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Summary:

This is the fourth of six reports from the project that studies special education in Russia, New Zealand and the USA. It consists of two parts. Part one is a study of special education in the USA based on written sources. The second part is an analysis in a series of interviews with teachers, parents and experts in the field. The study shows a strong push towards serving a diverse population of students with disabilities in inclusive settings. In spite of this there seems to be a high degree of separation between special and regular education. Categorisation is prominent, and the interviews indicate that special education especially writing individual program (IEP) - is strongly bureaucratised. Some states are applying inclusion oriented funding formulas. In spite of this there are indications that a great part of the funding is used to congregate students with disabilities in separate program and facilities.

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A Study of SPECIAL EDUCATION in the UNITED STATES

Report No. IV from the project:

Special Education at the Bottom Line. A cross-cultural study of the quality of special education practice²

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² This is the second of six reports from the project. All six reports are listed at the end of this report.

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PART ONE: A BRIEF OUTLINE OF SPECIAL EDUCATION IN THE UNITED STATES

Aims, design and methods of the project have been described extensively in the first report from this project (Stangvik 2002a). Stangvik (2002b) discusses special education issues and perspectives and is thought of as a theoretical platform for interview studies. A complete list of reports is found at the end of this report.

This report consists of two parts. The first part of the report presents an outline of special education in the United States based on available sources written sources. This outline serves as a background for the analysis of interviews in the second part of the report.

THE SETTING

Several writers (Walton, Rosenquist and Sandling 1989, Hallenbeck and Kauffman 1994, Pijl 1994, Ondrusko & Morsink 1996) present overviews of special education in the United States and compare United States with other countries. *Special Education Indicators. Statistics and Indicators* (2000) published by the OECD presents up-dated figures for disability categories and educational placement for students with disabilities for the United States compared to a number of countries. The ambition with this part of the report is to give some background for the analysis of interviews in the second part. The central themes in the presentation are the legal foundation of special education, the role of inclusion, to give some indications how the special education works as regards some important outcomes and to pinpoint some important current issues.

It is difficult to obtain an accurate picture of regular and special education in the United States. There are several reasons for this. In 1789, the Constitution of the United States of America was adopted; in 1791, an amendment to the Constitution reserved the authority for education to the individual states. This implies that the states do not have to follow federal laws even if most of them do so. A distinction should be made between binding and enabling legislation. The civil rights legislation

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is binding while federal education legislation is only enabling. Court decisions and funding mechanisms are the most important tools for aligning state decision making in education to federal laws.

State legislatures determine how federal laws will be implemented within their respective states, and they write laws pertaining to education. Each state has a department of education, which develops regulations and guidelines for education. Furthermore, each State, except for Hawaii, is divided into school districts that have a high degree of autonomy within the federal legislation. State departments of education are the link between the federal government and the local school districts. This process has strongly determined the features of the current educational system, especially the high degree of decentralisation of educational government and administration. The role of the federal government is modest. Until 1983, there was not even a federal department of education. Keeping in mind that there are 50 states and approximately 1600 school districts it would be pretentious to say that this short introduction gives a true description of special education in the United States. On the other hand, although each state has its own educational legislation, which has resulted in many differences between the states, the basic elements of the system are alike even if the outcome of the system may be very different for children and adults being served in the different states and school districts.

THE LEGAL FOUNDATION OF SPECIAL EDUCATION

The effort to extend the benefits of compulsory education to all children regardless of race, ethnicity, gender or disability began in 1954, when the United States Supreme Court ruled in the case of 'Brown versus the Board of Education of Topeka Kansas'. The ruling states that education is '(...) a right which must be made available to all on equal terms'. This court ruling had to do with racial discrimination, but came to be applied to discrimination of people with disabilities, too. The Rehabilitation Act of 1973 includes Section 504, which prohibits discrimination on the basis of disabilities and protects the rights of persons with disabilities in the areas of education, employment and housing.

However, until 1978, many children were denied access to public schools. Before that time a state might even have an exclusionary clause written into the state code which gave school administrators the opportunity to deny education to children for certain reasons. A common reason for denying children entry into school was a low score on an entrance examination likely to be an IQ test. Thus, many children were denied education in the public schools, and even in special schools or in special classes within the regular schools. Public Law 94-142, The Education for All Handicapped Children Act signed in November 1975 that came partly into effect in September 1978 and became fully operative in 1980, made it clear that all children in the United States have the right to an appropriate education, paid for by public money. This became known as the 'zero reject' policy, meaning that schools must admit all children and must provide an education appropriate for each child, regardless of disability or severity of disability. The general aim of this Act is described as follows:

'It is the purpose of this Act to assure that all handicapped children have available to them, within the time periods specified, free appropriate public education which emphasises special education and related services designed to meet their unique needs'

In general, the Act comprises the following aspects:

- Handicapped children between 3 and 21 years of age are entitled to free education
- Special education should take place in 'the least restrictive environment':
- A central issue of the Act is the IEP (Individualised Education Program); such a plan has to be made for every handicapped child and should be put down in writing
- Parents have the right to see all the documents that concern their child and to demand a hearing in case of disagreement on a (decision on) placement.
- Tests and evaluation materials should not be culturally biased and have to be formulated and/or administered in the child's mother tongue or in its own way of communication
- The federal government is obliged to contribute to the costs for special education.

The Education for All Education Act (Pub. Law 94-142) require all states to provide a free and appropriate education to all children with disabilities. The law has been strengthened by several amendments (cf. Verstegen 1999). The 1983 amendments of Pub. Law 98-199 expanded incentives for pre-school education programs from birth to 5 years of age and to provide early intervention and transition program .The amendments of 1990 (Pub. Law 101-476) changed the name of the law to the Individuals with Disability Act (IDEA) and included new categories of children. The law gives additional emphasis to the requirement of transition planning for disabled adolescents from school to adult life. In the same year, The Americans with Disabilities Act (ADA) was enacted, prohibiting discrimination on the basis of disability in employment, transportation, public accommodation and telecommunications. However, the entitlement for adult services seems weak. One of my respondents who has a thorough knowledge of this matter said to me:

I think people with disability sorely need some entitlement as adults, for adult services. We don't have that, you know, whereas all kids with disabilities have to go to school, that's what 94 - 142 did for us in the original IDEA but we don't have something analogous on the adult side.

There are also additional entitlements for special education for students with learning disabilities. Education of disadvantaged students (compensatory education) is

mandated in the Title I program³ of the Elementary and Secondary Education Act of 1994 (ESEA). These funds may not only be provided by identification based formula, but may be used to upgrade the entire educational program of the school. Many students served by the Title I program may have learning disabilities caused by their poor social background.

Special education entitlements

The IDEA amendments of 1997 adopt six principles as the framework around which education services are designed and provided. These are the availability of free and appropriate public education (FAPE), appropriate evaluation, development of an individualised education program (IEP), education provided in the least restrictive environment (LRE), parent and student participation in decision making, and procedural safeguards to protect parents and their child with disability.⁴

The purposes of this title are--``(1)(A) to ensure that all children with disabilities have available to them a free appropriate public education that emphasises special education and related services designed to meet their unique needs and prepare them for employment and independent living;`(8) Free appropriate public education.--The term `free appropriate public education and related services that-----``(A) have been provided at public expense, under public supervision and direction, and without charge;``(B) meet the standards of the State educational agency; ``(C) include an appropriate pre-school, elementary, or secondary school education in the State involved; and``(D) are provided in conformity with the individualised education program required under section 614(d).

³ Title I is providing \$8 billion this year to improve education for some 13 million children who attend 46.500 schools in high poverty areas. The goal is to improve student achievement by helping schools to upgrade curricula, extend learning time, provide professional development for teachers, support teachers salaries and purchase computers

⁴ Twentieth Annual Report to Congress, 1999, p. i

IDEA requires full educational opportunities to all persons with disabilities between the ages 3-21⁵. The IDEA defines 13 eligibility categories: Autism, deafness, deafblindness, hearing impairments, mental retardation, multiple disabilities, orthopaedic impairments, other health impairments, serious emotional disturbance, specific learning disabilities, speech or language impairments, traumatic brain injury, and visual impairment. The Department of Education has recommended these categories being replaced by a single category (Kerzner Lipsky & Gartner, 1997)). The proposed language would define an eligible child as one *who has a physical or mental impairment and who, by reason of that impairment, needs special education and related services. (p.65)*

Referral and placement

A child has to be declared eligible for special education before special education may be delivered. Students must, in other words, be declared disabled before they are allowed to receive special education services. First, school personnel must specify that a student has a disability, and second, they must specify the nature of the disability. Previous studies indicate that an average of six tests is used in the decision making process about a student. Intelligence tests were used more frequently than achievement tests. School personnel used intelligence tests as measures of cognitive capability, achievement tests as indices of level of performance, and a variety of measures of psychological processes to identify causes of problems (Ysseldyke & Algozzine 1995 p.231). Research on these referral and classification procedures shows conceptual problems in defining learning disabilities, that the instruments lack validity and reliability, and that they who administer tests are not knowledgeable enough to interpret the results appropriately (Kerzner Lipsky & Gartner, 1997,p.355).

According to PL 94-142 a decision-making process concerning whether or not a child is eligible for special education is only started when a pupil is put forward for referral, which in many cases is one by the regular class teacher. The decision making is based on a multi-disciplinary case-study evaluation (Pugach, 1985). After the child has been referred, one or more experts among whom is usually a school

⁵ States need not obey if a state law, practice or court order is inconsistent with these requirements.

psychologist examines the child. Next, the diagnostic information is discussed in a special education team meeting in which it is decided how the pupil should be classified and if they should proceed to placement of the child in a form of special education.

The federal law (IDEA) is precise regarding referral and placement procedures for school age children.

- 1. When a child in regular education displays difficulty with learning, the teacher, in consultation with the parents, notifies school administrators.
- 2. A multi-disciplinary team is then appointed, including the regular education teacher, a special education teacher, the parents, and appropriate school personnel who are familiar with the child's difficulties.
- 3. The team collects and analyses various existing data such as achievement tests scores, samples of the child's academic work, the records of the child's social behaviour.
- 4. The team examines these data and determines whether other tests are needed, such as intelligence tests, adaptive behaviour ratings, test of learning style and selected medical tests.
- 5. The multi-disciplinary team will use the combined results of formal and informal evaluation to determine if a referral to special education services is appropriate.
- 6. When the team makes a referral to special education, parental consent is required before the referral is acted upon. The enactment of PL. 94-142 gives parents right to due process in any change of educational program for their child. Parents are supposed to give their written permission for any placement change and are given several specific rights in that process. The IDEA also delineates specific requirements for local education agencies to provide impartial hearings for parents who disagree with the identification, evaluation or placement of a child.
- 7. After the parents have given consent, a team is formed for the purpose of writing an individual educational program (IEP).

Other measures taken to secure the quality

The IDEA mandated an individual education plan (IEP) for students age 3-21. For infant and toddlers through age 2 the plan is called IFSP (Individualised Family Service Plan). A transition plan is required as a part of an IEP. The IDEA also

requires that placement for special education services be reviewed annually to verify that the educational program is effective, and to determine whether special education services should be continued, revised or discontinued. A comprehensive formal evaluation is required every three years for children who have continuing special learning needs. Concerns about the fragmented and redundant instruction that students received in pullout programs and lack of efficacy of these traditional service models prompted Title I administrators and teachers to examine how to provide instruction to Title-I-eligible students that is linked to the general curriculum and classroom instruction. Recent changes to IDEA require that special education students participate in assessment and access the general education curriculum. It is not allowed to omit children with disabilities from achievement testing. Previously these kids might have been left out in order to keep up the average. The only ones to be exempted are the students with the most severe disabilities and they should not be more than 1-2 per cent of the total population. For them alternative assessments keyed to the general education curriculum must be provided. These developments may be important catalysts for integration and collaboration.

The inclusion policy

To educate children with disabilities in regular classes is a primary goal. The integration imperative of the 1975 Act prohibits removal of a handicapped child from the regular education environment unless that child cannot, with the assistance of supplementary aids and services be satisfactorily educated in the regular school environment. The IDEA Amendments of 1997 state

"[T]o the maximum extent appropriate, children with disabilities...are educated with children who are not disabled; and ...removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplemental aides and services cannot be achieved satisfactorily"(Par612(a)(5)(A).

An important goal of the 1997 revision was to give kids with disabilities substantive access to the general curriculum. Teaching should not be based on what you think is their disability. You have to teach them what everyone is learning. These changes are of course very inclusion relevant.

The law does not mandate inclusion. Even if inclusion is expressed as an important social goal the question to include or not is a question of professional discretion. Viewing special education as a part of a continuum of services may actually support exclusion for education purposes. In the USA a student cannot, according to the law, be placed outside the regular class without solid documentation of what is done to include the student. The law says that a student should be kept in the least restrictive environments, and demands that placement of the student outside regular class has to be based on solid documentation. On the other hand, court cases have demanded the continuum of services be preserved. The 1997 reauthorization of the Individuals with Disabilities Education Act (IDEA) calls for providing the greatest possible access to the general curriculum as a means of improving educational results for students with disabilities. Access to the general curriculum is most readily available by providing services in the regular education classroom. To improve access to the curriculum has an absolute priority⁶

Funding

Public schools are financed by public money collected in the form of taxation on income or on property. Local governments collect tax money from their residents and distribute the money to school districts within their geographic regions. This system may create many inequities. That is especially the case in the time of demographic changes. Furthermore, in upper class communities property is worth more. They therefore generate more property tax than poor communities. This creates inequities. One of my interviewees told me that several states have made pushes to move away from property task as a funding mechanism, but there is a serious problem:

That's a big problem for us because w/e don't tax our citizens at the rate, either within the states or federally, we don't tax at the rate that we really need if we were to pay for schools. So you get into a situation like we have in this state where we have a legislature that passes laws about how schools must change and what standards kids have to meet but they don't then provide the money to do that. So that's a common problem everywhere.

⁶ Applications for New Awards for Fiscal Year 1999; Notice [Page 10352] DEPARTMENT OF EDUCATION

In order to achieve more equality between communities states pass equalisation laws. Their equalisation formula may then take away some of the money generated for education in a rich community and use it in a poor community.

Funding is a joint venture between the federal state, the state and the local authority. When the cost per pupil for special education exceeds the cost per pupil for regular education, the state government reimburses local governments for the excess in cost.

Recent statistics show that 92% of the costs is paid by the states. There is a great variation between states, but on the average the state pay 56% and the local 36% of the special education expenditure. The federal state only accounts for 8% (Lankford & Wyckoff 1999, p. 149). The federal government provides funding to states and local educational agents if they agree to comply with certain conditions set out in handicap laws, and the rules and regulations for the implementation of these laws.

A 1993 study of 30 states showed that only four states used a system of funding based on school enrolment. The rest of them provided funding that in one way or another depends upon the number of students identified. There were four types of funding formulas used by these states (Kerzner Lipsky & Gartner, 1997,p. 41, Parrish and Wolman 1999 p.204-205):

- 1. Pupil weights, expressed as a multiple of regular education aides
- 2. Resource based funding based on specific education resources(e.g. teachers, classrooms, units)
- 3. Percentage reimbursement, funding based on percentage of allowable and actual expenses
- 4. Flat grant, a fixed amount of funding per student per unit

Most of them used the first one above. Oregon, for example, applies a single funding weight to all eligible special education students in the state. This means that the amount of state aid for every special education student in a district is twice that received for a general education student in that district.

Funding formulas used by the states and funding trends for 1994-95 are studied by Parrish and Wolman (1999, p. 204-209). One emerging trend at the federal and state levels is to use total district enrolment rather than special education counts as the basis for allocating special education funds to school districts. For example, under a state census-based funding system, districts with identical student enrolments receive the same special education aid regardless of the number of students placed in the program, the disabilities of these students where they are placed, or how they are served. The new model that more and more states are moving into and that the federal government is moving into is a population model. It's based on a percentage of your overall ADM (Average Daily Membership). This percentage is stipulated to 11 to 15 per cent of the school population.

Proponents assume that such models eliminate labelling and identification as a basis or funding and severs the link between placement and funding. They find that the special education population has been growing at a significantly faster rate than the general population threatening to raise the cost for the states to an unacceptable level. Parrish and Wolman (1999) conclude:

On critical question that confronts the development of future fiscal policy in special education is whether funding should retain its purely categorical nature. Reform advocates are questioning the efficiency of the multiple administrative and service structures needed by categorical programs and are calling for increased flexibility through the blending of funds to best meet the special needs of all students. (p.227)

THE WORKINGS OF THE SYSTEM

CATEGORISATION PRACTICES

The total number of children receiving special education is difficult to report because the states use different means to identify disabilities and to determine whether children with certain disabilities should receive special education. In 1993, the United States Department of Education reported to Congress that nearly five million children and youth from birth to twenty-one years of age received special education during the previous year. This represents about seven percent of all children at the same age group in the country.

The earliest progress in special education was in areas of severe disability: blindness, deafness and mental retardation. Today the largest category of disability in special education is specific leaning disabilities. In 1992, nearly two and one quarter of a million children with learning disabilities received special education; in 1977 the number was less than one million. According to the 1997-98 statistical figures the number served in federally supported programs was 12.8% of the total school enrolment. Over 90 percent of students served were classified in one of four disability categories: Learning disabilities 51.1%); speech and language impairment: 20.1%; mental retardation: 11.4; and emotional disturbance 8.6%. The law restricts the number eligible to be identified for funding to 12% of the school population. The allocation of federal funds is based on an identification-based formula. In practice this means that criteria for identification are used very differently. States and local school districts report widely divergent proportions in each disability category (Kerzner Lipsky and Gartner, 1997 p.38)

Definitions of LD, ED (emotionally disturbed) and EMR (educable mentally retarded) are not only inconsistent over states and categories but also inconsistent in time. Several states have repeatedly revised their definitions since the introduction of Public Law 94-142. Actually there is very little consensus, whether conceptually or in practice, on the definition of learning difficulties or the criteria for classifying children as learning disabled. Despite the federal regulations, it turns out in practice that the

decision of a teacher to refer a pupil for special education is crucial in the entire identification process and that it controls this process to an important degree.

PLACEMENT PRACTICES

There are several placement options:

- 1. Regular class: students receive the majority of their education in the regular class and receive special education for less than 21 per cent of the school day outside regular class
- 2. Resource room: students receive special education for 21-60 percent of the school day and participate in the regular class for the rest of the day
- 3. Separate class: students receive special education for more than 60 per cent of the school day with part-time instruction in the regular class.
- 4. Separate school facility: students receive special education in separate day schools (or residential facilities) for more than 50 per cent of the school day

In 1996-97, more than 95% of students with disabilities ages 3 through 21 were served in regular school buildings. A total of 46.2% were classified as being educated in regular classes, meaning they were removed from their regular classes to receive special education and related services for less than 21% of the school day (The number of students in this category has gradually increased). An additional 26.7% were in the resource room category, meaning they received special education and related services outside regular class for 21 to 60% of their school day (The number in this category has decreased). 22% of students with disabilities were in the separate class category, meaning they were served outside the regular class for more than 60% of the school day. A total of 4.8% of the students with disabilities ages 3-21 did not attend school with their non-disabled peers 3.4% was in public/private separate day schools, 0.7% in public/private residential facilities and 0.7% in homebound hospital settings. This last category has remained relatively stable.⁷ Since the 1990-1991 school year, the percentage of students with disabilities (ages 6-21) who participate in regular education classes, at least 80 percent of the time, has gradually increased from 33 percent to 46 percent during the 1996-1997 school year. Kerzner Lipsky and Gartner (1997 p.4) underscore that placement

⁷ Cf. Twentieth-First Annual Report to Congress. Section III

patterns varied widely based on student age, disability, and state practices. They present data showing a 10% increase in general classroom placements while resource room placements decreased by a similar percentage. More segregated placements, however, remained stable.

As far as the change in placement procedures are concerned two movements can be distinguished:

- The severely handicapped: from state institutions to public school facilities and from separate to regular schools;
- The less severely handicapped: more pupils to resource rooms, more noncategorical placements and fewer self-contained classrooms.

PROGRAM INTEGRATION

As soon as children deviate from the average, attempts are made to make provision for them by means of a separate program. The programs for pupils who deviate in any respect are mostly of the so-called pullout type. The process of changing this has had several stages.

- 1. The first stage of reversing separation began in the early 1960s, and was known as de-institutionalisation. During this time community-based schools were opened so that parents need not send their children away from home to state-owned institutions for an education.
- 2. The next stage, mainstreaming, began in the 1970s, when children in communitybased special schools and special classes were integrated into regular schools and classes for some portion of their education.
- The current stage, referred to as inclusion, began in the mid-1980s. Inclusion is broadly defined as the practice placing disabled children in regular classes to learn with children in the appropriate age groups, with special education services provided in the regular classroom.

There is some important factors within regular education which influence the inclusion process. Because of the large pupil population within elementary schools it is possible to work with two to three parallel classes per grade. Many schools make

these parallel groups as homogeneous as possible by separating slow and fast learners. As a result, teachers in the US have been accustomed to working in fairly homogeneous classes as far as level is concerned. In such classes a standard program for all pupils can be followed and the pressure for differentiation within a class is not very high. In this context regular teachers tend to regard deviant pupils as a problem. For these pupils the standard program is inappropriate, and adjusting the program within the normal class structure is considered highly problematic. A crucial problem in all this seems to be that regular and special teachers have limited contact with each other. Since their training and experience are very different, they also have different interpretations of their tasks in practice. As a consequence, the integration of regular and special education is limited. In practice, the regular teacher does not adjust the program to these pupils and does not know what the special teacher does in pull-out time. Although American education under Pub.Law 94-142 is generally seen as integrated, there is little curricular integration.

