tutoring help. But that's hard, because parents tend to see the tutoring as "help" and not the aides, and in effect they have the power of veto (which is also good, because it gives them an investment and involvement).

We're still wasting a lot of time in paperwork — there are reams of paper. All those goals on the computer look as if they're unique for the child, but they can be no more so than the prescription of orange juice for breakfast every morning. We are still dealing with stuff that's very obvious. If a child has a lisp, for instance, you don't have to have huge evaluations; the prescription may be obvious and not require five days of intensive evaluation. But because people are so litigious, it's done "just in case", which is wasteful.

The big thing that has surprised me is that the law has baptised and confirmed the whole system that was in place. The social workers, the different sorts of psychologists, are all anointed now. There's a great deal of territorial squabbling: "I'm in the regulations and you're not". There's a whole group of specialists, and sometimes you have to ask whether there's such an entity as a "learning disability". In a way, the law has inhibited new thinking about how children learn — an unforeseen consequence. But the individual education plan does focus on "What is this child's learning style?" So at least it forces people to put something down and think about it.

We have learned to make the education plans more appeal-proof. I'm not sure if that's better educationally, but it is better as regards the lawyers. Is the law unfair to the schools? A wise parent with a smart lawyer can tie up the schools for years. Most school people do want to be helpful, not immediately adversarial. But they also have experience of some unreasonable people. The difference between here and Boston is that here people are likely to question, challenge and think they could do your job; in Boston, they will conform and collaborate. The rich get richer. . .

We have about three or four appeals a year — fewer than in the early years when people didn't know what the law was about, and mostly settled without a hearing. We don't take on the parents unless we think they are unreasonable and mediation has failed. The hearing is nearly always about a private school, which we feel are such restrictive hot-houses, though if the child needs something we can't do, we'll agree to it. If we go to hearing, we win — in ten years we have learned only to fight when we *can* win!

At the first hearings we went to, there were four or five people, and we finished by lunchtime. Today, there are two or three days of pre-hearing meetings with the lawyers and ten or 12 people who have seen or touched the child and outside experts — because the opposition has them too. Now the hearing is in a much bigger room because 25 people are involved; it lasts at least two days; there's much more structure; it's taped, there are written briefs. Then it takes two or three months. And then it could go to court. I cannot believe that that is better for kids and educators. But it is better for lawyers, court reporters and hearings officers. It is a tribute to the wealth of the United States that we support unproductive people like this.

On balance, the law doesn't change attitudes. If you waited for hearts to change, you would wait for ever. You can't pass a law to say "Love your neighbour". But you can say "Don't discriminate". So this law said to the public schools "You will not exclude anybody: a child is a child and entitled to education". That, you have to say, is a step towards justice. But the regulations are over-prescriptive. As I said ten years ago, it would be better to have broad guidelines and let imagination and energy evolve different structures and approaches. If there had been a general mandate without all the inhibiting requirements, who knows what would have happened?

But the parental involvement, the right of parental review and the authority to settle disputes would have to stay. And there would have to be some kind of independent, publicly-supported body to train parents as advocates and find reasonable and mature people — not lawyers — to help them".

Integration: An overview

'For educators who feared that Chapter 766 meant that their schools would be overrun by profoundly disabled students, the reality was a complete surprise . . . Most of the students needing and not receiving special education were already in the regular classrooms. Serving them appropriately in many cases meant moving them out of the classrooms to more restrictive placements for at least part of the time.'
(Huron Institute study, 1982)

'Mainstreaming is the big issue. We've found the kids, we've got them into the system. So what are we going to do with them? Our view is that mainstreaming is not working at all. And that has to do with parents, school administrations — a whole complex situation where everybody suddenly agrees that the only way to get kids services is in restrictive placements.'
(Stephen Bing, director, Massachusetts Advocacy Center, 1985)

'Mainstreaming? The case is proven. We don't know any level of handicap that we can't find an example for. And it expands people's horizons. There is a new generation of children growing up with more tolerance.'
(Martha Ziegler, director, Federation for Children with Special Needs, 1985)

Chapter 766 is clear: it requires that all special needs students from the ages of three to 21 have access to a free public education within the least restrictive environment appropriate. The goal is echoed in national legislation. It has solid support both in Massachusetts and nationwide. The national Association for Persons with Severe Handicaps (TASH) supports it. The Huron Institute found a solid majority of all educators at every level agreed that students with special needs should be educated with regular education students to the maximum extent appropriate.

Yet in 1985, there is a major concern that special education is being increasingly provided in more restrictive settings. As funds for general education have got tighter, it seems, and class sizes have increased, there is pressure to move students out of regular classes; and as special education itself has to cope with more students, there's a fear that a sort of domino effect may be operating. The concerns are not new: some five years ago, the Huron Institute study found that educators were predicting precisely this effect of the then new budget restrictions.

The pressure doesn't necessarily, though, come entirely or even principally from educators. From the start of Chapter 766, it has been clear that a sizeable number of parents prefer more 'restrictive' placements for their children: the early Massachusetts appeals, for instance, showed how many parents wanted a private special school placement — either day, or, even more 'restrictively', residential. (National echoes of this preference have been recorded. An analysis of 12 court cases in which parents were seeking more restrictive placements for their children showed, in 1982, that nine were successful, and concluded that the courts were disposed to 'institutional placements' and don't generally take questions of cost into account. *(Least Restrictive Education for Handicapped Children: who really wants it?* by H. Rutherford Turnbull and colleagues, Family Law Quarterly, vol. XVI, No. 3).

If budgetary constraints are meaning less support for regular teachers from special education staff, then this may be persuading more parents, as well as teachers, that 'appropriate' means further from the regular classroom. Fred Andelmann from the Massachusetts Teachers Association makes a further point, about the way mainstream placements are made by special education administrators.

'Typically, it's the teachers who are good at working with mainstream kids who get more assigned than those who are hostile. The teachers who are against handicapped kids are in a tiny minority — but there are teachers, half of whose classloads are handicapped, and in the same school teachers with no special education kids at all. We've said from the start that the number should be limited to their proportion — it's an application of common sense. But no one agrees, as it's too expensive'. In this situation, it's perhaps likely that a number of parents will opt for a placement for their child that is more clearly 'special'. Whatever the reasons, 'often parents subtly, or not so subtly,' as Fred Andelmann puts it, 'come to view the education problems of their kids as problems with the regular system that can only be resolved by special education'.

The trend away from full-time special education in regular classrooms (Prototype 502.1 in the Massachusetts classification) has, however, been a feature of Chapter 766 ever since it came into operation. In 1974, around a third of children identified as having special needs were in regular classes; the proportion had fallen to around a fifth a year later; over the decade since, it has remained fairly stable around ten per cent. The proportion of students who remain in the regular class but get special help outside it for up to 25 per cent of their time (Prototype 502.2) has also fallen, from around 70 per cent statewide in the early years of the act to about 50 per cent now. This, it seems, is where the financial squeeze on regular education has been felt; the Division of Special Education's efforts to save some money by changing the regulations to require only a partial instead of a full evaluation on a child who makes a move out of this Prototype may also have contributed. The effect is seen in the rising numbers of children, especially older students, who are out of the regular classroom for up to 60 per cent of their time (Prototype 502.3); the numbers have also risen in entirely special classes and collaboratives (Prototype 502.4), as the numbers of children brought back from in-

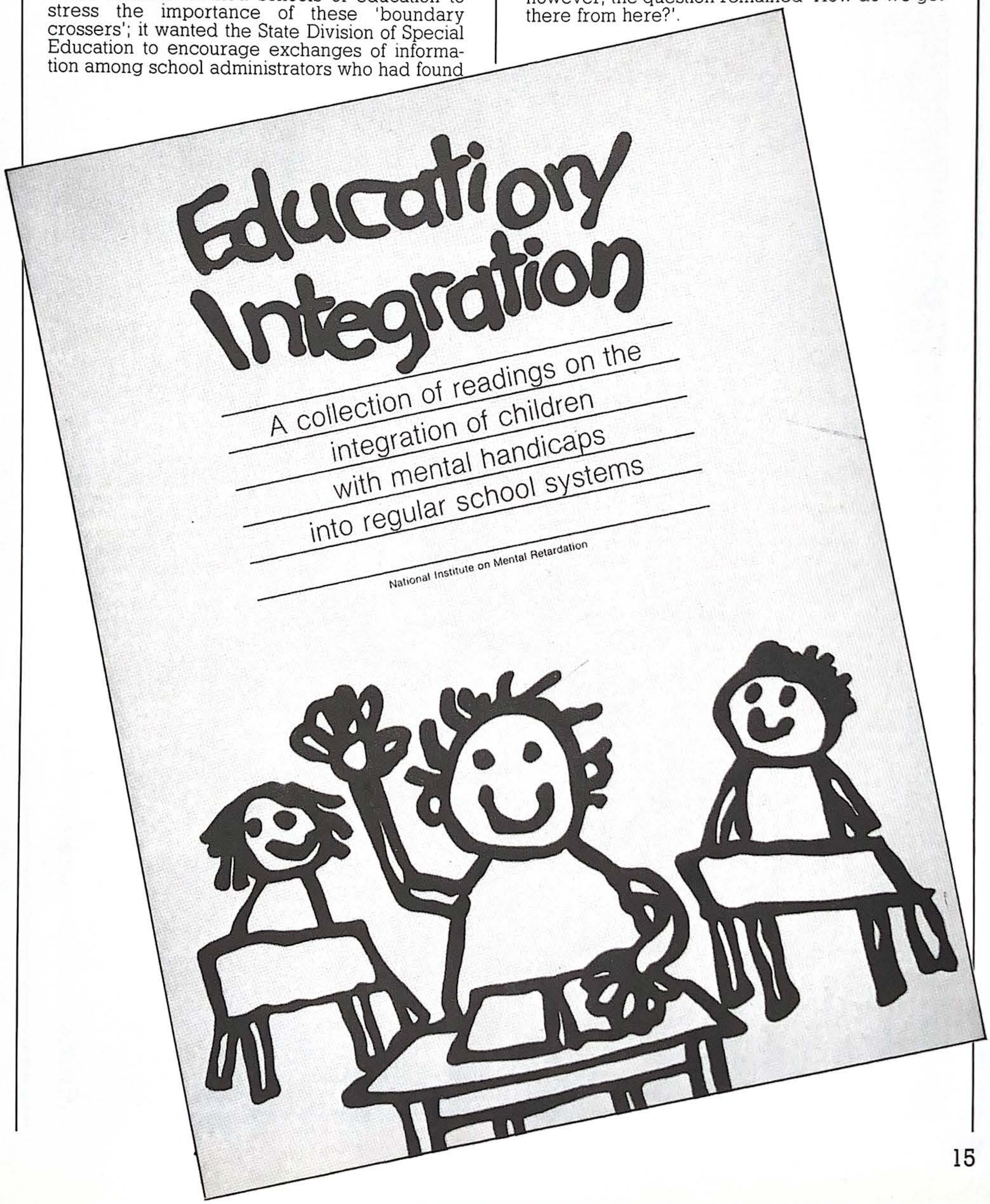
stitutional placements and private day and residential programmes has increased.

The lesson of these trends for anyone who wants to make special education more integrated with regular education seems two-fold. For a start, the degree of integration that is possible, if it is to be consistent with carefully meeting the needs of each child, depends crucially on a strong *regular* education system. It also depends on strong links (if not integration), at an *organisational* level, between the regular and the special administrations.

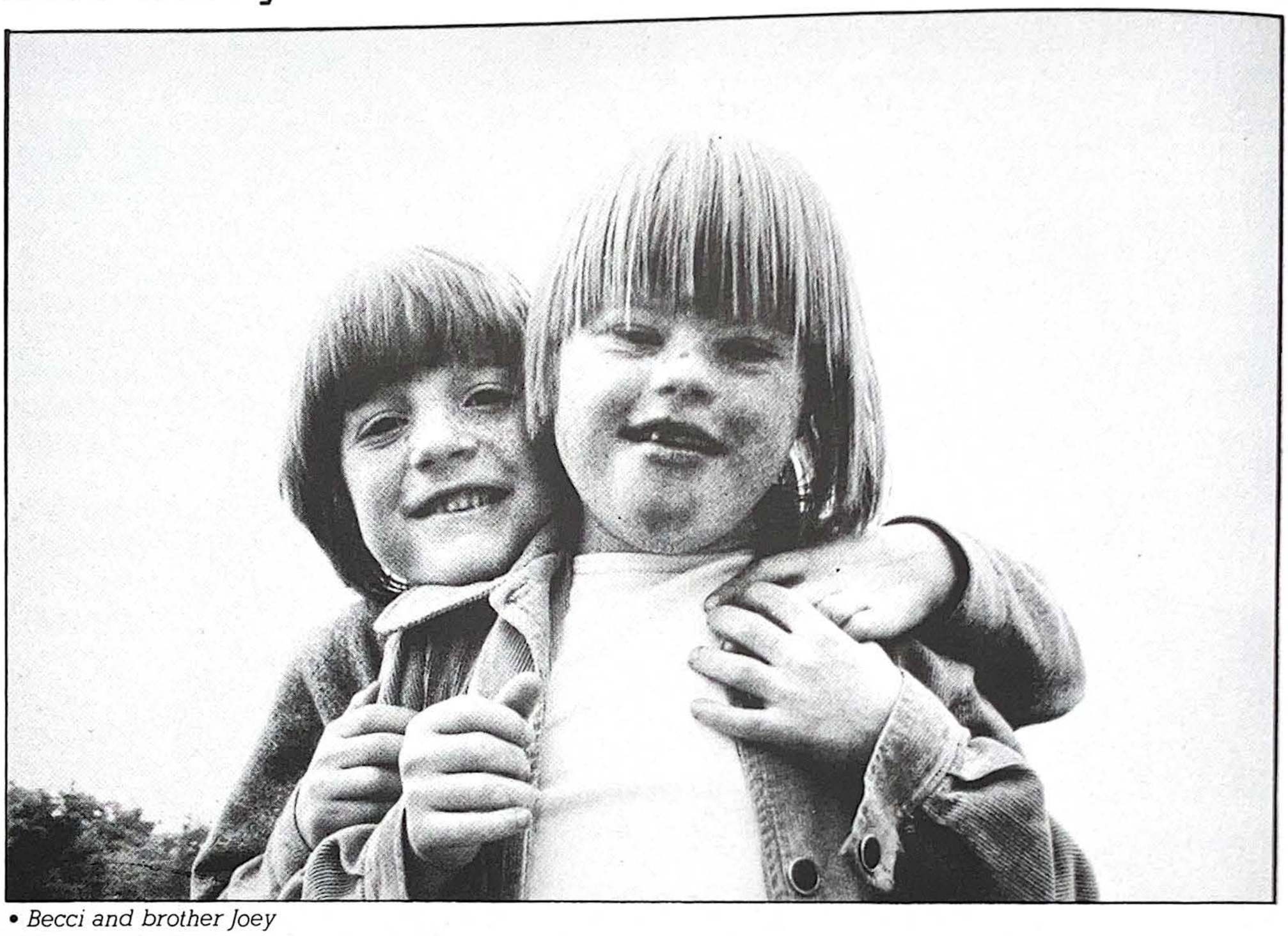
The Huron Institute found some encouraging signs of closer links between regular and special education. The sensitivity of many regular education teachers to the needs of handicapped students had increased; co-ordinators of individual children's programmes, resource room specialists were often doing important work in blurring the sharp distinctions between regular and special education.

The Institute wanted schools of education to stress the importance of these 'boundary crossers'; it wanted the State Division of Special Education to encourage exchanges of information among school administrators who had found them useful. But some five years on, as Fred Andelmann points out, the two strands of education remain on the whole distinct. The separation is not just at individual teacher level, but perhaps especially at the organisational one. The two bureaucracies remain separate. The Greater Boston Regional Center special education staff, for instance, certainly know their regular education counterparts. But there is no provision for formal meetings or collaboration.

