Including *All* our Children in Mainstream Schools and Communities

Realising the dream

Gerv Leyden and Andy Miller

Summary

For the parents of many pre-school children with significant special educational needs, choice of school represents a crucial crossroads for their child and for themselves. The path they choose (and many parents do not feel they have a real or realistic choice) will have significant and lifelong consequences.

This paper represents our attempts to place within an 'inclusive' context the struggles and difficulties faced by many parents as they try to make sense of often conflicting professional advice and pressures. In order to remain a major resource for their child, parents also need their own personal and community support networks.

Step I: realising the dream

The theme of our presentation to this conference[1] is inclusion. But our subtitle, 'Realising the dream', has two important components. Many people are surprised when we talk about dreaming and the truth behind the truism in the song 'Happy Talk' from *South Pacific*: that 'if you don't have a dream, how are you going to have a dream come true?' The dreamer, of course, may not achieve his or her dream. But the person with no dream has no star by which to navigate through life, no destination to reach, no dream to fulfil.

We all have dreams, acknowledged, *realised* or not. Dreams about our own future, fears and aspirations. Dreams about our family, and in particular the future happiness of our children and those we care about. Dreams that are about the hopes and aspirations which can be difficult to put into words. And so they are often dismissed as 'only' dreams, and not 'real' to the task of living our life and supporting those we love. Of course, if we do nothing about them, they will remain 'only' dreams. So we need to *realise* that our dreams may not be a distraction from life's purpose but, on the contrary, they may contain clues to help us discover what that true purpose is. And only then we can 'realise' our dream in the second sense of the word, of making something happen. Of *realising* it. As Judith Snow (1996) points out, 'sleep dies when you wake up, but the dream doesn't have to'.

For parents of children who are described as having special educational needs or disabilities, dreams and nightmares surround the short- and long-term future of their children. In some intuitive way parents know they want their children – with or without 'disabilities' – to grow up happily, to have friends, to learn, develop and thrive and to take their place as active, participating members of the community. Children are included from birth – they are born into the welcoming family and community. They play together in the same gardens and attend

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[1] This paper was delivered to the National Portage Conference (for parents and Portage workers), Northampton, 1997. It is offered to readers of *Educational Psychology in Practice*, not as an academic article but as a resource to support discussion and action.

the same playgroups when they are toddlers. But round about the age of four or five it is our attitudes and ways of organising education and allocating resources that will determine which children follow the path to learn, play and grow up with their friends, sisters and brothers at the local school, and which children will have those ties broken, and be educated separately.

For much of the last century in the UK, provision for children with disabilities or special needs was provided in segregated, specialist establishments. We have a historic legacy of charitable and philanthropic institutions which pioneered various forms of care, often residential. It was from this historical base that we later evolved our pattern of special schools for educating children with special needs. However, it is only in recent years, since the mid-1970s, that *all* children in this country with special needs and disabilities were entitled to any form of 'education' as opposed to 'care'. It is salutary to remember that many, if not most, of the adults with learning disabilities presently in our community received no formal education at all during their school age years.

In many other industrialised countries, including parts of Canada and the USA, not even 'care' was available for children with disabilities. Those unable to progress in their local school without support – always assuming support was available – could not rely on any other help over and above what their family could provide. And, lest we become complacent, relatively recently the very life of children with special needs or disabilities was under threat in many European countries.

In order to grasp the importance of meeting the needs of all children in mainstream schools and communities, it is helpful to think first about the impact of being *excluded*. When, in our workshops, we ask children, parents, teachers and psychologists how it feels to be excluded we receive remarkably similar comments. Terms such as 'lonely', 'invisible', 'not valued', 'life is not worth living', 'guilty', 'sad', 'angry', 'depressed' and 'rejected' reflect vividly distressing experiences.

When we ask people to describe how they would *act* in response to those feelings, they again have much in common. Children and adults describe how they would attention seek, break or steal things, cry, withdraw further from others, want to hurt others, destroy other people's possessions, starve themselves, or even take their own lives. Remember, this is *children* as well as adults who are saying these things to us.

