PLANNING FOR THE 2040s: EVERYBODY’S BUSINESS

Peter Mittler*
Emeritus Professor of Special Needs Education, University of Manchester.

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What kind of a future do we want to see for a baby born with a significant disability today? What changes will be needed in society and in our schools both for the child and for the family? What reforms might this year’s newly qualified staff bring about in our schools and services and in society as a whole by the time they retire in the 2040s?

The time is ripe to take advantage of new international and national opportunities to lay the foundations for a society which fully includes disabled people and safeguards their basic human rights. Each one of us can help to determine the values and priorities of the society in which today’s baby will grow up. The Make Poverty History movement has provided powerful evidence that the voice of ordinary citizens can shape policies and set priorities.

THINKING GLOBALLY……..

In all countries of the world, disabled people live at the margins of society and experience a much poorer quality of life than their fellow citizens.

- During the 1990s, two million children were killed and six million were disabled as a result of armed conflict and many more lost their families or became homeless refugees
- People with disabilities account for one in five of the world’s poorest people – that is those who live on less than a dollar a day and lack access to basic necessities such as food, clean water, sanitation and clothing (Inclusion International 2006)
- Over 85 per cent of disabled children live in developing countries but only around two per cent of these attend any kind of school
• Tens of thousands of disabled children still spend their entire childhood in appalling institutions (UNICEF 2007).

Because disabled people experience discrimination in all countries, the last three decades have seen the growth of a powerful human rights movement. An increasing number of countries, including the UK, have introduced legislation not only to ban discrimination but also to ensure access to schools, to the work place, to leisure and recreational opportunities and to the whole range of society and its institutions. Our task now is to ensure that current and future legislation is fully implemented.

*United Nations Convention on the Rights of Persons with Disabilities*

It is against this background that we can celebrate the adoption of the United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006). This Convention is the outcome of five years of work by a UN Committee on which people with disabilities played a leading role on an equal basis with representatives of national governments. The outcome has been welcomed by the disability movement but many issues proved contentious, not least that of inclusive education.

The Convention has been signed by some 130 countries but does not become legally binding in international law until it has also been ratified. Every ratifying country will then have to submit regular reports on its progress in implementing the Convention to a new UN Committee on the Rights of Persons with Disabilities which will also consider representations from organisations of disabled people. Its conclusions and recommendations will be published and available on the internet.

A Convention was needed because disabled people have time and again been overlooked in both international and national initiatives aimed at wider populations. For example, although the 1989 Convention on the Rights of the Child included an Article specifically focusing on the rights of children with disabilities, nearly all countries fell short of the relatively modest requirements of that article, many of them to a major degree (Committee on Rights of the Child 2006; UNICEF 2007). Similarly, the most recent review of progress towards the Education for All targets first set in 1990 barely mentions children
with disabilities, despite their explicit inclusion in the original objectives (UNESCO 2006).

The Convention is timely because it coincides with the UN Millennium Development Goals for 2015 (United Nations 2000). These include measurable targets for the achievement of universal primary education, the eradication of extreme poverty and hunger, reduction in child mortality and improvements in maternal health and the promotion of gender equality. Although some progress is being made, disability advocates have pointed out that none of these goals can be reached (particularly those relating to poverty and education) if disabled people are not explicitly included in the implementation programmes (Inclusion International 2006).

The Convention thus provides a unique opportunity for each country to make a fresh start in removing obstacles to the participation of disabled people in the life of their local community. Whether this happens depends on the strength of the popular demand for action. This in turn depends on people at the grass roots knowing about the Convention and putting pressure on their government to take it seriously. The disability movement cannot do this alone.

..........ACTING LOCALLY

In the United Kingdom, a major national review of policy and provision for disabled people and their families has been taking place and is now gathering momentum. Recent landmarks include:

- Disability Discrimination Act 1995
- Special Educational Needs and Disability Act 2001
- Every Child Matters (HM Government 2004)
- Removing Barriers to Achievement (DfES 2004)
- Improving the Life Chances of Disabled People (Prime Minister’s Strategy Unit 2005)
The last of these is particularly important, as it reflects a new determination on the part of the government as a whole to respond to profound dissatisfaction with current provision articulated at every level.

What matters now is the extent to which good advice and recommendations from the centre are going to be implemented at local level. Evidence on local implementation of legislation over the last ten years suggests that much depends on where you live. Where human rights are concerned, this is not acceptable.