By 1985, the issue of how great a divide there should be between regular and special education — or indeed whether that divide should exist at all — was being taken up nationally, and not just in Massachusetts. In its April edition, *Exceptional Children,* the journal of the national Council for Exceptional Children, devoted three articles to a proposal that the regular and special education bureaucracies should be merged. There were arguments against it, as premature; there were arguments for it. For the supporters, however, the question remained 'How do we get there from here?'.



Integration:
The story of Becci Ingram



Penny Millar

• *Becci and brother Joey*

Becci Ingram, a nine year old girl who has Down's Syndrome, goes to Stockbridge Elementary School in the Berkshire Hills School District, in Western Massachusetts. She is in a special class of eight children aged six to 13, all of whom have severe learning difficulties. This class is very much an integrated part of the ordinary school in which it is housed, and enjoys considerable inter-action with the mainstream children, both during regular lesson periods and in breaks, dinner times and extra curricular social activities.

The class has one full-time teacher and a full-time aid (helper); most of the children's week, apart from break-times, is spent together. But some, like Becci, join 'regular' classes for gym, art, music and reading and maths. In addition, children from the ordinary classes come into this special class regularly with their teachers for joint activities. Stockbridge School also has a pre-school class for handicapped children aged two years nine months to six years; a resource room serving 35 other children aged six to 14 (on a part-time basis) who have milder learning difficulties, and a special language class for a further eight children also aged six to 14. So it is an accepted part of the school system for a child in any class with particular needs to 'travel' to another class where those needs can be better met.

The Ingram family, which includes Becci's seven year old brother Joey, moved from England to Massachusetts, in July 1982 with a view to staying for just over a year so that Malcolm Ingram, an actor, could complete a training course with Kristin Linklater, America's leading voice teacher, and so that Elizabeth Ingram could develop her work as a healer and therapist.

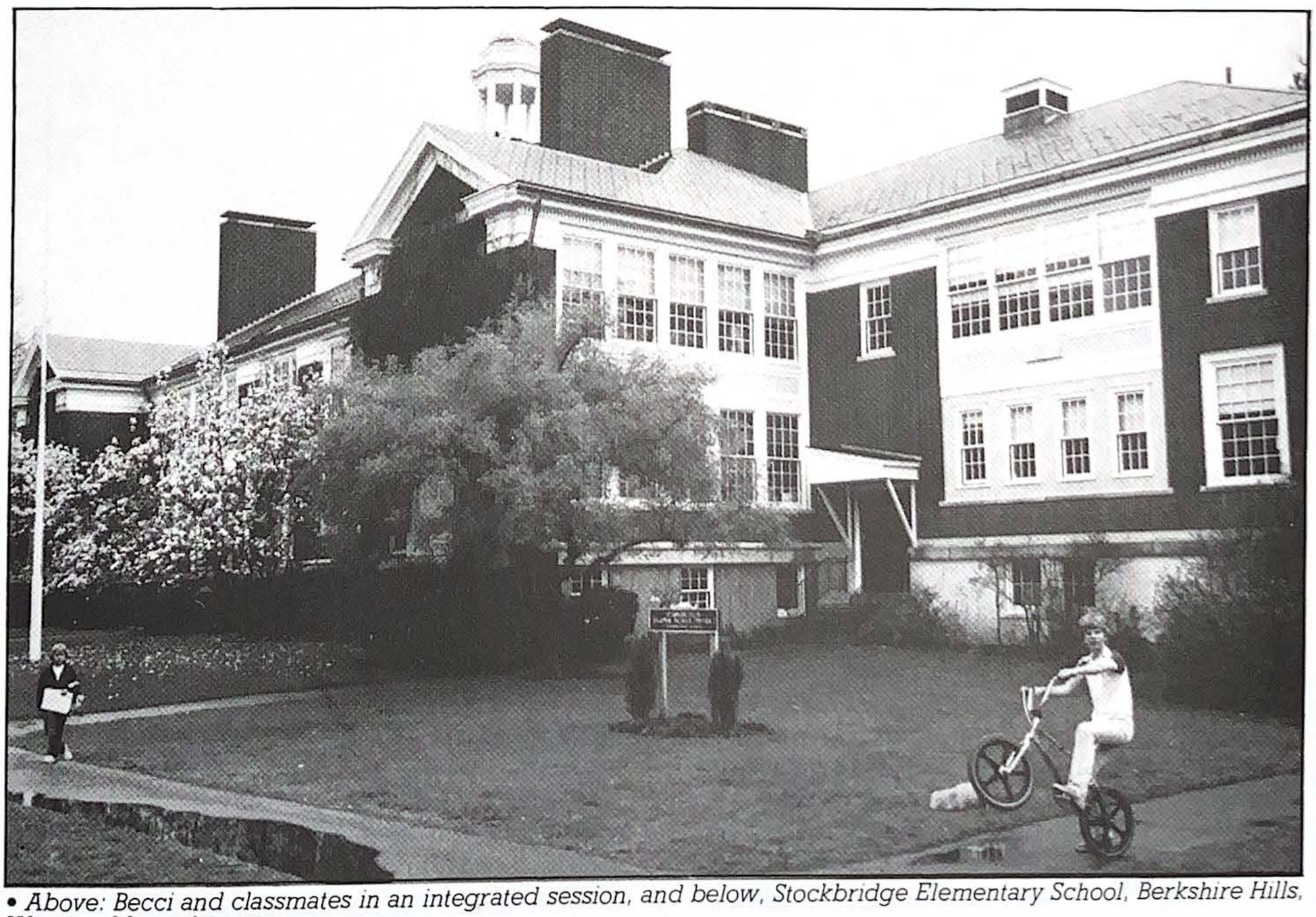
In their attempts to achieve an appropriate, integrated educational placement for Becci when they lived in North London they experienced many difficulties. After first attending a state nursery school and then a Montessori school for two years, Becci went to the local primary school where she was one of the first experimental placements for mentally handicapped children. She spent the normal period of two years in the reception class where she did well and was an integrated member of the class. Problems arose as the work became more academic and as it became evident that neither the school nor the Inner London Education Authority (ILEA) had any clear plans for her education other than within the existing segregated system. In response to the parents' pressure and concern from within the school, the education authority brought in a teacher from a nearby special school to work with Becci. But the family felt that there were still many things wrong with the placement — the fact that she had no peer group made her isolated within her class and it became clear that some restructuring of the school system would be necessary to meet her needs. At a fundamental level, they felt there was a lack of awareness of the issues involved in the education and development of a young person with Down's Syndrome in a local, urban community school, and in spite of a lot of good will from the head teacher, there was a failure to confront — and therefore to understand — the basic principles surrounding the integration of handicapped children in ordinary schools.

In her last term at the primary school, as an experiment, Becci was sent to the local school for children with severe learning difficulties (formerly classified as ESNS) for three days a week. During this time she regressed considerably, both in her language abilities and in her social skills, much to the family's deep concern.

With this background, the family moved to America, feeling they had been let-down by a local education service which they had hoped, since the 1981 Act, would have been nearer to understanding some of the *family's* special needs — as well as Becci's — as they attempted to try and achieve the 'impossible' . . . to have their daughter going happily to the school around the corner, and receiving an appropriate educational and social experience.

One of the first things to be arranged by the Berkshire Hills education authority was an assessment of Becci's special needs to be followed by a team meeting, or case-conference, to decide what services should be provided for her and to draw up the individualised educational plan (IEP). Five people took part in this team meeting — the director of special education, the special needs teacher who runs the class in question, the speech and language specialist, and Malcolm and Elizabeth Ingram. By Massachusetts State Law (as well as under US Federal Law), the LEA was duty bound to produce an IEP within 30 days of this meeting; in the event it was delivered in less time than that. The Ingrams, and Becci herself, all now say they are extremely happy with the placement and the extra tuition and facilities that she enjoys in Stockbridge School. Both educationally and socially they feel she has developed beyond all hopes or expectations. They say that this experience for the family has been light-years ahead of their previous one.

Here are some of their comments, (over page).



• *Above: Becci and classmates in an integrated session, and below, Stockbridge Elementary School, Berkshire Hills, Western Massachusetts.*

Penny Millar

• *The Ingram family in Massachusetts — Becci, Elizabeth, Malcolm and Joey.*

"Before going to the team meeting we had been prepared to fight for what we thought were Becci's needs, and persuade the staff that: (a) a truly integrated education was right for her; (b) that we were not overlooking our child's obvious handicap, and (c) that we were not being hysterical or mad. To our great surprise we found that everyone not only agreed with us but obviously thought we were very behind the times in our requests. People have been genuinely shocked to find that England is so out of date in relation to 'mainstreaming'. It seems to be taken for granted here that Britain will be far ahead of this country in these matters.

We are very happy with Becci's placement. The experience for her, and for us, has been very positive. She has progressed in leaps and bounds, both educationally and socially, and the school and the education authority here in Western Massachusetts feel sure that she will keep up the progress. At a basic skills level, real changes have already taken place, such as remarkable improvement in literacy and numeracy. Socially she is far more confident — through being in a peer group she now realises she is not always bottom of the class, and also sees that she in her turn can help others.

We can see Becci responding to the higher expectations that teachers and administrators around her actually have. You only have to look quickly down the plan (IEP) to gauge what some of these expectations are, and there are many more things going on in terms of educational, social and emotional input into Becci's life in school, than is ever put down in the plan — good though this one is.

As for the English 'plateauing' theory for children with Down's Syndrome, every single American we have mentioned it to has laughed at it. Some years ago in London we were told (just like hundreds of other British parents of children with Down's Syndrome), that Becci would 'plateau' at six, then when she didn't, it was going to be seven, then eight — and then we left for America! She has not plateaued, not by our family definition — quite the opposite — and she hasn't by the definitions of the various professionals who see her from time to time, or by the definitions of the teachers in the ordinary school she attends. Americans we have spoken to have no idea of the plateauing theory, which says that after an initial progress in educational and social terms, a child with DS will always level out and fail to go any further. It is a theory which encourages English parents to give up with their children.

In England, if you are the parent of a child with special needs, there is a constant pressure on you to give your child into the hands of professionals who know what is best — not because they have an intimate knowledge of your child, but because they are trained to work with children who fit under a similar label. Parents are made to feel 'difficult' if they put forward their own positive observations, and often the most hurtful phrase of all is: 'You haven't come to terms with your child's handicap' (whatever that means). The power that the professional has in England often destroys the parents' 'hope', and if this happens it makes living with and caring for the child even more difficult. In Massachusetts, the parents are involved at every stage of the child's education and their 'report' is an essential part of the child's assessment. Their relationship with the child is always considered, and they are able to veto any decision. This of course often makes for complications, and often gets in the way of the professional need for order and labels.

But it means that the child is able to be seen for

his or her self, and the *whole* of her educational life is taken into account, not just the time spent with the professionals. It is important for the child that the parents are helped, encouraged and included in every aspect of her life, because, as for all of us, the time spent out of school is when we put into effect what we learn in class, and when we grow and learn about life.

With no exaggeration, everything we were fighting for in London and never felt we achieved, has been given automatically here in Massachusetts. It is possibly *attitudes* that are the greatest gift of all. The English could learn a lot from Americans in terms of attitudes to handicapped children and their families. We went into the team meeting with a long list of demands concerning Becci's education and the special education director kept nodding his head and saying 'Yes, yes, yes . . .'. At the end he said: 'Is there anything else you want for Becci?' People here think you are mad it you get yourself into a fighting frame of mind in order to achieve integration, because it is taken as being automatic.

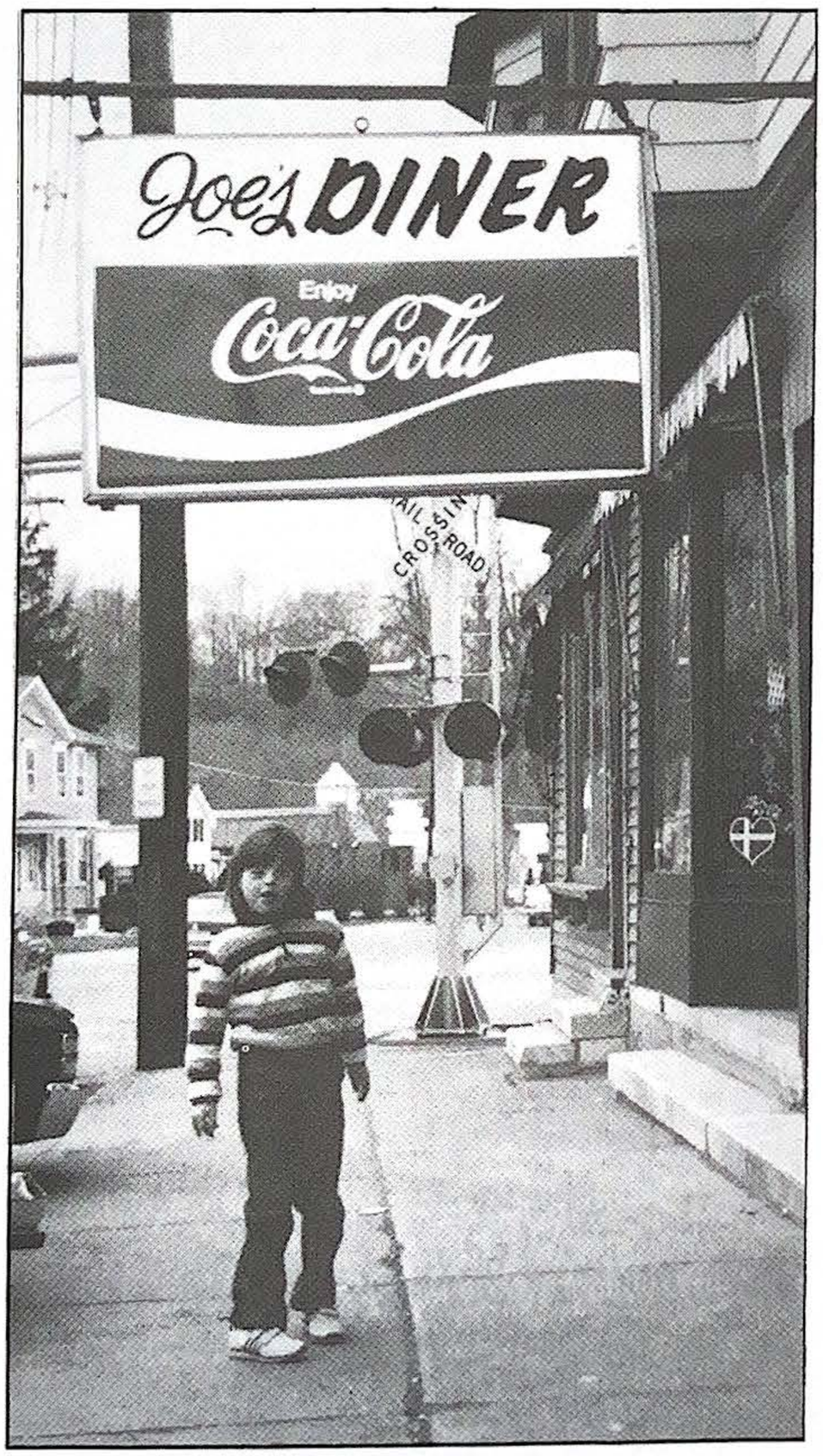
What this all means is that as a family we are all much more relaxed. We know that we have changed for the better as a result. The weight of having to fight every step of the way has been released, and for the first time we feel that there is some true support around. We can't tell you the difference this makes — to feel for the first time that we as a family are an integrated and accepted part of the world we are living in. We think it is something that no professional can understand, but that every family with a child with special needs knows about. Now that we have seen integration working we firmly believe it is right, and we are full of anxiety when we think of what will happen to us on our return to London.