According to McLaughlin (1999) a strong force or increasing collaboration between programs has come from research showing a lack of efficacy of pullout programs and the movement to create inclusive schools and classrooms. Most districts are seeking ways to spread the special education resources more broadly across he school as part of overall school improvement efforts targeted at raising student achievement levels. The prevalent instructional collaboration models being implemented in schools include (a) collaboration and consultation and planning instruction and (b) collaboration in instruction through team teaching. Collaboration also occurs at the central office levels when program administrators meet as part of teams for planning and ongoing administration. In summary, McLaughlin (1999) finds that efforts to promote greater flexibility and co-ordination in ongoing programs are successful in a number of school districts, largely due to a combination of strong local leadership, school site organisation, and teacher skills. A significant barrier to consolidation is the very history of categorical programs and the myriad federal and state program regulations. Historically, she says, school districts have been held closely accountable for ensuring that eligible students were indeed receiving extra educational services. Now, as a part of school reform, a more powerful type of accountability is emerging. This is accountability for improved student performance on critical educational outcomes. Although this new framework offers an opportunity

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for moving away from rigid categorical funding toward more flexible resource allocation, it is not yet a reality.

DISPROPORTIONATE ETHNIC REPRESENTATION

There is a disproportionate representation of racial and ethnic minorities, gender and students with poor social background in special education and in prevalence.⁸ Based on statistical data on ethnic representation in special education Artiles and Trent (2000) conclude:

These data suggest that Black students are over represented in MR and SED (Serious Emotional Disturbance) programs whereas Latinos are not over represented in any of the mild disability categories. A closer look at the total percent of ethnic group in mild disability program data presented in the B columns suggests that the difference between Black and White students with mild disabilities declined from 1986 to 1990 but it has been increasing in the 1990ies. (p.515-516)

This clearly indicates that the questions of equity and how to grapple with the needs of culturally diverse students in a diverse society are central issues in the United States today. This growing diversity in student population has increased the potential and practice for inappropriate educational placement of students. For example, in 1987, African Americans were 16% of the total enrolment in the nation's school system. However, in the same year, African Americans made up 27% of the students identified as having a behavioural/emotional disorder in the public schools. Artiles and Trent point out that there is concern by many in the United States that this 11% discrepancy is based on faulty thinking, biases, and inappropriate identification of culturally diverse students.

PROGRAM INTEGRATION AND INCLUSION

The practice of educating disabled children as much as possible with other children in the regular school setting: educators question the extent to which this can be done and be in the best interest of all persons involved. Hallenbeck and Kauffman (1994 p.412) draw attention to a present great controversy regarding the structure of special programs and services and the basic concepts that have guided special education practices for a century or more. The question is whether special education

⁸ Twentieth Report to Congress, 1998

should maintain an identity and function distinguishable from general education, and the extent to which students with disabilities should be provided education that is distinctive or not. This question is closely related to the question of funding as it is reasonable to expect that a funding system primarily based on the number of student identified with learning disabilities will serve to prolong the separation between special and regular education. As pointed out earlier only a few states use a system of funding based on school enrolment.

Strongly related to the preceding issue is the inclusion issue. The law says: *"To the maximum extent appropriate, children with disabilities...are educated with children who are not disabled...* Although the law does not mandate inclusion it is presently a focal issue. Some radical advocates of inclusion insist that all residential schools, institutions, special schools, and special classes must be eliminated and that all students with disabilities be educated in regular classes. They assert that all neighbourhood schools must include all the children in their catchment areas, regardless of any disability. More conservative supporters of integration believe that a full spectrum of placement options must be maintained, ranging from hospital and residential schools to full-time attendance in a regular classroom in the neighbourhood school. In the nineties court decisions has been in favour of the inclusionists. Summing up court cases relevant to inclusion Kerzner Lipsky and Gartner (1997) write: *During the 1990ies, however, courts have increasingly found that an inclusive placement, with necessary supplementary aids and support services, is appropriate for a wider range of students* (p.96).

THE EFFICACY OF THE SEPARATE SPECIAL EDUCATION SYSTEM

Despite improvements in special education services over the past twenty years, such factors as inadequate accountability over-reliance on separate settings, overrepresentation of students of colour in special education, inappropriate referrals to special education, and by siphoning resources to students who are not disabled special education continues to produce limited outcomes. Based on available research literature Fruchter, Parrish, and Beme (1999) report the following deficiencies of the system:

- 1. Accountability is very limited. There are no useful instructional standards and very little useful data on educational and behavioural outcomes
- 2. Far too many students are placed in separate settings rather than in more appropriate, less restrictive instructional settings defined by state and federal law
- Students of colour are overrepresented in special education and particularly overrepresented in separate special classes. Many students are placed in special education not because of disability but because general education is not meeting their learning needs
- 4. The cost of evaluating, transporting, tracking, re-evaluating, mainstreaming, and decertifying students who may not be disabled is siphoning off resources from a resource-starved public education system. Parrish and Wolman (1999 p. 221) present figures showing that an allocation of about one eighth of total school funding (12.2%)is being used to provide supplemental services for about one tenth of the school-age population (9.77%).

Summarising research Kerzner Lipsky and Gartner (1997) conclude:

- 1. Drop out of students with disabilities may approach one third.
- Less than half of these students left the school system with a regular diploma (43.9% in 1991-92). For learners with serious emotional 28.1%
- 3. Only 14.5 % of students with all types of disability who have exited special education take courses from secondary institutions
- 4. A National Longitudinal Transition Study conclude *across a number analyses of postschool results, the message was the same: those who spent more time in regular education experienced better results after high school.*
- 5. The unemployment is substantial. 20 % work full time and 13% part time
- 6. Racial, social and gender inequities: *Nation-wide, African Americans are twice as likely as Caucasians to be enrolled in special education programs* (p.19). Labels are applied differently to different ethnic groups the label of mental retardation being applied more frequently to the African American students and they are over-represented in the most restrictive settings.
- Gender differences showing an over identification of males in special education number(70 and 30 percent) and girls in special education having more severe disabilities

As regards accountability, research on the outcome of the separate system of special education has a long tradition in the United States. This research has been summarised by many writers (Kerzner Lipsky and Gartner (1997), Zigmond and Baker 1997 and Kavale and Forness 1999.

Ending their comprehensive review of available data on efficacy Kerzner Lipsky and Gartner (1997 p. 198) seriously question the efficacy of spending ever-increasing sums of money to maintain dual systems. This seems to be a fair conclusion.

The dissatisfaction with these results is the background of the Regular Education Initiative (REI) that proposes that the regular education system assume the primary responsibility for educating all the students in the public schools, whether they be gifted, average, or disabled. Proponents of the REI call for the end of the dual system of education and its replacement by a unified, integrated approach and policy. Pijl (1994 p.77-78) draws attention to a dilemma. On the one hand there are serious doubts about the effectiveness of pullout programs. On the other hand there is little scientific support for the assumption that the regular class is the most appropriate place for a wide range of pupils, including those with problems. It is also not known precisely what changes should be made in regular education in order to provide adequate education for all pupils. Summarising research on inclusive education for students with learning disabilities Zigmond and Baker (1997) underscore the fallibility of the present general education system to serve these students efficiently. They find that inclusion can be achieved for a much greater proportion of students than what is the case today. However, in order to achieve full inclusion a broader set of options is needed than those present in general education. They write

We must find a way to balance the values of inclusion with the commitment to teaching individual pupils what they need to learn. Future reform efforts that combine inclusive schooling with the additional resources and specially trained personnel needed to achieve individual educational goals of pupils with LD, in whatever service option is appropriate, might achieve that elusive equilibrium (p.114)

The REI has surely created controversy in regular as well as special education. Discussing the REI Winzer (1993) says: *In fact, the extent to which exceptional students can be profitably educated in association with their non disabled peers is perhaps the dominant issue facing special education in North America* (p. 384).

FACTORS AFFECTING INCLUSION

General factors that affected inclusion in regular classes were state-wide student achievement, population density, per capita income, human service expenditure per capita, and expenditure per pupil. The type of disability was also affecting the students' school environments. Students with deaf-blindness and multiple disabilities were least likely to be served in regular school buildings, and within regular schools students with mental retardation, autism, multiple disabilities, deaf-blindness and emotional disturbance were most likely to be served outside the regular class in more than 60% of the school day. There is also a steady increase with increasing age in the number of students in time spent outside the regular class.

Incentives for inclusive education

There doesn't seem to be a direct link between funding formulas and placement. Precise criteria of funding tend to result in less local flexibility. More general criteria like actual expenditure, special education enrolment, etc provide more local discretion and flexibility in the identification and placement of special education students. A new trend is emerging. Rather than counting the number of special education students as a basis for allocating funds to schools and districts it is based on the total district enrolment (Parish and Wolman 1999, p.210). The 1996-97 revision of the IDEA (Pub. Law 105-17) demanded placement neutral funding. The state must ensure that the funding mechanism does not encourage segregated placement, each IEP must relate programming for a child to the general educational curriculum, and states must establish performance goals and indicators for exceptional children and youth and must include children with disabilities in statewide and alternative assessments.

Teacher training

When discussing teaching in the United States it is necessary to keep in mind that the context of teaching may be different from most other countries in a number of ways. A comparative study of teachers in eight countries (Stoel and Thant 2000) distinguish the following differences:

 Unlike the decentralised U.S. educational model, with its 15,000 independent school districts and multiple sources of authority, the surveyed education systems

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were national or strong state-like systems. Consequently, teachers operate in less complex circumstances than in the U.S. Professional requirements and expectations are more coherent, consistent and less open to crosscutting demands and pressures.

- Teachers in most of the countries studied are rarely held accountable for student achievement. Nor are teachers abroad caught in the difficulties generated by the emergence of student achievement as a political issue.
- Other countries typically have national or state curriculum that guide teaching and dictates what must be covered in each class. This isn't the case in the United States where teachers much more independently with teaching and curriculum. The authors rightly points out: *While this simplifies teachers' lives and allows them to concentrate on teaching and learning, curriculum and planning directives from the central education authority may also reduce their autonomy and feelings of professionalism.*

The authors of this report conclude that It is probable that classroom realities, which have driven good teachers out of the system in the U.S., are substantially different in the US than they are abroad. U.S. classrooms, with their complex student populations and needs, may impose substantially greater burdens and more difficult issues and challenges than those faced by teachers abroad. This may of course also create a different context for and stress on teaching that may have negative impacts on students with disabilities. On the other this may also foster a quality orientation to teaching and curricular innovations which may serve students with disabilities.

Present programs for certifications and licensure seem to be important barriers for further program integration. Most special education teachers are educated in programs separately from the programs for educating regular teachers⁹. Goertz et al. (1999) draw attention to the fact that the trend in special education teacher licensure or certification is moving toward licenses in fewer and broader categories, while

⁹ The fact that most children with disabilities spend a considerable part of their school days in regular school settings have initiated innovation programs in teacher education aiming at creating a core curriculum for the two types and certification for teaching both disabled and non-disabled students.

special education certification has remained outside this discussion. By and large special education maintains a separate set of competencies linked to disability type and not to curricular focus. In addition, states differ in policies designed to prepare regular classroom teachers to work with a diverse group of learners. A 1996 survey inquired about the state certification requirements that address preparing all teachers to teach students with disabilities. At the elementary level, 26 states require all teachers to complete a course related to teaching students with disabilities. At the secondary level, 23 states require such a course. Additional questions about teacher policy in the survey included approval of teacher preparation programs, competencies required for certification, teacher certification tests and required practical experiences. The latter is particularly important as a measure of the extent to which teachers are being prepared to accommodate students with disabilities in general education classrooms. Only 10 states require general education teachers to have some practical experience with students with disabilities, and 1 state encourages but does not require such experience.

PART TWO: INTERVIEWS IN THE UNITED STATES

PERSONS INTERVIEWED				
Type of	No.			
stakeholders				
Parents	3			
Teachers	4			
Principal	1			
Directors	2			
Training & Research	5			
Executives	1			
Total	16			

The respondents in the United States are listed in the following table.

The background of the interviewees described in Stangvik (2000a). The table is based on formal description of their primary functions and cover, of course, very different experiences. One of the parents is a professor of education. One of the persons interviewed because of her role in training and research is also a mother of a handicapped man. A parent is working as a lawyer and advocate for other parents. One of the directors is working with research projects at the national level and the other is a director for a licensure program at a university. One of the teachers is a speech pathologist and another is a learning disability specialist. By means of the experiences of this collective of persons I hope to improve the understanding of special education in the United States.

What people told me can of course not be separated from my perceptions. These perceptions are selective and based on my own cognitive organisation of the problems raised in the interviews. Communication is a question of coding and encoding. Therefore, it is necessary to reiterate some of my assumptions about the role of parents and their way of responding to the interview. In the second report of the project (Stangvik 2002b) a number of assumptions were made about the role of stakeholders and their perspectives on special education. The point of departure was that such roles would inflict upon how they judge which qualities should be given priority. In the report different knowledge paradigms met in special education are also discussed. This discussion may be said to stage my approach to the interviews.

WHAT RESEARCHERS AND ADMINISTRATORS TOLD

DIANNE

Inclusion through educational reform

Dianne is a professor of special education and the mother of a handicapped son. Telling me about her background Dianne says very programmatically to me:

...mostly because of the research I've done on the schools and inclusion I have shifted from just working as a special educator to working as an educator. So now I'm an administrator for all the programs in the college. I prefer to teach in general ed. And make disability integrated into that.

This approach seems to be the core to understand her professional and conceptual agenda. Taking her point of departure in the developments in the last two decades she contends that separateness and inclusion can never be dealt with without dealing with school reforms.

In the 90ies the whole... the late 80ies and the 90ies the beginning of the whole inclusion process that started in the late 80ies I would say. And then in 85 you get this bigger general ed school reform focus. Now in the 90ies what you got was the mixing together of those two because we realised that you were never going to effect inclusion of kids with disabilities in general ed or the decrease of the separate schooling unless you dealt with the bigger school reform, you just couldn't. So, you see those sort of merged together.

And then she continues:

Had we not had that 1985 to 90 focus on general ed reform I think we would still be sort of stumbling along a special ed agenda in a very separate way trying to include one kid at a time using a more civil rights kind of approach. Now we've got a whole different discourse that we can draw upon that is really about changing how we are educating typical kids in order to prepare...

The fallacy of the 'one kid at a time approach'

Dianne makes a distinction between three points of view on special education:

- 1. The 'traditional special educators'. They are primarily interested in high incidence, mild, disabilities. *There you've got a very strong, highly specialist professionalism and they're kind of uncomfortable with any change because as one of my colleagues said once "I became a special educator instead of a brain surgeon" which reflects that whole, you know, I've gonna find it, fix it, you need something really special...*
- 2. Another point of view is still the civil rights thing, advocating for inclusion on a kind of a civil rights logic, a one kid at a time approach, get the circle of people together that need to figure that out and help them figure it out. That's still very powerful and that's how we learned the stuff.
- 3. Then she adds...a third voice is a growing voice about "we'll never really get anything sustainable or achieve scale across all our schools unless you do it in terms or broader school reform.

Dianne defines her position by saying: What people have really noticed - as I said before - is that there are all these inequities that are part of that system. Kids who are non-white, poor kids and so on.

To her the special education discourse is strongly related to the discourses on diversity and equity. To solve these problems systemic changes are needed. School reforms are the important tools of change. *So at the same time you've got this diversity, change schools around, have them be more student centred, be more focused on learning results, all these things going on in general ed. The same time as that's going on you've got to hear in special ed that that's exactly what we need for kids with disability and that's why the systemic argument...*

The consequence of linking those together, Dianne says, one of the things that happened is inclusion of kids, all kids, including kids with disabilities, has become part of the policy at the school level. But, there are some conflicts. They say they need to be more inclusive to all these different kids with disabilities. At the same time you've got the old traditional special ed, medical model stuff and educators who don't want to let go of that operating a practice that's in conflict with the growing policies.

Pulling systems together; developments and barriers

Dianne contends there has been a positive development during the nineties. The response on the general education side has been, at least rhetorically she adds, have been very good. *They say "Oh, sure, sure"… but then at the practice level it's much harder because the barriers are all the old ways of doing things and the ways of thinking that re harder to overcome than a broader policy rhetoric.*

Dianne finds a growing support for her reform approach to special education among practice based professionals, but not within academia. *They won't let go of any idea that they championed for a long time*, she says. Then she adds *I guess I would say that I personally and my immediate colleagues have made a strategic decision to forget the academic educators and to work with practice because we see that that's where things move anyway*

Further commenting on traditional educators she says *We'll learn from their research* but I think that they are at a disadvantage because they can't take advantage of a more pluralistic approach to understanding situations and phenomena...

Categorical legislation in education

Categorical legislation serves to maintain a dual education system. Dianne draws attention to the fact that education has remained very much categorical and hasn't kept up with other legislation.

Some other disability legislation, what would be considered much more social definitions. So disability for example is defined in some of that legislation, limitations in life functions, OK, so it's much more like the Norwegian that focuses on a fit between the environment and a person's capacity.

To my comment that it is a mixture of approaches she responds:

Exactly, so within the disability legislation for Americans with Disability Act, the Vocational Rehab Act. All of those definitions are at least functional and in some ways very socially constructed. The education law hasn't kept up with that, they remained categorical.

There is also a great variability between states. Federal legislation even serves to maintain a categorical system.

If you go and look it every state's legislation that's quite variable. There's part of it that has to have the federal categories because you have to report to the feds by those categories, but in many states they've moved to other kinds, almost like New Zealand with the intensity of service.

Counting for the feds

The states, Dianne says, may be fairly progressive and may want to discontinue labelling of kids but continue labelling to get money from the feds. So you have got a system where actually the federal definitions in education at least are quickly becoming antiquated. *...And what's ironic about,* she says, *it is that the federal money that to support is very little, it's something up to 300 dollars per kid. I mean that's nothing.* This is a small amount of money but it may be used much more flexible than the state money which is more rigidly controlled by the state legislature. The states are moving towards more flexible funding systems, Dianne says, but there are some influential mechanisms.

We're trying to move that way but because everything is not moving together you've still got all these conflicts so you double count. Then the problem of course for practice is which idea dominates so for the run of the mill administrators in the central office it's the accounting for the feds that dominates how they communicate with the teachers and how people work...

The diversity logic

Dianne strongly argues for a non-categorical model. According to what she coins the diversity logic she doesn't want to draw any lines. *Any time you draw a line about who's in and who's out then you can count on the fact that the lines are going to move and more will be out,* she asserts. Dianne raises herself the question what that means and answers the question.

Well, what that does mean in practical terms is that means noncategorical approaches that means new funding systems, it means a different approach to training of teachers that's more learning based, it means, you know, all that stuff...

Removing the barriers between special and regular education is an important part of the process. In the last twenty years the parallel system has begun to break down. People have begun to speak similar languages. As that's happened, as people have begun to speak similar languages, as we've tried to understand the general ed reforms I would argue that the influence has been in both directions. I think that he general educators who have been able to create a relationship with special educators have benefited with regard to all kinds of kids that are really not labelled special ed but who benefit from some of the same ideas.

On the flip side, she says, special ed was so separate and so individual focused that they had lost the concept of learning community standards citizenry, all those larger ideas about what schooling is trying to do. *And so I think in special ed we were for a while getting lost, trying to either fix kids or make them function adequately but not understanding the context...*Now Dianne looks for a cross pollination of the two education system, a new hybrid. She doesn't want the teachers to be the same, but they need to have a common core and a common discourse and each of them a different speciality *...so that they can bring as a group all those specialities to bear on these complex groups of kids.*

A poor linkage between homes, communities and schools

Dianne doesn't want to be too negative but says that that's a weak part of our system in general. She perceives the very poor linkage between homes and communities and schools to be one of the big problems in educational system in the United States. And of course being a mother of a gravely handicapped son has substantially influenced her experiences.

So my own experiences in all those years, you know, lan's 30 so he started school in 1975 -1976 so he's gone trough all the different models and versions but on the whole I've never been impressed as a parent except for the occasional teacher, the individual. I have not been impressed with the system's ability to listen to parents, to hear parents, to allow parents to be substantive contributors,...

What I would say about special ed and parent involvement is our law - the 1975 law required parent involvement and it required it in some very specific ways. Because the law, and I think this is a general criticism of our law, because the law was so detailed that very detail created almost more constraint. So what happens is that every parent gets invited to a planning meeting. But parent involvement in general

education is pretty much left to the cup cakes for the kid's birthday and being part of the parent teacher organisation and helping the school raise money for the extras. They come to the meeting with the decisions already made. If a parent wants to disagree you should listen to them but what happens is that in order for a parent to get heard they very often have to go to court, they have to hire a lawyer. So, and many parents don't have either the interest or the capacity to do that. Dianne tries to explain this situation to me by saying. *Our systems operate as institutions in our communities but not as parts of our communities.* Professionalism, she explains, is an important aspect of this.