Change at local level is more likely if there is evidence of local commitment from the community, including disabled people, families and professional groups in schools and across the whole range of services – especially if they join forces locally and nationally. The time for change is now.

AGENDA FOR REFORM

FAMILY POVERTY

Families with a disabled child are much poorer in every country. Here, eight out of ten families are reported to be “at breaking point”, with 55 per cent living in poverty and one out of seven families in debt, often amounting to sums over £10,000 (Council for Disabled Children 2006).

Although 85 per cent of mothers would like to work, only 16 per cent are able to do so, mainly because they lack access to adequate child care. Basic household expenses and child care costs are three times higher for families caring for a disabled child. Current family tax credits and other benefits are not only inadequate but systemically flawed for these families.

FAMILY SUPPORT

The Every Disabled Child Matters campaign (Council for Disabled Children 2006) revealed deeply disquieting evidence of the extent of parental dissatisfaction with support provided by Social Services Departments. For example, SSDs support only one in 13 families and are rated as poor by four out of five of them. Access to child care and to short breaks are top priorities for families but available
to very few. Many SSDs do not have accurate information on how many disabled children are living in their area or how many families are caring for a disabled relative over 70. There is little support for families in planning for the future.

In response to these criticisms, Aiming High for Disabled Children: Better Support for Families (Treasury and DfES 2007) commits £340 million of targeted expenditure over the next three years, including £280 million to increase the provision of short breaks for families and £35 million to improve access to appropriate child care. There are new proposals for ensuring that parents are given more information about entitlements and better opportunities for participation in assessment and decision making, as well clear monitoring and accountability procedures which should make it possible to compare national plans with local realities.

The Every Child Matters agenda (HM Government 2004) provides ample opportunities to address concerns expressed by parents and its website now makes explicit reference to the agenda set by Aiming High and other government initiatives.

REFORMING THE SPECIAL NEEDS FRAMEWORK

After the 80 per cent no confidence vote in social services, the finding that a mere 52 per cent of parents are dissatisfied with education may be a comfort to some but still seems alarmingly high.

Concerns expressed by parents have found expression in recent reports from the House of Commons Select Committee on Education and an all party group on services for disabled children (House of Commons 2006a, 2006b). The Select Committee described current SEN policy as “not fit for purpose” and called for a major review of the whole framework of provision, including statementing and resource allocation. The Children’s Commissioner for England has characterised the plight of disabled children and their families as a “nothing short of a national scandal.”

Parents’ complaints to the Select Committee highlighted:

• frustrations over the process and outcomes of statements
• children not receiving promised provision
• six times higher than average rate of exclusion from school
• lack of information about the child’s progress and ways in which parents and teachers can work more closely together
• poor provision for families from black and ethnic minorities
• transition from school

The special needs system is riddled with inequalities. Rightly or wrongly, resources go to children whose parents are prepared to fight for them rather than to those who lack the time, energy, motivation and money. Unlike children with specific learning difficulties or autistic spectrum disorders, the 172,000 children with moderate learning difficulties and the 135,000 with behaviour, social and emotional difficulties lack powerful advocates to lobby on their behalf. Debates in parliament reflect these disparities.

Although a great deal more money has been made available for special needs education, the funding system itself is deeply flawed. For example, is it fair to expect local authorities to pay for placements in residential special schools when these can cost up to £250,000 a year, inevitably at the expense of many other local children? Why can we not create a national or regional fund for such placements, on which Local Authorities could draw?

The response of education ministers to calls for fundamental reforms of the special needs system seems extraordinarily complacent, in strong contrast to the new momentum of change in children’s services generally (DfES 2006a). Despite what seemed like a fresh approach in the first few years of New Labour, special needs seems once again to be languishing in a backwater where ministers seem unable or unwilling to respond to demands for new thinking in a system that has become moribund and inequitable.

Special Schools

The government has also been criticised for failure to give clearer guidance on the future role of special schools or to ask questions about the huge local variations in the percentage of children attending special schools which are greater than in other European countries (Norwich and Gray 2006; Russell 2006).