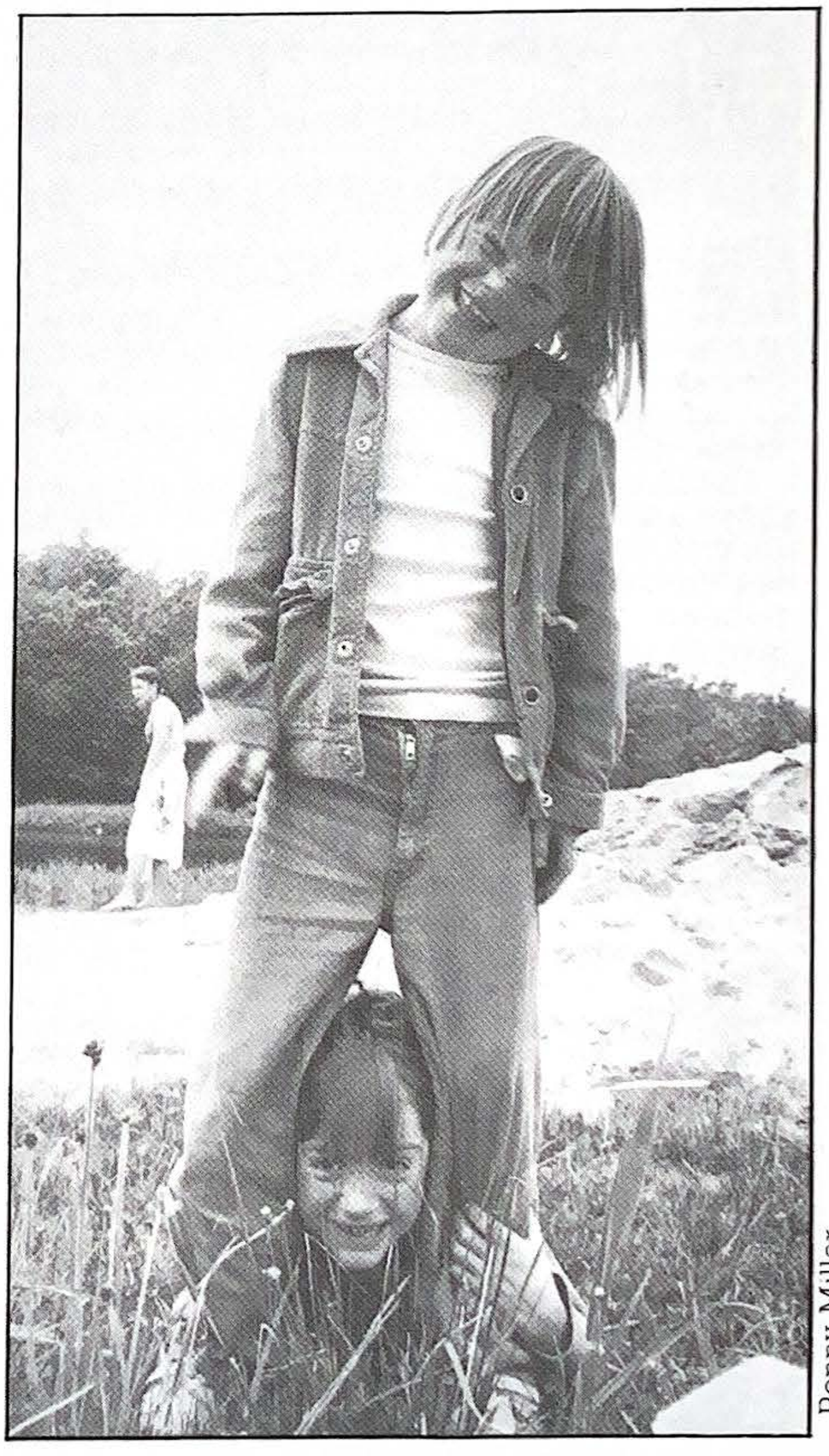
The next stage for Becci is to begin to realise that other people have needs, and that she will have to respond to them; this is an area where we would really like Stockbridge School to do more. What will maybe help her achieve this in America, is that you simply do not get any patronising attitudes in public towards your daughter who happens to have Down's Syndrome. The general public's reaction to Becci is the same as to her brother, whether it's in the town Library in Lenox a few miles away, the drugstore in Housatonic down the road or Joe's Diner in the neighbouring town of Lee; nobody makes anything special out of the fact that Becci has Down's Syndrome. It's awful to remember some of the public attitudes towards us as a family living in London — in the supermarket, visiting a museum, walking in the park — when you would get that sidelong glance from someone and probably a look of pity towards Becci.

Becci doesn't want any pity from *anyone* — not us, not her friends, not the education authority. As parents we don't want pity on her behalf and neither does her brother. It's *such* a relief to be more accepted for who we all are . . .

Becci has made friends with children with far greater handicaps than herself, but talking to their parents we see that the same integrated attitude applies — and in fact we feel they are somewhat surprised and even hurt by our questioning them about whether they find that their child is accepted by the community. And they are genuinely shocked at my accounts of the situation in Britain — appalled at the use of the terms mongol and spastic which they consider to be outrageous insults and damaging labels.'

(See over for Becci's IEP)





Penny Millar

Berkshire Hills Regional School District, Stockbridge, Massachusetts.

INDIVIDUALISED EDUCATIONAL PLAN

for

Rebecca Ingram,

birthdate: 7/4/74

Here is an extract of the major parts of Becci's IEP for the year beginning November 19, 1984

Profile

Becci is a very likeable and cooperative girl. She is functioning on a first grade (six-seven year old) level in academic skills. She enjoys being with the other children in her class and likes to keep busy. Becci works well in a small group situation. Unless verbally encouraged to finish all of her work she will stop midway and go off to play.

Additional information:
Becci is exempt from all district standardised testing (Basic skills).
Becci attends art, gym and music and library with her class.
Becci will be integrated with Kindergarten and first grade where appropriate.

Current performance level 1

Becci can recite the alphabet and can recognise and name all of the letters. She knows many consonant sounds. Cognitive skills are an area Becci does especially well with, being able to classify things by use and shape and know what to do in different situations and where to go for services. She can count to 30, read numbers to 20 and has a number comprehension to ten. She is in the first grade (six-seven year old) level math and reading books.

The general student centered goals in relation to these points are to: Improve and develop academic skills. Under teaching approach and methodology, monitoring and evaluation techniques and any specialised equipment and materials, the plan says: We use worksheets, workbooks, flash cards, games and manipulatives on Becci's level. The Brigance Developmental Inventory is used for testing and measuring progress.

Current performance level 2

Becci can print her first name, many lower case letters and draw a picture of herself including legs and arms. She holds scissors correctly and can cut out a circle of 12mm. She enjoys painting and working with clay, giving names to her finished products. Becci has some basic motor skills developed but does tire easily in this area. She enjoys music and moving to songs. The goals in relation to this are to: Improve and develop fine and gross motor skills.

Current performance level 3

Becci is a very independent and responsible girl. She is capable of taking care of her own possessions and meeting her own personal needs. She enjoys being given independence and responsibility. Becci gets along well with her peers but will order younger children around. One of Becci's strongest areas is that she is quite capable of making her wants and needs known. She is quite inquisitive and never hesitates to ask questions about anything.

The student centred goals for these last points are to: Improve social and daily living skills and to improve speech and language skills. Under the teaching approach and methodology, the plan says in relation to these same points: We supervise Becci in her dressing, eating and toileting skills where appropriate and correct and guide her toward independent functioning. We use experience charts, puppets, pictures, movies, games, flash cards, workbooks and worksheets to encourage proper speech and language use.

Specific student centred objectives

(To take place during *all* four terms which make up the school year).
Becci will:

- Develop a better understanding of quantitative concepts (few, many, less, more) and directional concepts (beginning, end, above, below, straight, crooked).
- Be able to say and know what to do when she sees a fire, breaks something that belongs to someone else and is approached by a stranger.
- Know the functions of community helpers (police, carpenter).
- Point to and name all letters of the alphabet, both upper and lower case.
- Progress through first grade reading series, *Sun Up*.
- Give correct sound of 20 consonants in initial positions.
- Demonstrate ability to recognise initial consonant sounds in spoken words by naming the correct initial consonant letter for 20 different letters.
- Read colour words (red, blue, green, yellow, orange, purple, brown, black).
- Read number words to ten.
- Be able to read common signs, (stop, go, in, out, boys, girls, exit, enter, poison, danger).
- Be able to read a calendar, (month, date and day of week).
- Count by rote to 50.
- Read numerals to 40.
- Progress through first grade math series.

- Write numerals sequentially to 20.
- Know addition sums to 18.
- Know subtraction combination with minuends to 10.
- Be able to name a penny, nickel, dime and quarter.
- Dial a telephone number given in writing.
- Complete an inset puzzle of 11-15 pieces.
- Be able to trace all capital letters.
- Print all lower case letters.
- Print first and last names.
- Draw a person including trunk, hands and ears.
- Copy a rectangle and a triangle.
- Cut a circle, square, triangle and rectangle within 6mm.
- Be able to stand on either foot for 10 seconds.
- Walk on a balance board on heel and toe, with assistance.
- Follow an exercise routine to music.
- Be responsible for a daily classroom chore.
- Be able to play with younger children without supervision.
- Act out parts of a story, playing a part or using puppets.
- Wash hands independently without a reminder.
- Clean up after herself without a reminder.
- Prepare a sandwich.
- Be able to use a knife for spreading and cutting soft foods.
- State her phone number.
- Deliver a two-part message orally.
- Increase general vocabulary both receptively and expressively.
- Be able to sequence a story or event.
- Answer who, what, where and why questions correctly.
- Be able to pronounce the 'O' sound in words in the therapy setting.
- Be able to pronounce the 'O' sentence in therapy setting.
- Be able to pronounce the 'O' sound spontaneously in the therapy setting.
- Develop adequate teeth closure for the 'S', 'Z' sounds in words.
- Be able to produce improved 'S' and 'Z' sounds in words.
- Be able to produce improved 'ST' sounds in words.
- Increase understanding and acceptance of other disfluent speech behaviour.

Integration: A Deaf and Hearing Impaired Collaborative

The deaf collaborative at Newton North High School brings in 44 students from 32 different local education authorities in the Greater Boston area, some of them choosing to travel as much as one and a half hours by taxi to get to the school of their choice. These students receive their education in fully integrated settings. Parents and students pick this ordinary school for two main reasons — because it offers integration, and because the Newton public school system has a very good name, both in Massachusetts and across America. (Newton North High School recently came twelfth in a nationwide league-table of high schools).

The 2,500 'regular' students in the high school are aged between 14 and 18 years while those in the collaborative, or Edco Programme as it is known, are between 12 and 21. A total of 17 staff run the programme — six are teachers of the deaf and six are interpreters; in addition there are two counsellors for the deaf students, a director of the programme and a secretary. All students and staff are fully part of the high school, taking part in lessons, sports, lunch and break-times and extra curricular activities. The Edco programme is, technically, a private company overseen by the Massachusetts education authority.

The educational and social programmes worked out for the deaf students vary according to the individual. It may be a co-teaching programme with the teacher of the deaf accompanying a student to the ordinary classroom, or it may be two or more deaf students going together to a certain activity with an interpreter. The key to the success of the integrated classroom work in this 12 year-old programme is, to a large degree, the support services that have been built up over the years, including a resource room for pre-teaching and re-teaching of what is going on in the regular classroom. There is also an English laboratory which allows each deaf student two additional periods a week to work on language, grammar, sentence structure and so on, and a speech and language session that works specifically on speech production.

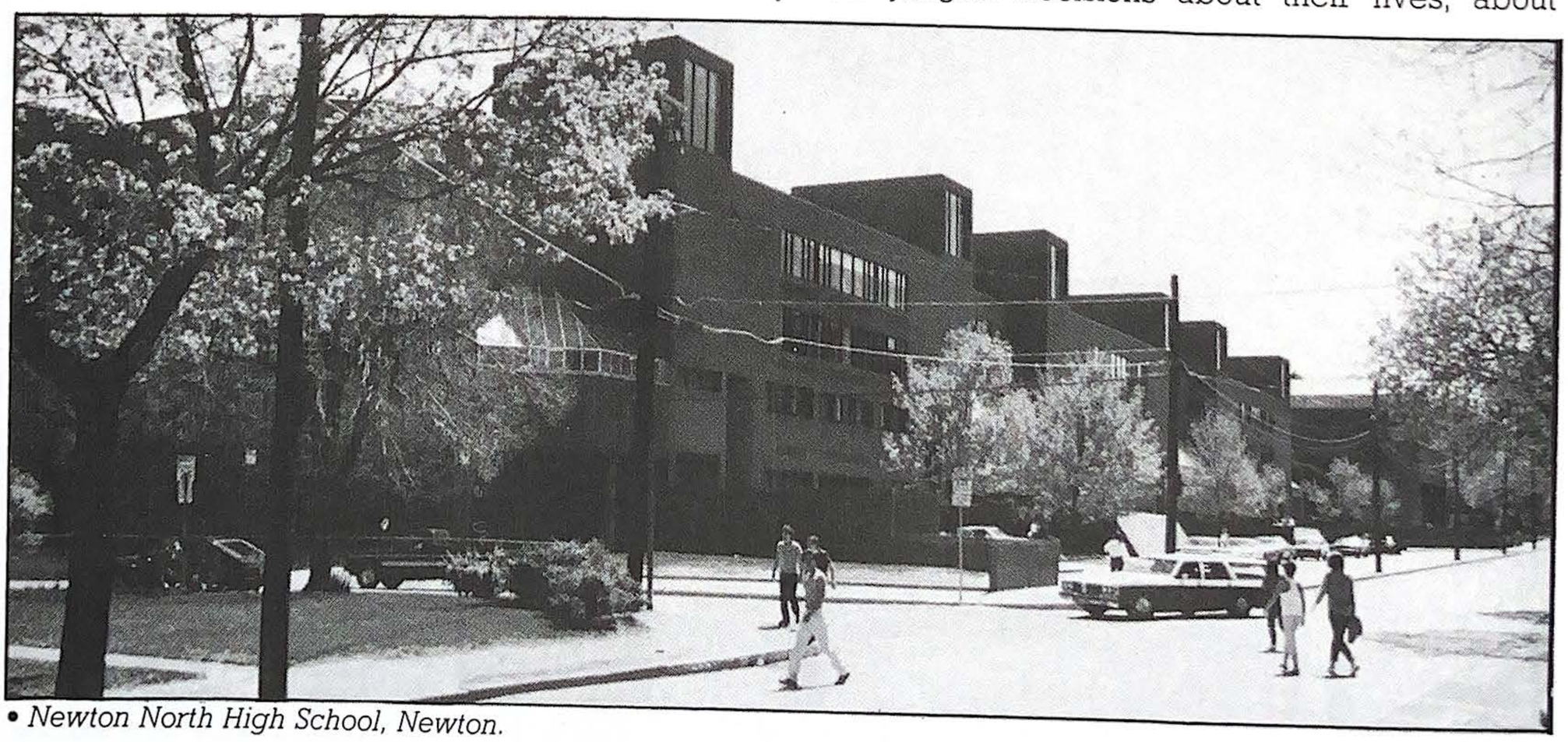
'This speech and language session,' says Ed Mulligan, director of the Edco Programme at Newton North 'is not a oralist bias we are trying to give the kids, but simply encouraging them to use everything they have got. All 17 staff are fully committed to total communication for the deaf students — that is, lip-reading, sign-language, facial expression, and speaking.' Another 'resource' cited by Ed Mulligan is all the after-school sports and club activities which have planed a vital role in the integration and educational and social development of deaf and partially hearing students.

'Those who do take part in these activities integrate much better into the ordinary classroom and reap the rewards of doing so. We are in no doubt about the benefits of students getting involved in things like athletic programmes, clubs, or music, art and craft and other special interest activities — the team spirit and camaraderie comes over into the classrooms, into the hallways, and into their whole school experience.

'Our main problem with the after-school clubs, however, has been transportation, and this has become a major issue in Massachusetts. The students get taxi-rides to school as part of their "related services" which are written into the IEP, but if a student doesn't go home at the usual time because he or she wants to go to a club, that means an extra taxi. The law is clear on this issue — handicapped children and non-handicapped children need to spend time together to share activities outside the classroom and outside regular school hours, and it states that they both have the same rights in this area. You can see some of the difficulties when I tell you that for some of our students the travel costs over a year are far greater than all the tuition costs!'

