

THE FORMAL EMPLOYMENT OF DISABLED PEOPLE IS NOT SPECIFICALLY DETERMINED BY ECONOMIC FACTORS BUT BY DIRECT TECHNICAL ONES OR ULTIMATELY BY SOCIAL INTERESTS AND VALUES. A SOLUTION, NEUTRAL IN ECONOMIC TERMS AND ACHIEVABLE IN TECHNICAL TERMS, TO THE PROBLEMS HINDERING THE EMPLOYMENT OF PEOPLE WITH DISABILITIES AND HEALTH CONDITIONS WOULD BE A REALISTIC TECHNICAL SOLUTION AND ACTUAL EMPLOYMENT, BUT ONLY IF THE SOCIETY MAKING THE RELEVANT DECISIONS AND AIMING FOR THE INCLUSION OF DISABLED PERSONS. IN A PERIOD OF ECONOMIC UPTURN WITH A HUGE EXPANSION OF THE LABOUR FORCE, HIGHER EMPLOYMENT RATES APPEAR NOT ONLY AMONG NON-DISABLED PERSONS BUT ALSO AMONG PEOPLE WITH DISABILITIES AND HEALTH CONDITIONS. HOWEVER, ONCE AN ECONOMIC DOWNTURN OCCURS AND THE DEMAND FOR LABOUR FALLS WE SEE THE APPEARANCE OF GROUPS THAT 'CANNOT BE

EMPLOYED IN A PROFITABLE MANNER'. THESE GROUPS INCLUDE NOT ONLY PEOPLE WITH **DISABILITIES** AND HEALTH CONDITIONS BUT ALSO UNSKILLED WORKERS, LONG-DISTANCE COMMUTERS, WOMEN WITH NO MORE THAN SECONDARY SCHOOL GRADUATION, IMMIGRANTS, THE ROMA MINORITY AND OTHERS, IN OTHER WORDS, ALL GROUPS IN A WEAK SOCIAL POSITION, TO WHOSE DETRIMENT IT IS EASIER TO IMPLEMENT **DISMISSALS**, OR WHO CAN SAFELY BE BLAMED FOR ANY DECLINING EFFICIENCY OF COMPANY OUTPUT. AS FINDING A JOB IS INCREASINGLY DIFFICULT IN GENERAL SO THOSE LABOUR GROUPS THAT ARE UNABLE TO PROTECT THEMSELVES ARE EXCLUDED FROM THE LABOUR MARKET WHILE INTENSIVE EFFORTS ARE MADE TO SERVE THE INTERESTS OF THOSE WHO BENEFIT FROM THIS **EXCLUSION**, WITH THE SUGGESTION OF SOME IDEOLOGY. IN THIS CONTEXT, THE LOSERS IN THIS GAME ARE GIVEN A LABEL TO LEGITIMISE THE SITUATION OR FOR SOME IDEOLOGICAL PURPOSES. LABELS SUCH AS 'LAZY', 'DRIFTER', 'LUMPEN ELEMENTS', OR NEGATIVE PERCEPTIONS OF PEOPLE WITH **DISABILITIES** OR HEALTH CONDITIONS ALSO SERVE TO DISGUISE THE

FACT THAT UNEMPLOYMENT IS ROOTED IN MACROECONOMIC AND SOCIAL INEQUALITIES LYING BEHIND THE DIRECT CAUSES. IT IS OBVIOUS THAT ONLY THOSE IN A VULNERABLE POSITION ARE EXCLUDED FROM THE LABOUR MARKET OR ALLOCATED TO LESS PROFITABLE JOBS. FOR SOME OF THOSE EXCLUDED, DEVIANCE IS NOT ONLY A REASON FOR, BUT ALSO A CONSEQUENCE OF, THE FAILURE OF BOTH THE LABOUR MARKET AND THE INDIVIDUAL. TO THE SAME EXTENT. WHEN ACCOUNTING FOR LABOUR MARKET SUCCESSES AND FAILURES, PUTTING INDIVIDUAL EXCELLENCE OR FAULT TO THE FORE SERVES TO FACILITATE THE EXCLUSION OF SOCIAL GROUPS UNABLE TO DEFEND THEMSELVES WITHIN THE LABOUR ENVIRONMENT. THIS UPSIDE-DOWN LOGIC IS ALL THE MORE DANGEROUS AS MANY DISABLED PEOPLE, AND GENERALLY ALL THOSE IN A MARGINALISED POSITION, BELIEVE THAT THE FAULT LIES WITH THEM. THE RESULTING FRUSTRATION REINFORCES HARMFUL BEHAVIOUR SUCH AS ALCOHOLISM, CRIME AND VOLUNTARY DROPPING OUT FROM THE LABOUR MARKET. FOR DISABLED PERSONS, EMPLOYMENT MAY CONTRIBUTE TO A LOWER PUBLIC BURDEN IN THE SAME WAY AS WOULD THEIR BETTER SOCIAL INCLUSION. ARGUING FOR THE MANY-SIDED NECESSITY OF EMPLOYMENT, TEGYEY SUMMARISED HIS VIEW AS FOLLOWS: 'IN THE EMPLOYMENT OF THE DISABLED WITH REDUCED WORKING CAPACITY, IT MUST BE ENSURED TO GIVE THEM THE MOST APPROPRIATE JOB OPPORTUNITY DESPITE THEIR HANDICAP, THAT IS, SUCH A JOB WHERE WORKING CAPACITY REQUIREMENT COULD BE PROVIDED TO THE FULLEST POSSIBLE. WHILE SUFFICIENT OUTPUT IS ACHIEVED TO ALLOW FOR THEM TO EARN THEIR LIVING ON THE BASIS OF THIS SUBSIDISATION, THAT IS, TO DEVELOP WORKING ABILITIES AND FINE-TUNING THOSE AS FAR AS POSSIBLE, ALL THE DISABLED PERSONS' SOCIAL