And I think the reasons for it are grounded in a broader general sense of lack of community. I mean, I think in America in general community has dwindled as a concept and as an experience. And within special ed I think it has a lot to do with professionalism, you know, you can't be in the sort of traditional special ed sense, the expert specialist and listen to parents. There's a fundamental conflict there. So I think overall educators think that they must tell parents what they're doing, but it doesn't feel to me that thinking big as a whole the system has any real serious value about listening to parents and engaging them as collaborators in the process.

Transition: "the translation of a public issue into private trouble".

Within special ed it is required that teachers begin planning for transition 6 or 7 years before the kid is expected to finish. So they're required to think about a transition plan, what is it the kid should really be able to do, what the priorities should be in terms of learning, they're required to be in touch with the adult support agencies and to make sure the parents know about them. They 're required to educate the parents, the student about what might be available to help them find jobs, find and so on. Then Dianne adds:

Does it work great for everybody? No, because here's no entitlement on the adult side. It's fine for the schools to tell me that there are these services. But there are waiting lists for the services ... So it's sort of like: the school can only do so much if the adult side of the system is underdeveloped and does not have enough resources to meet the real need. Different funding patterns ands lack of resources for adult services are important barriers. *You know*, she says, *we had a lot of money that the federal government poured into transition for about ten years and I think it made a difference*. It meant that 'adult service boxes and the school boxes' started creating ways to talk to each other and those have by and large maintained because the rule says you have to have a transition plan. So, there definitely are some optimistic aspects. However, lack of services have some dramatic effects.

Yes, and so, what happens to families is what Mill has called "the translation of a public issue into private trouble". You know, unless you have the knowledge, the sources, the energy, the time, and many parents don't by the time their kid's 21. They'll be fighting with the school system, they're tired of whatever. Unless you've got the kid at home and it becomes a private family trouble.

Inclusion in a diversity perspective

Responding to my question on inclusion Dianne says:

We increasingly don't use the word any more. We talk about self-renewing schools or schools that are able to use inclusive practices but we don't really use the word inclusion. And in part because we're trying to make a more systemic point...

Inclusion has been very much focused in a special education agenda. *So*, she says, *we've now shifted that agenda and we're seriously working with schools…!* To her students with disabilities are very diversified as regards both degree and type. The previous system, however, was only based on differences in type. We are moving more over to look at differences in a 'multicultural pluralistic society' kind of way, she contends. This creates a controversy between a special education and a general education inclusion agenda. She underscores the conflict between the diverse student base and the present normative practices of education.

As they recognise how diverse their students really are and the normative practices that they'd had are less successful, and so, they're sort of shifting too so that's a sort of another big shift I see.

She distinguishes two different stands: change or re-mediate. There is one group in special education which takes the point of departure in regular education and a more traditional scientist that views special education very much as designed to ameliorate or re- mediate problems. The latter group, Dianne says, uses pretty much one paradigm, one way of thinking about learning and knowledge and development.

Dianne views this as a paradigmatic conflict by saying: *So I do see that there's a rather large paradigm wall that we bump up against very quickly in special ed. We bump up against it a lot less in the general ed conversation.* She finds the explanation to this in the conflict between the pluralistic knowledge base of the general education diversity debate as compared to the special education inclusion debate.

Learning to become effective members of their communities

Asking Dianne what we should look for when evaluating special education she says:

What that means to me is that all the things that we do, we make up curricula, we set standards, we make judgements about kids, all of that has to be in the service of are they learning things that make them more successful members of their communities. If they're not then you change this other stuff.

In order to do that one has to construct a system of education that is responsive to individual children's 'personal signatures' whatever these signatures are. This system should honour and use their lives and their communities as a base from which they design how to learn to be an effective member of that community. When I ask her about how she looks upon the child as a learner she stresses the importance of meaningfulness.

From classical learning theory one learns that people learn things that are meaningful, and they learn it from the people around them. In accordance with her pluralistic approach to education she also takes a 'pluralistic approach to learning theory'.

It seems to me that you need to start with the more social constructivist ways of understanding learning, and you need to design education pretty much that way. Kids need to be it's a transactional event. Whether the kid is severely cognitive impaired or whatever their constellation of abilities and interests you've got to start with who they are and what's meaningful to them.

CONCLUDING REMARKS

Dianne's approach to special education is systemic. She resists a disability-based education. Her main focus is the improvement of general education and considers the division of education into two parallel systems of a barrier, which makes it difficult to cater for the diversity of the school population. Special education is basically regarded as a cul de sac. It hampers development by the individuation and categorisation of disabilities. Progress can only be achieved by reforms of general education and not by 'one kid at a time'. To her inclusion therefore becomes an obsolete concept. Reform and diversity are her key concepts. Population based funding, integrated teacher and common curricular goals for all children education are some of the necessary instruments for reforming general education. Community and transition are other important concepts in Dianne's approach to education. She draws attention to the fact that while there is a system of entitlements for education of children with disabilities there is not a parallel system for adult life.

ALFREDO ARTILES

Alfredo's research work is concentrated to cultural diversity in special education.

Broadening the concept of cultural diversity

Alfredo asserts that the knowledge base that is constructed in special education on diversity is not sensitive enough to issues of culture and differences in mainstream society. He has studied 22 years of publication in 4 selected special education journals and he found that less than 3 per cent of them were concerned with cultural differences. He concludes:

So the conclusion is the knowledge base we are generating in the special education field is not necessarily sensitive to issues of culture and differences as defined in the mainstream society.

Alfredo makes a distinction between real differences and constructed differences, and focuses the role of education in this process. He points to the overrepresentation of minority students in special education as one expression of how *constructions of difference mediate the way in which educational systems address the needs of students.*

Research has found this overrepresentation to affect groups differently. African-Americans tend to be most affected. Latinos and Hispanics do not show overrepresentation. When you start to segregate the data by state and by city and district then you find significant differences. Contextual aspect and political initiatives are important. For example, the political climate in California is different from Massachusetts. One has to take into consideration the current policies in place and funding formulas and so forth to make sense of patterns of differences.

Explaining the overrepresentation

To my question about the over representation Alfredo responds: *You know, as we say, that's the million-dollar question. We have been arguing about that for the last 30 years... He* offers several explanations, but he doesn't seem to be satisfied with any of them. One explanation he coins the 'cultural deficit explanation'. Minority students tend to come from low income backgrounds and they grow up in environments that do not allow them to be ready for school so they come to school with a number of deficits and have to do things they are not ready to. The other explanation he offers is what he coins the *structural sociological perspective'. Schools are microcosms of society and we live in a society that oppresses and marginalises groups. Whatever we see going on to ethnic minority groups in the larger society is reflected in the school, in this case by segregating students from these groups into a separate special education system. The referral system of special education is the tool for transforming marginality into special education practices. This system serves to individuate problems, which are truly social in nature. This is what I understand from him saying:

I think it's more complex than either of those explanations. I think it has to do with those things, but also with the way the basic assumption of the special education system that search for problems within the child.

Teachers and administrators lack familiarity and understanding of culture among ethnic minorities. The curriculum and many assumptions in the schools in the United States, Alfredo asserts, are based on the experiences of the white middle class groups. They tend to regard those experiences as the norm, as the natural way of the developing so whatever deviates from may be sometimes or always considered a problem.

Inclusion is a whole school approach

Inclusion is no simple solution. It has to go beyond changing names of programs and classrooms.

Well, Alfredo says, I think it's not going to make much of a difference when we have inclusive systems if we don't change very basic structures of what it means to be disabled, what t means to be ...in civil services, segregated settings and so forth, having s to the curriculum and so forth.

A deeper change is needed. You really get engaged special education and general education teachers in conceptualising their own identities, what it means to provide services and working together. *You know*, Alfredo says, *you would have to take a whole school approach to really get to the roots of this.* But, there is a serious problem here The problem in the US is that the major reform efforts do not tend to include special education agendas. The same is the case in the multiple education discourse. It doesn't include disabilities.

Training teachers

Teacher education is an important tool in order to prevent this overrepresentation.

So I'm looking at how we prepare teachers in teacher education programs and how teachers in schools are dealing with minority students as a way to understand cause you know teachers are the first person to refer students.

Alfredo thinks that diversity is treated in a very superficial way in teacher education and frequently based on cultural stereotyping.

This is the way Latinos are, this is the celebrations they have, this is the food they eat, this is how they dress, this is low they relate, they have this learning style. So we have this tension between stereotypes in acknowledging differences and at the same time trying to deny it.

A natural part of the special education discourse

Afredo's first priority is to push for a discussion on diversity issues and minority issues so that they become a natural part of the special education discourse as well

as of the general education discourse. We need to undertake a major campaign to raise awareness among people that culture does not belong to minority groups only. We live in a cultural world and we need to use a different set of lenses in order to make sense of what's going on.

Culture is also among white people and among all institutions, that we need to engage in research practice, develop a knowledge base that is concerned with these things, not only for those groups but for everybody.

Alfredo's second priority is teacher education. He underscores the important connection between training and practice. Working with people in schools and doing stuff in schools where the action is. And also making sure that we have a solid theory of how teachers learn. Because we have taken for granted that if we tell people what it takes to teach, this is the method they use, this is the thing they need to know about retardation they are going to learn it. We have done that for too long, we have never had a conscious awareness of how you learn from the information we are providing you.

Summary

There is an overrepresentation of minority students in special education in the United States. This is particularly the case as regards African-Americans. Despite of this minority issues have played a minor part in the special education discourse in the United States. Due to the lack of such a discourse in special education differences have been socially constructed without taking cultural diversity sufficiently into account and special education has been able to maintain an individual approach to differences. Referral processes have consolidated this individually oriented approach. Alfredo underscores the necessity for developing a knowledge base for general education as well as for special education, which takes into account all diversities in society. This knowledge base should be used to revise present teacher training.

ANN

Ann works as an education research analyst for the US State department of education. Her main work area is discretionary programs and inclusion of people with disability, including severe disabilities and ongoing reform efforts.

Inclusion is not only schooling and classrooms

Ann doesn't restrict her concept of inclusion to schooling: When I talk about inclusion I think about people with and without disability being educated together in school or are working together in a community or living together in a community in all aspects of life, work, recreation, play. She doesn't see inclusion as related to one classroom or one student. The whole school has to be restructured that make sure that the gifts and the skills of all students including those without disabilities are built upon so that there are reciprocal benefits for kids without disabilities just as there are benefits for kids with disabilities.

Inclusion: variability

When I ask Ann about the state of inclusion in the United States she underscores the extreme variability: In some communities some folks are reasonably well included and in others folks have to rely on segregated services. But there is legislation and there are lots of people working on it so I do remain optimistic but... The variability is more dependent upon where you live than the type of disability, Ann tells me. If separate programs for people with disabilities were set up before 1975 they have clung to them whereas other states that had not set up separate programs, separate institutions, separate bureaucracies included kids more in the existing schools resourcing constructions.

Promoting inclusion: Relationships and personality

Ann considers universities, which promote inclusion, committed people in the communities, teachers and, sometimes, visionary leadership at the State level to be important factors for promotion of inclusion. *And so I do think that a lot of the time it is personality or relationship driven,* she says. The experience of professionals and what they have been exposed to she also finds very important. Once people have seen inclusion or seen integrated systems and see how much better they are then

people become advocates. Then she adds b*ut a lot of people do not have that vision or have vested interests that lie elsewhere.* Even if people with significant disabilities, multiple disabilities and intellectual disabilities may have some of the toughest times type of disability might not be the most important factor. She finds attitudes and beliefs about disability to be the most important driving force.

Inclusion: serving a diverse and heterogeneous population

When I ask if she sees any educational efforts in the US to change those beliefs and attitudes, Ann answers that she definitely does. She sees that coming from the general education community. At the department of education there are a lot of people that are talking about re- inventing school so that they can serve the diverse needs of a heterogeneous student population. She describes that population for me.

We have kids with different language background, some people that are immigrants, some people that have been here a long time but have been very segregated and have a long history of poverty, you know, those are all big areas.

Court cases have been an important mechanism for improving the conditions for disabled people in the US. I ask Ann about her view. She responds:

I think a lot of the times those people may win a battle, they may win a court case, they may get a favourable decision but they often have lost the war in terms of getting a good program for their child.

She refers to several court cases to underscore this point. But, it certainly does create a momentum for people who are advocates to certainly use it and it can help drive things forward. *But*, she says, *I think that you've got to have some kind of upside-down legislative and obligate mandates*. But, even this is not enough. She finds that the law has a clear mandate of the inclusion of people with disabilities, but when people have a very different view of the law they read it differently. Laws are necessary, but they are not enough.

I think you often need a bottom of capacity building and work at the grass roots, the school level, and the community level to make sure that it really works.

We got the people out but the dollars did not follow!

When I asked Ann about the role of funding and categorisation she pointed to that service providers frequently congregate people who need support to live in care facilities and institutions and that the money flows to them. Bureaucracy is set up for that. Money does not follow the people into the community. And she continues: *So I think that's part of the deinstitutionalisation fiasco: Oh, yes, we got the people out but the dollars did not follow!* To my question about categorisation she draws attention to the fact that according to the IDEA 1997 you can provide non-categorical services to children up to age 9. She considers that to be an important push for fewer category-based services.

Parents are the conscience of the professional community

If you didn't have parents you would not have 91-142, you wouldn't have IDEA, Ann says. There are a lot of parent organisations, but they do not have any common policy. There are as many policies as there are organisations. The policy they choose is very much dependent upon the experiences of their children. Parents who have had bad experiences with inclusion and mainstreaming because the needs of their children haven't been addressed and don't want to put their children back where they haven't been doing well. They may not understand that keeping people in general education then some of the resources that keep flowing out need to come back.

Teacher education: A two track system

A lot of people in the school districts think that the universities are not teaching relevant skills and that what is being taught is not grounded in the context of today's school, Ann says. And conversely some universities do not give credit to teachers on the front line. Some programs are not very different from the time she graduated 25 years ago, she says. Specialisation is also a big deal in training continuing a two-track system of general and special education training. Ann comments on this: *Absolutely very, very separate habits of practice and separate training and then we get in schools and say: Well, now you need to work together.*

Development of a policy of interagency work

Ann finds education noticeably absent in inter-agency efforts. *Because it's such a big bureaucracy itself*, she says. But, there are certainly positions, in Government, for

people to co-ordinate disability research among the different agencies. This is now happening in education, health and human services. A lot of people have worked hard to try to make sure that here is more of a coherent disability policy, she says. But there is a lot more to go. She finds developments in the area to be very dependent upon the personality of people in positions.

IEP: 'just an exercise'

This was a real good opportunity for parents and then with the transition plan and for parents the student him-or herself and the school personnel to work together to design a school program that would meet the individual child's needs. She thinks that IDEA 1997 and the original ideas around IEP were lovely, that you would have parental involvement, that you would have people talking about child centred individualised decisions. But, she says:

I think that frequently unfortunately it is just an exercise. I think that people have tried to streamline it, I get a kick out of the idea of the idea of the computerised IEPs where you put in these characteristics and you get all of the same goals and objectives for the kids so...

At the end of my interview when I asked with her if she thinks there will be a progress for inclusion or would it go in different directions, she answered:

I think probably a bit of both given this melting pot in which a lot of people wonder who turned out the fire. There will be a lot of inclusion and there will also be some separatism on types of movement and think that both probably will move forwards and I am optimistic and I am extremely hopeful that inclusion of people with disabilities will progress.

Concluding remarks

Ann doesn't restrict inclusion to schooling. It also has to do with recreation, work and play. In order to promote inclusion in schools the whole school has to be restructured to be able to serve the diverse and heterogeneous population of students. She underscores the great variability between communities. Legal mandates, court cases, history of segregation, obsolete funding mechanisms, disability categories and a two-tracked education system serve to locate communities on the segregation-inclusion continuum. But, she underscores the importance of attitudes and the significance of

personalities and relationships of people in leading positions. She contends that the bureaucracy of the school organisation makes it difficult to integrate schools in collaborative efforts to promote inclusion. There are however, an important push for inclusion on both government and local level which gives her reason for looking optimistic towards the future.

JERRY

The IDEA's 1997 amendment does not allow states to wave more than 2 % of the kids from the assessment. This implies that all children with disabilities except the severely disabled have to be included in assessments. Jerry is a researcher in the area of assessment and my questions were naturally focused to this highly sensitive area. For technical reasons I was unable to record this interview. The main points made by Jerry are highlighted in the following.

- 1. To-day the question of accountability has been moved to the forefront. Therefore outcome assessment reforms are presently very important in the US. This interest dates back to the fifties and has been strengthened by international comparisons showing the USA to be somewhat in the middle.
- The United States do not have national curricula. The United States does not have a set of common goals. That is up to the individual 50 states to set, supporting social aspects of assessment.
- 3. Present system is mainly academically oriented and to much less degree taking social aspects into account.
- 4. Standards have been an important concept in this work. Assessments serve to divide students into two groups: Above and below standards.
- 5. When I draw the attention to the socio-cultural and the political context in the US that may support this division in schooling, Jerry pointed to the fact that communications skills are unevenly distributed in the USA.
- 6. He underscored the necessity to broaden the assessment methods without diminishing standardisation in order to make them more inclusive.
- 7. Assessment as an integral part of student work was mentioned as one viable method.

- 8. He referred to successful achievement of learning in regular classes when differentiated assessment systems are used.
- He divided goals of education according to age/school levels. Primary: Help to develop communication and social skills; Intermediate: Basic skills and later: Social skills for participation in society.
- 10. Responding to my question about the context in which these skills should be taught Jerry responded with uncertainty. He underscored the need for variations in settings, but did not relate this to inclusion.
- 11. According to Jerry the most important barrier for development was to find in the fact that regular schooling in its present forms didn't offer sufficient place for diversity

Concluding remarks

Assessment of this kind may certainly serve inclusion by showing that academic results may not be satisfactorily promoted by segregated settings for students with disabilities and by helping them to achieve common valued academic goals. However, academically and skill oriented assessment procedures in the United States seem to be based on a very restricted concept of accountability which doesn't seem to take social goals sufficiently into account. Assessment therefore should not be only related to standards, but should serve to promote the achievement of life goals. The division of students into groups above and below standards may maintain the labelling of students with disabilities across assessments. This may hamper their education.

ELISABETH

Elisabeth has a background in both special and regular education. Presently she is director the National Institute for Urban School Improvement and an associate professor at the University of Colorado, Denver

Inclusion: A concept of school reform

The National Institute, Elisabeth tells, was conceived as a way of organising and thinking about the value of inclusion as a vehicle for school reform itself. The institute is organised around three premises. First there is the need to be in urban sites, testing and using ideas around inclusion as a generator for school improvement. The second idea is that education and educational intervention cannot really exist without a climate for reform in a community in general. Much as you might market any kind of product in a consumer society and so we have a centre that's dedicated to the development of a marketing strategy around notions of inclusion in educational reform, Elisabeth says. The 3rd notion is that the scholarly audience, the practitioner audience and the leadership audience are really wilfully lacking in access to materials and rapid access to a variety of materials. The other project she is working on is funded by a state wide system's change grant in Colorado. It involves schools in building leadership teams and the use of the whole school system change model to collect information, use information to target certain kinds of reforms that are idiosyncratic and specific to the context of specific schools. The hypothesis is that by teaching schools and school professionals to do that work they will be better and better and better at serving the needs of diverse student groups.

From disability to differences: The hybrid teachers

When I ask Elisabeth about the place of students with disabilities in the projects, she responds that they don't really distinguish between the kinds of disabilities that students may bring to a particular school.

I think our premises are built very much on the notion that disability and other kinds of differences in school are social and cultural as much as they are indigenous to individual children.

Ultimately, Elisabeth says, *we're not very interested in the need to sort or categorise kids.* In order to accommodate schools to differences she has expectations for the relationship between educators who are specialists and educators who are generalists. She has is a vision of *hybrid teachers* who work in teams that accommodate and modify curriculum assessment and pedagogy to meet the needs of the kids who walk in the door in their classrooms.

Special education as a barrier

Discussing the role of special education, Elisabeth says:

In a lot of ways special education is more of a barrier... there's a new vision of how the school's ought to be organised that it is much of a support mechanism.

In her opinion, the creation of a federal mandate a nation-wide mandate on civil rights foundation to ensure that all kids at least had access to education was creative. But the implementation and the development of the model that followed were not necessarily congruent with the notion of civil rights. The model that followed was congruent with a medical model of diagnosis and treatment. It was congruent with the notion that groups of kids might need similar kinds of treatment and that what we needed to do was to have really effective ways of figuring out who could come into special ed and who had to stay out.

Special education as templates of the word in the law

Once in the assumption being that there were groups of kids who had identical needs and that we were able to serve them quite a prescriptive set of categories of children was played out. School systems, Elisabeth says, didn't do any creative thinking on how to serve this group of children. They simply recreated structures that were *exact templates of the words in the law.* Because the law is incredibly procedural and incredibly prescriptive they organised to meet the procedures of the law rather than considering "how are we going to organise in order to meet the spirit of the law?" Then Elisabeth continues:

The law is also predicated in terms of the processes for special education, very much of a logic positivistic view of the world. You remedy deficits, you fix them and then you put children back into some other place and not a very wise vision of the notion that disability itself - socially constructed or not - is something that people have as part of their human condition throughout their lives.