One of the main advantages of integrating deaf and partially hearing students, according to Ed Mulligan, is that the 'normal' student is there for the Edco staff constantly to compare their students with, and as a result they *raise* the expectations of their students. 'The norm is higher on a number of counts and in looking at the regular high school kids we can say to ourselves: "This is where *they* are at right now" and it gives us a very useful yardstick.

'The more experiences that we are able to open up for the deaf students, the better off they are. There are *tremendous* benefits from experiencing and coming into regular contact with hearing people.' Did the Edco programme recognise a separate 'deaf culture'? 'Yes, there is a separate culture and we support it. But what we are enabling the students to do is to make better judged decisions about their lives, about



• *Newton North High School, Newton.*

separate deaf cultures, to make choices about a host of other things affecting their lives.'

Ed Mulligan says some of the ordinary teachers in the high school report that, as a direct result of teaching deaf students in the ordinary classroom, their teaching of *hearing* students has greatly improved. 'And the more that the teacher of the deaf, or the interpreter assigned to the deaf students actually integrates into the regular classroom, the more the deaf students benefit.'

Counselling of deaf and partially hearing students in Newton North is very important, because there are lots of issues for students involved in this programme. They include: 'I think the hearing kids are picking on me'; 'When I look around in the class and see the whole class laughing, I think they are laughing at me'; 'My parents don't sign and they don't want me to sign'; 'When I went to the school for the deaf I had lots of friends, but here the hearing kids don't like me'; 'What does the audiologist really write down when I go to see them once a year?'. A lot of the worries are based on the deaf students constantly comparing themselves with the others and, according to Ed Mulligan, it is a question of getting the message across to the deaf students that what they are feeling is exactly the same as the hearing students.

A booklet on the Edco Secondary Education Programme in Newton, which describes the programme in words and pictures from the student's point of view, concludes:

'As we are being integrated in the regular schools we're being exposed to a multitude of people and challenges which is part of growing up in the mainstream of society, thereby affording us the opportunity to be responsible towards ourselves and others, build our self-confidence in coping with a predominantly hearing society, boost our self-esteem, attain social maturity and express ourselves as real human beings . . .'

Integration: The Roncker Case

Mainstreaming has brought its own growing body of case-law in Massachusetts, and many other states, with the outcome often having far-reaching effects beyond state boundaries. A 1983 court case of particular interest involved Ohio's system of segregating severely mentally retarded children into separate special schools. The case went to the US Court of Appeals and introduced some landmark findings to further the cause for integration.

Nine year old Neill Roncker was classified as severely retarded and his local school district decided to place him in a segregated special school. The boy's parents opposed this and a local appeals officer supported their arguments that the school district had not tried hard enough to secure maximum integration. The officer ordered a placement in a special class on a regular school campus. However, when it was taken to appeal to the Ohio State Board of Education, by the LEA, it was decided that Neill's education *should* be offered in a segregated school, but that he should interact with able-bodied children at lunch, breaktime and when being transported to and from school.

This Neill tried for 18 months, but made no significant progress, by all accounts. From there the case left the jurisdiction of the education authorities and transferred to the courts, with first a lower court confirming that a segregated special school placement was the right thing for Neill, and then the higher court — the US Court of Appeals — over-ruling this judgement. The Court of Appeals findings, which now stand, included the following major points:

1) No child can automatically be placed solely on the basis of their classification (eg 'trainable mentally retarded'). This, the court said, was a violation of the Federal Act, Public Law 94.142.

2) The Ohio school district's argument that the handicapped child 'would not benefit from mainstreaming' had failed to include benefits from integration at lunch-time, during gym and breaktimes and on transport to and from school.

3) The higher court condemned the school district's attempt to justify a more restrictive environment for Neill by saying that 'we tried integration and it didn't work'. They had failed to investigate 'whether the child could have been provided with additional services which could have improved his performance'.

4) The arguments in favour of segregation which say that 'all the special services are in the segregated school' was rejected by the higher court. It asked simply: 'Why *can't* those services be provided in an integrated setting?'. If a segregated school was considered 'superior', then a court must determine whether or not those services which make it superior could be provided in an ordinary school. 'If they *could*, then a segregated placement would be inappropriate under the Act'.

5) Arguments against integration on the grounds that the placement was too costly were also rejected; while costs might initially be large, the new investment of these resources in ordinary schools would open up the continuum for many children. Therefore expenditure would be both justified and required because it would not be just for one child.

6) The final argument put forward in the Roncker case to justify a segregated placement, was that the handicapped child was a 'disruptive force' in the integrated setting. The court said there were two kinds of disruption and rejected the arguments in both. The first was the disruptive impact of a new and complex educational programme for a child with special needs in an otherwise normal setting. The evaluation process leading to an individual educational programme (IEP) was exactly the place where *that* potential disruption needed to be addressed and resolved, the court ruled. Potential disruption was *no* justification for a segregated placement.

The other kind of disruption was 'unacceptable behaviour' by the student concerned. While short-term removal from an integrated setting was justified by misbehaviour, Public Law 94.142 insisted that in the long term, the student should be re-integrated. Non-disruptive behaviour in an integrated setting was an important goal and part of the IEP, but, the court asked, how could a student be taught 'appropriate integrated setting behaviour in a permanently segregated setting?'.

Thus all of the most commonly used arguments to justify more restrictive placements for handicapped pupils were found to be unacceptable under the court's decisions. It can be seen that all of the arguments were *administrative* arguments. The Court of Appeals concluded that administrative impediments can, and should, be changed and modified.

It put the burden back on to the school system to bring about changes, and to explain — if it could — why particular aspects of an educational programme were not available to children with special educational needs in the 'least restrictive environment'.

Parental involvement:
Parents and politics

'Ten years ago, when the law covering the education of handicapped children first came in, many of the 'first wave' of parents had to worry about simply getting their child into school — any school — particularly if she or he was severely handicapped. Now, parents of young handicapped children are the new wave. They take rights and services for granted. They have more confidence. By and large, the struggle has been achieved.'

So says Betsy Andersen, of the Federation for Children with Special Needs in Boston — whose workers include parents of children with special needs and other parents too, and whose existence highlights a major gap in British educational politics. The Federation works not just in Massachusetts but nationally to ensure that parents and professionals make the most of the education legislation. It has a Federal technical assistance contract of $2.2m over three years to coordinate the work of five centres across the country which organise parent training and information projects under the national act. It is in touch with over 60 programmes doing this work around the country, with $5m of Federal funding to help them — and that means, it reckons, some 300,000 parents helped each year.

Washington has also asked for a two-part evaluation of the spending of Federal funds on work that individual parent centres, nationwide, are doing. President Reagan's office wants to know how effective the work by these centres is and has asked: (a) Have parents actually learned about the law, the regulations and various procedures; (b) Have parents been able to effect a local change in relation to the education of their handicapped child, and (c) Have parents been able to participate and to have their children actually *receive* the services and programmes they feel are important?

The implication of this is that the Federal Government wants the consumers of this part of the education service actually to *know* about the law, and to be able to *influence* local change. In England by contrast there is far more rhetoric than actual parental rights and involvement.

One huge difference between this country and America is the status of parents and children within the different education systems. In Massachusetts, for example, it was taken for granted that the parents' contribution and involvement was totally valid and vitally important. The bureaucracies were fully geared up to taking *seriously* on board their comments and contributions. Parents were much more involved in the *drafting* of the legislation, particularly in Massachusetts, than parents are in this country; this gave them status when the law was implemented. In addition, it was possible for parents in the States to point to enormous omissions and bad practice in relation to the education of disabled children before 94.142 was drafted.

The effect seemed to be that parents think differently and far more positively about the education of their handicapped child. Parents' expectations were higher; the expectations of a particular child by local education authorities and individual schools were formed in the context of a belief that 'This child has the same right to opportunities of self-fulfilment as others'.

In view of the often repeated criticisms here of the 1981 Education Act's assessment and statementing procedures, perhaps the most startling aspect of Chapter 766 are the 'time lines' or deadlines within which the *authorities* — not the parents — must respond. (See *What does the Law Say?* page 2). To highlight just two: the evaluation (or full assessment as we know it here), *must* be completed within 30 working school days of parents giving their written consent. The subsequent draft individual educational programme (or statement as we know it), must be sent to parents within ten working days of the completion of the team meeting of parents, professionals and education officers to discuss the child's needs and provision.

Different nations, different cultures — can we learn anything from the USA? The answer is a firm 'yes', because the struggle — and social change — is basically the same. In this country, we seem only recently to have begun to confront certain fundamental issues thrown up by the Warnock Report (1978) and the 1981 Education Act. There are slow but small changes in practice in schools; there are grass-roots rumbles from parent support groups and parents of handicapped children, who want something different for their children.

The first two years of the 1981 Act in England and Wales being in operation (1983-85), have shown how difficult it often is to move from that rhetoric of 'parent-professional partnership' to the reality of parents knowing their rights and responsibilities and sticking up for both. If the experiences in Massachusetts are anything to go by, there is always pain behind any fruitful partnership. As one special education director in Massachusetts remarked: 'We have discovered growth and a far more positive approach through conflict; it had to happen!'

The Federation for Children with Special Needs offers ongoing training to parents (and professionals) to help them become more knowledgeable about special education laws. They answer all types of queries, have their own handbooks, leaflets and other publications and act as the national clearing house for similar parent-support centres across America. Betsy Andersen has been in it from the beginning. 'We haven't stopped at our successes. The near future will have to see handicapped children *themselves* having the opportunity to design and write their own educational plan. The logical next step from advocacy — which we have largely achieved — is, of course, self-advocacy. It has to come.

'The changing role of families over the last ten years has been very good in terms of parental involvement; parents' knowledge of the law; information for parents; access to records and files and parents working in schools. It has been a struggle for basic rights and a lot has been won, but there are still big gaps. We need to start giving young handicapped children role-models and career training from the age of two, just like we do with ordinary kids. We need to expose children with special needs to just as many possibilities as able-bodied children'.

Diana Cuthbertson, also from The Federation,

agreed: 'Handicapped children must get out and see for *themselves* and ask *their* questions about what they experience. They must be given information just like other children, so that later on, they can decide what to do. We simply don't know what the possibilities are; the jobs and workplaces of the future might be adaptable in a variety of different ways — who knows!?'

The picture in America a decade ago was similar to the present position in this country. Betsy Andersen: 'The essential problem for families ten years ago was that parents didn't know how to use the new law, yet they were being asked to be involved to a considerable degree, just like your parents are being asked now.

'At that time we were a loose coalition of parents and professionals and had really valued working together, exchanging a lot of ideas. It was obvious that we had to start holding training days, and without any knowledge of how you get a series of training days off the ground, we just went ahead and did it! This is now a very important part of our work, whether we are giving parents an individual understanding of the law and the new procedures, or training lay advocates to help parents at appeals.'

Behind Washington's current commitment to helping this now national network of centres, and to the concept of more and better information for parents is the belief that in the end parents are far more cost-effective when they work for what they want particularly if it is a better education for their handicapped child. This has raised a lot of questions, however, not least how you help parents who cannot express their wants as easily as others. The Federation are the first to admit this weakness in the system.

Nevertheless, the parent movement has considerable strength. President Reagan's first attempt to cut Federal aid for programmes for handicapped children in 1982, (see *The context of reform*), was categorically defeated by grassroots pressure. It is now very difficult for the President to go back on what amounts to a commitment to handicapped children, because that would be seen as a persecution of a minority group whose advocates have succeeded in achieving certain rights and services in recent years — and in achieving a fundamental shift in attitudes.

And while a key factor has been continued parental pressure on successive US Governments (which have had no real tradition of innovation or reform), a small, but significant, part of the story behind President Reagan's apparent 'sympathy' for this area of social spending, is the contribution of Republican political commentators and campaigners, who themselves have children with special needs, or who are closely associated with them and disability groups.

George F. Will is one such nationally syndicated columnist (on the right of centre), whose wife Madeleine was appointed in 1984 by the President as Assistant Secretary of Education for Special Education and Rehabilitation. They have a child with Down's Syndrome. Madeleine Will speaks out strongly in favour of integration. In January 1985 she made a rallying call for all parents to be united over the issue of 'least restrictive environment':

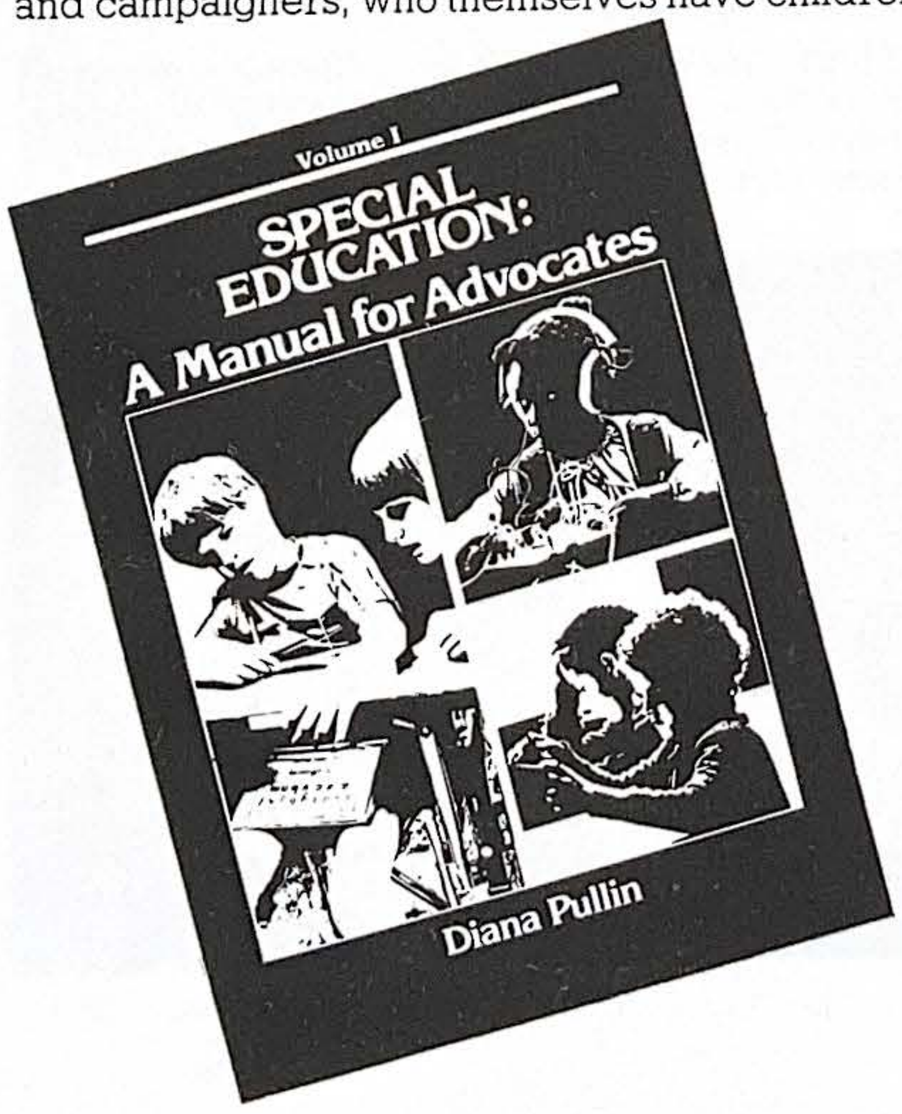
'I urge all parents to seek ways to improve efforts to provide the least restrictive environments to handicapped students. I am hopeful that the day will come when *every* handicapped child will be educated in a totally integrated setting with non-handicapped peers.'

