

Segregation, inclusion and the transition to adulthood for students with a visual impairment

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Introduction

This article presents a summary of a case study in a Dutch special school for students with a visual impairment. The practitioners involved wanted to change and improve their work with the academically less able teenage students. The case study was part of a research project for obtaining a PhD¹:

The following topics are addressed:

- segregation and exclusion of students with a visual impairment;
- challenges their teachers faced in preparing them for adult life;
- dilemma’s mainstream schools in the Netherlands encounter when trying to become more inclusive;
- the international debate about the position and the status of people with disabilities, focusing on concepts like integration, inclusion, participation, citizenship and the medical and social model of disability.

The international debate on integration and inclusion

Integration and inclusion were the two concepts used in the 1980s and 1990s to discuss the enrolment of students with disabilities into mainstream schools and classrooms (Farrell, 2001b).

Integration originated in the 1980s and was used in education to indicate *where* the student was educated: not in a special school, but in the mainstream school (Rieser, 2001) and whether the provision was organised separately from peers or not (for example in special classes, in separate units or in the mainstream class). Initially the focus was on system reform, which implied that the learning and teaching in integrated settings received little attention at the time (Vislie, 2003). Identifying reasons for the success or failure of integration policies, Dyson and Millward (1997) found that countries which have focused on changing the mainstream education sector have been more successful in developing more integrated education, than countries which have tried to reform the special education sector.

¹ Schuman, H. (2009). *The Transition to Adulthood – A Shared Responsibility. The education of visually impaired teenagers with learning difficulties and their exclusion from mainstream schools*. Saarbrücken: VDM Verlag.

Integration did not explicitly address the quality of education students with *Special Educational Needs* (SEN) were entitled to receive (Feiler & Gibson, 1999; Farrell, 2001b). Due to this rather limited focus the concept of *integration* generally failed to challenge that in the end “disability is a social construction” (Barton, 2003, p.5). From this perspective integration therefore:

- continued to operate within the medical deficit paradigm, focusing on what people cannot do, based on concepts of normality and abnormality, rehabilitation, and special educational needs, developed by non-disabled people;
- sustained the image of disabled people as dependent, socially dysfunctional, unemployed, and relying on social benefits and medical and social service providers;
- defined difficulties and challenges as located in the individual, thus labelling disability as a medical problem and a personal tragedy;
- functioned as a system of gate keeping of resources and service provision, allocating funds based on the labels disabled people have received and the assessments of their individual needs by professionals;
- denied disabled people in general, and disabled children in particular, to speaking for themselves and to exercising choice and ownership; and
- supported a traditional way of training teachers based on failing to cope with the traditional curriculum and focusing on individual remedial teaching programmes (Swain, Finkelstein, French & Oliver, 1993)

Integration, therefore in the late 1980s was considered to be a matter of fitting individual students into existing and unchanging mainstream provisions, expecting them to *assimilate* (Thomas, Walker & Webb, 1998), thus implying that they were welcome only when they were prepared to play by the rules of the non-disabled majority. Basically such an approach denied them the opportunity to “take pride in themselves” for who they are and what they are. Such an approach fails to address the issue why “disability provokes such negative feelings among non-disabled people” (Morris, 1993, p.101). This resulted in “an un-adaptive, unfriendly and hostile set of material conditions and social relations that cumulatively contribute to the marginalisation, disempowerment and exclusion of disabled people” (Barton, 2003, p.7). Therefore in the UK a new paradigm, i.e. the *social model of disability* (Oliver, 1996), emerged, supported by an alternative concept for integration, referred to as *inclusion* (Dyson, 2001). Thus shifting the focus from changing the individual with a disability or impairment to changing a disabling environment (Brown, 2001) and striving to overcome the on-going focus on the so called individual deficits of disabled people (Barton, 2003).

Inclusive education from this perspective would demand of schools to engage critically with the transformation of the “deep structural barriers, including the social base of dominant definitions of ‘success’, ‘failure’ and ‘ability’” (Barton, 2003, p.12). This would involve “a political critique of

social values, priorities and the structures and institutions which they support” (Ibid.). It would also involve a public process of naming and celebrating differences and engaging with the identification of what it is we value about one another (Ibid.).

Although these scholars write from a UK perspective, their analyses seem rather universal to me. Social justice and equity are often viewed as outcomes of inclusive education. It seems unlikely, however, that the traditional school system, supported by current government initiatives which focus on marketing principles of cost-effectiveness, accountability and raising standards in narrowly defined areas of the curriculum, would be able to realise social justice and equality of opportunity for all in inclusive settings (Lloyd, 2000). The transformation of schools into inclusive and flexible learning environments seems to depend, ultimately, on the recognition that the difficulties of disabled people “do not arise primarily from their own bodies or minds but from the way society has treated them” (Shakespeare & Watson, 2001, p.548).

Although the reform of the mainstream school system therefore seems the decisive issue in the progression towards more inclusive education at a national level (Dyson & Millward, 1997; Farrell, 2001b), the real contest for more inclusive education seems to be at the level of schools and classrooms (Ibid.). However, in the UK for example, the current emphasis on conformity, improving results and league tables, and the lack of recognition among policy-makers of the inappropriateness of the curriculum for many young people at risk, for example because of social disadvantage, poverty and minority status, create and sustain SEN (Evans & Lunt, 2002), and probably exclusion.

It may be necessary to re-address and critically re-think the whole issue of *Special Educational Needs* itself because it may be that from an inclusive viewpoint the term “is no longer helpful, reflecting a ‘within child’ or medical model to guide planning” (Gerschell, 2003, p.104). The Index for Inclusion (CSIE, 2000) suggests the replacement of the concept of Special Educational Needs by the term ‘*barriers to learning and participation*’, which actually challenges the capacity of the school and its staff to decrease their impact on creating SEN and sustaining forms of exclusion. Such an approach seems to demand a more holistic view of students (Corbett, 2001), where strengths and preferences and opportunities for choice are the starting point for developing educational programmes for all within a whole school approach of valuing differences, and where “all students get a fair deal” (Gerschel, 2003, p.106).