The problem is that once we are excluded from a group and denied active participation, it is a desperate struggle to get back in. For many people with disabilities this is a lifetime struggle.
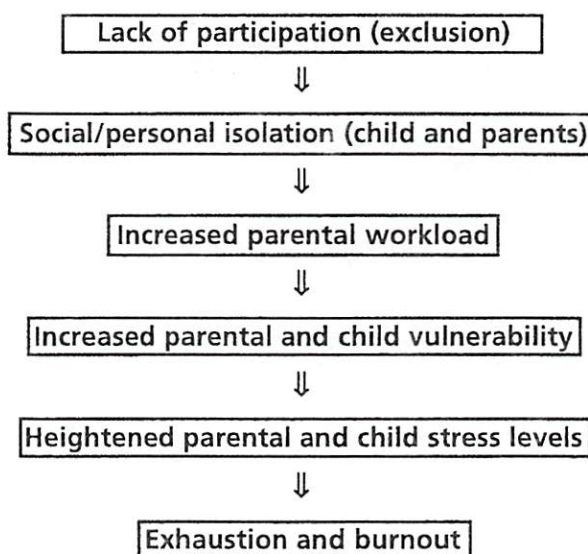
Step II: including yourself

There are no glib solutions we can offer parents who want a mainstream place for their children. In many areas of the country it is a long, hard struggle. If parenting is a lot of hard work, parenting a child with high level needs is a lot of additional hard work – on top of a lot of the existing hard work! Consider the extra work involved in bathing, dressing, playing with, stimulating and loving your child, shopping and putting to bed while juggling appointments with doctors, therapists, psychologists, education department officers, special educators and nursery staff. The list seems endless. So we are not surprised to meet parents who work harder and harder to fit it all in, at the expense of their own personal and social life. The paradox is that while 'you can't do it on your own', most of the time it seems as though you have to. The price is generally the loss of time with friends, social contacts, personal interests and activities – the very things that give us much of our identity and sense of self and purpose. There is a very real risk involved in severing our community links. Parents who become excluded risk the adverse consequences described in Figure 1.

Step III: avoiding stress and burnout

If we reach the levels of stress leading to exhaustion and burnout, we are in no condition to help ourselves,

Figure 1. Adverse consequences of exclusion

Lack of participation (exclusion)
⇓
Social/personal isolation (child and parents)
⇓
Increased parental workload
⇓
Increased parental and child vulnerability
⇓
Heightened parental and child stress levels
⇓
Exhaustion and burnout

never mind our child. What can we do to avoid burnout and keep ourselves and our family healthy? Professor Tom Cox (1978) at the University of Nottingham has researched and modelled stress as the mismatch between our perception of the amount and difficulty of the work we have to do, the mountains we have to climb, compared with our perception of the time, skills and resources we have with which to do it. Further, this mismatch is accompanied by those draining and troubling thoughts and feelings that stop us enjoying life and working at our normal levels of efficiency and calmness.

One of the most pernicious aspects of being stressed is the effect it has on our perceptions, thinking and planning. The tasks we have to do seem overwhelmingly complex and daunting, while our abilities and resources, in comparison, are pathetically inadequate. Most parents know what it feels like at times to be stretched to the limit (and beyond), but to the really stressed person, life seems impossible. Our own talents, strengths and supports appear to disappear at the moment we most need them.

Fortunately there are some clues from the research about what we need to put in our stress-busting toolkit to help us out of this negative spiral. In order to reach for it we need to recognise that when we are seeing the world through depressingly jaundiced eyes we must deal with those thoughts and feelings, *as well as* taking direct action to deal with the pressures and demands that were the source of the stress in the first place.

First of all, taking some *control* over the situation has a powerful effect on reversing that negative cycle. For those who have become isolated, this will involve *re-including yourself* on your own agenda. Add yourself to that list on the fridge door, or the back of an envelope of 'things you have do something about'. Create time in the day for yourself – this is not indulgence but survival for you and your child. Remember, if you want to strengthen your own resources you have to start with the most important one of all, *your* self.

Secondly, there is overwhelming evidence of the importance of social and family support and links with the community. Pick up the 'phone and revive those lapsed friendships that have been pushed out by exhaustion or the crammed daily family timetable. Parents can find themselves cut off from the neighbourhood community when their child does not attend the local school and the social connections it generates. Such events as music festivals, bonfire discos, Christmas plays, sports days, swimming galas and open days and 101 ways in which parents get together to celebrate (or endure) the school year.

A Sheffield family expressed their own experience in these terms:

'As a family with a disabled child, particularly if an only child, it is all too easy to lose your place in your local community. The local school is a focus of the community (unlike a centralised special school) and integration into that school opens the doors back into the community.' (NPS, 1997)

The Oxford Dictionary defines the verb 'to exclude' as 'to deny membership or participation to'. Sounds familiar? The lesson is that to 're-include' your child you need to start by 're-including' yourself.