On the one hand, Ofsted provide evidence of the high quality of work in special schools. 20 per cent are rated as outstanding and less than one per cent as inadequate. Only nursery schools
receive higher ratings. On the other hand, 28 out of every 100 children with severe and profound learning difficulties now go to ordinary schools (DfES 2006b). According to Ofsted (2006),

“Pupils with the most severe and complex needs were able to make outstanding progress in all types of settings….effective provision was distributed equally in mainstream and special schools visited but there was more good or outstanding provision in mainstream schools with additional resourced units than elsewhere” (p.63).

So why do hardly any children ever transfer from special to mainstream schools (Fletcher-Campbell and Kington 2001; Mittler 2004)? How often is the possibility of a planned transfer to the child's local school even considered? Are all the children thought to be too severely impaired and do all parents reject the possibility of a supported mainstream placement? How many parents would opt for a mainstream placement if they could be sure that their child's educational and non-educational needs could continue to be met? Will the new specialist schools who will act as ‘trailblazers in forging links with mainstream schools’ be assessed by their success in relocating their own pupils to neighbourhood schools? Such questions are ignored in government policy statements and in Ofsted reports.

TRANSITION FROM SCHOOL

Turning to the specific needs of disabled school leavers, we have to ask why, after 40 years of broad consensus on what needs to be done, arrangements for transition can still be described as a Black Hole? (House of Commons 2006b)

Young people and parents continue to complain that the services and supports which they received during childhood simply disappear once they leave school. Individual needs and entitlements identified in statements are no longer valid. Neither young people nor their families are properly consulted about their needs and priorities. Placement decisions tend to be short term and there is little evidence of long term planning for independent or supported living or employment (Hudson 2006; Mittler 2007).

The reality for most young people with intellectual impairments is that they spend a few years attending a variety of courses in
Colleges of Further Education or Day Centres but that there is then no further provision for them. The majority continue to live with their ageing families and very few enter supported or open employment (Aston, Dewson, Loukas & Dyson 2005).

Legislation which has been in place for 20 years but not implemented calls for joint planning beginning at 14 between education, social, health and employment services, with the full participation of the young people and their families. But recent research suggests that a fifth of young people with intellectual impairments leave school without any kind of transition plan (Fyson and Ward 2004) and that schools have found it difficult to persuade representatives of other agencies to participate in school leaving reviews. Local Partnership Boards set up in the wake of Valuing People (Department of Health 2001) are supposed to include a ‘transition champion’ but have largely failed to involve education, employment or housing or succeeded in planning the kind of seamless co-ordinated transition arrangements envisaged in numerous official reports and committees of enquiry.

In response to universal criticism, £19 million has now been allocated within the new Aiming High for Disabled Children programme specifically to improve the transition experience for young disabled people (Treasury and DfES 2007), together with clear quality standards and targets to improve on current practice and provision in all parts of the country (DCSF 2007). Whether this initiative will be more effective than its many predecessors depends to a large extent on local vigilance and advocacy.

A BETTER QUALITY OF LIFE FOR ADULTS

So what are the prospects for today’s school leavers and young adults compared to those of their predecessors in the 1970s? What kind of a future do they face by the time they themselves reach retirement age?

Despite vast improvements in services, the quality of life of disabled adults and their families remains far below that of the rest of the population. Poverty, unemployment, poor health and housing, discrimination and exclusion continue to be everyday experiences. As a society, we start from a very low baseline in enabling disabled people to enjoy basic human rights.
In 2001, a bold blueprint for the future of people with intellectual disabilities was published by the Department of Health. *Valuing People* is based on four principles: Rights, Independence, Choice and Inclusion. People with intellectual impairments were full members of the working party which drew up the proposals and play a key role in monitoring implementation and outcomes (Department of Health 2001).

In 2005, the Valuing People Support Team published an interim report in non-bureaucratic language on the impact of the White Paper, drawing on evidence from families, service users and service providers, as well as official data. The report is summarised as follows:

- “People are being listened to more
- Person-centred planning, done properly, makes a difference in people’s lives
- The Supporting People programme has helped many more people to live independently
- Direct payments are helping to change people’s lives
- Organisations are working together better at local level”.

However, the report stresses that there is still a long way to go.

“Change has not happened as well in some places and on some issues – so things are not going better for everyone…big change is only happening where people wanted it to happen….in some other places little has changed. Put bluntly, too many people in public services see *Valuing People* as optional - something they can get away with not doing” (DH 2005, p.6).