The sheer existence of special schools in itself, like the one I was working at currently, thus is in direct conflict with the central idea of inclusion which recognises that people with disabilities are entitled to be part of the mainstream of life and that excluding them is an injustice (Corbett & Barton, 1992; Swain et al., 1993; Barnes, Mercer & Shakespeare, 1999; Barton, 2001).

It remains important therefore, to acknowledge that the vested interests of specialised institutes might, in themselves, interrupt the further development of more inclusive social and educational practices for children, teenagers and adults with a visual impairment. Special schools still admit students because mainstream schools tell parents that they cannot cope with the student’s special educational needs

anymore. We need to recognise that regular schools may use the sheer existence of a highly specialised provision for students with more complex and multiple difficulties as an excuse for referral of their more challenging students. The effect of such practices, however, may result, as seems the case in the UK, in “removing objectionable, unwanted students and thereby enabling the mainstream system to function more effectively” (Barton & Landman, 1993, p.42). Special schools then serves to perpetuate “an old tradition of releasing high-status regular education from ‘deviant’ and problematic students” (Emanuelsson, 2001, p.140) and pacify teacher opinion, both in special and mainstream schools, on the inclusion /exclusion issue, in favour of exclusion (Stangvik, 1997).

Politics, education, exclusion and inclusion

The discussion in many western countries so far seems to indicate that education itself has become increasingly a politicised and economised concept (Halsey, Lauder, Brown & Stuart Wells, 1997). The government of the UK for example tries to pair education with the perceived needs of a modern society and link explicitly economic success with educational performance (Wolf, 2002). They emphasise competition between schools and they stimulate schools to focus on public relations and a strong business sense of staff and management (Evans, 1996; Gunter, 2001; Wolf, 2002; Carr, 2003). Within this economic and political spectrum however, Giddens (1998, p.103) argues that inclusion should refer “in its broadest sense to citizenship, to the civil and political rights and obligations that all members of a society should have, not just formally, but as a reality of their lives. It also refers to opportunities and to involvement in public space”.

Hughes (2001, p.32), however, focuses on challenging aspects connected to the concept of citizenship and suggests that when “wealth and independence – qualities inimical to the experience of disability in modernity – are the essential qualifications for any claim to citizenship”, the concept may serve to perpetuate the exclusion of disabled from the public domain. Students, in particular those who are at risk of being marginalised, may be subjected to educational practices in our schools which reflect the hierarchy in society: the ‘liberal education’ of the ‘thinking classes’, the utilitarian training of some of the rest, and those who would be left to pick up whatever knowledge and skills they needed in the course of being employed (Edwards, 1997, p.x).

To overcome the risk of providing our students with an impoverished curriculum, focusing solely on their employability, we considered self-empowerment and self-direction to be indispensable for achieving equality of opportunity and citizenship in society (Rioux, 2001). The challenge of developing an empowering curriculum for these students, however, seemed at least contentious and problematic. It forced us to rethink questions like: What do we want our students to learn? What do they need to learn? What do *they* want to learn? How do we come to know?

The debate in the Netherlands

In this section I will briefly discuss the state of affairs in the Netherlands regarding the debate about the integration or inclusion of students with disabilities and /or special educational needs in mainstream schools. A more elaborate discussion is presented in another paper.²

The Netherlands has a system of compulsory education, split into primary education and several types of secondary education. Compulsory education in the Netherlands starts at the age of five (although as many as 80% of four year olds attend school) and ends when students become eighteen years (OC&W, 1969).

In recent years regular schools were challenged to accommodate more students with SEN. Special schools therefore had to rethink their position because of dropping student numbers and were obliged to develop new services to support the teachers in the regular schools who had a student with SEN in their classes, in our case students with a visual impairment (De Groot, Ruijsenaers & Kapinga, 1996). In the Netherlands the education system focuses on early streaming. In the final year of primary education, at the age of 12-13 years, the cognitive abilities of students are assessed and the outcomes on the nationwide tests determine which type of secondary education a student is entitled to go to:

- A form of practical training for the students with moderate learning difficulties. (in Dutch *Praktijkonderwijs*) which does not lead to a formal qualification. Its most important target is to support the transition of students to the labour market (OC&W, 1998c).
- Pre-vocational secondary education (in Dutch *VMBO*) for the more average students (60% of all students) of whom many will continue in senior secondary vocational education (OC&W, 2003).
- Senior secondary education (in Dutch *HAVO*) and pre university education (in Dutch *VWO*) for the more able students (35% of all students) who are opting for further study in a Higher Education Institute (OC&W, 2003).
- Special secondary schools for teenage students who are not accepted at one of the former types of education (OC&W, 1998a). These schools were part of a Regional Expertise Centre. These Regional Expertise Centres cater for students with a specific disability, for example having a visual impairment or a hearing impairment, and may provide pre-vocational secondary education. Many of these centres however focus on teenage students with learning difficulties and offer them a functional curriculum which should prepare them for adult life.

Until the start of the 1970s policymakers, professionals working in the education sector and parents took it for granted that students with SEN received their education in special schools and highly specialised institutions (De Hoop, Janson & Van Kooten, 1998; Kool & Van Rijswijk, 1995; Van Luit & Meijer, 1995). Gradually a division developed between the mainstream sector and the special sector. The special education sector not only showed an increase in student numbers, but also an increase in

² Schuman, Hans (2003). *Special Education in the Netherlands, recent developments and the debate on integration and inclusion*.

types of schools. In 1920 there were four different types of special schools in the Netherlands; in 1949 fourteen and in 1969 nineteen (Kool & Van Rijswijk, 1995). The Special Education Interim Act (OC and W, 1985) that provided the legal and financial framework for special schools in the 1980s and 1990s distinguished fifteen types of special schools.

During the 1980s the dual system of mainstream and special schools was criticised fundamentally for the first time. As early as 1981 the National Association of Parents with a Visually Impaired Child organised a study day focusing on *The integration of blind and partially sighted students in mainstream education* (Vereniging van Ouders van Visueel Gehandicapten, 1981, Preface). At this study day a mother of a blind child presented the following account of her experiences:

It is the nature of science to generalise. The facts collected deal with only one phenomenon, in this case blindness. So these are referring to the blind child in general. The same rationale is used when thinking of provisions. These are applicable, good and useful for *all* blind children. But, only the people, who *live* with the child, are in a position to notice what distinguishes *this* child from every other child.