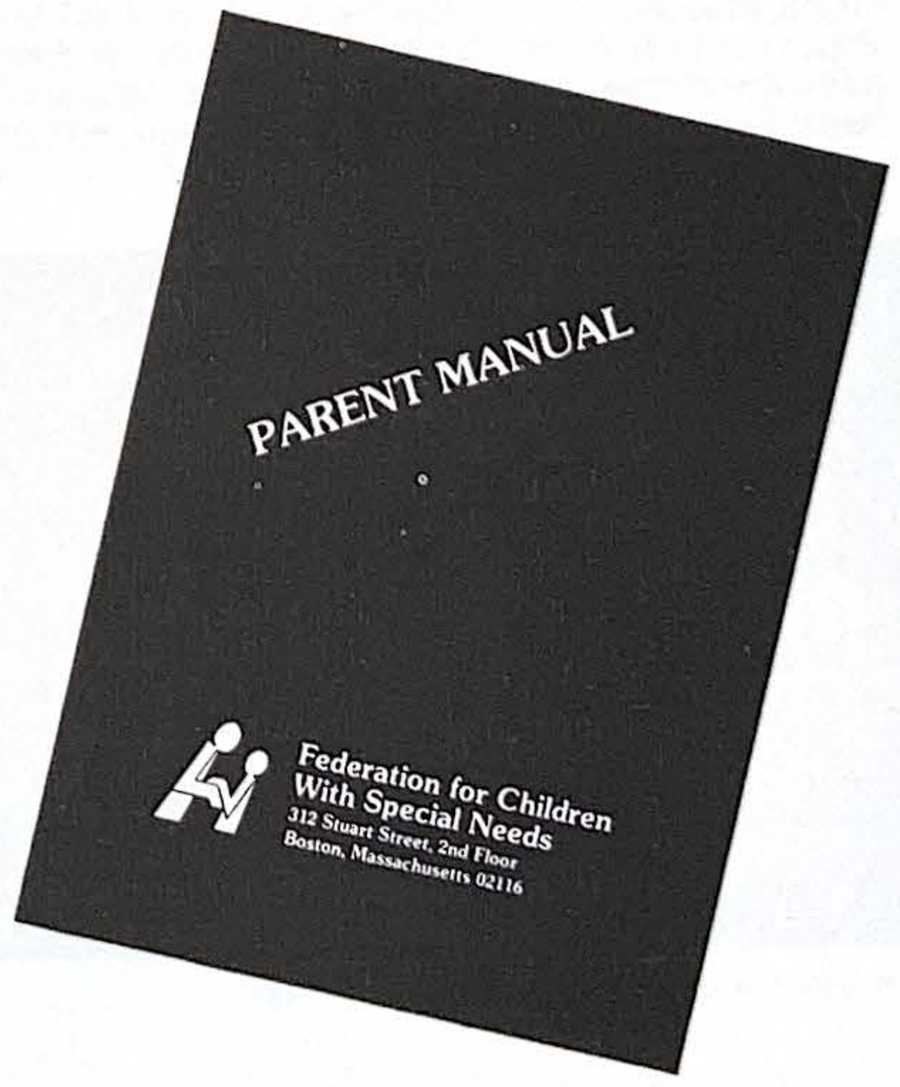
In a column called *A Magna Carta for the Handicapped* in the New York Times about the same time, George Will wrote that disabled people 'have been excluded from fair social participation, not because of their handicaps, but because of handicapping social attitudes.

'Handicapped citizens are as fully citizens as those of us who are mentally non-handicapped or temporarily able-bodied. They are just beginning to have access to social benefits that other citizens take for granted. When P.L. 94.142 was passed in 1975, 25 per cent of all handicapped children were under-served and another 25 per cent had no educational programmes at all.'

The Federation for Children with Special Needs argues that a decade after the American legislation was passed, two major points can be made about integration, or mainstreaming — one about philosophical principles and the other about practice. Integration as a philosophy, and as a basic human right, is, it says, firmly established in the education system. And the change in practice now means that many more children with special needs are educated alongside their non-handicapped peers in ordinary settings (to a greater or lesser degree), than is the case in England and Wales. Betsy Andersen said that while things were by no means perfect, there wasn't any doubt in the minds of most Americans about the *rightness* of integration, whether at a school level or beyond.

The remarkable way in which the 'rightness of integration' has become part of general thinking in places like Massachusetts is, according to the Federation, highlighted by the next 'problem': to improve the transition process for a disabled young person once their entitlement to education ends at the age of 22. (See *What Next? The Turning 22 law*, page 32).





Parental involvement:

Parents and professionals — the balance of power

'There's a certain cynicism about empowering people: "How far can we go to give them rights if that includes the right to obstruct, or bloat our budget?" There are those who dismiss the provisions of Chapter 766 as "a 1960s experiment". But support for the act is very broad-based. It is not like efforts to help people who are black or poor. It is, in fact, a middle-class programme.'
(Senator Gerard D'Amico, chairman of the Massachusetts State Education Committee)

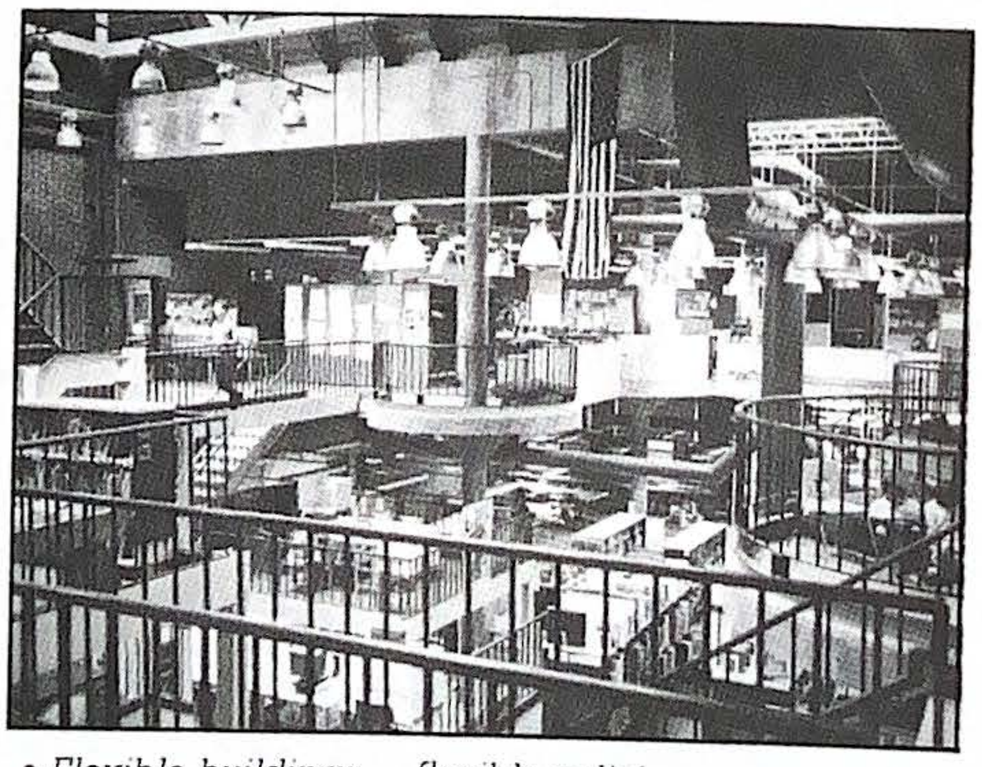
'Dear Chatters, It is that time of the year again when I must attend the annual review meeting for my special needs son. Oh, how I dread these meetings! Although I know my rights and have attended review meetings for several years, I get depressed and anxious beforehand. No matter how prepared I am, the special education teachers always seem to throw in some item that unnerves me. When I ask "Why wasn't I notified about such an important issue?" they are silent.

When I ask for something to be written into the individual educational plan they listen, but never include it. I know I can reject the plan, but this means a war with the school and without the $10,000 plus for a lawyer, our chances of winning a hearing are nil.

Any suggestions on how to be more at peace before these annual "report and testing" meetings, would be greatly appreciated.'
('Mom of L.D. Child' Boston Globe, 5.5.85.)

'My concern is to increase the information and involvement of parents, to persuade them that encounter and confrontation are okay. When you get a parent who has that information and involvement, it's beautiful to see the things that can happen.'
(Patrick Davis, mediator, Greater Boston regional education centre)

Chapter 766 came into being, not as an educator's reform, but as the result of considerable and broad-based public pressure. Its regulations were drawn up not by bureaucrats, but by citizens' taskforces coordinated by the state's special education advisory committee. The thrust has continued: the revision of the regulations which has to happen every three years was, in 1985, out for comment to some 100 organisations and individuals. It is, as one observer puts it, 'an advocates law'. Or, as many educators have put it over the years, it is quite unfairly biased in favour of parents and against the school administrations.



• *Flexible buildings — flexible policies. . .*

But how does the balance of power and influence work out in fact? The law provides two major points where this can be tested: the individual education plan and the appeals system.

Individual education plan (IEP)

Almost everyone the Huron Institute study team interviewed agreed that individual education plans were a good idea; all but a few thought it a 'giant step forward' to bring a multiplicity of

perspectives to bear on finding appropriate goals and services for individual children instead of, as used to happen, placing them on the basis of a single, individually-administered test. The team found a dramatic improvement in the way the plans were drawn up over the first five years of Chapter 766; in fact, it found that in some ways monitoring and training had succeeded too well, yielding plans that were detailed to a point that was both unrealistic and unnecessary.

But what happened after the plans were made? Huron found that they were filed — and generally not even in the school building. Regular education staff seldom used them. Only a few educators at any level, were genuinely enthusiastic about them. Parents were seldom aware of the details of their child's plan. Their concern was more with placement decisions, the quality of their child's school life and indications of progress. A few used the plan as a lever to hold the school accountable. But it was rare for parents to use it as a way of assuring that specific educational objectives were met.

Nevertheless, what the IEP procedure had done, by the time the Huron studies were made, was to bring parents far more into touch with the people who were responsible for their child's education than many had been before. The Gallup surveys found that as many as 90 per cent of parents had met with someone in the schools to discuss their child's education during the past year, and for about a fifth of parents, the majority of meetings were at their own request. Not far short of three quarters of parents whose children were in elementary programmes and more than 60 per cent of those whose children were in secondary ones said they were satisfied with the willingness of school staff to listen and explain. That raised questions of parental expectation: Huron also found many 'vulnerable' families — newly arrived, non-English speaking and those categorised as having multiple problems. But the finding that up to 61 per cent of all educator groups (except teachers) thought parents now had too much influence over the content and place of their child's education says something about the changing balances of power and influence. And the fact that a clear majority of all educator groups also said that they thought parent participation resulted in a better education for children with special needs, says something about a more generalised reform that comes from the procedures designed for individuals.

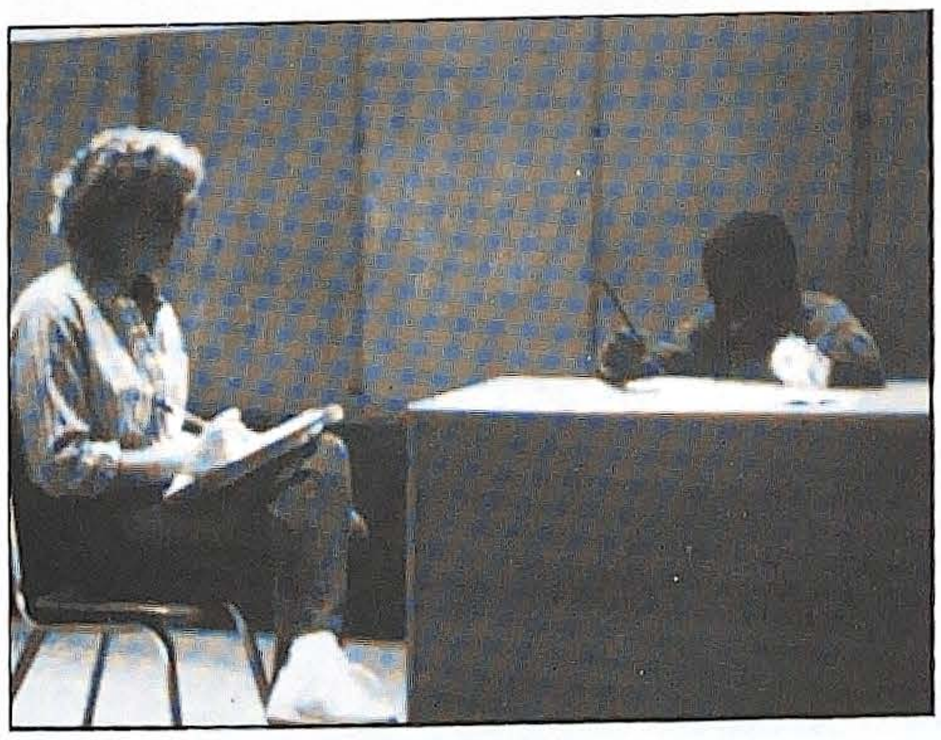
Appeals

Parents who don't like what is proposed to meet the special needs of their child can appeal to a formal hearing and from there to the special education advisory committee and ultimately to the courts — and Massachusetts is said to yield more rejected education plans than states ten times its size. But as it works out, fewer than one per cent of these go to formal hearing. The large majority of objections either disappear as parents don't follow up on the formal procedures (discouraged perhaps when they see what these might entail) or are resolved through mediation. And mediation, most people seem to agree, is the best way of resolving disputes.

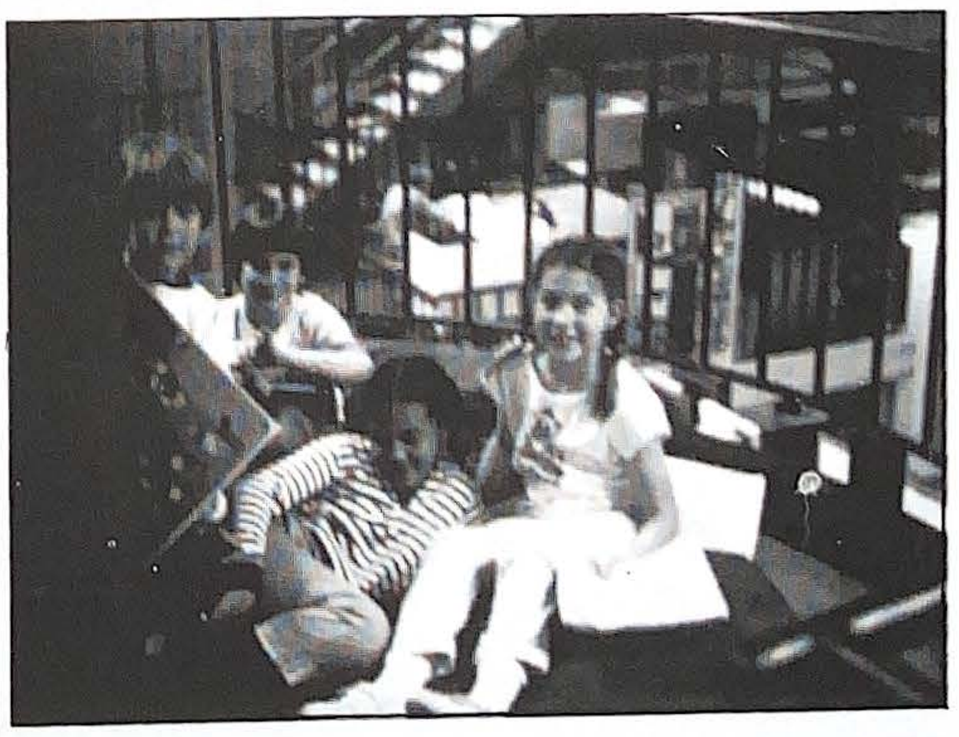
There are, though, some reservations. Mediators are part of the Division of Special Education's teams in the regional centres rather than independent people; some critics have questioned whether they can really be impartial. The alternative of the formal hearing, however, is time-consuming, costly, adversarial, and often of dubious benefit in outcome. (Over the years, in fact, the outcome of hearings seems to have been fairly even-handed. The Huron Institute study found that between 1977 and 1980, 47 per cent of hearings found in favour of parents and 52 per cent in favour of schools. By 1985, the Greater Boston Regional Centre, which has some 400 rejected educational plans each year (two per cent of the total) was reckoning that fewer than ten per cent of these went to a hearing; of those, about a third were decided in favour of the school, a third in favour of the parents and a third resulted in a compromise between the two).