Conflicting world views

Answering to my question "Do you feel that there is a conflict in the community of special education on these matters?" Elisabeth says: *Yes. I think there is a huge conflict.* She feels this conflict begins with a schism between different ways of understanding the world, about epistemology. It has to do with how people think that knowledge develops and how social systems evolve over time.

She makes a distinction between two approaches to social systems. There is one which she coins 'the behavioural kind of approach' to the building blocks of systems and building blocks of redundancies and reinforcement in order for systems to work efficiently. She describes this approach by saying:

...and that's a world view way of thinking about things and if you live in that world view then you look for things that aren't working and you fix those things that aren't working and you create structures that are all built on tinkering of a system.

She contrasts this way of thinking to the *social construct is a notion of the way we make meaning in our lives.* According to this notion social systems exist anyway - regardless of whether or not someone wants to purposely design it or not.

... you push social systems and you help them to evolve over time by getting the people that are engaged in them in building consensus around what they want to accomplish and moving forward and making sure that everybody who ought to be part of that system, who belongs to the community is really involved in making decisions around the ways the community is going to be structured.

Somewhat pessimistically she adds that this is a very different approach to the development of our work than what I think we have right now. Explaining her view to me she says:

The logical positivist viewpoint seems to be predominated in my viewpoint by the privileged, by predominantly males and it certainly is the point of the realm for government politics, the scientific world and the medical world.

But, a little further she somewhat balances her view:

I believe that the dominant view is still the positivist viewpoint. But I also believe that there's an emerging ever growing voice of the social constructivist, the critical theorist that are becoming more widely read, and more widely discussed, the postmodernists, the deconstructivists but I think they are still the minority.

The role of the judiciary branch

The advent of special education is, according to Elisabeth, founded on civil rights and court cases. In fact, the law was initially built on court cases like most of the laws in

the US. Most of the laws in this country that are set at the federal level are always tempered by clarification in our judicial system. The judicial branch, Elisabeth says, both lays the groundwork for creating new laws and also clarifies and articulates laws that already exist.

...and in fact in a lot of ways if you think about the three branches of our government, the executive, the judicial and the legislative in many ways it's the judicial and the legislative that have so much power and the executive branch, with the exception of the ability of the president, to articulate and act as a spokesman, the spokesperson for the people's will is never as strong as the other two, ultimately, fundamentally.

The goal of education: Democracy and participation

When I ask Elisabeth about the most important goals of education and special education, she tells me that the main role of schooling is to lay the foundation of a democracy. The ultimate goal of everyone is being free and making personal choices. They ought to be fully informed and educated so that they're able to analyse all facets and choices The personal choices that they make should promote development of a community where justice reigns for everyone. This way of thinking is *a Jeffersonian notion of the meaning of democracy and carried out in a lot of the great thinkers of the 19th century, she says.* This way of looking at the goal of education, she says, is threatened by today's consumerism.

...living to consume which I'm afraid is really where a lot of American culture is. It is that that has driven a lot of the influence on American public education policy. We need workers, we need people to have skills, they need to be able to fit niches.

On the market side - on the consumer side of the equation the purpose and function of public schooling is to produce more workers for the consumer society. It is very likely that there is not much of a role at all for people with disabilities. *Because*, she says, you would have to work really hard to create the accommodation, the modifications but it may not be sufficient if you were thinking about it in that perspective to do the work that's required to make that happen. In her opinion in relationship to the goal of democracy the notion that there are some people who may not come to self determination as rapidly as other people does not preclude their participation in voicing what their needs are in participating in our communities. And she asserts:

And in fact it's incompetence not to figure out how to modify and adapt the methods of communications, the skills they need in order to be fully participating members and for us to figure out how to make sure their voice is there. So I think we have a fundamental responsibility to do that.

A bottom-up strategy of change

At the end of our conversation I ask Elisabeth about main barriers for development in her direction.

The first things she mentions is the lack of clarity about the public purpose of education in the United States and very little recognition - or value - given to informal practitioner based knowledge. Almost every innovation that's created, she says, comes from the top down. It's policy generated, it's driven by the school boards, it's driven by educational researchers and universities.

The ultimate end of that is that most practitioners, many practitioners, do not trust their own competence as professionals and, in fact, unlike architects, lawyers, doctors, do not continue to professionally push themselves over a lifetime of practice, and so I think that's an absolute fundamental flaw in our work

There are probably cultural anthropological reasons, she says, for the place that teachers hold in our communities. But until practitioners themselves believe that they have the professional knowledge and seek to balance out the power of equation in terms of their own practice it's going to be very, very difficult to develop communities.

Concluding remarks

Elisabeth approaches inclusion from a general education. To her inclusion is a question of reform and change in education. Differences in schools are social and cultural as much as they are indigenous to individual children. Real changes may only be won by changing teaching in schools. The 'hybrid teacher' is an important tool in this process of change. She utilises knowledge of the specialist and generalist teacher to modify curriculum assessment and pedagogy to meet the needs of all

students. By relying mainly on a medical model special education becomes barrier to change. It affords a too restricted picture of individual differences and is not congruent with demand of civil rights on which special education was based. Special education is based on an epistemological fallacy of logical positivism. By grouping kids by identical needs and serving them in a prescriptive set of categories the objective is to remedy and to fix deficits. The social construction of disabilities is overlooked. According to this notion you help systems to evolve over time and help people to evolve consensus around what they want to accomplish. The role of schooling in a democracy is to support people in the process of being free and to make personal, informed choices. In this process professional teachers who trust their own competence are needed.

ROBERT

Robert is professor of special education. He has done research around how to help people with difficulty in learning to learn more effectively with a particular interest in children with more severe disabilities. Work with children with autism and behaviour support has been a primary focus for many years. A primary goal has been to follow their students, to listen, to watch, to observe and to be much more effective than they are at adapting when their children are not succeeding. A particular interest was in how to build constructive learning environments for children who are behaving in dangerous and destructive ways.

Changing the unit of analysis

One of the things he has learned from this work, Rob tells me, *is that while we can come up with really effective strategies and procedures the major hindrance is the overall systems in which learners and parents and children operate.* Then he adds:

So we've been actually trying to look at if you were changing the unit of analysis from individual children or even individual classrooms to entire schools and communities. And that's a big challenge.

This change of unit is an important characteristic of Rob's work.

Special education: extending circles

I think the fascinating thing is, Rob says, *special education is always defined by what you say regular education is.* He uses the circle metaphor to illustrate the difference between those we really want to reach and those who are actually reached. Regular education draws a barrier.

It says "We can't go outside that barrier, I don't know what to do for this child, I don't know what to do for him or for her. This person's too big, this person's too smart, this person's not smart enough, this person has bizarre behaviour and therefore they're not inside that circle."

Rob sees special education as the system of strategies, technologies and philosophies that extend the circle and get it further and further and further out so that we are reaching more and more and more people. An important principle is *if education really works it works for everybody.* In order to remove these barriers there has to be a will to include everyone.

We talk about special education as if it is a technology or something but I think special education really starts with the belief of people within the culture that everyone belongs.

This perspective has societal implications. Special education is really at the heart of defining how a society defines itself.

Evaluating the situation in the United States Rob says a good job has been done to find ways of allowing people not to have contact with people with disabilities. So they really haven't had to come to grips with whether they're willing to include or not include. There's a lot of language about being supportive of diversity and supportive of difference but he thinks that there is a lot more language than there is actual behaviour.

Engineering effective environments

Rob is a behaviour analyst and very interested in understanding how people develop and maintain behaviours. He thinks more of what people do than of the internal process. What makes behaviour analyses a useful tool and a useful construct for thinking about special education is that behaviour analyses is a technology for engineering effective environments. Children learn from their environment and this interaction has to be the focus of study. They learn to pay attention to different things. A child seldom has learned the behaviours by himself or by herself. *You watch how people respond to their behaviour and they have been taught by that environment.* This perspective has lead Rob to a sense of really trying to understand better how to help peers, siblings, families, teachers and administrators to understand how a person with disability is experiencing the world at their end and how they're learning from it. And they are learning the same way as other children.

So if you accept that a person with disabilities is different and must go off to somewhere different then you behave one way. If you say "That child is a member of our society and that child learns the same way that we learn but is experiencing the world a tittle bit different, you must understand how they are experiencing the world and you must learn about that.

Teaching in a pathological system

Being a special teacher you to be very observant. You have to watch the child and to let that child's behaviour teach you. To do this willingness is not enough. One needs to understand concepts of behaviour and how to use those concepts as well as actual experience with children to have confidence to tackle unknown situations. Special education by definition means that you're always being faced with a different child, a different challenge, something you don't know. To work with kids who bring very significant behavioural challenges requires a level of sophistication that simply is not present in most schools. Most schools, Rob asserts, don't know the theory; the teachers have not been adequately trained to do functional behaviour assessment at that level where they are able to do the clinical interventions.

But, Rob, definitely observes some barriers in his way of working.

..., the structure that they're in, the system I think is pathological both for children and for teachers, and in part because we built school on assumptions and then those assumptions are not a part of an inclusion of special education, we take special education on as something separate.

Then he continues:

So within the USA if you think about special education as initially some separate schools, completely parallel systems, children who are typical

and children who are separate, they're not in a circle within a circle, it's two different systems altogether, right?

The way the systems are set up is not designed well for people who aren't all of the same type. Special education teachers are taught that they are different from the regular education teachers. A collaborative approach is needed, but the system is not set up to do that well, Rob says. To build social networks you almost have to operate outside the environment, the structure to make it happen. That's why a whole school approach is needed.

So here's what we've learned: We've learned that the single best way to deal with children who are having difficult behaviour is not just to focus on that child but to focus on the entire setting. So we're emphasising what we call school wide rather than individual discipline.

Rob tells me they have also learned that most serious problems are not the kids with severe disabilities, but the kids with no disabilities or mild disabilities that are being highly disruptive.

Efficient and inefficient schools

Rob has change projects in different parts of the United States so it feels natural to ask him about differences. He answers:

Poverty, size, cultural diversity. You go to Hawaii, the schools in Hawaii are very, very, very large, 3000 students in the school. The cultural clashes are very intense and you have small cultural niches that are very territorial, which are in conflict with many of the inclusive messages. You also have high levels of poverty, which are linked to low levels of language, low levels of reading.

When I ask him about what characterises schools that work efficiently he distinguishes three conditions for me:

- Clarity and importance of the administration. If a school does not have clear leadership none of the things that we recommend function because people start doing things, the message gets diluted, nothing happens
- An approach to team development, not lone rangers, not individuals but a system where we can work. There must be willingness to invest a team of people, typically 7 to 10 people that include the administrator

3. The team has been given a clear mandate from the faculty

Unsuccessful systems on the other side are characterised by being underfunded, chaotic, poor predictability and lack leadership and technical competence.

The social skills to work in larger systems

At the end of my interview I ask Rob about his priorities and his perspectives on the future. Organisation change is important to him. Organisations have to be created that give better room for both children and adults to work together in more complicated ways. He favours the present trend towards documenting accountability. Despite the fact that he believes much of the testing to be badly conceived he feels this move will direct education toward teaching quality.

Criticising present trends in teacher training where people want to train people over the Internet he underscores the necessity to learn from the observation of the interaction of children with their environments. He concludes:

Your job is to create effective environments. Pay attention. The environment that works one year may not be effective the next year, and the beauty of special education is the skill you bring to adapt the environment so it's effective for those children and I think the ...remember the old fashioned special ed classroom where the teacher could do that all by herself. Now, what we're saying in "Do that in the context of the regular school" and the answer is you can't do that by yourself. You need to have the technical knowledge, the behavioural knowledge and you need to have the social skill to work within a larger system.

Concluding remarks

For Rob special education is systems, strategies, technologies and philosophies to reach and to include more and more students in regular education. Whether this is going to succeed is dependent upon a belief within culture that everyone belongs. By segregating students with disabilities from the mainstream people haven't come to grips with whether they are willing to include or not. The parallel system of special and general education is pathological in the sense that it creates barriers between children and groups of teachers and hinders a coherent approach to diversity in education. In this situation a collaborative approach that focuses the whole school

and not only individual children is needed, and in his change work Rob works to establish teams of teachers and administrators at school units. As a behaviour analyst he underscores the ways children learn social as well as disruptive behaviours in interaction with their environment. A goal of his work is therefore to teach special teachers to work with larger systems.

NANCY

Nancy works as a director of the ministry of license program. She trains principals and superintendents to get their license so they can be principals and superintendents. She has been an assistant superintendent in a public school and a director of special education for a school district. Her master and PhD was in curriculum and instruction. Nancy also has an adopted son, 17 of age, who has learning disabilities.

Public Law 94-142: Paperwork

Funding is one of the big issues. You have school districts who really can't afford to fund what all parents want. Because there is not the resources to fund a school district often has to deny that parents really need everything they need. *I think movements like inclusion is really good but it also assumes that there are resources for instructional assistance that there aren't,* Nancy says. She also draws attention to class size. With 34 - 35 kids in each class inclusion of students with disabilities gets harder. And there's also an assumption that the regular teacher has a sort of training to do the differentiated instruction all of which Nancy thinks a lot of teachers in the existing work force don't have. Then she adds:

...but I really think the largest problem is the amount of paperwork required from 94 - 142. I think it has become a compliance mandate where so much energy is put into the paper and writing the goals.

What really suffers, Nancy says, is having the resources or the time to really implement the goals. *So you have a lot of problems with the papers that don't get realised during the year.*

Nancy finds a lot of the IEP work is very paper driven, very individualised, very direct instruction, very working on basic skills. These processes tend to direct education away from the general curriculum. When I asked her about the impact of the IDEA on these processes, she answered that the law has made people responding and the rights of people with disabilities have made progress.

...but I do think it's a law out of control now. Think it's much too much paperwork and I do think it's got to the point now that all the rules and regulations are preventing what it most intended to do, which was that kids have a free, appropriate public education.

I take this to mean that the procedural aspects of the law. Litigation is an important part of special education. Litigation in one state has an impact on another state. There are ways to avoid litigation. *But districts do not have the resources to provide for all kids*, Nancy says, *so when you get a parent who makes a lot of noise you provide for their kid unless it really gets to the court and mandates that the system needs to change.*

The law made students with disabilities a protected class and they needed to be, Nancy says. One has just kept adding on to it ...but it's become a system that is so clumsy now that... what people do now is they comply and they get political and they cover things but they really can't do what it needs to do.

Inclusion: mixed motives

Nancy finds academics very supportive of particular philosophies like inclusion. They can often prove it works well because they generally study it by getting a grant, they get many resources, more resources than schools really have. In this way they are able to study it under ideal conditions. They haven't the practical experience to fully realise the problems of implementation.

You know what I mean, because they have a grant and they got support and that's good because it moves the field forward. But I do think there is a gap between what university people think and what practitioners feel they're able to do. And I think maybe the practitioner needs to be a little bit more flexible or adaptable but you know, maybe the professors need to be a little bit more realistic about what really happens out in the school. In order to implement inclusion the regular classroom needs to have enough resources and that the number of students is kept on a reasonable level. *You know, you can pour a lot of money into supporting one or two kids. But if that's one or two kids in a class of 30 kids or 32 it's really hard.*

IEP: a continuum of services

If you get a 4000 dollars per regular child you get 9000 dollars for a special education kid in Oregon. The money goes into the general fund for a school district so they don't proportionally give it to special education, Nancy tells me. Because of the IEP process being an individualised program you do need the full continuum of services.

... so it's not like you can say we are going to have a resource room and put it into a smaller class size and you cannot say we're going to have a self contained room because for kids with individual needs. You really need both

But the lack of resources is a barrier for having access to this continuum. The result is that there's not just enough resources to go around. If you do get resources it's very categorical how it's distributed so it can't be used as flexibly as it needs to and it really doesn't help to reduce class size so that kids can be significantly included.

Teachers do not have much time to work with families

When I asked Nancy if she felt that inclusion in the special education field is a concept mainly related to school or is it a concept related to other aspects of support, she answered me: *I think most teachers are most struggling to keep up with their daily work loads so they don't have much time really to work with the family and the community.*

In her opinion families who advocate for inclusion in the school also advocate for inclusion in the community but she doesn't think there are many teachers who really put a whole lot of energy in the family. But there is a difference. Nancy feels that a lot of parents with severely handicapped kids are very involved because they really do need support so she feels the support is stronger when the severity of the handicap increases.

To serve the kids

When I ask Nancy what she thinks are the most important issues now in this field she first mentions *to teach teachers how to use differentiated instruction so they can really serve the kids*. She also wants to somewhat redirect the attention from ADHD and autism towards children who are severely emotionally disturbed (SED)

Now autism is really a big thing, you know, and a lot of kids are being, you know, determined to have autism. They're requesting more than 40 hours a week, 80 hours a week of direct instruction, so 1 think SED is a very big issue because there are some kids in school that is very scary.

Then she reiterates that the paperwork is a really big issue.

When I asked her about the future in this area Nancy draws attention to an upcoming issue. She told that people who have regular children are feeling like all these kids with disabilities or gifted kids get a lot of services. If you have a regular child without any kind of disability you're at a disadvantage. These parents are now becoming advocates for their children's needs. *The scales have tipped a little bit too much in one direction*, she says. Then she adds *Now, I have a child with a disability too so I kind of experience a little...*

Supporting her son: efficient teaching and social goals

He is 17 and he does math like a second or third grade level. Nancy says they never depended on the public school for support. She paid for private tutoring for him and he is in an alternative school right now, which is much more of a school that focuses on building a community and less on academic skills. Being close to the university knowing how to access any sort of services have given many opportunities.

It was an alternative school but I took him every day to this teacher who is the best teacher I've ever seen and she had reading instruction with him every day for 5 years, so he is a terrific reader.

Nancy's goal of education for her son is well expressed when she says that he is not going to take a tenth grade math assessment when his math skills are at second grade. Because my basic belief is if I can just have him feel good about himself the rest will follow, you know what I mean?

Nancy feels that the public system supports him. But it doesn't for all. *If you understand IDEA and you're a resourceful person you can get a lot of stuff to happen for your own kid and I do think it advances the system for other kids not as much as your own kid.*

The special teacher's role

She underscores that we need people who aren't necessary in special education who are compassionate and knowledgeable about special education. And she really appreciates people who move out of that role. At the end of the interview she comments on that new role:

Right, like I teach curriculum foundations and alignment and implementation and I just teach it so that I know it will work for all kids and I wouldn't do that if I didn't have my special ed background, ...

Concluding remarks

The procedural aspects of the law have become very important, and paper work has become the burden of special education. Much energy is being put into writing goals and doing paper work. Special education is directed too much towards individualisation and basic skills. This serves to direct education away from the general curriculum. In turn that doesn't serve inclusion. Class size and inadequate teacher training for delivering differentiated instruction are other factors. Individual programming for students is dependent upon a continuum of services adaptable to a diversity of needs but resources are distributed in very categorical ways reducing flexibility and not supporting changes in the regular class environment. Nancy wants people who are knowledgeable of special education to move out of their traditional role and to utilise their knowledge to develop teaching that work for all kids.

Tom

Tom has worked in special education for almost 30 years. Now he teaches at Harvard University and works at the education development centre in Massachusetts. Prior to this he was the director of the office for special education programs for the US department of education and responsible for special education at the federal level in the US. He has also been a local special education administrator and superintendent of a school.

Focusing the outcome of special education

I asked about the present situation in special education. Tom thinks we are moving from a period in which people were primarily concerned with getting kids into school, getting needs identified and to one where people are more concerned about educational results and whether children are learning and whether the schools are meeting their needs. He also emphasises inclusion and the consequence of that.

Because of that I think there is a much greater emphasis on inclusion, of kids being educated more with their non-disabled peers, and I think there is also much greater emphasis on inclusion within the curriculum. The kids are learning what other kids are learning in school.

Inclusion: getting research into practice

For Tom inclusion means that children with disabilities are educated in regular classrooms as much as possible with supports and accommodations required. The possibility to create a more inclusive school he says us dependent upon attitude.

You know there is a kind of deep seeded attitude about disability meaning children are incapable and I think that there is a history in most cultures, including this culture, of separating and segregating people with disabilities whether in institutions or in special schools.

He also underscores that there is a need for people to understand the instructional approaches that work with various types of children, being able to implement them and says there is a real need to emphasise getting research into practice and into the hands of teachers and school administrators.

Being aware of what the children with disabilities are achieving

Discussing the present relation between special education and regular education in the US, Tom says it varies from district to district. But, on the whole he thinks that there is a much closer connection between special education and regular education than maybe there has been in the past. Some of that is due to the fact that in the US special education has become very large. Close to 20% of the money in education is spent on special ed. So general education has to be much more concerned about special ed.

I think with the emphasis in the US on all kids meeting higher standards and the fact that kids with disabilities need to be part of the educational accountability system that increasingly superintendents and general ed folks have no choice but to be more aware of special education and much more aware of whether or not children with disabilities are achieving.

A placement neutral funding formula

The federal government provides about 11% of the funds or 11 - 12% of the funds for special ed, most of the funds are provided by state and local moneys. So an important question is if there is put into it any specific incentives to stimulate certain policy developments in the US. In the past, Tom tells, under the old special education law states were given federal money according to the children with disabilities they served. The other incentive that might operate was state money or local money. But federal money was based on the child account. That changed in the last IDEA authorisation of the special ed law. People were more concerned about too many kids being in special ed. So the funding formula changed to census formula.