In particular, the report highlights disappointing progress in:
- transition from school into adult services
- getting people into employment
- exclusion of people with complex needs
- lack of recognition of the needs of black and ethnic minority families
- neglect of older carers
- lack of access to short term care.

It seems that although *Valuing People* has undoubtedly benefited many individuals and families, its impact over the country has been
uneven, to say the least and has depended to a large extent on the commitment of local agencies. This needs to change.

TACKLING INEQUALITIES

Inequalities affecting people with special needs and disabilities are merely one element of much deeper and more pervasive inequalities in our education system and in society as a whole. In particular, links between poverty and educational under-achievement, as between poverty and disability, have proved stubbornly resistant to intervention, as the government is now belatedly recognising,

A recent report from the Centre for Equity in Education at Manchester University has concluded:

“When New Labour came to power in 1997, it evidently felt that it had the means at its disposal to create an educational system that at the same time was able to deliver high standards and equity. Our contention is that as far as equity is concerned, the programme has failed to deliver” (Ainscow and Dyson 2007, p.32).

A wider equity perspective is reflected in an influential report from the Fabian Society Commission on Life Chances and Child Poverty (Fabian Society 2006). This summarises a wealth of evidence on ways in which poverty undermines life chances in education, employment, health and housing and makes a series of proposals designed to narrow the inequality gap between different sections of our society. The report’s educational proposals include:

• targets to reduce gross inequalities in health and employment should be extended to education;
• admission policies should be reviewed to limit segregation by socio-economic background;
• the school audit and inspection systems should develop a clearer focus on narrowing inequalities.

Several ministers in the Brown government have expressed support for these proposals and a new Fabian Society study group is now focusing on education.
Proposals for educational reform have to move beyond the obsessive focus on standards, tests and examinations and begin to address the wider social and personal needs of those who have been failed by the system. There are signs that the government is beginning to recognise this.

The *Every Child Matters* agenda already envisages schools working much more closely with other agencies and local organisations but this does not take us very far beyond what happens already in some areas. In an integrated and inclusive children’s service, schools would become the focal point for support and services for all children and their families in the neighbourhood. The extended schools programme is a big step forward but there is still a lot to do before the local school is at the heart of all services for local children.

Every secondary school should contain at least one teacher with advanced qualifications in personal counselling. Ideally, schools should enable several staff to attend courses which would support them in using at least basic counselling skills but such courses are hard to find and not generally considered a priority.

In addition, every school should have access to a named social worker. The area social work team working with children and young people could be based in a secondary school and its members would be accessible on a contractual basis to all the primary schools in a defined area. This would help to break down attitudinal and administrative barriers and reflect the more unified service for children and families which is now accepted as necessary and which has been very successful in Early Years provision. Priority should be given to full time social work appointments to special schools and schools in areas of poverty and disadvantage but such appointments could gradually be extended to all schools.

The Fabian Society has also presented convincing arguments for all schools to have access to a nurse for at least one day a week, with a view to increasing access over a period of time (Bamfield 2007). School nurses have played a key role in being a first port of call for children and young people on a wide range of health matters and have made a major contribution to the prevention of teenage pregnancy in some countries. Why are there so few of them?
Bringing social workers and nurses into schools is in principle no different from the service agreements which have enabled other scarce professionals such as educational psychologists, physiotherapists and speech and language therapists and other health professionals to work in schools. Schools have successfully absorbed large numbers of learning support assistants. Is it not time to include social workers and nurses as members of a multi-disciplinary school team?

EVERY FAMILY MATTERS

Bringing families into closer partnership with schools is perhaps the biggest single challenge for reducing inequities in education. Despite general agreement with the principle of ‘working with parents’, the gulf between home and school remains uncomfortably wide and we need to find new ways of supporting teachers and parents to develop much closer working partnerships.

The government has produced a useful if modest starting point for discussion and school action, appropriately entitled Every Parent Matters (DfES 2007) but an agenda for the future needs to consider more radical departures from current practice. For example:

- Can we find ways and means to provide time for a teacher to visit the family of all children before they start school and ensure that such visits continue once a year, at least until the end of primary school?

- In the short term, can we return to the idea of home-school liaison teachers which was touted in the 1960s but has never taken off nationally?

- Can we increase the near-zero attention given to parents in the initial training and continuing professional development of teachers?

- Can we give much higher priority to preparation for parenthood in all secondary schools?