Milton Budoff, of the Research Institute for Educational Problems, who conducted a detailed and long-term evaluation of the hearings process (*Due Process in Special Education,* Brookline Books, 1982) characterises it like this: 'So much acrimony — and the children are left in the system'. The Massachusetts hearing process has become a particularly legalistic and procedural one: the hearings officers are not now the 'social worker types' they were at the start (and still are in other state appeal arrangements) but lawyers; the early change of name of the Bureau of Child Advocacy to the Bureau of Special Educational Appeals reflects the change of emphasis.

In this context, Budoff's study found, parents and school personnel as well were distressed and strained. The very process of preparing for a hearing drove them further apart rather than enabling them to work together for the good of the child in question: 'Once parents decided to pursue an appeal, parents and school personnel ceased to communicate about the child's needs'. The school's focus was on preparing a written document which would serve as evidence at the hearing; their tendency was to work on presenting a unified view among their staff rather than debate what the child really needed. And at the end of the day, the only people who were content with the outcome were the parents whose child was confirmed in a private placement — a placement that they had often made before the process began. For those whose children had remained in the public school system, the result was too often further conflict.



. . . The Pierce School, Brookline.



Nevertheless, Budoff concluded, the appeals system acted as a spur to more generalised reform in special education, playing its part in creating programmes from which many other children could benefit. And it played its part too in ensuring that school systems worked to make individual education plans more specific. Given the huge legal and other costs that are now an inescapable part of going to hearing, this generalising effect is clearly crucial: the vast majority of parents who can't afford it would otherwise get little benefit from the system at all. By 1985, there was a move from the Massachusetts Advocacy Center to make a pool of money available to support appeals, and so dent this discrimination. But even if this became available, the general feeling seems to be that the formal redress built into the act will continue to be valuable far more for the example set by a few cases than for the numbers who actually use it.

The issues of parent education in the possibilities and intent of the act, and of *group* advocacy on behalf of children and young people with special educational needs seem finally far more important to the balance of power and influence in the act's workings. The Huron study found little organised parent effort to consider general programme accountability, to maintain service levels, to resist budget and staff reductions or to assist and inform parents in vulnerable families; parents and staff seemed to have little time or energy left for these larger responsibilities when work for their own individual children took up so much of both. One mechanism for pressing wider concerns was built into the act, through the local and state advisory councils. But by 1985, according to Martha Ziegler of the Federation for Children with Special Needs, the problems of finding people with the time and energy to make these effective still remained.

The need for parent education is one that she and many others are acutely aware of, and not just people on the 'advocacy' side of the educational scene. There may be some local questions about the independence of the mediation service. But what is striking to the outsider is just how much emphasis people at all levels of the bureaucracy seem to put on the need to build up informed participation by parents so that the act works better for children who aren't middle class.

'I received in the mail today a form from the Lexington public schools asking me to give permission for my child to have something done to him called a Partial Core Evaluation . . . I never associated John's slight speech problem (he was seven and lisped) with that menacing and frightening form that came in the mail today. As the form is written (with such full stress on my rights, with a description of the high-powered specialists who might be called into diagnose my child's special needs) I was sure that some terrible thing had happened to my John which I, as his mother, was the last to find out about . . .

Until I talked to the school principal and found out that only his speech problem had landed John in the midst of all this paper confusion, I was upset and I was frightened. I know we live in an impersonal society and that bureaucracy is part of life. But if someone had just taken time to put in that awful form letter a little phrase in parentheses that said "It's just John's speech problem", I would have had an easier day today.'

Parental involvement:
Handicap awareness in ordinary schools

'Do you ever want to see again?' asked the nine year old girl. She was talking to a blind woman who had come into the classroom as a 'consultant' for that morning's handicap awareness session.

'No. I've come to terms with it. I've known for so many years now that there is no possibility of me getting my sight back, that I completely accept my blindness.'

We were in a regular fourth-grader's class (nine to ten year olds) in Devotion School, Brookline, Massachusetts, not far from Boston. It was the end of a successful morning-long session about blindness and some of the issues involved.

'If you're thinking something' said a ten year old boy in the same class, 'can you *see* in your mind what it is?'

'Some blind people *can* see pictures and images — it depends on when they lost their vision. Others can't. If you have some distant vision from childhood of, say, what a house looks like, then yes, when you think of a house, you can see one in your mind. But for me, I lost my sight before the age of two, so, no, I can't remember any images.'

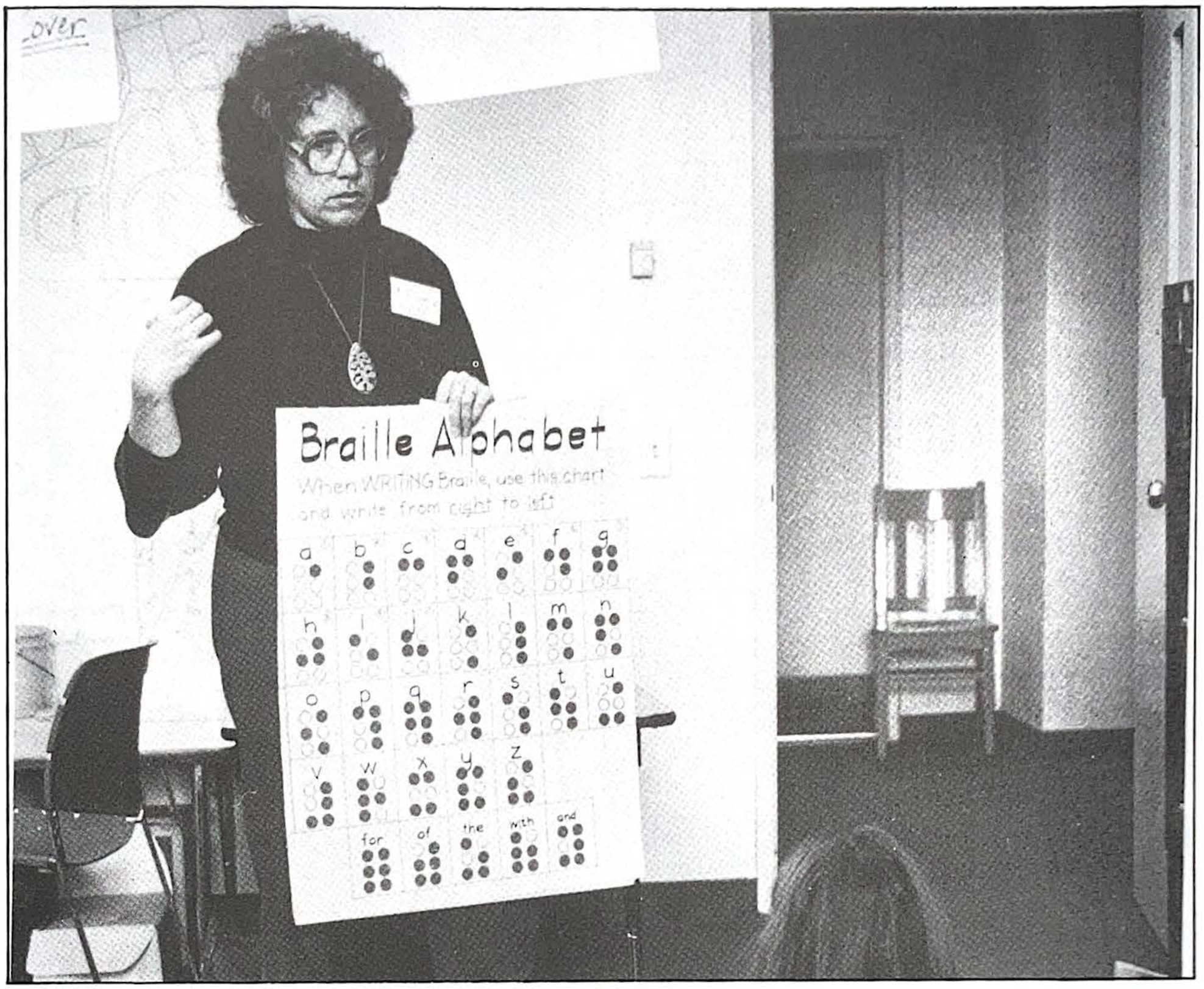
'When you dream . . .' a ten year old girl asked hesitantly, '. . . do you see any pictures, like we do?'

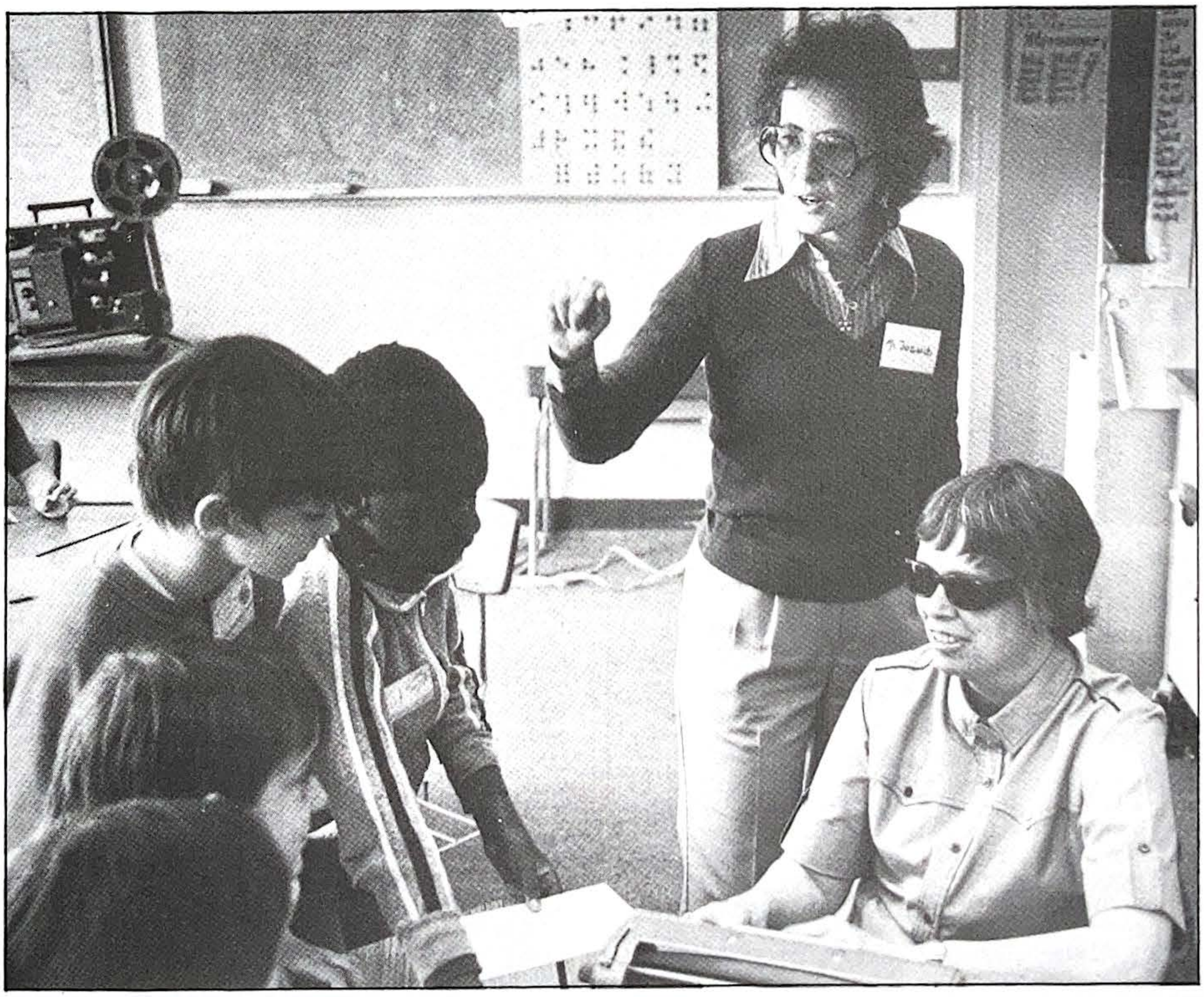
'Again, as far as I am concerned, I don't. I know other blind people who do, but I don't dream in pictures.'

'Do you know what you look like? Do you know what your dog looks like?' asked another.

'No, I don't really know what I look like, though of course I know what size I am in clothes and shoes. I get a lot of help from my family — my husband, and my three children — so far as clothes and dress is concerned. I know what my dog *feels* like, but I don't have a *picture* of that.'

Handicap awareness programmes have been growing steadily in ordinary schools in the States over the last few years, and those involved in the running of them agree that one of the most satisfy-



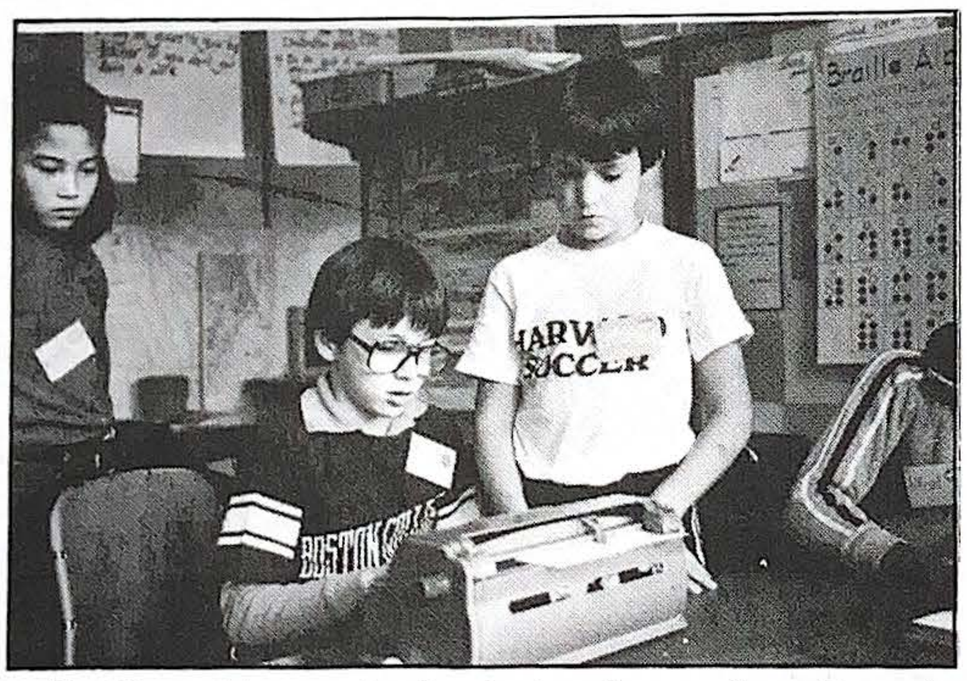


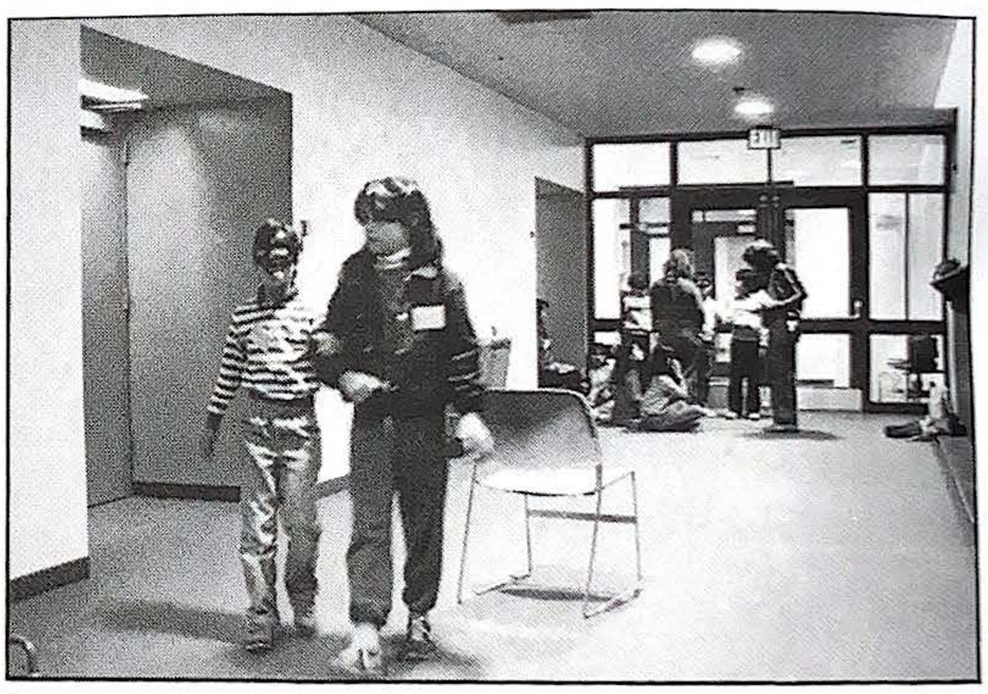
• *Parents teaching the handicap awareness programme at Devotion School, Brookline.*

ing and rewarding learning experiences for the children is the question and answer session at the end. Ironically, with so much integration of children with special needs in Massachusetts and in Brookline education authority itself, Devotion School had no children defined as having special needs. There was, however, something special about the school's population, which was one quarter Russian, one quarter Chinese, one quarter Israeli and one quarter American.