In other words, states got a certain amount of money based on their census and various poverty indicators. So the funding formula changed from a child account funding formula to a census and poverty funding formula.

The federal money in special education goes to states. States must distribute most of that money to the local school districts,. They can keep some of it for state wide purposes but most of the money must be sent down to the local school districts and distributed on the census and poverty basis. A district will get a certain percentage of the money, a certain amount of the money based on the census of the district. If that district had a high level of poverty they would get some more money.

In the past some states provided more money for instance segregated placement than integrated placement but under the new federal law, the 97th amendment says

the states must have placement neutral funding formula. In other words they cannot have funding formula that promote segregation or inappropriate integration.

Not a two track system

According to Tom close to half of the children with disability are served in regular classrooms in the US. These kids mostly receive support from personnel like speech pathologists, physical therapists and so on. But most of them receive support from special education resource room teachers. Another 20 - 25% of kids are served in resource rooms about half of the day, and these kids are served again by resource room teachers. About 25% of the kids in the US are either served in special classes or special schools.

When I ask Tom if he feels that in the US there is actually a two track system still with special ed in one track and general ed in the other, he answers

No, I wouldn't. I think that there is much more integration than that. If you take the number of kids 50% of the kids are in regular classes most of the time. It's too high to call it a track so I wouldn't agree to that.

Incompletely developed service systems

Tom is not satisfied with transition from school to society in the US. He thinks there has been some progress in that area but progress can be very difficult for a couple of reasons. One is that the adult service system is incompletely developed for people with disabilities, particularly for people with more significant disabilities. So for instance if someone needs a community residence or might need support of employment it may or may not be there for him or her. So that makes the transition difficult. And for people with milder disabilities, sometimes there is no service delivery system at all. And so transition is very difficult. On the positive side - increasingly more and more people leaving special education either go to job or go to post secondary education, and you know, that's a very positive trend. The number of young people with disabilities going to colleges and universities has really increased significantly, So that's a very positive trend. On the negative side kids with disabilities

have a higher dropping out of school, particularly children with learning disabilities and children with emotional disturbance.

Teacher training: decentralisation and variability

When I ask Tom if he feels that teacher training in the US is adequate for the development of inclusion he answers that over all education is very decentralised and states do things in different ways and they're allowed to. So some states do a great job in teacher training and require for instance general education teachers to have training in the area of disability and other places do not. It is also the issue of preparation for special ed teachers to serve in supportive role inclusionary settings. *Some places do a good job in that and other places do a poor job. So it varies from one place to another.*

As regards the most important problems to be solved in the future, Tom says *I think that getting kids with disabilities proving their achievement in school is a major challenge that we face.*

Achievement and living an independent life

There are still too many kids who have very low skill levels who shouldn't That is particularly kids with learning disabilities and kids with emotional disturbances. The drop out rates for kids with disabilities is a major struggle and also effective transition to adult life.

To my question about what he considers to be the main criteria for evaluation of special education, he answered me:

Well, the main criteria would be the same thing we evaluate school for other children. You know, are kids leaving school capable of living an as independent life as possible, of working, on going on to post secondary education. I think we'll be looking at the same things that you'd be looking at for other kids, recognising of course the kids with disabilities, you know, require often times more to get there.

Concluding remarks

Inclusion is also a question of inclusion into the curriculum and what children with disabilities are learning in school. In that way inclusion serves to move the outcome of education into focus. The fact that close to 20 per cent of the money in education is spent on special education underscores the importance of studying the results of special education. There is also a need to develop instructional practices that work with various groups of children. The adoption of new funding formulas is also important in order to support inclusion and there has been a significant move to implement a census based and poverty based formula which doesn't demand the counting of children with disabilities. The law even states that funding should be placement neutral.

Transition is a significant problem in the US due to incomplete service systems. There is a positive trend, however, which shows that more students with disabilities go to jobs or continue to study at colleges and universities.

GENERALISING INTERVIEWS

The general ambition is to be able to serve a diverse and heterogeneous population of students more effectively. In order to meet the needs of the students reforms of general education are necessary. Population based funding, integrated teacher and common curricular goals for all children education are necessary elements of these reforms.

Traditionally, special education has been designed to serve this heterogeneity. However, special education has been based on a very restricted picture of individual differences. The disability-based approach to differences is coined inadequate and sought to be replaced by a concept of diversity, which offers more room for social and cultural differences. At a theoretical level I take this to indicate a shift to a paradigm of knowledge that puts considerable more weight on the social and cultural construction of differences in society and which underscores that differences are not only indigenous to individuals.

The disability orientation of special education is judged to be too narrow and to serve as a barrier for true educational reforms. This orientation is associated with the maintenance of a continuity of placement options that serves to divert attention and resources from educational reform. This orientation is kept alive by a funding bureaucracy and by referral processes based on categorisation and labelling of individuals. Elisabeth draws attention to the theoretical inadequacy of this approach when she says special education is based on an epistemological fallacy of logical positivism. By grouping kids by identical needs and serving them in a prescriptive set of categories the objective is to remedy and to fix deficits.

From these points of view the 'one kid at a time' approach is judged obsolete and has to be replaced by a reform approach to regular education. School bureaucracy is a reform barrier, which makes it difficult to integrate schools in collaborative efforts to promote inclusion and by a two-tracked system of special and regular education. A push for inclusion at both government and local level gives some of my respondents a feeling of optimism. It seems like the orientation towards inclusion has moved the outcome of special education into focus. Only 1-2 per cent of students with severe disabilities is allowed not to be assessed.

Assessments of this kind may certainly serve inclusion by showing that academic results may not be satisfactorily promoted by segregated settings for students with disabilities and by helping them to achieve common valued academic goals. However, academically and skill oriented assessment procedures seem to be based on a very restricted concept of accountability which doesn't seem to take social goals sufficiently into account. Assessment therefore should not be only related to academic benchmarks, but should serve to promote the achievement of life goals.

There is a strong feeling that too much weight is pun on the procedural aspects of the law. Paper work has become a burden of special education.

There are several moves to change this situation. Probably most important is the move to stimulate placement neutral funding and funding that isn't based on counting of students but based on census and poverty levels. There is also a move to change the very common two track teacher education programs and to increase the number of teachers with endorsements in special education. The demand for outcome - related accountability assessments of special education is another move that may support inclusion by aligning the curricula of special and regular education.

WHAT TEACHERS TOLD

CLEO

Cleo has worked in a special education department at the university level and as a special education teacher. Cleo teaches in an *inclusive setting* and she has an *inclusive classroom*. The school she works in has disbanded special education and resource classrooms and spread out all but the students with the most severe disabilities to regular classrooms. The school doesn't have any self contained classrooms but they have a support class where students may get help with their schoolwork. *Some kids will be pulled out of an explore or an elective, for instance they may not get shop or something,* Cleo says.

They cannot broaden their curriculum

To my question about the problems met when implementing this teaching, she responded:

I think that the biggest problem is that the general educator don't think they know how to teach the child with special needs and they sort of want to say: 'Well, someone has to come and help'. If I don't have help I can't do it. That's one problem.

Then Cleo continues: What I see I think a lot of teachers.. most teachers who have been teaching a long time think that they cannot broaden their curriculum and I think those people probably haven't been sort of keeping up with the modern ideas. They haven't been making changes that would be good for all children so they think that if their way of teaching is very narrow then they probably aren't going to meet the needs of kids in general.

They get money for those kids

An important question for me is if students with disabilities who are taught in regular class have to be categorised. Cleo tells me that they have a case manager who manages 38 students who are on the IEP. They get money for those kids who are identified. These kids will also be focused and categorised in informal communication.

When we do talk about them in that identification when we're testing which kids will... it says in their IEP that they can take the test, you can give them more directions, that's OK, we talk about how is so and so behaving. Well, what are their goals, so, yes, we do make identification around.

The teacher is much more involved

There is a closer contact today between special end regular teachers. Until a couple of years ago the special educator would do the IEP, would meet with the parents, might contact the teacher, but would write up a goal herself. It would just stay there and the regular classroom teacher had very little input. But in Cleo's district today they have simplified the goals. The special education teacher still writes them up but she will ask the teacher: What will this child be, what can I expect? I don't know this child, you teach them every day, I just have a piece of paper, help me. And so the teacher has more input. The goals are written 3 times during the year. The students are graded 3 times and the classroom teacher is responsible for marking. She may conclude they've met their goal, they're working on the goal, and there's no progress toward the goal. This is sent to the parents. *So in our district*, Cleo says, *the teacher is much more involved and meets with the parents, with the special educator, speech teacher, whoever else use to be in the meeting, so quite a few people.*

We cannot give them help

When I ask Cleo how she feels teacher attitudes to this type of inclusive school setting, she says *frustrated*. Staff cuts and increase of class size from 18-20 children to 25-30 children has frustrated the teachers. *We cannot give the kids who work more slowly, who have trouble, who need help with things, we cannot give them help*, she says. The only assistance regular teachers have in their classrooms is 8th grade students coming to help students in the 6th grade. But, to Cleo, this is a good thing.

I think the hardest part is getting the one who struggles, who has a disability not to think bad about having someone always help so that's the hardest part. But I think having a peer trying to explain something to you sometimes is better than having a teacher explain it so that works too.

If you try to teach respect then you have an inclusive setting

Cleo tries to teach children to be respectful of each other. *Respect yourself, respect others, respect this place,* she says. I asked if this ought to be taught in an inclusive

setting. Yes, because if you try to teach respect then you have an inclusive setting, she answered. If everyone is respectful of everyone's ability... so I guess,... yes. Later on she adds I want my students to be respectful of each other and to be respectful of themselves, and I think if they do that then they can all work together.

We don't have much music, we don't have shop

The most important barriers Cleo perceives is that her goals are not appreciated outside the classroom. Many of her students lack parental support and a work ethic. She also feels the financial status of schools to be an important barrier.

We don't even have art classes any more, we don't have much music, we don't have shop, we don't have all these wonderful things that attract kids and make them interested in learning...

Cleo feels her colleagues are very creative and inventive and recognise all the ways to teach but that the attitudes of the general public are not supportive.

I think that the general public still feels that a book and a pencil and a piece of paper is the way to teach and so a lot of people say: What's the matter? Make them read and answer this question and that will tell you that's a smart student.

DEBBIE

Debbie is currently principal of an elementary school of 138 pupils from kindergarten through the 5th grade. She has been a special director for the school district and has a varied experience as a special educator.

The school is in the first year of a pilot program, Debbie tells me, where they bring kindergarteners from across the district who have been identified as having disabilities. They go to their neighbourhood school in the morning and then they're bussed over here in the afternoon. That gives them a double dose of kindergarten, more language that they try to focus on with them, and socialisation kinds of skills. In

addition to the 14 students in this class they have another 15 students on special funding.

Funding by the number of kids

The district provides them with some extra resources and they determine their resources that they get based on the number of students they have. *They try to take into consideration the severity of the kids and their needs. It's really hard to weigh that and figure that out.*

Because they have taken on the kindergarten they keep a full time teacher. If they didn't take on the afternoon kindergarten they would have had a half time special ed teacher. In addition they have got some educational assistant time. The amount of time depends on the number kids you have. So they identify what the students' needs are.

Identification: Teamwork and paperwork

They have a school psychologist who does assessment in addition to their special education teacher. They have an autism specialist who will come in and help with evaluation. If they suspect a hearing impairment, hearing disability, etc. they have specialists who come in countywide to help with that assessment and identification. They determine what assessment they will do and who's going to do it. They have to make sure that they evaluate all the areas of disability that they suspect, not just a narrow evaluation. After it is all done a team including a parent talk about what the assessment information tells them. In the meeting it is determined if the team thinks that a child has a disability. If the child has a disability there is a whole lot of paperwork that has to be done around that and there are a lot of legal procedures.

We have to include the parent in all decisions now. It's the eligibility and the planning, the individual plan. We have to notify the parent every time we do anything whether we're going to assess or change anything the parent has to be notified the minimum. In many cases the parent has to actually sit there at the table with us making that decision with us. They can't do certain things with kids with disabilities as far as suspending them, expelling them, excluding them from school for their behaviours. *Oh goodness, there are a million of them,* Debbie says. After they have identified a student as having a disability they do an IEP with the parent, with the classroom teacher having to be there, the special education teacher, sometimes the school psychologist is there. It could be a huge meeting depending on what that child needs. And that IEP is good for a year. You can come back before the year is over if you think you need a change, if the parent wants to take a look at it. Typically it will run a year.

So it really depends on the child where the child will go

Kids have different days, Debbie says. They all start the day in their classroom and some kids, if they're on the IEP for reading and the reading is at 9 o'clock in the morning, some kids would then leave their classroom and go to the learning centre. They might go with the special education teacher or they might go with one of the educational assistants for some small group instruction. And then they could go back after reading. If they have math it may be the same thing. They may go somewhere, or it could be that the special education teacher is in their classroom or they have an educational assistant in the classroom to help a child. *So it really depends on the child and what their needs are where the child will go. Some are pulled out for instruction, some get extra adult in the classroom...* Will it happen in the classroom, outside the classroom, will it be a small group or will it be a one on one, and that's talked about in the meeting.

Inclusion: You've got to look at what the kid needs

For several years the district funded inclusion, Debbie tells. They got a lot of training around it and they brought all those kids who had been placed outside the schools

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back and served them in the schools here. They increased their staffing. And then the tide started changing again and we started sending more of the kids out.

I think what we found over the last 10 years is that you need to go not one way completely or the other. You've got to look at what the kid needs. Being in your neighbourhood school and a classroom can work for some kids and you can take another kid with the same kind of disability and it won't work for that kid.

Debbie thinks the main thing that excludes kids from the classroom is behaviour and recapitulates a case with me. When I ask her how they validate placement decisions she says they involved people from outside to come in and consult with them. They go through a special ed director and they call in a behavioural specialist and someone who helps to develop plans for kids like him.

And so we did those interventions and we worked with them for months trying to design a program and all the time I'm talking to our special ed director and she knows we're having trouble here. We're not feeling good about what's going on with this kid.

The IEP: much more usable for teachers

Teachers are using assessments differently today.

They're asking the school psychologist "What does it mean in the classroom?" "What does it mean for me as a teacher?" And the school psychologists are talking their language now because they know they are going to be asked those questions. So it's not just "Here's the test. Now put it away, it doesn't give you anything valuable."

So the tests are much more useful now and their specialists are giving much more information when they ask for it. Debbie thinks that teachers are much more involved in the planning. *I know here at our school,* she says, *our special ed teacher puts it in a way that the classroom teacher can understand it and use it.* When she writes the report she writes right on that IEP. Here's where the kid was, here's where they are now. She thinks that's much more usable for teachers. I take Debbie's observations to mean that an important change of perspective of special education is taking place. While regular teachers previously have looked upon special education as less relevant for their own classroom practices they are presently more apt to focus consequences of learning disabilities for regular classroom teaching.

We're thinking a whole lot more before we're pulling them out

In spite of these tendencies Debbie does not say yes to my question if schools have become more inclusive in the 90ies. She isn't sure about that.

If we talk about the regular population that is in schools, LD, communication disorder kinds of kids I think that the amount of pullouts, push outs push in have been about the same. I think it fluctuates, goes back and forth. I don't think that has changed a lot. And I think we've found a good balance that we're comfortable with

Debbie doesn't seem to support the Regular Education Initiative (REI) when she adds but I don't know if that's a big change because I think we went in one direction where all of the services were pushed in the classroom and I don't think that's the answer for all kids. After some reflections she says, however, I think we are including more. We're thinking a whole lot more before we're pulling them out and put them somewhere else. It's a lot harder to do that now. She finds it is probably more costly to run full inclusion as you have to have more resources to be able to serve the kids with learning disabilities because you spread all these resources all out.

There is a number of teacher assistants at the school. Four full time assistants and a number working part time. They are used to teach kids. They'll go in and provide extra support in the classroom. Some pull kids out and meet with the teachers once a week for planning. Debbie meets with them once a week with the special ed teacher. *Then we'll problem solve kids, we'll talk about strategies,* she says.

To provide an environment where they can reach their potential

When I ask Debbie what her goals are for the 14 or 15 kids she has on special funding she says she wants to be able to provide an environment where they can reach their potential whatever that might be. And so that they feel good about themselves and feel like they are accepted. One of the problems, she says, is that they don't feel good about themselves. They feel different and it's hard for them to feel different. We do a lot of grouping of kids and we group for all different reasons.

So we're trying to neutralise... Being grouped and going into learning centre... I had a newspaper team of 3rd, 4th and 5th graders. They are pretty gifted kids and we studied newspapers, and so we go to the learning centre that's where my group works... and we mix all kinds of kids

up and you're coming and going for all different reasons and that neutralises that stigma. But kids still know, they still know. I mean, I never found a way to erase that. Whether you're helping in the classroom or helping outside.

Debbie feels that social stigma is the most important barrier for these kids. It has to do with society in itself. Lack of understanding.

We know that kids can be cruel. We try to teach them to be kind and care about each other, unfortunately I think it's part of the human nature that's going to sort out what is perceived as the weak ones and I think that is a huge barrier.

KATHY

Kathy is a resource room teacher at a high school of about 1400 students. The special education program has 31/2 teachers and they serve 200 students with a variety of handicapping conditions. She has a very long experience of special education in a wide variety of settings.

The bread and butter of our program is the classroom

The program Kathy works in a program they call SOS or skills of success. It is a touring program that helps students to complete all the assignments they need to complete in order for them to get regular diplomas. This is a part of the regular program. Every student has 8 period class offerings. One of these classes is the SOS class. The rest of the time they're out in regular program classes. They're in English and science and math and history and social studies. *Everything other students do they do*, Kathy says. The subject that regularly is most difficult for them always is English. It is followed very closely by math. Kathy describes the situation this way:

And we just help them through with what they need and often it involves reteaching, you know, just breaking it down to simpler, smaller steps and they say: Oh, OK, I get this and off they go.

This is Kathy's largest class period. She has 17 kids when they are all there. Every one of them is doing something totally different. She has two adult educational assistants and one high school student who is trained as a peer tutor and all four are, she says, usually incredibly busy because all the kids need help.

Then the master computer kind of figures out...

Most kids who are found eligible actually appreciate the help, Kathy says.

Then the master computer kind of figures out what periods work best so the kids who are with me this year may not be with me next year, they may be with one of my colleagues because it fits their schedule better.

We let the computer do that and because we are very like-minded, she says. Kids can move from between the colleagues and get basically the same stuff. We do it a little differently because we are different people but we as a department are very clear about what we want for kids and how we do it. Some kids in the program Kathy has never worked with, she says, and it is purely up to the computer.

...to please the paper pushers...

I asked Kathy who are the people doing the IEPs. She feels she has to streamline the process and feels that as a conflict.

The letter of the law, the writing of an IEP is impossible to do when you... I do 70 IEPs a year. I would do nothing but write IEPs if I did them the way the department of the federal government.... So we as a department have streamlined it in a lot of ways.

She continues:

I can't individualise when I've got a room with 17 kids. What I can do is give them a little bit of what they need and get them going like... but I don't write that stuff down. If I did I wouldn't have time to work with kids. So what my paper work looks like and what I do with kids is really very different. The paper work is to please the paper pushers and I guess the way I get away with it is I keep my parents happy.

You know, she says, their kids are successful, their kids are happy here. She likes the parents and they like her. They get along really well. I keep them informed and I figure if I get sued I will be sued by an unhappy parent not a happy parent so that's where my energy goes. So I'd rather pick up a phone one day and say: Oh, this didn't work very well than fill out forms and send home reports.

Inclusion has to make sense

Kathy describes the role of her program when she says:

The regular program is as inclusive as it can be and still maintain a high school standard. Special ed then picks up the slack for the lower end that doesn't really fit in the regular program...

In another part of the interview she says:

I mean, I don't believe a vulnerable wheelchair kid should be in... who intellectually haven't much going on should be sitting in a US history class. I mean I believe that as well as you know, a lot of my colleagues, so I am not a: Let's include everybody anywhere sort of person. I believe that what is most important is that people are included appropriately in content they can handle.

The lower functioning kids and the mentally retarded kids take art, they take home economics, things that they can actually do. They take introductory science and introductory social studies.

They can handle that stuff, she says, but we're not putting them in upper level classes, it makes no sense. They can't do it intellectually. Everybody in the room knows that they can't do it so why are they sitting here. So that to me makes no sense...

For Kathy inclusion *has to make sense.* It makes sense when it is appropriate and when you can justify it. There are lots of parents and parents support organisations that I think take inclusion to a really ridiculous level, she says. She puts her view on inclusion this way:

I think it is important that kids are a part of their social community and I think it's really important that kids being around other kids in a normal, natural setting. I think pushing kids in wheelchairs and in beds around to classrooms just pretending that they're like everybody else and ignoring their handicap is unfair to the kids and to the system...

...helping a kid graduate...

When I asked Kathy about her teaching philosophy she underscored the close relationship between special education and regular education.

I would say special ed exists because regular ed exists and that we should never ever forget that we need regular ed and we are a support to them, a help to them and a support and help for kids that's why I'm here doing what I'm doing. That we are not better, we do not know more, that what we do is different and complementary and it feeds the final picture which is helping a kid graduate from a system because in our culture that diploma matters. It would also be nice if they learned a lot but it is the paper that for them also is often the goal.