Parents, teachers, neighbours, and perhaps friends and relatives are best placed to assess which of the general provisions apply to this special child. Therefore it is necessary that parents, teachers and all other people involved in raising this child, jointly investigate what possibilities, challenges and difficulties they foresee and which services and provisions they think appropriate for this child (Ibid., pp.7-8; emphasis in the original).

This mother wanted these services and provisions provided for in the mainstream, neighbourhood, school. She also mentioned the barriers, put up by professionals, she had to overcome:

- Deterrence: integration is only suitable for very bright and well-adjusted children.
- Disqualification: the parents have not yet learned to cope with their child's impairment, with its special status.
- Tutelage: parents are not competent enough to judge the impact of a visual impairment and to cope with sensitive periods in their child's development (Ibid., p.8).

At the end of the study day the parents agreed on the following statement:

We, parents of blind and partially sighted children, demand the opportunity to make the choice for mainstream education for our children, without losing the right of equal financial settlements and the professional support children in special schools receive (Vereniging van Ouders van Visueel Gehandicapten, 1981, p.32).

The political debate of the mid 1980s focused on the rights of children with special educational needs to be educated with their peers in mainstream schools (De Groot et al., 1996; UNESCO, 1994; Pijl, Meijer & Hegarty, 1997). A major outcome of this debate was the emphasis on parental involvement

and participation. Parents should have a real choice: if they want their child at the neighbourhood school everything should be done to make this possible (OC&W, 1995; OC&W, 1996a). Knowledge, facilities, resources and expertise were still key factors in the education of these children, but these should be applied, from the child's and parents' perspectives, in the least restrictive environment (Pijl et al., 1997). Not only parents of a child with a visual impairment started advocating for mainstreaming, but also other parents' groups with a disabled child. In 1986 for example, Dutch parents of children with Down syndrome founded the Association for an Integrated Upbringing of Children with Down Syndrome (In Dutch the *VIM*). Their main aim was "to create opportunity of choice for parents to have their child with Down syndrome educated in the mainstream school" (Scheepstra, 1998, p.1). The coordinating Federation of Parents' Associations (in Dutch *FvO*) partly took over the idea of integration under the motto: *mainstreaming when possible, special when necessary* (Ibid., p.3).

In the same period more and more scholars started to challenge the division of the Dutch education system (Doornbos & Stevens, 1987a; 1987b). An important aspect of the discussion was the recognition that the special system was becoming too expensive (De Hoop et al., 1998; Kool & Van Rijswijk, 1995; Van Luit & Meijer, 1995). Other key considerations were:

- The existence of an elaborate system of special education in itself ensured that mainstream schools were tempted to shift the responsibility for the education of students with SEN to the special schools. These practices were reinforced, because "there was no generally applied norm against which children were measured; it was much more a teacher-related standard based on the degree to which the teacher was able to cope with differences in the classroom" (Meijer & Stevens, 1997, p.120).
- The criteria mainstream schools used to refer students to special schools were too subjective. Evidence showed that "there was considerable overlap between pupils who were placed in special schools and those who were not" (Ibid., p.119).
- The referral of students with SEN was incompatible with the idea that differences between people should be valued positively in modern societies (Stevens, 1997).

To stimulate the process of integration of students with SEN in mainstream schools the Dutch government started in 1990 the campaign *Together to school again* (in Dutch: *Weer Samen Naar School* or *WSNS*) (OC&W, 1990). The main aim of *Together to school again* was reducing the number of children to be referred to special primary schools and to "bring the special provision to the student instead of taking the student to the special provision" (OC&W, 1996, p.9). Educational resources were re-allocated from special primary schools to regular schools to stimulate the intake of students with SEN (Kool & Van Rijswijk, 1995; OC&W, 1996).

Gradually it became clear however that the current practices in mainstream schools, for example whole-class instruction, strict teaching periods, homogeneous grouping, the existence of a standard

curriculum, rigid procedures of assessment and repeating classes, practices still very much present in Dutch primary and secondary schools, were not compatible with a more inclusive education system (Stevens, 1997).

Parents still found it hard to getting their child into a regular school (Van der Hoeven, 2005). In the interviews I had with the parents of our students they suggested that ignorance and obstinacy of teachers and support staff in regular schools, eventually caused them to make the painful decision of sending their child to our school:

“Ursulla went to the infant school nearby. It turned out into a disaster. They were too protective. I said let her try for herself, no problem when she falls. But they kept her from many activities. She had lots of fights with other children because she wanted to touch them, their clothes, because she could not see” (mother Ursulla). And Beth’s mother reported that “Every special arrangement Beth needed caused problems. They did cooking there but Beth was not allowed to participate; they thought it would be too dangerous. When they went camping she was not allowed to participate in activities at night”. Contrary to what is often argued, i.e. that special education, rather than mainstream education, is over-protective of its students; this mother suggested that over-cautious teachers in the regular school prevented her child from really participating in school life and engaging in challenging activities.

Another mother reported:

“Ken is more at ease now. If we had sent him to a regular secondary school nearby, he would turn into the nasty child he was. They would call him names and he would explode and start fighting again. At this school he feels valued. He is popular with the other students and the older students really like him. At the exit conversation we had when he left the regular primary school, they said: he is just a nasty kid, difficult to handle”.

The parents suggested that Ken’s psychological and emotional well-being was at threat in the regular primary school. They felt that the teachers were resentful of their child. The parents suggested that teachers were unaware of the difficulties Ken experienced. Because he had quite a degree of sight left the teachers seemed less convinced of the usefulness of certain adaptations, for example large print, clear hand writing on the black board, and extra checking whether Ken had actually been able to read what was written or drawn. Hence Ken did display challenging behaviour which went from bad to worse and the school did not seem able to find any solutions. The end result was a school which wanted to get rid of one of its pupils, totally frustrated parents, and, moreover, a young person who had to attend a special school at some 150 kilometres distance from where he grew up.

Therefore scholars emphasise that for the development of a more inclusive education system it is important to create favourable conditions for more inclusive practices at the four levels of the education system: at classroom level, at school level, at the level of cooperative networks of special and regular schools and at national level, for example legislation and financing (Meijer, 1995).