One of the remarkable features of this handicap awareness programme, and the one in the neighbouring education authority of Newton, is that they have been written and are taught by a network of volunteers — parents and other interested people. In Newton there is a group of over 250 parents who ensure that each year, every ten year old child in the authority's ordinary schools experiences the programme, which covers blindness, hearing loss, physical disabilities and mental retardation. People who have been involved with teaching handicap awareness say that the age of nine to ten is the best moment in the development of a young person for this kind of programme and the related issues to be put across.

The programmes in Brookline and neighbouring Newton are parent-run and parent-administered with a budget from the LEA for materials and speakers' fees. Sue Epstein from Newton explained: 'The origins of the programme came from parents of handicapped children in Newton who wanted to help their





• *Braille-writing and role-playing for pupils at Devotion School.*

children fit into ordinary schools more easily, in the firm belief that this would later on help them in the transition into society.'

Ordinary schools vary in the enthusiasm with which they welcome the parents coming into the school to teach the programme, and put children through a variety of experiences, role-playing and information gathering exercises. The wide range of experiences for the children includes being in a wheelchair for the first time; having their fingers sellotaped up to make it difficult to undo shirt buttons etc; being blindfolded and then pouring and drinking orange juice; learning the basics of braille and using it; watching short films about different disabilities and the issues involved, and at the end of the session taking part in the discussion with the 'consultant'.

Sue Epstein said none of the ordinary school teachers are actually opposed to the idea. But as she pointed out, there is a world of difference between a class teacher working *with* the volunteers over the several weeks that the programme lasts for a group of children, and one who shows little or no interest or enthusiasm. 'Some teachers simply hand over their class and leave the room, and we don't mind that — we are totally geared up to do it all ourselves. Others are more keen on the project and really help in the preparatory work prior to each session, like asking the children to go through a barrier check-list in their school and home and to imagine what a physically handicapped person might experience, or telling them to blindfold themselves at home before eating their bowl of cereal in the morning, or play the piano with the blindfold on.'

The organisers claim there is a real benefit to these programmes being run by volunteers from the community, rather than professionally trained people. Over the years, according to Sue Epstein, the volunteers in Newton have endorsed a voluntary local community-based model rather than anything with a 'professional' air about it; local people are making a local contribution to the town's schools. 'The spin-off is that we have "educated" about 600 adult volunteers in Newton — it could even be argued that the adults get more out of it than the children. We *know* it has had a large impact on the local community.'

Initial problems when the Newton programme started ten years ago included its dominance by white middle-class parents; those schools which could not get sufficient volunteers were inevitably in the poorer areas where parents couldn't afford to take time off because wages were lower or many were single parents. That has now changed for the better and the organisers argue that the most effective way of recruiting volunteers has always been word of mouth.

Among the spin-offs is the expansion of relevant material in both the local school libraries and the public libraries in towns, mainly as a result of children asking for new books and new information. But without any doubt, says Sue Epstein, the most important part for the children is the discussion with the consultant from one or other disability organisation. 'The most difficult speaker to get was one who was mentally retarded. We discussed it for a long time and in the end we invited a mentally retarded person who was able to answer questions.'

Susan Sternfield from Brookline's handicap awareness programme, which is run along similar lines, said they faced the same problem when it came to teaching ordinary school children about mental handicap, but they were determined to include it. 'We went to a self-advocacy group — the Squaws and the Mohawks Social Club in Newton which gets mentally handicapped people to speak up for themselves. It was amazing when these three young people came to our class; they had a really positive attitude and answered lots of questions from the children — they *really* got into it!'

She said the strength of the programme in Brookline rested on the whole effort being a local community one, run by parents in the area who have children in the schools or who are closely connected to the schools. 'This puts a natural limit on who becomes involved, and it has been said to us that disabled people themselves should be teaching ordinary children about handicap awareness. Some disability groups have said "What about us doing it? Able-bodied people too easily present a stereotype picture of people with disabilities."

'Our answer is that we are *not* presenting a

stereotype view. We feel very strongly about this issue. A lot of us have children with special needs ourselves and we talk with them about their differing disabilities. In addition, it happens that two of the current group of volunteers going into the ordinary schools are physically handicapped. However, the main issue is whether the teaching of handicap awareness programmes is done by a locally committed group of people from the community who are motivated for a variety of positive reasons, or by agencies more removed from the area.

'We have a programme that fits into the school structure. We are not portraying outdated or patronising attitudes about disability. All those involved in the programmes so far — including our "consultants" — say it is a *good* package. Yes, it works!'

Do handicap awareness programmes support or actually help mainstreaming of children with special needs in ordinary schools? The answer is 'Yes' if mainstreaming is already part of a particular school's life. If it is not, then it is not an issue, and there doesn't appear to be a strong connection — as was the case at Devotion School, Brookline.

Questions of cost

'Is this a "runaway" law? It will work its way through. There are some kids who have costly programmes. But as public school programmes get better, we will be able to increase their integration. The act is not at all a financial disaster. It is doing great things. And it's a preventive programme for the future also. It makes sense, because the problems stay and they get more expensive as they become more chronic. And it is a birthright, as for other citizens.'
(Senator Gerard D'Amico, chairman of the Massachusetts Education Committee)

The Gallup study found that of all the aspects of Chapter 766, the one that drew the most negative reaction was that of its cost. Some five years later, nothing has changed. People within the education system are complaining of a lack of cash to implement the law more fully. People outside it are still saying that special education in Massachusetts — the state with the highest per capita income in the US and one of the lowest unemployment rates — puts too great a burden on local communities. The budget has continued to rise.

To an outsider trying to grapple with the complexities of a funding system that involves Federal, state and local money, it comes as something of a relief to read in the Huron Institute study that most educators didn't understand the funding formulas either (even though many claimed they did). But the Massachusetts experience over the past ten years offers some lessons at least which are worth noting elsewhere.

From the start of Chapter 766, special education in Massachusetts has not had the level of funding that was promised. The State did not, in the early years, deliver anything like the amount it said it would to boost local effort; the cash it did put in came off the budget for the general education that is now experiencing such financial constraints. Neither, since the national special education act was passed, has the Federal government delivered as promised. PL 94.142 came in with the aspiration that the Federal government would contribute a third of special education costs. That proportion now stands at six per cent.

Since the early 1980s, the situation has been further complicated by Massachusetts' own version of our rate-cap: 'Proposition 2½', which limits increases in local property taxes to two and a half per cent of the total property value in any year. In this situation, as Senator D'Amico puts it, 'Something has to give. The locals are paying more than they want. The state is paying more than it might want. There is a new game: everyone is blaming everyone else'.

The problem is not one for special education alone. In mid 1985, students and school committees in ten cities and towns filed a class action suit in Massachusetts Supreme Court against the State, alleging that the heavy reliance on local funds for education meant that poorer communities were offering poorer quality schooling than rich ones and so perpetuating unconstitutional inequalities and denying equal educational opportunity. Under the current funding formulae, for instance, one district, Hanson, was able to spend only 49 per cent per pupil of what was spent in wealthy Brookline. 'To eliminate disparities in per pupil spending', the plaintiffs said, 'the Commonwealth would be required to remove some or all local control over expenditures in education'.

That case was expected to last until January 1986. Meanwhile in 1985, a new education reform bill was on the stocks, designed in part to redress some of the imbalances between state and local funding; there was a review of educational costing as well.

By then, Massachusetts could look back on a decade of Chapter 766 funding which had shown some shift in those balances. In 1973/74, just before the act came into force, the state share of special education costs was 30 per cent and the Federal, three per cent. By 1982/83, those proportions were 36 per cent and six per cent.

One of the important reform proposals is to swing a higher proportion of the costs of residential placements — the ones which are far and away the greatest at $40,000 or more a year, and the focus of public grumblings about 'runaway costs' — from local school districts onto the state.

It was these costs, the Huron Institute study found, that drew the most negative reactions to Chapter 766; four or more years later, they are still cited by critics of the law who see them as soaking away the money that regular education badly needs. Yet of all Massachusetts children and young people with special educational needs, fewer than four per cent are in private day or residential schools. And against that, the public school achievement over the decade has been enormous. The number of handicapped children in state institutions has fallen from nearly 2,500, to around 500; the number of children in private placements has fallen from 3,200 to under 900. With the cost of keeping a child in a state institution currently running at well over $40,000 a year, 'legitimate and understandable complaints

about some of the costs of Chapter 766 need to be weighed' as the Division of Special Education has it, 'in the broader context of the human and fiscal savings which the law is creating'.

What has been happening, in short, is partly at least that number of costs which used to be absorbed by the state have been transferred to local school districts; the 1985 debate is about how the balance should be redressed.

The way forward isn't yet clear. The Federation of Children with Special Needs, for instance, wants to decrease reliance on private residential placements by having the education department open its own group homes for children who can't live with their families, and to see a programme of home-carers under the education act who could make it possible for more children to stay at home.

The development of *general* education programmes will also have its effect. There is a proposal in the education reform bill, for instance, for a large 'essential skills' grant from the state; if this goes through, it could make a difference to the current trend to class more children as having 'special' needs, rather than simply the need for remedial help that should be provided within the regular system.

There is still a point of principle at the base of all the complicated wranglings over the balance between state and local effort. One of the clear aims of Chapter 766 in putting financial responsibility on to local districts was that each should provide for its own population with special needs rather than sending children away from its school system. At least some observers are questioning whether an increase in the proportion of state contribution for residential care won't dent that principle, by taking away from local districts the incentive to find their own creative solutions for their children who have very challenging special needs.

By 1985, though, one very important fact about special education in Massachusetts seemed established. Despite the high costs of individual residential placements, despite the generous interpretation of numbers of children with special needs, the average cost per child was working out at not nearly as much as some people believed. The Huron Institute study found that the large increase in costs that came with the early years of the act was over, and that these were no longer a burden on poor urban communities — even though there was still considerable variation in the range of options provided, according to a community's wealth.

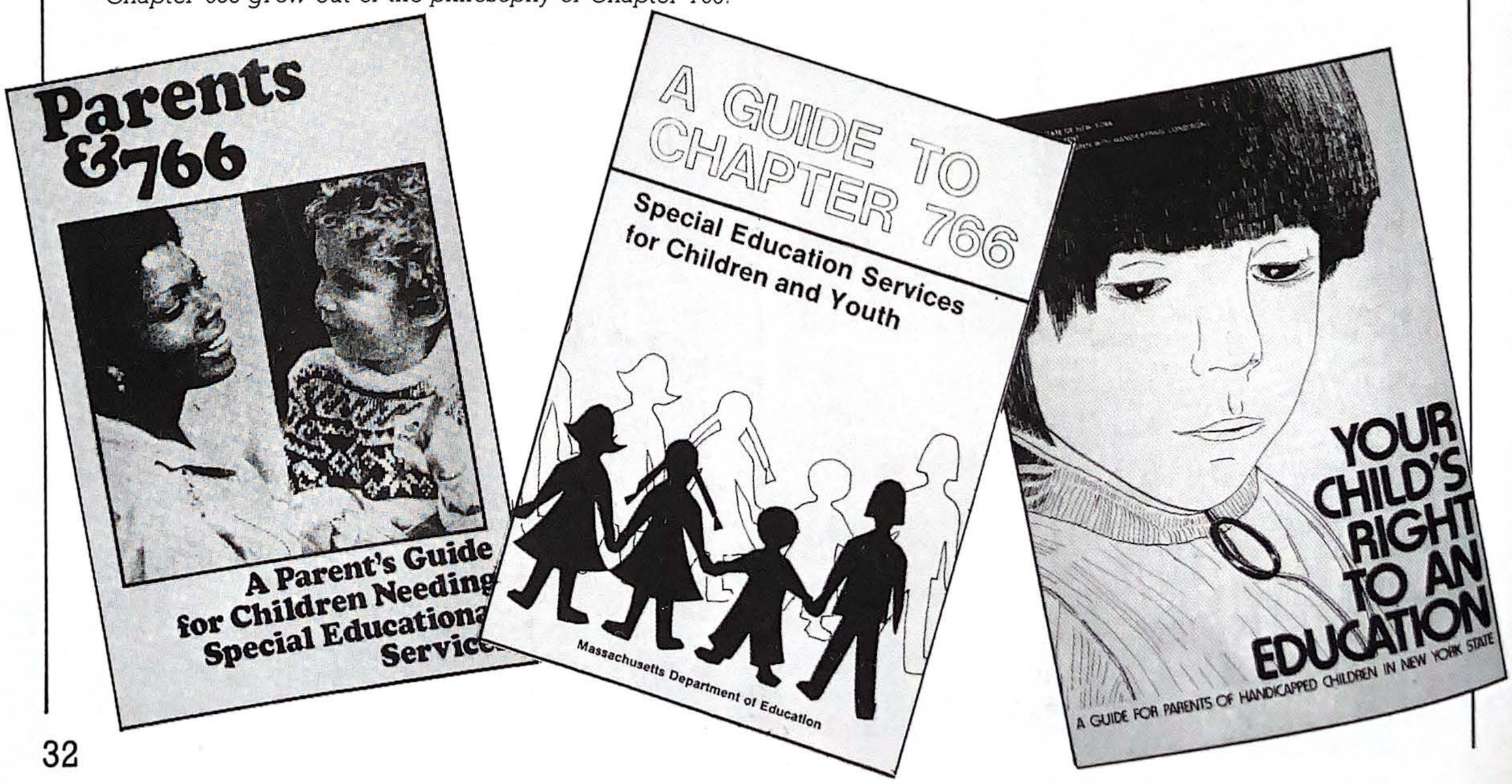
By 1985, Roger Brown, the state's associate commissioner for special education, was able to assert that special education was not impossibly costly at all. On average, he says it costs less than $1,000 more a year to educate a child with special needs in Massachusetts than it does to educate one who is not so defined.

What next? Chapter 688 the 'Turning 22' law

Chapter 766 entitles every student defined as having special educational needs to continuing education. In Massachusetts, every general pupil must stay at school until they are 16. But those in special education are entitled to education until they are 22 or when they graduate from high school.

This provision was particularly ambitious because when Chapter 766 came into effect, Massachusetts, in common with most American states, had little happening in special education at the secondary level. A national survey of 10,000 school districts in 37 states, published in 1975, showed that only nine per cent provided this, compared with nearly half who had elementary school programmes; Massachusetts seems to have been more or less in line. So it had a long way to go to meet the new requirements. In addition, as the Huron Institute study pointed out, it was at the secondary level that opposition to the philosophy of Chapter 766 could be expected to be greatest: high school teachers in general concentrated more on subjects than on the wider needs of children and many schools gave priori-

• *Chapter 688 grew out of the philosophy of Chapter 766.*



ty to academically able students.

In view of all this, the Huron Institute concluded, it was 'remarkable' to see what had happened by 1981. The growth in special education provision had been greater at secondary level than any other; the number of students aged 14-18 almost tripled in the first five years of the act. Resource rooms were a common provision; some districts had transitional programmes for students with severe intellectual handicaps; many schools had introduced new occupational education programmes; 'alternative' high school programmes which worked in new ways were making academic achievement possible for many students for the first time.