Kathy thinks that about 80 per cent of the kids in the classroom will get a diploma. She tells me she has become progressively more academically oriented. I've always thought school work and academics was important, she says, but she thinks the whole department has kind of moved with her. Compared to most schools she suspects the school spends more time and energy doing more support work for other classes.

You drill him to death in multiplying fractions

She doesn't feel the role of special education very encouraging.

A lot of special ed programs still do what special ed teachers are trained to do. You do your little testing and you find out he doesn't know how to do multiply fractions. so you drill him to death in multiplying fractions and you let him fill out. And boy, he can do this one little unit and that means nothing in the big picture. It means absolutely nothing in the big picture.

To produce and to be a part of

When I ask Kathy what she thinks is the most important goal of education she answers me:

I think it is most important that kids be a part of producing, a part of their community. And I think kids need to be pushed in order to challenge themselves, and I believe that's what I do. I'm part of a system and part of a larger community and my job is to help kids understand how they can fit in that community. In order to achieve this goal kids have to take responsibility for their own learning.

We get parents of kids coming in for elementary and middle school exams and you know, oh, they can't read very well so you should just give them their diploma. I don't think so. The kid's got to earn it and if they can't earn it they don't get it.

Special education: learned helplessness

Kathy feels like high school is the first place where natural consequences fall into place and she thinks special ed makes that worse. It has created what she calls *helpless, pathetic, dependent students.*

The way special ed works in elementary schools to me makes no sense at all. I think special ed produces, trains kids to be helpless. You know they come to high school to sort of sitting there waiting for you to do all the thinking, all the planning. They take no initiative, and I think they've been trained to do that, that's the sort of sitting there waiting for somebody to snap their fingers, don't do anything till somebody gives you a cue

Kids should be held accountable for their learning and Kathy feels it's a flaw in the whole system that kids are allowed to pass through it and to have no reason to do anything other than intrinsic motivation.

Kathy's priority is to help kids to get through to other classes and she doesn't think that most special programs have the regular program as a top priority like it has for her. She blames special education as a discipline and the universities for this situation.

And I think special ed as a discipline fosters that, and certainly the universities cram it down everybody's throat. You know, this university teaches the student teachers that regular teachers don't know anything and that they're going to come and fix everything, but they're taught nothing about regular content or overall curriculum or, they don't know how to teach reading. So they're taught this little package how do you remediate

Out of touch with the real world

Kathy feels there is a grave conflict between the reality of the school system and the model that is recommended for special education. They have got 200 kids and you're

supposed to have a planning meeting and call in all the community services and the kids' parents and the relatives...

For a learning disabled kid that's reasonable. But they've got the system laid out that would, you know, for each kid is about 10 to 12 hours, I've got 70 IEPs, that's my whole work year and I haven't taught a lesson.

When I ask Kathy about the future she talks to me about what she calls *excuse making*. It's a cultural thing, she says.

Oh, this poor kid has an attention deficit so he can't do this. In your classroom you're supposed to provide special needs aid and he can't do his and so you're supposed to provide something special for him and so: Oh, I can't do this I have allergies so...

She feels for the regular class teacher. You may have classes with 30 kids and nobody is considered to be normal and all of them is supposed to have something totally individualised. Then she expresses her social philosophy to me.

And the fact that we believe that everyone needs to cater to our needs I think weakens our society and cripples us a culture because nobody sucks it up and does it.

To parents who want to see everything written she wants to say *I* can either spend time doing this paper or *I* can teach your kid. *I* cannot do both because your kid is one of 70 for whom I'm responsible

To allow people to expect that everything is going to be totally individualised is absolutely ridiculous, she says. There is no money coming for special ed, more and more people qualifying all the time.

WENDY

Wendy has worked in special education for about 20 years. Currently she specialises in working with children ages birth to 3 who have disabilities and whose families are living outside of the USA because they have a connection with the US's government. She is a private subcontractor to the government whose services include screening, assessment and evaluation, intervention, transaction and service co-ordination. All her work is done in natural environments. She goes to the family home, the park, wherever the child is as part of their life.

To start young

Wendy wants to see outcome and she realised that if she wanted to look at outcomes for people with disabilities she needed to start young. Because when she met children when they were in middle school and high school and talked to their families they already had the idea that their children could not achieve. But when she works with young children you might say to parents: "*What kind of adult do you want, what are you raising, at age 21 what is your vision for this child and how can we begin to get there?*" Then she saw families react to her in a different way. She says *I couldn't get to them before the idea that their children could not achieve was set and that's critical to me.*

But the school is not the world

The biggest problem for efficient work Wendy thinks is that people think too narrowly.

They have an idea of what a person with disabilities is and what they can and cannot do. So, rather than looking at open ended outcomes they're very narrow in their view of what can happen and I think those of us who are involved in schools seem to think that school is the world.

But the school is not the world. People spend a smaller amount of time in school - hopefully - than what they will do living in a community and living in a society. Then she adds:

I think we remove ourselves from society too much. We're microcosms instead of being part of what the rest of the world is doing. We're apart from it.

The law: force people to accept change

Wendy has worked in special education during a lot of law changes. I therefore asked her about the importance of those changes. She responds that it is basically a question of moral changes and the law doesn't talk about moral and philosophical changes. The law may, however, force people to accept changes.

I think that laws give us a way to force people to accept change who otherwise would not change. People who were not open in their thinking. Who don't want new ideas and new ways of doing things. If you go to them and you have the law in your hand then you have something to begin to make them change and the administrator who would not make changes otherwise understand that they may need to protect themselves from a lawsuit if they don't.

Bringing down the image of their students

Wendy was working with profoundly disable individuals when the 1975 law came. Before that everything was totally segregated. The law meant a big change.

the law gave me an entry to the school system that I did not have before. Suddenly it wasn't just a private agency that was overseeing programs, it was the public school system. Big change in funding, big change in philosophy.

It opened their communities. But she found it really interesting that even among special educators there was great conflict about bringing these people out of institutions and into the public school system.

...they put us into separate school with all these people who were considered educable and trainable, and they were prejudiced against me. They did not like having us there. They felt like we brought down the image of their school and their students.

The goal: To be a part of...

I ask Wendy what she feels is the most important goals and objectives of special education and she answers:

To be part of everything else that happens in our society as opposed to be apart from it.

We need to lose the "special" in special education, she says, and see ourselves as global educators. We have colleagues who need to benefit from our knowledge and our love of that speciality just as we need to learn from them.

To build that idea of sameness

She underscores a basic principle in her work.

As soon as I meet a child and the family I begin to point out to them how much their child is like other children as opposed to being different from them. Now, she is trying to build that idea of sameness rather than focusing on what the differences are.

No one comes into my clinic for the services

The natural environment has become her educational tool.

No one comes into my office, no one comes into my clinic for the services, I go to them for everything because I want them to see that they can be successful in the society. Sometimes I am teaching in a grocery store and just wherever the family goes and wherever the problems are that's where I go because I feel like if I tell them "Oh, you have to come to my clinic that's saying that there is something so special here...

Later on she says:

When I encounter teachers and professionals who tell me "Oh, no. I have to do this in the clinic, I have to do this in the school" I think "You are valuing yourself, you're looking at it through adult eyes."

To see another way of doing things

There are barriers for changing this way of doing things.

It's difficult for people who handle budgets who can only let money flow in a certain way, to see another way of doing it. I remember when I had to fight the people who handled textbook money and told them that profoundly handicapped people didn't need reading books but they needed other learning tools and to them those were the textbooks.

The union was another barrier. They had rules that protected the teachers so the teachers only worked so many hours and so many hours in a day.

So we had to work with them to say "OK so the teachers are still working 35 hours a week but it may be that on Tuesday night she is working from 6 to 7 in someone's home and she may be working on Saturday morning in the park. And that was a big switch in their thinking and for them to realise we were not taking advantage of the teachers doing that.

Mileage for teachers driving from house to house had to be reimbursed. That created another problem. The budget people panicked, Wendy says, just because it was something new, something they had never thought of.

The law also said they had to do it

Big changes in the law were taking place in the nineties, which gave them a way to change the reluctant agencies They would go to the person in charge of the budget and say:

My teacher has to go to this child centre to work so we have to have a way to get her there and the idea that when we meet one... because the law also says that we're responsible for transportation for young children when we tell them "The group is going to need a library and I don't have a car and we have to get them there" Suddenly I was going to the person in charge of the school transportation and saying "Can't you buy car seats so that I can put my little kids on your bus and take everyone to the library?

Well, Wendy says, of course the first times we got "No" but over time they did and they understood that she was not asking for myself or philosophy but the law also said they have to do it.

A very fluid system

At the end of my interview I ask Wendy, what she thinks about the future of special education. What she wants is a development of an educational system that offers full range of options based on what children and their families need. She believes that at times there are people who need a separate system, they need a segregated classroom to meet their needs at that time. But she also believes that people with disabilities function in the regular classroom.

... and so I want a very fluid system where children move and it's not based on aiding periods or, you know, any of those traditional things. And I think that as educators we have to be very, very flexible, so there may be a time where I'm back to a sixth grade class where I started out and there may be a time when I'm supporting a person with a profound disability in a grocery store.

We have to stop seeing ourselves as special, Wendy says. We have to see ourselves as global service providers, you're either an educator or not. Then she ads: What I've learned is the needs of the people I worked with profound disabilities were not so different from the needs of the university students that I worked with as far as what they required from me.

JACKIE

Jackie is a speech pathologist. She has also worked for ten years as educational assistant in special education. She assesses and gives therapy to kids all the way across the board in a large range. Coming out of the speech pathology program she didn't really think of herself as a special educator, she tells me. But now in the 3rd year in the system she really feels as if she is a special educator and a part of the special education team and very much thought of as part of that team

I'm spread very thin

Jackie is working very itinerant. Some days she works in three schools and some days in two schools. She works in a combination of in class, working in people's classrooms, regular education classrooms and working with kids who are identified with speech language disorders in a pull out situation. She also helps kids who are not identified with pre reading skills. At the high school level she even co-teaches a reading class. Jackie describes her work situation by saying:

I'm spread very thin. I have about 80 kids on my case load and those are kids that I give direct services to, I write their IEPs, I do their meetings, I do all of the assessments, it's a lot of kids.

She works with a range of skills. The majority of her caseload is donated to language, language comprehension, and expression of oral and written language. But a fair part of her caseload is kids with autism and mental retardation.

Jackie spends a lot of time working in regular classes. She works mostly in primary classrooms. *Classroom teachers at 3rd grade, 4th grade and 5th grade are less apt to ask me to come in and work in their classroom, she says.* When they have come to know her and they see that she has something valuable to offer they welcome her to their classrooms. She is also a part of a team working on reading working and on a project for the whole school helping teachers to find a better way to serve kindergarten's first grade and second graders needs for beginning reading. So she

has been very involved with teacher training throughout the district, going in and modelling lessons for classrooms.

...it takes a lot of time...

Along with doing all of the testing for the 80 kids on her caseload Jackie has to do all the paperwork for them and meetings. Meetings and paperwork take a lot of her time.

To make a child eligible for special education I probably have about 15 pieces of paper, 15 forms, and they're different from the form E has which is 20 miles away. These forms have changed four times the last two years. When I ask if these forms are issued by the school district, Jackie replies *it is for every school district. We're all required by our state to have papers that say certain things and different districts use different papers but they say the same thing.* Families move back and forth.

... and the paperwork can be different in each district they go to and to spend the time to pick up a file when a new student comes in and try to figure out where they came from and the paperwork that needs to be done... you could almost have a position just to do that, a special education position just to do testing, just to review paperwork but that's all part of our job.

The IEP process

Jackie collects information for the IEP. She talks to the classroom teacher to get information and to the other special education teachers who are seeing the children. She tries to get information from the parent. *The best practice would be to observe the child in the classroom*, she says, *and I don't always have the time to do that*. Then she has to put all this information together and make it fit with what the State is requiring right now. They have assessment bench marks at every grade level and their special education department wants them to write our goals and objectives and their IEPs to the benchmarks.

Then there is the IEP meeting. For a very simple child who is just receiving services from Jackie there might be just 3 or 4 people in the meeting: The principal, the parent, Jackie and the classroom teacher. *That's the most simple child*, Jackie says.

The more complicated the child you might have advocates from different. *I've been in meetings where there are 15 to 20 people for really involved,* she says. Jackie lists the people who may participate at the elementary level.

- 1. The principal
- 2. The classroom teacher
- 3. A parent
- 4. Herself as a speech pathologist
- 5. A special education teacher when the child is receiving math or written language services
- 6. The school psychologist
- 7. Sometimes a reading specialist may attend
- 8. Sometimes there is a regional consultant who is an autism or behaviour specialist

Some IEPs are easy. Parents are appreciative of what is done. But then there are other ones. Describing such a case for me Jackie says:

...boy, that IEP was hours. The parents brought videotapes, they brought advocates, they brought a giant flip chart where they had blown up the previous IEP. They went over issues, they went over family, it was a very difficult but satisfying at the end for everybody and we came out with a good IEP. I think it is more difficult to write a good IEP on a severe child.

Teachers very seldom look at special education paperwork.

I ask Jackie if the teachers have time to access such information.

They don't view that as their job, she replies.

In fact we're kept in 2 separate folders in an office. We have one folder with special education papers and one folder that has previous report card information, health information, family information and that's the folder a teacher looks at. A teacher never even looks in the special education folders. So we have a whole different system of paperwork for regular education and special education. There is a great difference between elementary school and high school. Whenever she writes an IEP on a student the teacher is there for one thing and she always makes sure that the teacher has a copy. At the high school level there is very little communication between teachers and the special educator.

So we tried to provide a little piece of paper that briefly explains goals and we tried to give it to a teacher, put it in their mailbox and say "Please read this" But that's about as far as we can get.

Paperwork tracking

As Jackie's answers to my question clearly indicate a cleavage between regular education and special education I ask her if she feels there is a two-track system, She replies:

That is definitely the case. I think it's more of a track if you looked at the funding and paperwork than it is in actual practices, unfortunately, and sometimes that make the actual practices be more tracked because we have to adhere to the funding and the paperwork. So I think that is my answer though that the funding and paperwork are definitely tracked. Practices were trying to get onto one track but we're hampered by funding and paperwork and it depends on where you are.

She feels that in practice they are trying to merge, but that they are hampered by leadership that doesn't adapt, obsolete funding systems and inadequate education of teachers.

There's not social benchmarks or behavioural benchmarks

The State department of education has benchmarks along with the teachers. They are very general and you can write it in a very general sense. The classroom teachers understand the bench marks, Jackie says. These benchmarks are broken down to grade level. When I ask her if there also are non-academic benchmarks, she replies that's interesting, there's not social benchmarks or behavioural benchmarks, there's not and that's interesting. Then she expands on some consequences of this.

That's an interesting point because as special educators we have concrete areas and parameters around what we are responsible for and, like say, your regular and special teacher in an elementary school, their parameters are within reading and within math and written language. My parameters are within spoken and written language but behaviour and social interaction are outside of that. The she concludes:

I deal with social communication with the children but I'm not authorised to make a child eligible for my services just for social communication...

Holes where students can fall through

Then she gives me a practical example of what this really means in practice. It's about a 4th grade boy that she has. He does not meet criteria for language services from her. He doesn't have a learning disability. His intelligence is good he's within normal intelligence. He is doing very poorly in school due to behaviour and social issues.

I'm looking at having to disqualify him for my services because he doesn't meet my criteria. He doesn't meet criteria for any other area of special education services but he needs support to be successful socially and academically and there's no vehicle to provide that support.

...to get them as high as their potential

Jackie's goal is to provide any support that a student needs to be successful at the highest level they can be successful. Her main goal is working with reading and literacy and her goal as a speech pathologist would be to provide support to classrooms, to groups of students that need support. When I ask Jackie about the social aspects of this competence oriented goals she replies:

I think it would be great if we could incorporate social goals for kids and a society goal for what we're turning out in our public schools...boy, that is a daunting task...

...to the degree that they can be included

Jackie supports inclusion on certain conditions.

I've worked in schools where they have taken a total inclusion policy, where they've taken students no matter how they're functioning, put them in a classroom. I would support total inclusion only when support is given for that student. You cannot initiate a philosophy of inclusion and not provide the supports you need to do the program.

Some years ago they initiated a total inclusion program. The classroom teachers were terrified and special teachers felt as if they would then have to accompany the

kids into classrooms and work as the assistant and they didn't like it. The school district couldn't afford the number of assistants to support the children and peopled who wanted to have their kids included moved in. *So it was an artificial ratio*, Jackie says. But then she adds:

But I think what has come out of that is a pretty inclusive system by not creating special classrooms to put these kids in and we haven't gone back to that. We don't send children out of our district to Eugene to be in special classes.

The pullout groups they do today aren't just for special education kids. When I ask her about the attitudes of teachers to inclusion Jackie tells me she has not ever met a classroom teacher who is comfortable with inclusion. She thinks it has also something to do with curriculum and how we compartmentalise subjects, not thinking broadly enough in a theme. *Because*, she says, *once you work with classroom teachers and show them how the student could fit in and have some good functional learning in their activity they're exited about it and will do it.*

...it's like night and day.

At the end of the interview I ask Jackie what she feels about the future. She tells me that her teamwork in schools has encouraged her. The regular classroom teachers, the itinerant specialist, even the principal has been supporting groups of kids depending on their needs and without looking at labels. She thinks that is going to set precedence.

We'll get to the point where we support kids depending on needs and I think by continuing our inclusive practices even at the level we have them now we are turning out young adults who are much more accepting, much more... it's like night and day.

Then Jackie adds:

For my projection into the future I would love to see schools use to dump all their special education money into one pot and use it to support all kids.

GENERALISING INTERVIEWS

What do these interviews tell me about the perspectives of these teachers on the system for delivery of educational services, which they are a part of?

The questions I have raised have touched upon different elements of this system: its organisation; the characteristics of the students to be catered for; its adaptation to differences in needs; its management processes when defining eligibility to services and developing IEPs; the goals the teachers set for their educational work; the role of special education.

Within their frame of reference the teachers work creatively to adapt their educational services to individual needs and to deliver them in inclusive ways. Wendy does most of her work in natural environments; Kathy helps her students to get a diploma and Jackie spreads her services over several schools and settings and the flexible use of resources in Debbie's school. There is a constructive lack of traditional routines in the work of these teachers. The interviews convey active problemsolving strategies and an approach to education, which I will describe as inventive and pluralistic.

One thing that strikes me, however, is the absence of a system's perspective. The dialectic between individual needs and characteristics of the school system is seldom touched upon critically. Inclusion is judged as an important principle of these teachers but it is primarily seen as a relationship between needy students and their classroom teachers. Inclusive special education isn't thought of in terms of any fundamental changes of the delivery system but mainly as broadening the curriculum, improving the ratio between needy and not needy students and between students and teachers/assistants in the classrooms. This perspective makes inclusion dependent upon a constant flow of new resources. I take this to mean that inclusion doesn't have a clear value base. This is particularly pronounced at the high school level when one of them says: *I think pushing kids in wheelchairs and in beds around to classrooms just pretending that they're like everybody else and ignoring their handicap is unfair to the kids and to the system.* When resources are not in place the principle of inclusion may be overturned by the demand for a continuity of service options. In such a system placement is determined primarily by individual

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characteristics. As one of the teachers said: *It really depends on the child where the child will go*. In reality where the child will go may depend mostly upon available options in the system.

The expressed need for having a continuity of service options is reinforced by an academic goal orientation. The IEPs are monitored by academic benchmarks. The social role of the student and the transitionally character of schooling are seldom mentioned. When these things are mentioned it is mainly in relation to school achievement. The interviews convey, however, a feeling of conflict between the social goals of some of the teachers and the academic values on which the system is based. It appears to me that when this value base is maintained inclusion can not become an imperative. At the best inclusion is a principle that may be muddled through by dedicated people. This seems to be the case here. On the other hand I read from the interviews that this work has established practices that have served to make regular teachers more involved and to move the system forward in an inclusive direction.

There is a heavy *street level bureaucracy* associated with processes of distributing scarce resources. One gets a feeling of a paradox. More time may be used to define eligibility to special education services, to write IEPs and to make all decisions legitimate than the time used to teach they who are found eligible. To put it bluntly, one easily gets a feeling that the ambition to implement *due processes* has become more important than the ambition to educate. I understand Jackie well when she says I *would love to see schools use to dump all their special education money into one pot and use it to support all kids.* Despite of this teachers feel that practices might be more inclusive than the two-tracked formal system may indicate.

All these managerial processes of selection, identification and educational planning are strongly associated with formal and informal categorisation and labelling and serve to maintain the division between special and regular education. They draw a line between students differing in quality and teachers differing in responsibilities. *In fact we're kept in two separate folders in an office*, Jackie explains, when she tells me how information about the two categories of students is kept. Regular teachers seldom know much about students who do not belong to their folder.

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Generally spoken, the basic objective of the system these teachers work in seems to be to help students with disabilities to achieve their academic potential. The teachers personally have social goals for their students but these goals do not seem to sufficiently materialise in practical work. When needs are discussed they seem mainly related to academic benchmarks. Social role functions and transition to society do not seem to have any strong feed back on teaching. A shift of perspective is needed if inclusion is to become an imperative of the system. At the best mainstreaming is presently a working principle for developing practices. This principle is bound to extradite students who do not fit the present benchmarks to the lower part of the present continuum of service options.