Moreover the inclusion of more students with SEN in regular schools would also demand more in-service training of teaching professionals, new and innovative teaching and learning devices, new teaching strategies, different forms of grouping, more need for cooperation, teamwork and multi-disciplinary approaches (Pijl, 1997). To support the inclusion of more students with SEN in regular schools the concept of adaptive teaching was introduced in the Netherlands in the early 1990s (Van Luit & Meijer, 1995; Stevens, 1997).

Adaptive teaching stands for educational practices which take into account that *all* students have different educational needs; that teachers acknowledge the differences between their students; and that they accept that these differences are durable and valuable (Van Luit & Meijer, 1995). Adaptive teaching recognises students as the rightful owners of their own learning process (Stevens, 1997). Adaptive teaching presupposes however the willingness and competences of teachers to adapt the curriculum to allow access to students with SEN. However, it seems justified to argue that, although the numbers of students in the different educational settings may have shifted, the traditional system of segregating students with SEN is actually left unchallenged in the Netherlands. The model of continuum of provision which gradually developed from the 1980s and which runs from the regular classroom setting through within-class support and special classes, to the special school with boarding facilities (Kool & Van Rijswijk, 1995; OC&W, 1996; Limpens, Nekkers & Ter Pelle, 2003) seems to serve the best interest of both the mainstream and the special education sector. The basic idea supporting the model is that students with SEN have a right to be in a setting from which they will benefit most, i.e. *the least restrictive solution for the individual* (Ibid.). However, research indicates that the process of mainstreaming more students with SEN have come to a halt in the Netherlands (OC&W, 2003). This is in line with national and international research which shows that the preservation of a dual system of regular and special education carries the risk of on-going exclusion of students (Meijer & Stevens, 1997).

The discussion so far indicates that our special school still owes its existence to the exclusion of pupils with a visual impairment from mainstream education. However, it is also important to stress that during the past 25 years quite a few students with a visual impairment successfully completed their education in a mainstream school and that the peripatetic services of the special schools played an important role in achieving this. Evidence also shows that parents in particular played an important and stimulating role here. Nowadays about 60% of all visually impaired students in the Netherlands are educated in mainstream schools, supported by peripatetic teachers of the various expertise centres. These figures, however, also imply that 40% of all visually impaired students in the Netherlands are still educated in special schools.

Challenging our views and everyday practice

The exclusion of students, who were not able to cope with the attainment targets of the mainstream system, was also recognizable in our school. Students of the primary department who could not cope

well enough with the traditional and standardised academic subjects, especially Dutch language (writing, reading and spelling) and mathematics were placed in a special unit (internal exclusion). Just as many of their peers in mainstream schools they experienced failure and exclusion during their primary school years, supposedly to meeting their 'special learning needs'. However, placing them in the new unit also met the teaching and instructional needs of their teachers who found it difficult to educating them with the other students. Now, eight years later the aim of our innovation project was the re-integration of these students in the department for secondary education because, formally, although they were in their teens, they were still receiving the primary school curriculum and were treated as if they were still primary school students.

Therefore it seemed important in our project, which focused on the development of an empowering curriculum for these students, to acknowledge *and* to challenge our personal and "traditional individualistic deficit approach to disability" (Barnes & Mercer, 2001, p.13) as well as our "dependency creating services and overtly paternalistic approach" (Ibid., p.14).

It also seemed important to challenge our traditional ideas of the standard curriculum, standard assessment procedures, the year group system and the fixed number of teaching hours per subject for every student (Lloyd, 1996). It seemed to us increasingly dubious to "run all children through one and the same educational gauntlet" (Carr, 2003, p.146) and still expect to be able to include the students who did not fit into this straightjacket. As curriculum developers we needed therefore to recognise that "there is potentially as much injustice in treating unequals equally as there is in treating equals unequally" (Ibid., p.188).

We also had to rethink the values we cherished. Modern western societies place high value on autonomy, independence and personal competencies. This emphasis on autonomy and independence, however, may produce "dependency as a wholly negative social attribute and as a form of alterity which, in turn, legitimates processes of exclusion and oppression" (Hughes, 2001, p.25). therefore we wanted to provide the students with experiences of choices and rights, and, for example, in relation to the much used concept of independence, stimulating them to asking for assistance when and how *they* require and want it (Barton, 2001, p.10), thus advocating a prominent role for student self-advocacy and self-determination, including decisions about the level of independence the individual student regards as best serving his /her interests. This implied that procedures were needed in which students were encouraged to assess and express their personal strengths, preferences and needs and to co-decide with the professionals involved about appropriate ways to meet and develop them (Rioux, 2001). Such procedures would demand that teachers were able to take up different roles, for example as facilitators of learning and as coaches of learners. They would be expected to differentiate to the strengths, needs and preferences of the individual student, identified through a collaborative process with parents and students of consultation, exchange of information, sharing of views and ideas, decision-making and individual curriculum and support planning (Stevens, 1997). This *adaptive process of communication and teaching* however, requires teachers who are willing to meet parents and students as partners,

possess the knowledge, skills and attitudes to handle diversity; to practice differentiation; to adapt to individual and sometimes very specific educational needs; and to be knowledgeable of and have access to a wide range of teaching and learning materials (Ibid.).

In our specific case it seemed therefore important to connect the debate on the inclusion of students with a visual impairment in mainstream education to the social debate regarding the marginal position of people with disabilities in general (Oliver, 1996). The marginalised position of disabled people is considered to be the result of a *medical-deficit model* which locates the difficulties and challenges disabled people encounter on a daily basis as the outcome of a personal tragedy of which they are victim (Ibid.). Disabled people, however, challenge this view and suggest that an unequal distribution of power and resources favours non-disabled people and discriminates and oppresses disabled people, forcing them into dependency, unemployment, poverty and marginal and segregated positions (Ibid.). They promote a *social model of disability*, which demands equality of opportunity and legislation to end discrimination, marginalisation, oppression and segregation (Barton, 2003; Oliver, 1996).