But there was, the study concluded, still a lot to be done. There were still quite some gaps in services. In addition, some of the provision segregated students who had, while younger, been in more integrated settings. There was a danger that 'alternative' high school programmes could become dumping grounds for all the students with problems of behaviour. Regional vocational schools (part of the regular system and roughly analogous to technical colleges) tended to exclude special education students, because of the limits of their programmes or issues of safety or transport problems — even though many school districts tried to rely on these schools because they had no special provision of this sort of their own.

By 1985, there were still some shortcomings in providing for older students with special needs. They still tended to be in more segregated settings than younger ones. The 'collaborative' programmes — set up for students with 'low incidence' handicaps by several school districts working together — could sometimes be quite self-contained and have the added 'special' disadvantage of drawing from a wider than local catchment area, however rational a solution they might be for the special needs of the young people they served.

Nevertheless, by then, some 2,500 young people aged between 19 and 22, those whose needs were most intense, were continuing to receive education, and very many of these were in mainstream settings. Collaboratives were very often in regular high schools; many students were receiving vocational training through part-time placements in jobs; not far short of a fifth of the students in the 26 regional technical schools were defined as having special educational needs. By then, too, the courts had played their part in assuring this continued education for those students who needed it. In the 1984 case of *Stock vs. Massachusetts Hospital School* it was ruled that the school had been wrong to graduate a young man who was mentally retarded, because it only did so so that it could stop being responsible for his education; the court ordered that he should have three years' compensatory education.

Already by 1984, the Massachusetts Association for Retarded Citizens (MARC) was wondering what would happen next for young people whose special needs were most intense. As they left the education system, many needed one or more of the social services provided under the umbrella of the Office of Human Services. But there was no guarantee that they would get an appropriate programme. The problem of transition was — and remains — compounded by the fact that Chapter 766 has outlawed labelling by type of handicap, whereas adult human services are very much categorised for specific disability groups.

So MARC started campaigning for transitional arrangements. And in October 1984, Chapter 688, the 'Turning 22' law, came into effect.

This law provides a single point of entry for severely disabled young adults from education into the human service system, through an Individual Transition Plan (ITP). Anyone is eligible who is receiving special education services and graduating or turning 22 years of age on or after March 22 1984; in need of continuing services; and unable to work 20 or more hours a week in competitive, non-sheltered employment. Those who receive disability pensions or are officially registered as blind qualify automatically. The eligibility of others is assessed through a review of the records and/or personal interview and assessment, by a new unit at the Massachusetts Rehabilitation Commission.

The responsibility for invoking the process is that of the local school districts. Two years before the young person is due to finish their education, the Chapter 766 evaluation team should forward their case to the appropriate human services agency. That agency — and there are 14 of them in the Office of Human Services, covering corrections as well as services to people with different handicaps — then becomes responsible for establishing eligibility and developing the Individual Transition Plan. Those plans stay in effect until they are replaced by an adult service plan. The whole process is closely monitored by the new Bureau of Transitional Planning at the Executive Office of Human Services, whose field director, Mary Lou Maloney, was formerly director of MARC.

By May 1985, when Chapter 688 had been in force for some seven months, she and her team of two were already monitoring 1,000 plans. She was expecting 1,800 in the first full year of the law, and about 700 a year thereafter. She was also expecting five more members of staff, so that the Bureau can strengthen the other sides of its work that have already vigourously begun: the training of parents, teachers, human services agencies and schools in the act's provisions and the gathering of data on which future service planning can be based.

According to Mary Lou Maloney, the education people are very pleased about the act and the human services agencies less than thrilled at the prospect of having to plan in coherent detail and have the implementation monitored. Parents are either hopeful or resigned to the prospects of fine promises but lack of cash to fulfill them.

The act has, however, brought new state money into the human service system, to the tune of $4m, to boost existing provision by purchase of services or development of new programme models. Included in this sum is a special 'crisis' budget of $375,000 for people who are not adequately served and need a service very quickly.

In addition, the new act offers a mechanism for far more coherent future planning of services. The details of each ITP — which covers day-time, residential and other needs and enters both what the customer ideally should have and what they're actually going to get in the real world — go into the computer. This way, Mary Lou Maloney hopes, her Bureau will build up a detailed picture of the gap between needs and provisions on which future planning can be based. Already there is a study in hand to gather more information about 'low incidence' handicaps.

One built-in shortcoming of Chapter 688 is that it covers only the services provided by the agencies that come under the umbrella of human services. Very many people, for instance, will need supported housing of different kinds as they get into their adulthood, but the Office of Community Affairs, which is responsible for the state's low-cost housing programmes, is not under that umbrella. Moving into other agencies that could help the people covered by Chapter 688 is, Mary Lou Maloney says, the next priority. For now, the task is to implement the act's provisions — and work on new community programme models for people who have historically been served only by medical or penal institutions.

As others see us

By coincidence, Roger Brown, Massachusetts' Associate Commissioner for Special Education, was visiting schools in England at exactly the same time as Mark Vaughan and Ann Shearer were visiting Massachusetts.

How did he find our system?

'We are at least 15 years ahead of you. After my visit here, I'm even more convinced that mainstreaming as a philosophy works very, very well. Most children who are in special schools in England would be in our regular public schools — either in special classes for up to 60 per cent of their time and regular classes for the rest, or in full-time special classes. For instance, I went to a school here for the 'moderately retarded'; there was not a single one who in Massachusetts would not be in one or other of these placements.

'Categorisation of students is a problem in England. In Massachusetts, bright physically handicapped children would be in a regular class for all but 25 per cent of their time, with special education outside it for the rest. Hearing or visually impaired children could, with an interpreter or other help, be in the same setting, or at least in the regular class for 40 per cent of their time.

'There seems to be very little going on for special students in regular secondary schools here in England — in fact, nothing at all. It was disheartening to me to speak to a young man who had been in the same special school for 13 years. Efforts in further education seem hardly to be beginning. In Massachusetts, education for young people with special needs is mandated up till the age of 22.

'As I've read, the 1981 Education Act is an excellent act. But it's not being implemented. There are some dedicated and under-resourced teachers. But I question whether even the will to implement the act is there. Parent involvement needs a lot of improvement. There's a need for training for teachers . . . There's a need for a change in attitudes.'

The future: Pointers for special education in Britain

The United States is not Britain and Massachusetts is not an English county. But despite all the differences in the history of special education in the two countries and in the laws and customs as well, the Massachusetts experience of reform over the past decade offers some clear lessons for Britain — for schools, education authorities and parents.

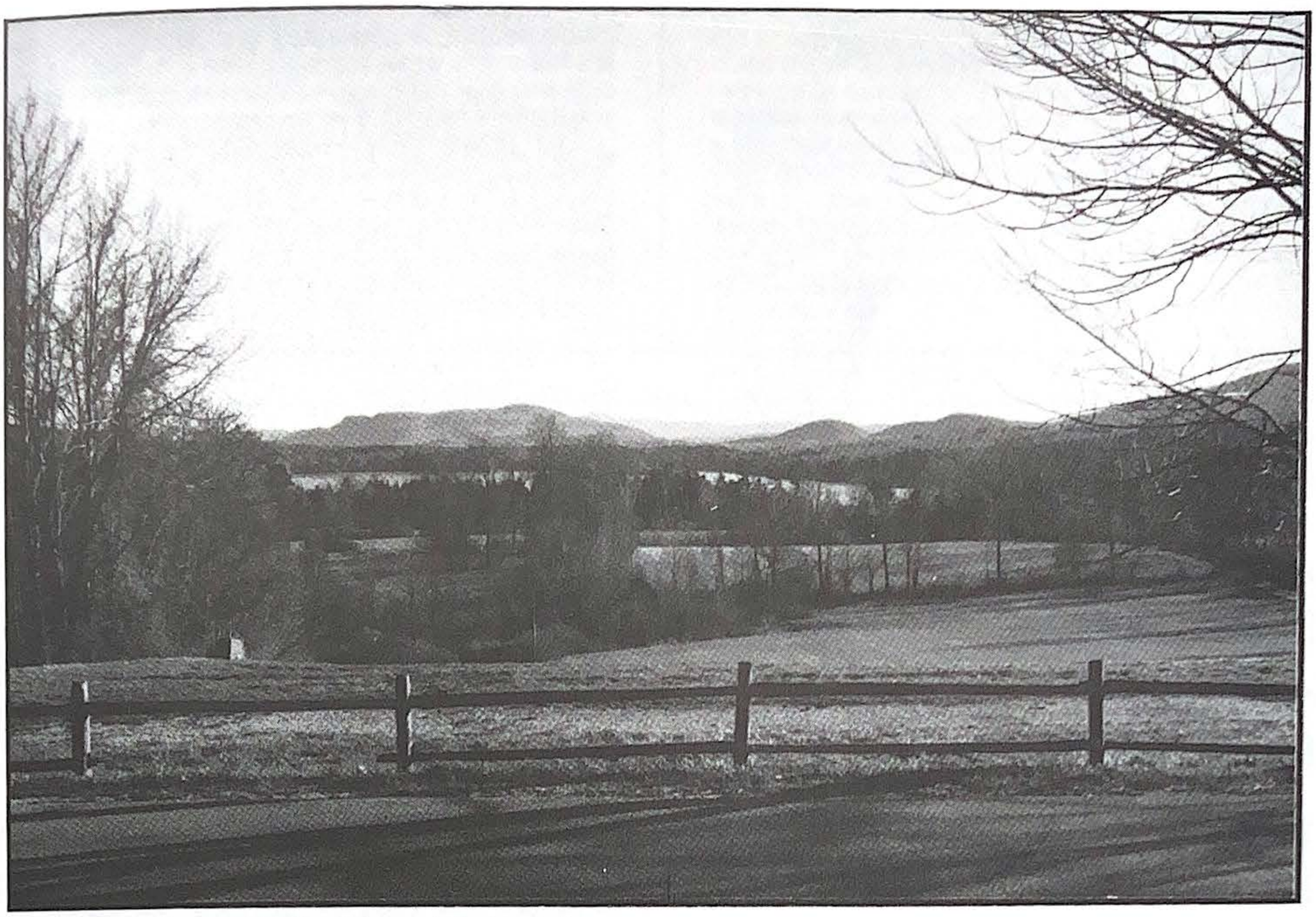
The most important of these has to do with commitment. All sorts of people in all sorts of places in Massachusetts believe that children and young people with special educational needs have a right to participate as fully as possible in the mainstream of their local educational community — and so in the social life of the wider community as well. The belief has brought a raising of expectations — and that has had its positive results. If the Massachusetts experience shows anything, it shows what can be achieved if the commitment is there.

This commitment is enshrined in law: Chapter 766 clearly requires that all students with special educational needs have access to a free public education within the least restrictive environment, appropriate to each individual. But at least as importantly, the commitment has been worked for and reinforced and refined by very many people and interest groups. A solid majority of teachers and others professionally involved in the business of education support it — and their own professional organisations have played their important part in creating and reinforcing that support. Lawyers and advocates have used the courts to refine the law's intent and expression in practical administrative detail — and more widely, the appeals system has been used to generate continuing reform. Perhaps most importantly of all, parents have been educated in the promise and potential of the law, so raising their own expectations for their children and for themselves as essential contributors to the educational process.

So the commitment is shared by very many people at very many levels — and the results of that are striking. For a start, the special education system in Massachusetts has been radically reformed within the relatively short space of a decade. Difficulties and shortcomings of course remain. But so does the fact that very many children and young people with special educational needs are having those needs met within a far richer educational and social context than a segregated system can ever offer. What the Massachusetts experiences shows is that if the commitment is there and expectations are consciously raised — among parents, teachers, administrators and students themselves — then special education can grow out of its traditional segregative constraints.

This matters crucially to children and young people with special educational needs. But it matters too to all of a community's children. The experience in Massachusetts shows that by reforming 'special' education, education itself is reformed.

This has important practical aspects: an emerging lesson from Massachusetts is that a successfully integrated special education system depends fundamentally on a strong and cherished *general* education system. But this interdependence is not just an organisational one. Young people in Massachusetts — whether they are defined as having special needs or not — are increasingly living a new sort of educational experience together. They are not just being schooled in a traditional sense. They are being offered an education in a new concept of community which is enriched by the variety of gifts and abilities of its members rather than impoverished by the exclusion of some.



• Massachusetts is not an English county but . . .' above — the Berkshire Hills in the western part of the State and below, the city of Boston.

How can young people in England and Wales be offered the same sort of education?

- We need far stronger public promotion of the philosophical ideals that underlie efforts to reduce the segregation of people with handicaps — in schools, colleges and beyond. This should begin with the Secretary of State for Education and Science and involve parent and citizen groups as well.

- We need handicap awareness programmes in regular schools as part of the ordinary curriculum. As in Massachusetts, parents themselves could be involved in these. So, importantly, could organisations *of* people with different disabilities.

- We need local education authorities and schools which give far better quality information and support to parents and parent groups on the 1981 Education Act's provisions and procedures, as well as on different placement options and teaching techniques.

- We need far more local parent support groups which offer information, training and back-up materials for families who have a child with special educational needs.

- We need far more flexibility in the regular schools' structure and curriculum — not only to enable a welcome for hitherto excluded groups of children, but also to allow more options for 'ordinary' children, like the learning of sign language.

- We need amendments to the 1981 Act's procedures, including the introduction of team meetings to discuss the most appropriate provision for a student with special educational needs. These should involve staff, parents and older children themselves *before* major decisions are put into draft statements.

- Local education authorities should develop mediation, rather than involving the formal appeals machinery, in cases of dispute between parents and the LEA.

Parents of young people with special educational needs — and those young people themselves — have in Massachusetts a far higher status than they do in Britain. Increasingly, they have an awareness that they, like any other

citizens, have rights. And increasingly, others have that awareness too. 'Mainstreaming' is not just an educational aspiration; it is an expression of the fuller opportunities that people are growing to believe should be offered to anyone with a disability; it is a mark of changing expectations about the place of people with disabilities in their society.

And one of the most important ways in which that can happen is to build change into the school system. In Massachusetts, it is often children who are teaching their parents about a new way of being, a new sort of social pattern that doesn't exclude people because they are 'different'. These students will grow up with a new 'normality' — one which accepts rather than rejects the variety of human ability and experience.

That is why the Massachusetts educational system is important — not just to those directly involved in it, but to us all. That is why the 1981 Education Act in this country is such an important lever for educational and social change. And that is why it is so important that we continue to work to make the most of its opportunities.

Useful addresses

The Association for Persons with Severe Handicaps (TASH), 7010 Roosevelt Way NE, Seattle, Washington 98115. Tel (206) 523.8446.

Council for Exceptional Children, 1920 Association Drive, Reston, Virginia 22091. Tel (703) 620.3660.

Federation for Children with Special Needs, 312, Stuart Street, 2nd Floor, Boston, Mass. 02116. Tel (617) 482.2915.

Massachusetts Advocacy Center, 76 Summer Street, Boston, Mass. 02110. Tel (617) 357.8431.

Massachusetts Association for Retarded Citizens (MARC), 217 South Street, Waltham, Massachusetts 02154. Tel (617) 891.6270.

Massachusetts State Department of Education, 1385 Hancock Street, Quinzey, Mass., 02169. Tel (617) 770.7500.

Massachusetts Teachers Association, 20 Ashburton Palace, Boston 02108. Tel (617) 742.7950.

Office of Human Services, 1 Ashburton Palace, Room 1109, Boston 02108. Tel (617) 727.8065.

Office of Special Education and Rehabilitation, US Department of Education, Assistant Secretary Medeleine Will, 400 Maryland Avenue SW, Switzer Building, Room 3627, Washington DC 20202. Tel (202) 245.3192.

Research Institute for Educational Problems, 29 Ware Street, Cambridge, Mass. 02138. Tel (617) 868.0360.

United States Department of Education, 400 Maryland Avenue SW, Washington DC, 20202. Tel (202) 245.3192.

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