If these local contacts are not available, use the networks you have, and build new ones. Perhaps use your Portage contacts and network other parents. If there are no support groups in your area, Portage or otherwise, why not organise one? The 'Circles Network' can help in the planning of support circles for parents, carers and adults as well as for children (see the list of useful contact addresses at the end of this article). Crucially, *re-include yourself* into the community. By including yourself, not only do you build your own strengths and make rewarding contacts, you also greatly increase your child's opportunities for making connections with other children and adults outside the immediate family – a further step to inclusion.

The third component of your personal 'anti-burnout kit' is a strategy to deal with the source of the *problem* you are facing or the focus of the *dream* you want to fulfil. If your dream is for your child to have an inclusive education, then it will not just happen. The dream also needs a *priority* place on your agenda. But don't forget you need *supports* and *allies* to keep it there. You seldom see professionals 'flying solo' to potentially difficult meetings, and parents need to learn that lesson. Do your homework in advance, but make sure you only attend case conferences with a supportive adult. Don't just stop there; in order to get things changed, especially in organisations, you need to identify and cultivate your allies. The National Union of Teachers (NUT) and the Association of Educational Psychologists (AEP) have both passed resolutions in support of the UNESCO Salamacar declaration on inclusive education. Write to them and ask what they are doing to implement it in your area. Allies can be found in some of the most unexpected places. Find and use them.

Above all, it is important not to underestimate the power of parents working together, not only to provide mutual support, but also in getting things

done. The literature in this country and abroad emphasises the importance of leadership in creating inclusive schools and services. Leadership is not the sole prerogative of heads of services, schools or organisations. Community leadership – by parents or adults with disabilities – can exert a profound influence on LEAs, schools and other agencies. This influence can be expressed through meetings with officers, councillors and committees, and through educating the local media about what parents want for their children, and all people with disabilities within the local authority. Newham provides a remarkable example of how a parent's fight for her child to have a mainstream education transformed the attitudes, provision and rights for all children with special needs in that authority.

'Never doubt that a small group of thoughtful, committed citizens can change the world: indeed, it's the only thing that ever does.' (Margaret Mead in Pearpoint, O'Brien and Forest, 1995)

Step IV: learning about inclusive education

Parents are learning more and more about inclusive education – and providing the information and impetus to challenge the more stereotyped views of some professionals. Organisations such as the Alliance for Inclusive Education provide training, support and advocacy on behalf of children and parents, while the Bristol-based Centre for Studies on Inclusive Education (CSIE) sponsors and disseminates a wide range of research and information on inclusion and the performance of LEAs. Jack Pearpoint and Marsha Forest from the Centre for Inclusive Education and Community in Toronto have also run conferences and workshops on inclusion and inclusive tools in a number of UK venues, including working with us at the University of Nottingham. There are increasing opportunities for parents, professionals and LEA officers to learn about the 'why' and 'how' of inclusion.

What are the values that underpin an inclusive school or community? The basic, core value is simple. All children are included. No ifs or buts. In the words of one special services administrator in Ontario, there are only two criteria for admission to our 'regular' schools:

'the child needs to be aged six ... and breathing. Any parent, no matter the degree of difficulties faced or experienced by their child, can knock on the door of their local school and expect to be welcomed.'

Diversity enriches, exclusion diminishes.
Parents know the importance of their child's earliest experiences, especially schooling. The nursery and early years are the best time for children with disabilities or special needs to learn in mainstream settings, and the best time for schools and nurseries to learn how to meet their needs. So why are there so many barriers in the way of parents in the UK who want a mainstream place for their child with a disability? The simple answer is that many educators, LEA officers, teachers and psychologists do not recognise the value of inclusive education, or genuinely believe 'it's not possible, not desirable' or 'it wouldn't work here' (perhaps one of the most frequent objections we encounter).

Well, perhaps it is impossible. But impossible glimmers are coming to light in LEAs across the country, in Warwickshire, Leeds, Newham, Bradford, Somerset and Oxford, to name but a few. And an increasing number of individual schools are learning how to include children – children who not so long ago would have been in segregated settings. (The CSIE has recently produced an audiotape of interviews with children, classmates, parents and teachers describing how schools have achieved this, and the benefits for all involved.) Some LEAs are beginning to recognise the benefits of inclusive provision.

Nottinghamshire LEA has devised an ingenious system of resource allocation which avoids the need for time-consuming, unwieldy, often bureaucratic (and costly) statements and devolves special needs budgets and support allocation to the level of local school clusters. The substantial financial savings are redirected to create *further* resources for the support of *more* pupils in mainstream schools (See Gray, 1992).