A characteristic of the medical-deficit model is lack of opportunity for disabled people to speak for themselves. Teenage students at our school also had little say regarding the teaching and learning which would best meet their interests, needs and visions of their future. One of the major challenges of our project about the development of an empowering curriculum therefore became the development of innovative practices which would give these students and their parents ample opportunities to speak for themselves and to make decisions which would fit their views and interests. Views and interests which may be very different from those of their teachers or other staff involved. This promotion of *self-empowerment* and *self-advocacy* which are key features of the social model of disability, needed to become a key characteristic of our practices too. We were aware, however, that education in a segregated setting, in itself, might reduce the chances of our students to receiving an appropriate preparation for and transition to adulthood and living and participating in the community. This awareness in itself implied the deconstruction of our values, beliefs and political convictions which were the result of our upbringing, education and experience within a system which favoured the medical deficit paradigm and resulted in segregated provision and decision-making by professionals, as the best option for disabled people.

The students and their parents expected an educational offer which would build on the interests and strengths of the students and which would prepare them for adult life and active citizenship. It is important to stress the notion that their employment-oriented education was at the same time their final experience with formal education. There was a certain risk, however, that we, preparing them for the labour market, were focusing too much on the achievement of vocational skills and too little on broad and general skills, needed to become active and involved members of a democratic society (Corbett & Barton, 1992; Carr, 2003). We focused therefore on:

- *a broad and general curriculum which connects learning to the everyday experiences of the students;*

- *more opportunities for the students to become involved actively;*
- *the appeal to students to assume responsibility for their own learning; and*
- *adaptive teaching to make the curriculum accessible to all students.*

However, we realised that the change process at our school would not be easy or straightforward. Apart from addressing our personal values and views we would also need to identify how to actually design and implement a rather complex and wide-ranging change process. A recent evaluation of government policies in the Netherlands indicates that top down models of change and prescriptive structures and procedures which are imposed on all schools, without taking into account the specific contexts of the individual school, are at risk of resulting only in superficial changes (Dijsselbloem, 2008) or of requiring adaptations on an almost continuous basis. International research indicates the same outcome (Evans, 1996; Hargreaves & Fullan, 1998).

It seems reasonable, therefore, to conclude that every educational reform, whether nationwide or school based should start within the schools and with the teachers who work there (De Groot & Van Rijswijk, 1997; Pijl et al., 1997; Stevens, 1997).

Changing an existing practice

The school which is discussed in this article is a special school for students with a visual impairment, aged 4 to 20 (see Figure 1). From 1998 the school had the obligation to develop into a Regional Expertise Centre (OC&W, 1998a). The school has several departments and it runs peripatetic services for students with a visual impairment who are in mainstream schools or in other special schools.

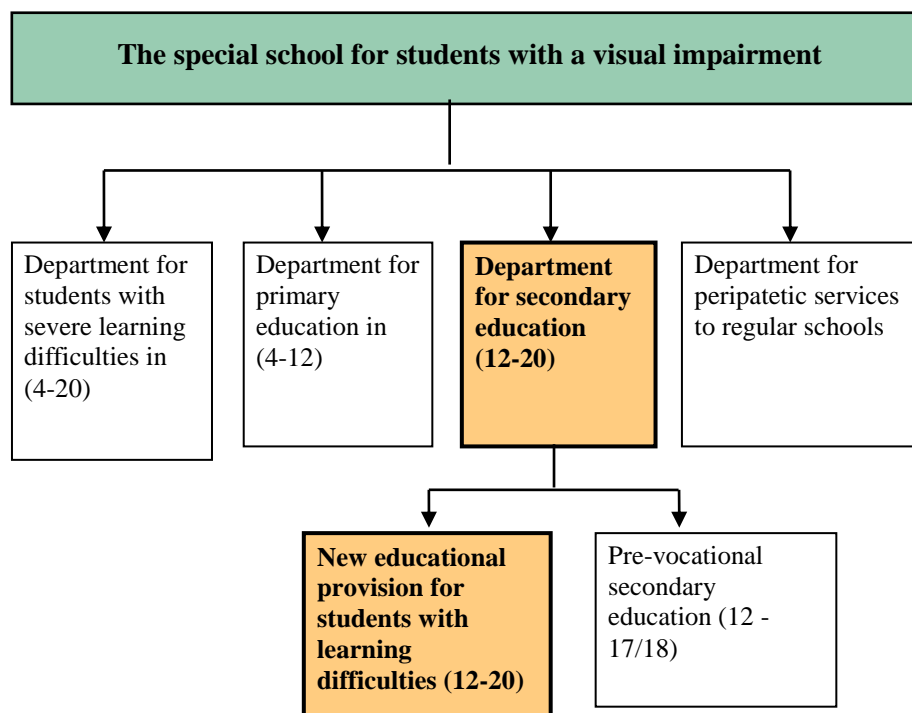
Within our special school 240 students receive special education. Through its peripatetic services the school supports 540 students, most of them attending regular primary and secondary schools in the Netherlands. In effect 60% of the students with a visual impairment in the Netherlands are educated in regular schools (Limpens et al., 2003; OC&W, 2003).

The case study focused on the teenage students (12 to 20 year olds) with a visual impairment and moderate learning difficulties. Moderate learning difficulties mean that their IQ is between 60 and 80 (WISC-R). These students often face additional challenges, for example, epilepsy, physical disabilities or non-hereditary brain damage.

In this unit we had 30 students at the time. These students do not acquire a formal qualification. The majority of these students were expected to transit to day care centres after completing their education. For these students we wanted to develop a new educational provision which would better meet their strengths, give them a voice, stimulate them to advocate for themselves and support their transition to paid work whenever possible.

Figure 1 Organisation of the school

(Numbers represent the age-range of the students concerned)



Student voice became the focal point of our efforts to change and improve our practices, i.e. developing opportunities and practices for the students to express their views regarding the education which would best fit their talents, their needs and their future prospects. It seemed important therefore to ask them how they feel about attending a special school, that is assessing their views about the issue of segregation. All the students I interviewed said that they would prefer a regular school over a special school. However, the students were also clear about their experience that the regular school they went to treated them differently from the other children, thus denying them the same opportunities.