TRAINING AND PROFESSIONAL DEVELOPMENT
Plans for a better future must include a radically new approach to training and professional development. The new Children’s Workforce Development Council (2005) which has been set up to identify skill shortages and develop frameworks for training will need to ensure that disability awareness and relevant experience are built into all levels of training and that continuing professional development and opportunities for further specialised training are made available to all.

As a nation, we give very low priority to the training and professional development of people working in the field of human services. Too few staff who are paid to provide care or deliver services to disabled people receive appropriate training or continuing professional support. There are signs that this is beginning to change but progress is slow. What is needed is an end to tinkering and a new strategy which will provide fully funded professional development pathways to all levels of staff.

If disabled people are to enjoy a higher quality of life in the community, there needs to be a much higher level of disability-awareness on the part of people working across the whole range of generic services – e.g. child carers, social care assistants, social workers, general hospital staff, police and public service employees across the board.

Training is still largely delivered in single discipline boxes. At a time when staff are being asked to work across professional boundaries, what opportunities are there for joint training between teachers, social workers, psychologists, doctors, nurses and therapists? And how often do parents and disabled people themselves contribute to staff development programmes?

Even within education, training has always had low priority and lagged far behind policy and professional developments. The special needs element in the initial training of teachers first recommended in the Warnock report 30 years ago is very difficult to deliver and depends largely on the time available to the SENCO of the school in which the trainee is placed. Although the Teacher Development Agency’s Standards for the Award of Qualified Teacher Status now include relevant competencies and the courses are inspected by Ofsted, there is very little time to meet these requirements, especially during the 12 weeks which PGCE
students spend on campus. The TDA is now developing guidance materials and exemplars for newly qualified teachers, as well as an electronic portal for SEN and disability tutors (Teacher Development Agency 2006).

In contrast with other professions, continuing professional development is still not seen as a priority or as a requirement for practice or promotion. Individual teachers are expected to negotiate a development programme with their managers, in the light of what is available locally or through distance learning and often have to pay for it themselves. There are few opportunities to follow a coherent specialist programme or to study for an award-bearing course. It is a sad reflection on the low priority given to staff development that 14 years after the introduction of the SEN Code of Practice, the government and its agencies are only just beginning to think seriously about the training and accreditation needs of SENCOs.

**CONCLUSION: START NOW**

2008 could mark a historic turning point for disabled people and their families and for everyone with a personal or professional commitment to working for social justice and an end to discrimination. At the international level, the UN Convention on the Rights of Persons with Disabilities provides a clear framework for disabled people to attain the human rights which have previously been denied to them. This parallels our national review of policy and practice. The overarching goal in both cases is to ensure that disabled people of all ages have access to at least the same opportunities and life chances as are available to their fellow citizens.

Whether these opportunities are realised depends in large part on the interest and commitment of civil society, particularly national and local voluntary and professional organisations. Using the internet, such groups can keep a watching brief not only on what the government is proposing but on the nature and quality of what is – or is not- happening locally. This is important because the history of the last 40 years provides depressing evidence of an endemic post code lottery which results in unacceptably wide local variations in the implementation of legislation and policy initiatives.
Finally, any agenda for the future includes a special responsibility for teachers. Because it is disabled people themselves who have taken the lead in fighting for their rights, teachers have a distinctive role in working with parents to support young people in becoming the next generation of self-advocates by acquiring the confidence and skills to speak for themselves and to take their rightful place in planning for the future (Mittler 2001).

The self advocacy movement in Britain was launched in 1972 and is now part of a powerful world-wide federation of disabled persons. The fact that its leaders include people who were labelled ineducable and were certainly not thought capable of speaking for themselves or having an opinion of their own provides a humbling lesson on the dangers of under-estimation. 40 years ago, how many of us would have predicted that any young people with Down Syndrome would achieve good GCSEs after completing five years of mainstream secondary education, or that people with intellectual impairments would be running their own organisations or addressing the United Nations?

The self advocates who will be the change agents of the future are now in our schools. Given the opportunities, what might the next generation achieve?

REFERENCES


Children’s Workforce Development Council (2005) www.cwdcouncil.org.uk


Based on a talk given at Sunfield Professional Development Centre, Clent in November 2006 to commemorate the 35th anniversary of the 1971 Education Act which transferred responsibility for the education of children with severe learning difficulties from health to education authorities.