WHAT PARENTS TOLD

JAN

Jan is Damien's mother. He is a nine years old boy. He had an open-heart surgery when he was 2 years and 3 months old, and during that surgery he had a stroke which affected the whole left side of his body. When he came home he couldn't raise his left hand at all. After a lot of physical therapy, occupational therapy, speech therapy anyone that didn't know Damien really didn't notice his problem. Computer work and typing is about the hardest thing for him to do, Jan says. It took him till he was about 7 to learn how to tie his shoes, it is not easy to tie your shoe with one hand because his left hand would not open and release on command. It takes him a lot longer to catch something and he was pretty much 6 months behind in kindergarten compared to the other kids. But, Jan says, once he gets it he can cover ground in no time but his hardest problem right now is reading. When I ask Jan how she feels Damien is served in school, she says: *So here they just kind of all embrace them and they all do whatever they can to help them and that's what makes it really nice here.*

So everybody's aware of Damien

Damien has only visited this school. He also went to kindergarten here. *So everybody knew Damien coming in to school and what his problems pretty much were,* Jan says. She really feels that the psychologist and the teachers support Damien. She tells me about when he flunked his hearing test the speech pathologist said: *No, no way!*

...and when he did the tones he couldn't hear even what would be equal to our voices so they knew that it wasn't true. But when they put it in words like: Damien, touch the picture of the dog in the same tone he could hear it. So that's a piece to the puzzle that they're working on now, that we have no clue. He has everyone back up there so...

Damien's school is small. That's important to Jan.

..., this school is such a family, you know, it's just, the principal stands outside the door before school and after school and says goodbye to each child by name. And each teacher knows every student, it doesn't matter what grade they're in, so everybody's aware of Damien and, you know. Different things, if they see him and he is on the computer and typing with just his right hand they know and tells him to get his left hand up there and use it, you know.

Later on in the interview she says about the school:

Yes, and the kids are just very good and embracing one another here. That's one thing that has been one of the best benefits for him. That they don't make fun of each other, it is not allowed here either but they don't do it.

He thinks he is special because he gets pulled out

Damien spends about half of his day in the resource room with the special ed teacher and the speech pathologist. He has also repeated a grade. What Jan says to me indicates that she is a little bit anxious about Damien being isolated from the other kids. Once he's kept on reading I think there will be a big improvement and less of his day will be spent away from the other kids. Damien does not react negatively about being pulled out of his regular class. It's rather the other way around.

And I know I've seen a lot of kids in the past that are pulled out of the classroom to go to other places to learn, kids make fun of them and whatever but Damien has the biggest self esteem you've ever seen. He thinks he is special because he gets pulled out whereas they have to stay.

So there's a lot of communication between home and school. I really like that The school is always sending notes with Damien home. These are pages for him to do at home, or a little summary of what he's been working with. Then his regular teacher and all of the kids know exactly what they're learning and what you need to do at home to enforce their learning.

Jan feels she is a part of Damien's IEP. *It's not like I'm just sitting in the room*, she says. She has taken part of all the meetings. And they always ask her: Is there

anything you would like us to work specifically on? She is always asked: How do you feel about this. Talking about the IEP process she enumerates 6 participants. *And everybody plays their part*, she says, *everybody comes in with what they know about Damien and they put it all together. It works really nice the way they do it.*

The thing that I really want to see is just that learning remains fun for him.

There has been a point when things have been just too frustrating for Damien. He's had wonderful teachers but his homework was frustrating. But they said don't do it, don't fight with him to make him do it. Write a note and tell me this is too hard or whatever. Based on these experiences Jan concludes:

I think that's the main goal that I have with him. I mean that he does get pushed to the point that he needs to be and doesn't get to slack off and don't do his stuff but that it remains fun and he is encouraged to go further and not be a drop out, you know.

Nobody else would notice he has a problem

When I ask Jan about Damien's future she says that she doesn't know if she really thought about that because she thinks Damien's situation is not always going to be this way.

You know, once he catches on to reading he'll be OK, you know, so, and then with social skills and that kind of stuff he's just like everyone else, nobody else would notice he has a problem.

Evidently Jan expects that Damien's problems will be corrected and he will acquire a completely normal role.

Don't tell me I can't do something because I'll prove you are wrong

When I ask if his disability affects his playing Jan tells me he just played basketball this year. He was on the basketball team. You would think that with your left hand not working quite well that it might kind of hold you back but he was one of the best players on his team.

He is just a go-getter! I mean it is just in his personality that: Don't tell me I can't do something because I'll prove you are wrong. So I think that's what

has got him as far as he is because they didn't expect him to get back half of what he has with his hand, and his left foot turns in just a little bit when he runs. Whatever he can do to play or be with other kids he's, you know.

Yes, he's a part of ...

Yes, he's a part of... no matter where he is he'll bring himself into it. You know, he's just got that personality, Jan says. She feels that Damien's problems are primarily a school matter. The social network is in place. The family is very involved in their church. They do youth groups and Damien hangs out with the middle school kids, he thinks he's one of them, Jan says, and they don't look at him any different.

CONCLUDING REMARKS

The first that strikes me is the positive voice of this mother when she talks about what the school offers her son. She really feels that she and the school are playing on the same team in order to support her boy. One naturally wonders how such a success story is constructed. Is it 'real' or is it just a psychological construction of a mother who doesn't want to confront realities and who is disciplined in a small local system to suppress conflicts related to her son's education. Or, is it simply so that the school has been able to develop an ecologically valid educational program for this boy that juxtaposes his specific needs, his personality, his social setting and the school resources. I can't say. There's probably a little of both. I would have expected that for many parents pulling out a child with these minor specific needs for half the time from regular class would cause some problems. On the other hand this story also shows that one can't look at inclusion in a single-minded way. This boy seems to be well included even if he is out of the class for a part of his day. This clearly shows that inclusion is a broader concept than mainstreaming.

JUDITH

Judith is a lawyer. Judith has a daughter of 20 years of age with Down's syndrome. Her daughter has been in public school all the time. This will be her last year because in this state you go to the end of your 21st year.

It was an incredibly nasty and bitter battle

Judith tells that they first lived in Brooklyn, New York, and actually the daughter had wonderful teachers like TV movie specials. It was a great experience, but

... it was an incredibly nasty and bitter battle to get it from day one and frustrating and painful and very upsetting. The teachers were wonderful but the administration and the support services were not there and the administration was nasty beyond belief. That's just an overview, I can give you a million details...

This happened in the middle of the 80s when the girl was 5 years old.

Filed for due process and I went to a hearing...

Due process hearings have been an important part of Judith's life with her daughter. She filed for the first time when the girl was 5 years old because Judith felt that her daughter's placement was not appropriate. She was almost strangled by a fellow pupil. She went to the hearing and was told that she wasn't entitled to physical therapy although she was 5 years and could not walk up and down stairs, she was very delayed physically, no terribly fine motor skills, not very delayed intellectually, she was reading already and doing some arithmetic. Judith lost the hearing and put her daughter in a private kindergarten which wasn't on the government list so she could not be reimbursed with that.

I decide, you don't decide.

The following year she went to every single program in the whole Brooklyn and chose one that looked wonderful. She tells me about her experiences looking for a program.

I saw programs where the children looked wretched, where children were crawling and making sounds in the corner. I saw a teacher pull a child's hair and break a toy in half. I saw terrible things. I just stood in the back of the room watching. They were not even ashamed...

She told the placement officer she had found this wonderful program, not far from her house. When the placement officer said: No, you can't have that, you have to have this one where Judith had seen the teacher pull a child's hair Judith said 'no'. Basically she meant over *my dead body*. And the placement officer replied *I decide*,

you don't decide. Judith was going to file for due process again, but this time she knew somebody on the board and her daughter was placed where she wanted her to be placed. This was a wonderful program, Judith recalls.

That was a 2 year program and she loved it, it was wonderful and the teacher was like a TV special and she had a retarded child of her own. A grown child, she had gone back to school and become a special ed teacher.

But her daughter outgrew the program and Judith had to look for a new program.

This time you're not winning

When Judith's younger daughter started in a neighbourhood school she wanted this daughter also to start in a neighbourhood school. So she went to see it and it was great. The teachers looked wonderful, one block from home, the same school with her sister. It looked really nice. But the placement officer remembered her. She remembered that she had a friend in the board of ed and she got a placement that she didn't want her to get. Judith recalls the following conversation:

No, your daughter can't go to her neighbourhood school. I said: Why, ordinarily she can go to her neighbourhood school, she would have in the normal course of things have gone here, why can't she go here now? She said: Last time you won, this time you're not winning.

Then Judith ads: I took it again to the board of ed and I won again.

The support services were also terrible

Her daughter had problems with her speech. In the computer room the speech therapist was supervising a computer kid at the same time She went to see and right in front of her he was ridiculing the speech children to the computer children. *So I said 'no'*, she tells me, *this isn't going to work, I want a private therapist to come to the house.* After that her daughter was evaluated three times and didn't have any speech therapist for three months. Then she got a therapist who said she only could see her daughter at night. Judith couldn't accept that because her daughter was totally exhausted at that time. Then the speech therapist made appointments but didn't show up. You know, Judith says, my life was not so easy, my daughter was

always sick, my other daughter was very unhappy. You know these frustrations did not help. She called the board of ed and said:

This is not working, it is November... December... it's January, 6 months, it is an important time and no speech. Tough! This is the agency, this is what we've got. OK, I'm filing a lawsuit. All right, you can hire your own person,...

So she hired her own person.

If she wasn't a lawyer she would have been shoved in a closet in every IEP meeting, Judith thinks, and wonders how a mother who isn't a lawyer can live through this. It is so humiliating, it is so aggravating. They tell you you don't know anything, you don't need anything, you don't deserve anything, why are you bothering them...

But she also refers to positive experiences. The teachers were good and her daughter loved the speech therapist she finally got.

I devoted my whole life

Judith is an attorney. She tells me she was very interested in her career but she didn't work for the first 10 years.

I was very, very interested in my career, but when I saw that it was not going to work and because of her unstable neck and child care wasn't that appealing and...

She has always worked at home. *Luckily my daughter gets a lot at home*, she says. I didn't work for the first 10 years. She taught her daughter how to read before she started school. Her husband is very devoted to her so it was possible to give her at home what she wasn't getting at school and it wasn't like if she didn't get it there she didn't get it. So it wasn't life and death like it is to some people. *But*, Judith says, *still it would have been nice to get more. It was no fair...no, forget physical therapy, there is no physical therapy if you're not in a wheel chair they told me right away.*

I regret bitterly to this day

When she went to middle school, the special ed teacher whom Judith liked and respected very much urged her to mainstream her daughter and put her in a regular class and resource room part of the time. She regrets that decision. Academically this was good, but the special teacher didn't follow up in the mainstream class. Judith talked to the regular class teacher and asked how is it going?

He says: Well, she is not very verbal, she just sits there, she sits there all the time. I said: Not verbal, she reads Nancy Drew, what do you... Well, I talked to her and she doesn't answer, I assumed she can't talk.

Judith was called to a meeting where the school said she needed too much individual cueing in order to stay in the regular class. Judith reports the following conversation:

Judith: Fine, give her an aid.

They: No, there's no money for an aid.

Judith: The law says that if she can be educated in the least restricted alternative she's entitled to be and you can't say: We have no money, you have to provide her free, appropriate public education in the least restricted alternative, that's what the law says.

They said: That's just legalities. There's no money, you don't get it.

The gym teacher: Well, I want to know how bad her neck is and I want to know what my liability is if anything happens to her in my class.

She didn't exist

Judith gives a depressing picture of the social situation of her daughter. Socially mainstreaming was a disaster for her.

I made little visits, it was like a 10-foot wall was around my daughter. Nobody sat down at the table in the lunchroom that she sat at, she had the whole table to herself if I came at lunch time. She was like just totally excluded. She didn't exist. It was just total isolation. Judith tells me other parents experiencing the same thing.

... one mother told me she paid kids to talk to her kid during recess, one mother told me she put it in the IEP that 5 people had to say hello to her daughter every day. You know every day I get this. It wasn't just the experience of my daughter.

She graduated in a small school with 100 to 150 kids at the graduation. There was a slide show with kids in it and like an hour of awards, awards for the most courageous, awards for the bravest, award for the cleverest, award for the cutest kid. *It was like we were invisible, totally invisible*, Judith says. So they decided mainstreaming wasn't going to work. Judith felt very guilty because her daughter became more and more withdrawn. She didn't want to talk to anybody...

They didn't tailor it to your child at all

Judith describes the IEP to me in this way:

Get the IEP back in pre-printed form, you know, none of the stuff we talked about is on it. Call them, what about the stuff we talked about? Oh, yes, we forgot about it, OK? A month later another form comes, it's on there but in the meanwhile nothing has been happening.

She recalls the conversation:

Judith: *How is math?* They say: *No math this term, no time for it.* Judith calls them: *What do you mean there is no time for math, it's on her IEP?* They say: *All right, we'll give her a little self teaching book and the secretary can supervise her. She can sit next to the secretary and the secretary can supervise her. OK, I said, OK.*

She doesn't want to be too negative. As I said a lot of her teachers were wonderful all through. It was the support service that wasn't there. What they offered was great but if you needed anything else it wasn't there. They didn't tailor it to your child at all.

To learn the things she needs and to feel good about herself

Judith's goals for her daughter are pretty simple, she says. She wants her to learn the things she needs to have the best life she can have and to feel good about herself. She did not get that adequately, she got it to some extent but not adequately. Judith says. She didn't really get any teaching 5 years and she hasn't got any math.

What do you do when you go to a store and you want to buy this and deal with credit cards. She hasn't got that and the cooking is a joke really. They have fun but they don't really learn anything.

She wasn't really included, she was mainstreamed

Socially Judith thinks maybe mainstreaming would have worked and would have been great for her if it was done at all. But she wasn't really included, she was mainstreamed and sat in a classroom with other kids but she wasn't included in any way whatsoever. There was really virtually no attempt or energy put into including. Judith met with the resource room teacher, she met with the regular teacher and made suggestions but no real attempt was made to include. *My daughter was totally rejected*, she says.

She goes to her room and she closes the door

Today the daughter doesn't want any mainstream activity, camp or a club. She would only have been a special. She's afraid of regular people and they have indeed made her afraid of them, Judith says. When people come over she goes to her room and she closes the door. *It would have been nice if that was different...*

Other parents

Judith is also working with other parents as a lawyer. When people call me as a lawyer they're in hysterics, she says. There's always like some last straw. They've been fighting for 10 years and now they just can't stand it any more. They have crises and they just don't know what to do with them. They cannot deal with it any more and they have really been trying to work it out and there's just no way that it can work out. A lot of time the parent is single. They're dealing with these problems from a job, and if they talk on the phone too much from the job they'll lose the job and they don't eat, so whatever the school does they do.

A monitoring agency called OSEP - Office of Special Education Problems comes from Washington every few years. They monitor compliance with special education laws and regulations. It's done by satellite in each county. Judith was asked by the president of the ARC - the Association for Retarded Citizens to sum up the evidence for the county. In that capacity she listened to the whole state. There was so much frustration and bitterness of parents. The basic complaint was harassment she thought.

Why can't you protect our children from abuse and harassment? That was one of the dominant complaints. Heading, pushing, knocking down, making fun touching... sexual...

There's no money

Well, the main problem with the law, Judith says, is that it is not funded on a federal level, less than 10% is funded by the feds so naturally the local school districts don't want to do it. Judith exemplifies how big behaviour problem was neglected. *Of course when he got a lawyer they classified him as a special ed case, but that's the way the districts are dealing with it.* If you have a lawyer there's a pretty good chance your child will get an aid, she tells me. They'll just take it away from somebody else whose mother doesn't have a lawyer.

CONCLUDING REMARKS

Judith has watched her daughter's education both through the eyes of the mother and the eyes of the lawyer. From the perspective of the lawyer her story underscores the difference between the words and practice of the law. Because the necessary support haven't been in place it has been impossible to cater for her specific educational needs despite the fact that all necessary laws are in place.

Judith blames the situation on the lack of funding. This creates a vicious circle. When the law is put into practice for one person the resources are taken from somebody else who also needs them but who hasn't filed a due process hearing or a lawsuit. Her story shows that even a lawyer may have problems of succeeding in the system. One may just ponder on the situation of parents who haven't got this background. Judith's story even indicates that connections at times may be as important as a background in law. Judith doesn't blame the teachers. She recalls very good relations with many of the teachers through these difficult years. She mainly blames the processes of placement and eligibility.

The dramatic part of Judith's story of her daughter's education is the story about the social and personal impact of this education on her daughter. This is the mother's story. Judith's goals for her daughter's education have been that she wanted her to learn life skills and to feel good about herself. Judith doesn't feel that these goals have been achieved to any reasonable extent. On the contrary all the education has been devaluing her daughter and forced her into social psychological isolation. It is interesting to observe that Judith blames herself for having decided to mainstream her daughter. Her story at this point clearly underscores the difference between mainstreaming and social inclusion. Mainstreaming is just a placement decision while the decision to include must result in educational changes.

Judith conveys a rather disturbing picture of special education of a moderately retarded child in the United States in the 1990ies. In my opinion the background of this mother adds credibility to her story and she supports her story with information that indicates that this may also be the story of many other parents.

PHIL

Phil is a professor of education. His son Ian is 30 years old. Ian needs what they call 24-7 support, it is someone who needs support around 24 hours a day 7 days a week. Phil describes him by saying: *He has a great smile, a terrible taste in music and he likes to play it very loud when his father's around too. He also has a long list of labels.* Ian uses a wheelchair, has severe spastic movements and severe mental retardation. He lives in his own home and has a couple of persons who live with him. He also have people who help him to get about in the community. *So he has a pretty good life, has a nice job that he has had for about 7 years*, Phil says.

lan works at the university 20 hours a week. He goes around to small satellite coffee shops away from the main food service at lunchtime and supplies them with

whatever they need. Traffic is restricted on campus and Ian comes with his own set of wheels. A personal support agent who also is working as an advocate for him located this work.

Here's no federal mandate for adult services for folks with disabilities

It took them about 6 years of working with the system after Ian left school still living at home to get the financing figured out with the bureaucracy, Phil tells. Unlike special education there's no federal mandate for adult services for folks with disabilities.

So for example there are a couple of thousand adults with developmental disabilities in Oregon on the list for residential support and that means they are not getting any residential support. They're qualified, they're eligible but they're just on a list waiting to get an opening. That couldn't happen with special ed services for kids because there are mandates providing services but there is no mandate like that for adult services.

After having fought the bureaucracy for these 6 years lan's expenses are funded from a number of sources - Medicaid, which is the federal low income health program, support for his intellectual disability, support for his physical disability, supplementary securing income. In this way he is able to pay for his home and his support people. Phil ads:

The money we get from the state and the federal doesn't cover all of his expenses but we're lucky enough to be able to help out with that so we fill out the remainder.

To my comment that the funding appears very complicated Phil responds:

Imagine, my wife and I are people who are professionals in the system. We know all the jargon, we know about bureaucracies and stuff and it is very hard for us to make sense of it. So imagine other families...much less if you're an individual with disability and on your own without a family trying to figure this stuff out. It is huge... very complicated. If you make one little mistake you can lose your eligibility.

lan's a nice kind of personification of a whole generation of change

Phil says:

It just so happens that those 30 years of his life have seen these dramatic changes in special education policy and law and the emergence of a disability rights movement, lots of civil rights protection, deinstitutionalisation, all of these huge changes that have happened the last quarter, the last 30 years have been reflected in lan's life along the way.

He describes lan's educational situation to me. The years are only approximate.

- 1. 1975: Ian is excluded from attending school.
- 2. 1975: The federal law was passed and they had to provide a program. Ian was sent to a half private and half-public day school for children with disabilities 45 minutes from home. It was a special school for all around the region. By contracting out to the regional schools the local schools district didn't have to provide programs for children with these disabilities. *We didn't like this so the next step was he did go to one of the public schools*, Phil says.
- 3. 1980: After lobbying and advocating together with other parents he started to go to a local public school. It was a self-contained class within the school for children with disabilities. This was a school across the town that was used because it was accessible. They were really dissatisfied with this solution.
- 4. 1982: He was moved to a neighbourhood school. Phil feels that lan going to a neighbourhood school was a break-through for a principle. It isn't enough to be eligible. The neighbourhood is the natural place to go for most children. It was still a self-contained class but he got a lot more out with other kids. *It became a wonderful tool for him to make friends and have kids interact with him and get to know him and know how to talk to him so it worked out really well*, Phil remembers. The family moved around a little bit and increasingly became more and more dissatisfied with separate settings and pushing lan to be in more inclusive settings.
- *5.* 1985: In high school he was spending a large part of his school day in a general classroom
- *6.* 1988-91: Spending time out in the community in an integrated setting, sampling possible jobs or other key survival skills.

Looking back on these 30 years Phil says he has learning a lot about how limited their vision had been 30 years earlier when people were telling them to institutionalise lan So going from that kind of interaction with professionals - pretty much like you should sort of abandon this kid to, by the time he graduated from high school, feeling like he participated in the graduation ceremony. He had a lot of friends without disability in the high school. He went to his senior dance prom with all the other students and stuff. That was a huge progression from... and in a fairly short period of time. It's been neat to watch.