Elisabeth, for example, who was only able to distinguish light from dark, reported that she was in a mainstream Montessori primary school, but that she could not cope with so many children around her. She said: “They had classes with about 30 children. I knew only a few of them”. It seems that her teachers did not realise that Elisabeth, in trying to get to know the other students, needed hands-on support and encouragement, that is, planned intervention and guidance of her teachers and support staff, because as Lowenfeld (1983) already made clear: a visual impairment presents three basic limitations to people with a visual impairment, focusing on:

- the range and variety of their experience,
- their ability to get about, and
- the level of control of the environment and the self in relation to it.

This implies that teachers should be aware that it is far more difficult for an almost blind child to get hold of the surrounding world accidentally and unintentionally as most children do, for example by interacting with the world through play. Therefore specific knowledge *and* a raised and durable attentiveness and consciousness about the impact of a specific disability seem essential when we expect teachers to work with *all* children. This may require a different way of educating and training teachers, both teachers in mainstream and in special schools.

Carolyn, 18 years old at the time of the interviews, said that she would have liked to attend a regular secondary school because she thought that being educated at a regular school would have enhanced her chances to getting a job.

The cases discussed above suggest that the whole discussion of accommodating students with disabilities in regular schools is at the least problematic and complex. Plans and legislation in many countries tend to focus on the same package of measures, for example the quality of provision, the clarity of procedures and scaling-up (Farrell, 2001), leaving unchallenged the experiences of many students with special educational needs who face discrimination in regular schools which “is deep-rooted, pervading all aspects of their lives” (Corbett and Barton, 1992, p.5). There is a risk that, without critical analysis of the wider system of unequal power distribution and oppressive social contexts in our societies, and thus in our education systems, an exclusive focus on procedures and quality assurance in education and training with regard to SEN provision, will perpetuate segregation and exclusion of pupils with disabilities and SEN (Oliver, 1996; Barton, 2003).

Therefore a systems approach in itself may not yield success. Instead, as research indicates, teachers’ values, beliefs and attitudes should be the focal point of changing an educational practice (Evans, 1996; Fullan, 2001; Senge, Cambron-McCabe, Lucas, Smith, Dutton, & Kleiner., 2000). A more fundamental rethinking of “helping young people to prepare for life and also for remaking the world in which that life is lived” seems necessary (Hargreaves, 2004, p.1).

My research indicates that only a small number of students in the unit for students with learning difficulties came to our special school when they started their school career; the majority came after spending some years in regular primary schools; and quite a few made the change only after they had finished their primary education and were in transition to secondary education at the age of twelve. Most parents preferred a regular school over a special school for their child. They decided to send their child to us, however, because they could not cope any longer with all the frustrations they had experienced with the regular school.

They took the decision despite the emotional stress it caused. One mother gave a moving account of the emotional impact it had on family life when her son went to our school at the age of thirteen and had to live in one of the residential houses:

“Since our son went to your school my husband has been grieving. He started to re-decorate the kitchen before the summer holidays, but had not been able to do anything during the past six months. In all our lives we haven’t cried as much as we have done this summer”. And the father

reported: “Of course I miss him. All the simple things we did together after school hours. They are just simple things; but they are all gone now”.

Other parents who live far away from the school reported that the early years were most difficult, both for their child and for them:

“He had to leave on Monday morning very early. And back on Friday evening very late. And it was awful to see your child crying when leaving, feeling terribly homesick. Now he is at ease. His friends are there. It makes it easier for us. But we would rather have him living with us. Therefore when he comes home on Friday we celebrate”.

These examples indicate that the exclusion of students with disabilities from mainstream schools is causing grief, pain and distress among all involved. Working at our special school placed us therefore in a rather difficult position. We were aware that our work might sustain exclusionary and disabling barriers for our disabled students (Barton, 2001). On the other hand, we were responsible for and dedicated to providing them with the best education possible to support their successful transition to adulthood, focusing on working and living in a more accepting and welcoming society than we know today.

Therefore we tried to respond to all pupils as individuals by reconsidering our curricular organisation and educational provision (Sebba & Ainscow, 1996). Through this process, we wanted to increase our capacity to accommodate all pupils with a visual impairment and learning difficulties and, in so doing, would reduce the need to exclude these pupils internally (Ibid.). We acknowledged however that during this process of change there might be a “tension between pressures for effectiveness and pressures for inclusiveness” (Evans & Lunt, 2005, p.42). We therefore monitored the development of more inclusive practices within our unit for students with learning difficulties by critical reflection on the following questions: “How are learners connected into the curriculum? What strategies are used to ensure that they all learn in a meaningful way? How are differences addressed and treated with respect?” (Corbett, 2001, p.55). However we also added a fourth question: What do the students think of their education and the support they receive? We intended therefore to develop opportunities for these young people to challenge and discuss our views and the practices we planned to develop. We formulated the following points as necessary for creating an enabling, empowering, and inclusive educational practice for all students who applied for placement into the unit:

- A school culture which is supportive and collaborative and where teachers share their problems and anxieties. Therefore we introduced a procedure of peer consultation to promote and improve collegial relationships.
- A school policy which invests in people on the shop floor. The project plan we developed, therefore, resulted in extra resources necessary for in-service training, professional development, and curricular changes.

- A school practice which actively invites students to become active participants, whose views are taken seriously and where all students are engaged in learning activities at their own level which they are able to master successfully (Corbett, 2001).

Teachers were challenged to become “architects of more inclusive communities of learning” (Tomlinson et al., 1997, p.280), providing their students with positive images of dealing with diversity, which hopefully would support and empower them to make personal choices regarding their future inclusion in society.

We were aware, however, that a shift of policy and the introduction of a new paradigm (the social model of disability) would not necessarily imply that a shift in thinking would occur or that practices would actually change, because we realised that there is a risk that “the same people, albeit with different job titles and perhaps plush buildings, are doing the same things to disabled people although they may now be doing ‘a needs-led assessment’ or ‘producing a care plan’” (Oliver, 1996, p.71). The actual dilemmas regarding the development of more inclusive and empowering practices seem complex and contentious because “they depend ultimately on value judgements about what is important or desirable in human life and not just on empirical fact” (Wilson, 2002, p.61). Therefore we had to face the task of clarifying, and defending the value judgements on which our work relies (Ibid.).