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National Personal Assistance Policies

What We Need and How to Work for It?

ENIL Webinar on Personal Assistance, September 14, 2020

We need to work for national personal assistance policies in our countries. What features must they contain in order to empower us, and how can we work for such policies?

First, what do we expect from such a policy? What can personal assistance do for our lives? There are many examples of how assistance users have managed to live with the help of their assistants but here is my story.

In 1961, at the age of 17, I contracted Polio. As a result, I have been using a ventilator, an electric wheelchair, and increasing assistance with the activities of daily living ever since. In 1966, after five years in a hospital, a scholarship enabled me to move from the hospital ward in Munich, Germany to a dormitory room at the University of California in Los Angeles.

The transition from patient to student was made possible by the scholarship that not only covered my expenses as a student but also contained direct payments for personal assistance. With that money, I hired, trained, paid, scheduled, and supervised fellow students as my assistants. I was able to pay them competitive wages, i.e. wages that they would have earned for working on campus at the libraries or cafeterias. They assisted me with everything I needed to concentrate on my studies and to enjoy life as a young adult living by myself for the first time. I had to learn to express my needs, had to learn to be the boss. That was difficult and I made many mistakes. But my mistakes have been valuable lessons.

In 1973, I moved to Sweden to work on my dissertation. Again, I hired people there as personal assistants. With their help, after completing my academic training, I worked as a researcher at the university.

Throughout the years, I must have employed hundreds of students, immigrants, and people between jobs to work for me. They not only enabled me to study and work but also to live the way I wanted, with a rich social life, with many interests, romantic relationships, with travel for work and pleasure. With their help, I became involved in disability work nationally and internationally. I founded several organisations, traveled and lectured widely, was recruited for research positions overseas, and headed international projects.

Personal assistance was also the key for me to getting married. My wife and I were confident that, with the help of my assistants, I not only would take care of myself, independently of my wife, but could also share household chores and work around

the house, on an equal basis. (That was the plan but it has not always worked out that way, I'm ashamed to admit.) My wife would not be my life-long, unpaid nurse. We wanted a relationship where we both, independently of each other, could develop and grow, pursue our interests, and have a meaningful career. For example, we both traveled in our work to meetings and conferences in Sweden and abroad. When we did travel together it was because we choose to so and not because I needed her as an assistant. The decision to have a child was also based on my personal assistance. My assistants would enable me to have an active part in raising and being close to my child. For instance, as a small child my daughter and I went shopping for groceries or fishing. My assistant would stay behind us and only interfere to prevent an accident.

The Swedish social security system pays me a monthly amount of money for which I employ seven parttime assistants to provide me with 18 hours of personal assistance a day. I can pay competitive wages. With that money, I have been able to live in the community despite my extensive disability. I am a profoundly ordinary person. There is nothing special about me, I have no exceptional gifts or talents. Many, many people in my situation could have equally fulfilling lives. What is special about me is that I have had personal assistance throughout my entire adult life. That is, sad to say, very special. In countries without personal assistance services – that is, in most parts of the world – I would not have had any self-determination. With only help from my family, I would have been very limited. In a residential institution, I probably would have died decades ago.

From my experience with personal assistance since 1966, I conclude that a personal assistance policy that is to enable you to live with the same choices and conditions as your non-disabled brothers and sisters, friends and neighbors must meet three main conditions.

First, we must have control over our personal assistance. The more we can adapt and fine-tune our personal assistance solution to our unique person and life circumstances, the better we learn how to handle this tool, the better will be the quality of our lives. That, in turn, requires that we recruit, employ, train, schedule, and supervise our assistants.