Despite trying to strike a positive tone with people involved in lan's education Phil says:

But I think what we did was we learned that a lot of parents had to use the special education law as a tool, that no matter how strong an advocate we were they couldn't just ignore us. They couldn't like say "Get out of here".

Increasingly they came to think that the inclusive approach was very important and wanted to figure out with the teachers how to help lan both becoming included with the general program and working on goals that made sense for him. Phil evaluates their relationship to the school system when saying:

So for the most part we had people who worked well with us, particularly in high school I think, both at the administrating level and in the classrooms we felt like things worked pretty well and we were working together, problem solving and looking for opportunities and things like that. At earlier levels it was more of a battle sometimes, battle is probably too strong a word but there were definitely periods where we were not happy with lan's program.

It was an important safeguard, a legal framework, but...

During lan's last years of schooling Phil felt that things were changing. It was less of a struggle to convince people. The IEP became an important part of the process. It was an important safeguard and legal framework. It had to be a plan for lan's education and they could have specific items addressed. On the other hand, Phil draws attention to a procedural compliance mentality that says we have done our job if we meet these 7 steps of the law. If we send the parents a letter about a meeting within a certain number of days then we have done our job in terms of parent involvement. He also draws attention to the fact that the IEP perpetuates a kind of categorical approach. *You've got to have a label. You're this type of disability rather*

than that type which means you need this type of specialist rather than that type, Phil says. This doesn't work well for inclusive approaches. It allows for distancing and separation even if the physical presence is still there.

It has for example encouraged the sense of ownership by the special ed system. Even if a child is full time in a general ed classroom we'll hear teachers talk about "Oh, these are the included children, or they even talk about "Those are the IEP kids" as a kind of substitute label for...

The gap got worse the older lan got

When I ask how he feels the school has responded to Ian's individual needs Phil tells me he has grown in his understanding of curriculum adaptation. He criticises the developmental model, which characterised most teaching in Ian's early school years. Here the curriculum was driven by the child's developmental stage. This meant that Ian's curriculum increasingly lagged behind because he was at a different developmental stage and he would work on very different things. This model doesn't pay attention to age appropriate stuff, Phil says. The next stage was to move towards the functional curriculum. This allowed for a much more age appropriate approach by saying: *What does lan need to function in whatever domain we're looking at, communication, what does he need to learn to communicate?*

lan needed a skill based and age appropriate approach, but gradually Phil became dissatisfied with the functional model. The main reason was that it become too much separated from the environment he needed to be a part of. So he moved to what he calls an activity based curriculum.

It wasn't necessarily a departure from functional skills but what it said was "Let's look at the activities of life that Ian was to be involved in or we as Ian's family wanted him to be involved in. What activities do we do as a family? What activities does Ian do as a high school student?

The question now was how one could embed his curricular goals within these activities to allow him to succeed. Phil explains this strategy:

He's not going to eat totally independently but let's look at the meal time activity, let's look at the shopping activity, whatever the priorities are of that particular family and person. And then, what are the combination of supports and the combinations in skill training that we can embed within that activity to allow him to participate in them fullest way possible?

Phil felt that this was really a jump forward in his curricular thinking. But he doesn't feel that this approach has won through in special education. They work rather isolated on skills and are dominated by specialists. Activity based learning makes better sense to general education teachers, Phil tells me.

If you talk only in terms of skills they'll say grasp and release, some fine motor skill, a high school teacher would say, "That has nothing to do with my English lessons." But you say "What are you going to do, what's the activity in class" and you have a team that say "OK, you're doing this group reading, here's all the opportunities for Ian to participate in that activity and work on grasp and release in amidst of that activity so he's participating along with all the other students. He's working on something very different but it's the same activity that they're all working on together.

Phil does work in teacher education. Quite naturally his way of thinking has brought him to work more with general ed teachers than with special education teachers. He wants to integrate teacher education and resists the parallel tracks they have in their education programs.

To become active citizens in a democracy

I ask Phil about what he thinks is the most important goal of education. He refers to John Dewey who talked a lot about that you don't prepare people to be citizens in a democracy by creating authoritarian environments and by separating people out.

You prepare them being citizens by having them practice being citizens. So you create this active environment in the schools, in the classrooms, a range of people with a range of skills and ranges of opinions and figuring out how to make that work.

According to Phil the strong productive worker focus narrows the range of options for people with disabilities. It narrows the vision rather than enlarges it and translates into what is called back to basics, writing, arithmetic. The medical model is the other one that is very much a barrier, this category called defect, kind of a logic that focuses on either cure and remediation or custodial kind of responses and that has

not much to do with either being productive worker or being an engaged citizen. It's more being a sick person.

When I ask him about the present ways of assessing learning he absolutely recognises that we need to be accountable and to see if kids are learning. But he is utterly critical to the ways assessments are implemented and says:

It's very much a paper and pencil standardised choice kind of thing that has very little connection to what kids need to be learning and it's a case of assessment driving curriculum rather than curriculum driving assessment.

He draws attention to authentic assessment and portfolio assessment It is an approach to assessment that is much more adaptable to the full range of kids, including kids with severe disabilities so you have these sorts of large areas of goals for communication, habits of reasoning, etc.

Redefining support

At the end of my interview I ask Phil about his ideas of a better model of education for students with disabilities. The first step he says is to get rid of the separate bureaucratic structure of special education. We need an educational policy - not a special education policy and a general education policy - in order to merge and to create a common conversation how to work with diverse learners. Then, he says, we have to rethink support and change what he calls the continuum logic. This logic assumes that the most segregated setting has the highest intensity of support. Then students are to be removed when needs change. Of course what happens in reality, Phil says, is that they get stuck in one setting and don't leave.

Instead, redefining support is not tied to a particular kind of place but let's begin with the common setting wherever that common setting is and figure out the various ways to embed the support in various degrees of intensity without pulling the kid out of the setting.

Concluding remarks

Phil speaks with two voices: the voice of the father and the voice of the professional educator. There is always a reflective distance in his answers to my question as he

searches to transform his private experience into educational principles. Despite this I sense all the struggles that have taken place in order to help lan to get the supports he needs and to help him to acquire and to maintain a positive role in an inclusive setting. During the years two important tasks have been constantly on Phil's agenda. The first one has been to get lan a school program that was so inclusive as possible. However, this was first achieved when lan reached high school.

The second one has been to get access to support for lan in a society where there is no federal mandate for adult support services. Here Phil and his wife have had to use all their ingenuity as professionals and have been able to create a mosaic of functional support services for lan - at times after battles with the bureaucracy. During the interview Phil conveys to me at least a moderate degree of success but he fully realises that his and his wife's professional background has been important in this process. Still there are 2 thousand people on the waiting list for parallel support services in the state

Phil views the separation of students with disabilities from the mainstream of society as inconsistent with education for democratic citizenship, which he considers to be the long-range goal of all education. Taken this goal as a point of departure he underscores the necessity for an integrated education that embraces disabilities and all other diversity in society related to gender, race and social background. He judges the present bureaucracy and mainstream thinking on disabilities of special education to be barriers for the achievement of a common education.

GENERALISING INTERVIEWS

The experiences the three parents convey to me are different. That's reasonable. Damien's learning disabilities do not really put the school system at the test like the disabilities of the other two. His problems may successfully be taken care of by minor modifications of the school setting while the two others are in need of more fundamental changes of educational settings and support services in order to learn and to develop. How are these challenges met? What do the experiences of these parents tell about the adaptation of the educational system to specific needs?

The first thing that strikes me is the difference between these voices. Jan's positive experiences with Damien's education may most certainly have much to do with the rather small impact on his disability on learning and behaviour. But there is more to it. Damien visits a small school where teachers and other students respond positively to him and make him feel part of the group. And his problems are always handled in close contact with the family. One gets a sense of professional and social leadership behind the school's activities that has contributed to a school code that makes up a favourable setting for students with disabilities and their families.

For Jan's Damien personality and needs seem to match well the available support system of regular class and pullout for special education. She seems to have adopted this model of education for her son. For the two other parents things are very different. They have children with moderate and severe disabilities and both of them judge the existing support systems as inadequate but for some different reasons. Judith traces the negative impact on her daughter's social and psychological situation to the lack of social and educational support. The lack of this support she finds particularly pronounced when her daughter participated in a mainstream setting. As a lawyer she treats her daughter's school situation during the interview very much as a rights discourse and a legal matter. Her daughter hasn't got the education she is entitled to according to the law and its amendments and judges lack of funding to be the primary cause of this. Phil, on the other hand, raises an education discourse. He judges his experiences with his son in the light of a general goal of education, which should be to create a common education that is able to

adapt to diversity without separation. He views the categorisation bureaucracy and the continuum logic of special education as barriers to his project of inclusion.

CRITICAL ISSUES

The1975 law and its amendments have constructed a firm legal basis for the education of students with disabilities. There are several barriers for putting the law into practice. Restricted federal mandate and funding is one such barrier. Another barrier has to do with a rather restricted concept of schooling, which may restrict diversity push for separation in education. And of course there is all this variability between states, districts and cultures that makes it difficult to talk conclusively in any study about the United States.

Within these restrictions the problemsolving capability and the innovative perspectives I have met during my interviews impress me. There is an extraordinary dynamic in thought and practice of professional people I have met and the parents I have met do not refrain from the struggles necessary to improve the education for their children.

At the end here I take the opportunity to raise a number of critical issues which have been observed during the two parts of the study which I have distinguished during this work. Having the perspective of a foreigner I may certainly have overlooked important issues.

INCLUSION AND PROGRAM INTEGRATION

Statistics show a rather clear tendency towards more integrated and consolidate programs of education for disabled students. A very high percentage of students with disabilities are taught within regular education. However, the pullout model is the dominant one and research indicates that there is a rather low degree of program integration and consolidation and that the efficacy of the model is low. The results of inclusion programs have been modest. This is the background of the so-called REI debate, which has been the hottest controversy in special education in the country.

The interviews clearly substantiate the importance of this issue. There is a strong feeling that the traditional special education logic has to be replaced by a diversity logic that works to reform organisation and practices of general education in order to

improve its capability to serve the diverse school population in inclusive ways. The impact of this situation on students with disabilities is that hey may be mainstreamed into regular classes but seldom socially included. There is a strong feeling that this cannot be adequately achieved today without relying on the traditional special education logic. This logic serves to maintain the division into special education and regular education and to delay reforms of general education. The interviews indicate that there are important moves to change this situation. Some universities establish new integrated teacher training programs, federal money is used on school innovation projects and the new assessment and accountability drive may stimulate the development of a common curriculum for special and regular education.

IDENTIFICATION PROCEDURES AND DECATEGORISATION

Presently the special education clientele is categorised into 13 different categories. Research clearly shows that the identification and assessment procedures are not good enough. The results are great variability and invalid classifications. A key issue relates to the conflict between this classification system for disabilities and the present move towards inclusion and needs oriented identification of disabilities.

From the point of view of my interviewees these identification and categorisation processes are regarded as important elements of the special education logic. It is based on the idea that intensity of support is defined by a continuum of placement options. This way of thinking tends to replace true educational changes of regular education by categorisation and placement decisions. The lack of funding as well as the 'one kid at a time' funding formula turn these identification and placement processes into a heavy bureaucracy of IEP and due process meetings and hearings. The teacher interviews show that filling in forms has become an important part of the work of many teachers. Interviews even indicate that this work may have only small impact on the work of regular teachers who teach the children with specific needs for parts of the schooldays.

ETHNIC DIFFERENCES

There is a disproportionate representation of African Americans in special education and labels are applied differently to ethnic groups. This raises the problem of the cultural and social function of special education within schooling and the problems of meeting the needs of a diverse population of learners in ways that nurture respect for the diverse cultures that exist with the predominant culture.

NEW FUNDING FORMULAS

Most states apply a funding formula that demands identification of students with disabilities in order to release resources for special education. This system is controversial from several points of view. There is presently a move towards a census-based system and a system based on school enrolment.

There is also a rather strong feeling through the interview that much of the funding is used to congregate people in care facilities and institutions. One of the interviewees said it this way: *We got out the people but the dollars didn't follow*! The lack of a federal mandate for community support makes it difficult even for parents who are also professionals in law and education to muddle through a patchwork of resources from a multiplicity of sources. The risk of staying permanently on the waiting list for others is an imminent risk.

TEACHER TRAINING

The dual system of teacher training is not promoting program integration and consolidation. How to change the system of certification and licensure is a core issue. One of my respondents puts it this way: *Absolutely very, very separate habits of practice and separate training and then we get in schools and say: Well, now you need to work together.* There is a strong move today to change the very common two track teacher education programs and to increase the number of teachers with endorsements in special education.

THE ROLE OF THE FEDERAL STATE

Court cases and federal funding seem to be the two legs that special education use to move forward in the United States. The approximate 10 per cent contribution from the Federal State is presently too small to support efficiently a progressive policy of special education. This situation results in great variability between states and between districts as regards investments in education due to differences in property taxes.

The interviews show that this situation may make the federal law formulations about a free and appropriate education for all children with disabilities into rhetoric. The lack of a federal mandate for adult services adds to this conflict.

THE TRANSITION PERSPECTIVE

The special education logic and the problems of eligibility associated with this model threaten to turn due process meetings into courtrooms for legal struggles between home and school. This seems to be particularly pronounced when there is a mismatch between the needs of students and the support that the school is ready to make available. Because the school model is strongly academically oriented and doesn't allow sufficiently for social goals and community orientation the gap between needs and the school model increases as the student become older. This separation of school from society may be especially detrimental for students with moderate and severe disabilities who are strongly dependent upon a transition perspective.

REFERENCES

Artiles, A. J. and S. O. Trent (2000). Culturally/Linguistically Diverse Students. Encyclopaedia of Special Education. Reference for the Education of the Handicapped and Other Exceptional Children and Adults. C. R. Reynolds and E. Fletcher-Jantzen. New York, John Wiley & Sons. Volume1: 513-517.

US Department of Education(1999). To assure free appropriate public education for all children with disabilities. The twenty-first annual report to Congress on the Implementation of the Individuals with Disabilities Education Act,

Fruchter, N., T. B. Parrish, et al. (1999). Financing Special Education :Proposed Reforms in New York City. Funding Special Education. T. Parish, J. G. Chambers and C. M. Guarino. Thousand Oakes, California, Corwin Press, Inc.: 176-200.

GOERTZ, M. J., McLAUGHLIN, et al. (1999). What Will It Take? Including Students With Disabilities in Standard-Based Education. Funding Special Education. T. B. Parrish, J. G. Chambers and C. M. Guarino. Thousand Oakes, California, Corwin Press, Inc.: 41-62.

Hallahan, D. P., C. E. Keller, et al. (1988). "Examining the Research base of the Regular Education Initiative. Efficacy Studies and the Adaptive Learning Environments Model'." Journal of Special Education 21(1): 29-36.

Hallenbeck, B. A. and J. M. Kaufman (1994). United States. Comparative studies in special education. K. Mazurek and M. A. Winzer. Washington, D.C., Gallaudet University Press: 477.

Kavale, K. A., S. R. Forness, et al. (1999). Efficacy of special education and related services. Washington, DC, American Association on Mental Retardation.

Lankford, H. and J. WYCKOFF (1999). The Allocation of Resources to Special Education and Regular Instruction in New York State. Funding of Special Education. T. Parish, J. G. Chambers and C. M. Guarino. Thousand Oakes, California, Corwin Press, Inc.: 147-169.

Lipsky, D. K. and A. Gartner (1989). Beyond Separate Education. Quality Education for All. Baltimore, Paul H. Brookes Publishing Company.

Lipsky, D. K. and A. Gartner (1997). Inclusion and school reform. Transforming America's Classrooms. Baltimore: Paul H. Brookes Publishing Company.

McLAUGHLIN, V. R. (1999). Consolidating Categorical Educational Programs at the Local level. The Funding of Special Education. T. B. Parrish, J. G. Chambers and C. M. Guarino. Thousand Oakes, Calif., Corwin Press, Inc: 22-40.

Michal S. Berres, D. L. Ferguson, et al. (1996). Creating Tomorrow's School Today. Stories of inclusion, change and renewal. New York, Teacher College, Columbia University.

National Center for Education Statistics, E. T. S. (1993). 120 Years of American Education: A . Statistical Portrait, US Department of Education, Office of Educational Research and Improvement.

OECD (2000). Special Needs Education. Statistics and Indicators, Organisation for Economic Co-operation and Development (OECD): 155.

Ondrusko, M. F. and C. V. Morsink (1996). Special Education in the United States of America. Special Education on the Move Current Changes in Special Education in the Netherlands, Russia, Sweden, the United Kingdom and the United States of America. K. v. Rijswijk, N. Foreman and L. Shipitsina. Leuven / Amersfoort, Acco: 97-107.

Parrish, T. B., J. G. Chambers, et al., Eds. (1999). Funding Special Education. Thousand Oaks, California, Corwin Press, INC.

Parrish, T. B. and J. Wolman (1999). Trends and New Developments 'n Special Education Funding. What the States Report. Special Education Funding. T. Parish, J. G. Chambers and C. M. Guarino. Thousand Oakes, California, Corwin Press, Inc.: 203-229.

Pijl, S. J. (1994). United States. New Perspectives in Special Education. A Six-Country Study of Integration. Cor]. W. M.eijer, S. J. Pijl and S. Hegarty. London and New York, Routledge: 55-78.

Pugach, M. C. and a. C. L. Warger (1996). Curriculum Trends, Special Education , And Reform. Refocusing the Conversation. New York, Teachers College, Columbia University.

Ricard A. Villa, J. S. T., William Stainback and Susan Stainback (1992). Restructuring for Caring & Effective Education. An Administrative Guide to Creating Heterogeneous Schools. Baltimore, Maryland, Paul H. Brooks Publishing Company.

Rothstein, L. F. (1990). Special Education Law. New York, Longman.

Rutherford Turnbull III, H. .R, Ann P. Turnbull (1998). Free, Appropriate Public Education. The Law and Childen with Disabilities. Fifth Edition. Denver, Love Publishing Company.

Snyder, T. D. and C. M. Hoffmann . U.S Department of Education, National Centre For Education Statistics Digest of Education Statistics ,1999, NCES 2000-031.

Gunnar Stangvik (2002). Background and Design. Report No 1 from the project " Special Education at the Bottom Line. A Cross-cultural Study of the Quality of Special Education Practice". *HiF-Rapport 2002:6*, Finnmark University College

Gunnar Stangvik (2002). Special Education in a Comparative Perspective. Report No 2 from the project " Special Education at the Bottom Line. A Cross-cultural Study of

the Quality of Special Education Practice", *HiF-Rapport 2002:7*, Finnmark University College

Stohl,Carol. F.,Thant, T-S. Teachers' Professional Lives - A View from Nine Industrialised Countries. Milken Family Foundation. Washington DC. March 18, 2002 <u>http://www.c-b-e.org/PDF/TeachersLife.pdf</u>

Verstegen, D. A. (1999). Civil Rights and Disability Policy \ Historical Perspectives. Funding Special Education. T. B. Parrish, J. G. Chambers and C. M. Guarino. Thousand Oaks, California, Corwin Press,Inc.: 3-21.

Walton, W. T., J. Rosenqvist, et al. (1989). A comparative study of special education contrasting Denmark, Sweden, ad the United States of America., Malmø, Sweden: School of Education: 29.

Winzer, M. A. (1993). The History of Special Education. From Isolation to Integration. Washington, DC, Gallaudet University Press.

Ysseldyke, J. E. and R. Algozzine (1995). Introduction to special education. Boston, Houghton Mifflin Company.

Ysseldyke, J. E. And Algozzine, R (1995). Special Education. A Practical Approach for Teachers. Third Edition. Boston, Houghton Mifflin Company.

Zigmond, N. and Baker, J. M. (1997). Inclusion of children with learning disabilities in general education settings. Inclusive Education - A global agenda. Sip Jan Pijl, C. J. W. Meijer and S. Hegarty. London and New York, Routledge: 98-114.

LIST OF REPORTS

Gunnar Stangvik (2002). Background and Design. Report No 1 from the project " Special Education at the Bottom Line. A Cross-cultural Study of the Quality of Special Education Practice". HiF-Rapport 2002:6, Finnmark University College

Gunnar Stangvik (2002). Special Education in a Comparative Perspective. Report No 2 from the project " Special Education at the Bottom Line. A Cross-cultural Study of the Quality of Special Education Practice", HiF-Rapport 2002:7, Finnmark University College

Gunnar Stangvik (2002). A Study of Special Education in Russia. Report No 3 from the project " Special Education at the Bottom Line. A Cross-cultural Study of the Quality of Special Education Practice", HiF-Rapport 2002:8, Finnmark University College,

Gunnar Stangvik (2002). A Study of Special Education in the United States of America. Report No 4 from the project " Special Education at the Bottom Line. A Cross-cultural Study of the Quality of Special Education Practice", HiF-Rapport 2002:9, Finnmark University College

Gunnar Stangvik (2002). A Study of Special Education in New Zealand. Report No 5 from the project " Special Education at the Bottom Line. A Cross-cultural Study of the Quality of Special Education Practice", HiF-Rapport 2002:10, Finnmark University College

Gunnar Stangvik (2002) Exploring the Issue of Quality in Special Education. Report No 6 from the project " Special Education at the Bottom Line. A Cross-cultural Study of the Quality of Special Education Practice", HiF-Rapport 2002:11, Finnmark University College