The development of an empowering curriculum

As referred to before, students of the primary department who could not cope well enough with the traditional and standardised academic subjects, especially Dutch language (writing, reading and spelling) and mathematics, were placed in a newly developed unit. Just as many of their peers in mainstream schools they experienced failure and exclusion during their primary school years. Like many students with SEN these students were dependent on the motivation, time and skills of class and subject teachers to adjust the content of primary school text books or to develop new content themselves. Hoogenkamp (2000, p.23) suggested that many of the educational programmes of these students, especially when they become older, are “based on text books and teaching strategies which do not fit the age, learning styles, competences and future prospects of these students”.

As our students became teenagers, some of the teachers in the secondary department were asked to teach these students practical subjects (for example Design and Technology and Horticulture) because the students displayed boredom, difficult behaviour and lack of motivation to study the traditional academic subjects. The teachers concerned adapted parts of the curriculum they already used with the students in pre-vocational secondary education (Schuman, 1998a; 1998b). They learnt that these new students were generally very motivated to engage in practical work which was demanding and which they considered to be useful and sensible. They seemed to value work which “resembles work in the real world” (Schuman, 1997; 1998a). The teachers of the secondary department who started to teach these students thought that many of them were rather good at their work and that they were able to

carry out their tasks really well, both co-operatively and independently. The work they did, for example maintaining the school gardens, made them aware of their working potential and suggested fields of work they might like to explore in the future, for example during their work experience (Ibid.). The work of scholars like Bruner (1996), Elliott (1998) and Lowenfeld (1981) stimulated a critical discussion of our traditional academic curriculum for these students and challenged us to look for alternatives to traditional teaching and learning. Gradually the foundation of our new curriculum became the notion that just as people acquire many of their experiences from the local community, so must schools obtain subject matter for teaching from this source. The students will then be able to build upon experiences they bring to school, and may seek new experiences after inspiration from the school (Elliott, 1998, p.75).

We started to critically discuss the position of these students with learning difficulties within the school. The students were in their teens already but were still part of the department for primary education. We felt that they had a right to be included in the department for secondary education. This led in 1997 to the development of a Preparation for Employment Programme for these students (Schuman, 1997). The aim of the Preparation for Employment Programme was to improve their transition from school to various forms of labour. At the time nearly 95% of these students went to the day care centres of specialised institutions while retaining money from social security. We thought however that some students had the competences to get into paid work in regular workshops and businesses or in semi-sheltered workshops where they would also earn their own money (Ibid.). The Preparation for Employment Programme would start when the students were about fifteen or sixteen. They had acquired the basic knowledge and skills because they had already learned the practical subjects (for example Design and Technology, Horticulture and Home Economics) for two years. During these lessons they had learned how to use a wide range of tools and equipment to, respectively, cook a decent meal, manufacture products from raw materials like wood, metal and synthetic fibres and to work the garden.

The programme and the activities we developed for the Preparation for Employment Programme aimed at preparing the students to perform as low skilled workers (Schuman, 2000). An inventory was made of the knowledge, attitudes and skills our school leavers were expected to have mastered successfully when entering the job market in unskilled and low-skilled occupations. From the start the vocational programme was directed at the acquisition of generic skills rather than training the student for a specific occupation (Schuman, 2000). The focus was on the impact a visual impairment might have on the acquisition of these skills and collaboratively the teachers involved developed an evaluation instrument for their Preparation for Employment Programme which would monitor the performance levels and the progress of the students (Ibid.). The Preparation for Employment Programme indicated that the curriculum for the students with learning difficulties should focus more explicitly on their future adult life. The students were challenged to reflect on questions like:

What kind of work will suit me?

How am I going to find a job?

Where can I live?

Can I live independently or is living in a small group more appropriate for me?

How am I going to spend my leisure time?

Will I be able to manage my own financial affairs? Etcetera.

A literature review indicated that teacher commitment was the most important prerequisite for changing and adapting the curriculum to the needs of individual students (Bates, 1998; Bruner 1996, Hargreaves & Fullan, 1998). There was evidence however that “teachers’ practice won’t change without corresponding changes taking place in their implicit theories” (Elliott, 1998, p.84).

Therefore the teachers of the Preparation for Employment Project gradually recognised that “it is only when a teacher reflexively examines the understandings which shape his or her practice that he or she is able to reconstruct them as a basis for improving their practice” (Ibid., p.98).

The class teachers reported however that their teenage students still lacked motivation for the more theoretical subjects and were showing “challenging behaviour” (Schuman, 1999). On the other hand the teachers of the practical subjects regarded these students as their most motivated and committed students. This raised the question: “*What are the reasons why these students become so disaffected with most of their learning*”?

Gradually the class teachers started to realise that more rigorous change was needed in the near future. They were not exactly clear about “*what to do and how to do it*”, but they showed commitment and willingness to critically and collaboratively rethink their everyday practices. It seemed that they wanted the education of their students to *become more employment relevant and employment focused and more supportive of future participation in society* (Ibid.).

The class teachers suggested that the ideas behind the Preparation for Employment Programme (Schuman, 1997) might provide a solid basis for developing a new programme and a new curriculum for their students. They said the parents were satisfied with the Preparation for Employment Programme, but they still questioned the quality of the academic subjects and the process of transition to employment. Parents also suggested that:

- *they did not get adequate and informed feedback on their child’s performance levels, progress and development;*
- *they were not fully informed of what teachers were aiming for; and*
- *it was unclear what options and choices were available for their child* (Schuman, 1999).

Some parents suggested that their child should have the opportunity to do their work experience in regular businesses instead of day care centres. Retrospectively the parents seemed to have stimulated the teaching staff to critically rethink and challenge:

- their personal and collective views on disability and the education of disabled teenagers with learning difficulties;
- the impact of a visual impairment combined with learning difficulties and other challenges (for example epilepsy) on teaching and learning;
- the content and provision of the current curriculum;
- the role and the position of the students and their parents.