Meanwhile, Newham has systematically, year by year, included more and more of its children in mainstream settings, with the target of making this possible for all children in the early years of the Millennium. Inclusion *is* possible – but it takes planning and hard work. And again, hard work on top of existing hard work.

Another objection often raised, and sometimes by parents who do not have a child with a disability or special need, is that inclusion adversely effects the learning of the rest of the children. This is a difficult area into which to carry out research, but the evidence is starting to harden. For instance, the National Association for the Education of Young Children (in the USA) reports that children in inclusive classrooms:

- demonstrate increased acceptance and appreciation of diversity
- develop better communication and social skills (see UK research with primary aged pupils by Lewis (1996))
- show greater development in moral and ethical principles
- create warm and caring friendships
- demonstrate increased self esteem.

Properly planned, inclusive arrangements do benefit *all* children.

While inclusive education may not be easy to achieve, it is simple to describe. It is a system where all children are valued and included, their gifts, contributions and shared humanity equally recognised. This often requires a shift of perspective for professionals, including educational psychologists like ourselves, who need to put on a different pair of lenses and see the child through the eyes of someone who loves him or her really well. Inclusive education is good education – for *all* children. This is what 'inclusive' means. It is about a healthy learning and growing environment, where diversity means richness and variety, not disintegration, and where differences are valued, not feared. In fact, inclusive education is about creating a school that is a learning organisation for children and adults. And a school which sets out to learn how to include all children strengthens the capacity of its teachers, pupils and parents, to problem-solve and exercise their creativity and humanity. (See Miller (1996) for an account of the benefits of joint teacher/parent problem-solving in respect of children with highly challenging behaviour.)

If we get this right, there are profound benefits for all children. One 18 year old, Claire, described what she had learned through tutoring Benny, an 11-year-old boy with Down's syndrome:

'I've learned that he doesn't speak very clearly, so I have to listen harder. But when I do listen, what he says makes sense. And sometimes you have to listen behind the words. For instance, this morning he asked for a glass of water. I got him one, but I don't think he was thirsty, I think he was bored. And I've learned that sometimes he finds it hard to learn, and then I have to find out a different way to present it to him so he can crack it. That made me think about my own learning, especially in physics which I want to study at university. So now I try out different ways of learning the things I find especially hard, where previously I would have got stuck and felt bad about myself and my work.'

Who benefited most, Claire or Benny?

Well-documented and researched tools such as peer tutoring, mentoring, buddy systems, peer mediation and counselling all contribute to an ethos where all are involved and all contribute. (See Leyden (1996) for research review on children as 'the hidden resource' in classrooms.)

Of course, adult supports and classroom resources are crucial. But they are only one part of the mosaic. If we really believe in the importance of community we need to start by involving the community in the life and education of children with disabilities – to write the peer group back into the special needs script, and the child with special needs back into the peer group. Such a step extends our understanding and use of supports. As one special needs co-ordinator explained: 'The more we have learned about including children with disabilities in our school, the fewer resources we need.' Inclusion is not a cheap option, but neither is segregation when we take all the financial, educational and social costs into account.

The theme of our presentation to this Portage Annual Conference has been the significant opportunities beginning to open up for parents of a child with a disability who want a mainstream educational and community experience. In the past, for most parents, this has been less of a dream and more of a fantasy. But, as we have seen, there are encouraging signs from individual schools and LEAs that progress *can* be made, and hopes that the new Green Paper on special needs will move us from a period of controversy and conflict into co-ordinated action. The contribution of parents at the present time is crucial if we are to effect change. Education is for the benefit of *all* our children, the local community and the greater society. Our own experience has taught us that most parents want a well-organised, welcoming and *inclusive* school for their child, but have been discouraged by the obstacles put in their way. The formerly remote dream is now eminently *realisable*. Whether it happens, and how quickly, will be influenced by parents affirming what they want for the children – *all* the children – they love and care for. We have heard rather much of the rhetoric of 'parental choice' in education over the past decade. Let's make it happen.

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Addresses

Alliance for Inclusive Education, Unit 2, Ground Floor, 79 South Lambeth Road, London, SW8 1RL.

Centre for Studies in Inclusive Education, 1 Redland Close, Elm Lane, Redland, Bristol, BS6 6UE.

Circles Network, Pamwell House, 160 Pennywell Road, Upper Easton, Bristol BS5 DTX.

Parents with Attitude, 44 Cowlishaw Road, Sheffield, S11 8XF.

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