Research in general is about creating new knowledge (Scott and Usher, 1996; Brew, 2001). In addition it is possible to argue that educational research should support practitioners to make sense of their educational practices with the aim to change and improve it (Carr and Kemmis, 1986; Elliott, 1998; Pring, 2000). Educational researchers who are studying their own practice as a particular case are participant observers who acknowledge their role in what they discover (Gillham, 2000). They aim at gaining an “in-depth understanding of the situation and meaning of those involved” (Merriam, 1998, p.19). Characteristic of this research was its emergent design and the multiple sources of evidence (Merriam, 1998; Gillham, 2000). We realised that for this research project it would not be clear from the start what exactly we were going to do, who was to be involved, which procedures should be followed and what results were to be expected. Thus we had to start without a clear, detailed and straightforward itinerary. However, from the discussions we had with the students, their parents and the teachers, four elements seemed important to tackle:

- What was wrong with the current curriculum and what should a new and more empowering curriculum look like?
- Why did the students not feel responsible for their own learning and how could we support them to experience more ownership and hence become more motivated and committed?
- Why were so many parents dissatisfied with the education of their children? Why did they send their child to a special school, which often implied having them boarded? What do they expect from our education and which role do they see for themselves? How can we stimulate the participation of parents at key stages of their child’s school career?
- Why did the teachers feel insecure and dissatisfied with their work and why did they seem to experience a lack of ownership when thinking of their work? How can they raise their self-confidence and self-esteem and develop a genuine sense of ownership?

We aimed therefore at developing an innovative educational practice, focusing on:

- the characteristics of an empowering curriculum for students with a visual impairment and learning difficulties;
- educational policies and practices which would stimulate and support more active participation and involvement of parents and students at all key stages of the student’s school career;

- ways to empower practitioners to take charge of the change process themselves and to participate in innovative approaches of small scale practice-based research which would underpin and guide their decisions; and
- engagement of parents and students as important sources of information to evaluate the outcomes of an educational change and to understand more deeply the impact of a visual impairment and learning difficulties and their consequences for the curriculum.

Outcomes and conclusions

The experience of disability

Although I had been working at this special school for fifteen years, I did not fully understand the anxieties parents experienced when raising a child with complex challenges, until I interviewed them.

The anger and frustration they felt when schools were refusing their child and the lack of understanding they experienced in their relationships with relatives, friends, acquaintances and teachers were present in almost every interview. Giving these parents and their children a voice may help other people realise that the debate on inclusion is basically a debate about human rights, about the entitlement to live and learn in the community where one is born and to be valued for what one is. Parents reported that the disability of their child had a profound impact on their psychological and emotional well-being, their social relationships and their family life. They suggested that *the educational exclusion of their child was preceded and enforced by exclusionary experiences in nurseries, pre-school education, and primary education, as well as in more informal environments, such as in shops or at family gatherings*. It is possible to argue from their accounts that the medical-deficit model of disability remains dominant in Dutch society. The use of this model continues to cause discrimination, marginalisation and segregation, for example placing disabled students in a parallel system of special schools. These outcomes concur with views which suggest that discrimination of disabled people is deeply rooted in society (Barnes and Mercer, 1996).

The parents in this study are in favour of a more humane, inclusive and welcoming school system, thus implicitly advocating the social model of disability (Oliver, 1996). Their accounts give evidence of the hurt and the guilt parents experienced when they finally had to take the decision of sending their child to a special school. Their pain greatly increased when their child had to live in one of the residential houses as well, because of the travelling distance and travelling time. The voice of these parents indicate that, in effect, the existence of a special education system, as we witness currently in the Netherlands, is an injustice and perpetuates the marginalised position of disabled students and their families.

However, a considerable number of parents also reported a significant increase in the well-being of their children and raised feelings of self-esteem, since they went to our special school. These accounts indicate the complexity of the issue, but at the same time, challenge Dutch society and the Dutch

government to re-conceptualise their policies and views regarding maintaining a dual system of special and regular schools.

Disability and the transition to adulthood

The parents I interviewed were deeply concerned about the future prospects of their children in a society which increasingly emphasises individualism and rewards individual achievement. The growing emphasis on self-advocacy, independent decision-making, and taking care of and being responsible for oneself (Meijers and Wijers, 1997), is considered by the parents as potentially disadvantageous to a successful transition to adulthood of their children. The current cut-backs in social benefits and the privatisation of, for example, the health care system, seem to exacerbate their anxiety.

A recent report by the Dutch Social and Cultural Planning Office (SCP, 2006) supports the parents' views that young people with a disability face greater risk than their non-disabled peers of, for example, staying or becoming long-term unemployed, working in low-skilled jobs, or working only in small part-time jobs. The same study also suggests that disabled adolescents seem to have fewer friends than their non-disabled peers.

To support the transition to adulthood of students with a disability it is suggested that they need to acquire self-determination skills (Laragy, 2004) which would grant them the opportunity of taking on real responsibilities (Corbett and Barton, 1992).

This research supports the view that students with learning difficulties *can* acquire self-advocacy and self-determination skills, and that they are able to become worthy interlocutors when it comes to discussing, for example, their educational career, their future prospects, and their transition to adulthood, for example during their Individual Education Profile meetings.

Disability and employment

Corbett and Barton (1992) connect the transition to adulthood to gaining paid work. They argue that “the extent to which individuals are able to participate in employment will be an indicator of the reality of their adulthood” (Ibid., p.25). However, evidence indicates that the prospects for disabled people in general for finding and keeping a job are meagre (Berthoud et al., 1993); for people with a visual impairment they are even worse (McBroom, 1995).

This research project provides evidence, however, which shows that a well worked out curriculum and a rigorous support programme can help more young disabled people with learning difficulties to get into paid work. Characteristics of the programme which seemed to add to the success were:

- a well-developed social-emotional competences building programme, starting in the first year of secondary education and covering three lessons a week;
- a Preparation for Employment Programme, starting when the students were in year three when they were about 15 years old;

- a work experience programme which started in year four and which gave students the opportunity to work in regular businesses; and
- a student support programme throughout their school career which focused on the development and stimulation of self-determination, choice, ownership and speaking for themselves.

The latter seemed crucial. It gave students the opportunity to express their views and ideas resulting in making the choices which they thought would best meet their needs and preferences. These meetings, where the students and their parents co-designed Individual Education Profiles and tailor-made curricula, resulted in Individual Education Contracts. These became the heart of the empowering curriculum we developed. The interviews with the parents and the students give evidence of the value of these Individual Profiles and Contracts because they clearly addressed educational content, assistive devices, preferred outcomes and issues of responsibilities.

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