Second, we need direct payments from the government to pay our assistants' wages, that is, money paid directly to our banking accounts. Without controlling the money, we cannot be the employer and must accept any services that the government selects for us. Without direct payments, we have no choice, are stuck with services we don't like. Also, without controlling the money, you don't have the final word in important decisions in recruiting, setting wages or dismissing employees. You will be object, not subject. Your assistants will have a different attitude toward you. If you are not the boss, if you cannot switch service providers you cannot enforce good service quality and you are made to feel dependent on your assistants.

Third, the Direct Payments must cover the cost of all the hours of assistance we require, and enable us to pay competitive wages. Without decent wages people working for us may expect our gratitude. Under these circumstances, we cannot expect prompt, competent and reliable workers. With assistance insufficient in the number of hours and insufficient in quality, you have to rely on family and volunteers. You will be dependent, must make compromises and concessions. Planning activities or larger projects will become very difficult.

How do we work for personal assistance in our countries? How can we convince our governments, members of parliament, the media and, most importantly, the general public of our right to personal assistance?

One argument is in the area of economics. But, please, do not claim that personal assistance is cheaper for the government than residential institutions. That might backfire. Institutions with very few staff and crowded conditions like Third World prisons are definitely cheaper per inmate than personal assistance. Instead, we argue that with the same amount of money that institutions receive from the government for each of their residents, most residents could have better lives living in the community with personal assistance. In most countries, governments pay more for keeping us in an institution than for enabling us to live in the community. In Spain, for example, an institution received €2,400 per month for each resident while someone wanting to leave the institution could count only on €750. (The figures are from 2007 but their relationship is probably still the same today.) We can only speculate about the reasons why owners of institutions are entitled to such generosity from the government. Perhaps it's simply that they are better organised and have more money than our movement, have a better lobby, and better friends in government.

Institutions are capital intensive – considerable money is tied up in land and buildings. Personal assistance is labor intensive – almost all the costs are wages. Our assistants are low-income earners who use their wages for food and rent. This promotes the domestic demand – an excellent way for lifting a country out of a recession.

In Sweden, personal assistance has become a labor market instrument. Some 50,000 persons work as assistants or 0.5% of the country's total population. Many of my assistants would have difficulties in finding other work and would have to rely on social welfare payments from the government. Doesn't it make more sense to use direct payments for enabling us to contribute to the community, for allowing our relatives to work in their chosen field of interest, and, at the same time, for putting our assistants to work? We must make the general public understand that direct payments for personal assistance are not costs but investments – investments in people's ability to contribute to society.

The other argument for direct payments for personal assistance are health and safety issues in residential institutions and parental homes – the alternatives for assistance users. The media ever so often report about physical and sexual abuse of persons with disabilities in institutions and – to a lesser degree – in families, in particular, where parents as the sole caregivers are over-burdened and burned-out.

There is ample scientific evidence that institutionalization, through lack of stimulation, exclusion from family, friends, class mates, and the community, leads to retarded development and loss of social skills. I lived five years in such a place, from age 17 to 22. It took me nearly a decade to recover from the damage of this most horrible period in my life.

The current Corona pandemic provides further evidence of the dangers of institutionalization. So far, a higher percentage of older persons has died in institutions than in the community. It would not surprise me if this were also true for younger persons with disabilities.

A third argument are our Human Rights. The European Union, as a whole, and all its member states have signed and ratified the United Nations Convention on the

Rights of Persons with Disabilities. According to Article 19 of the CRPD, we have the right to living independently and being included in the community, at conditions equal to others. The General Comment Nr 5 in its operational definitions makes it very clear that residential institutions must be phased out and replaced by personal assistance services.

Sure, we shouldn't need to enumerate these economic, health and safety, and legal arguments to convince people of our right to personal assistance. In a decent society, all citizens have equal opportunities for living in the community in safety, health, and enjoyment of their innate potential. But, as we know all too well, we don't live in decent societies, we have to make them decent first.

I suggest the following strategy for working for a decent society.

More accessible housing

Our societies have to become more accessible. To replace residential institutions with personal assistance services, we must have more accessible housing in the community. Otherwise, many persons with disabilities – even with personal assistance – would still be forced into institutions. We need Universal Design in housing. For that, building codes for new construction and grants for housing adaptation of existing buildings must be in place.

Coalition building

In line with the CRPD General Comment Nr 5, residential institutions are to be phased out by redirecting resources into direct payments for personal assistance. To get that far, our movement has to become wider. As Founding Chairperson of ENIL, I'm proud about our organisation and its achievements. But we have to get better at coalition building, particularly at the national level. In many European countries, the disability movement is still divided into organisations for and of persons with disabilities. On top of that, organisations are mostly oriented along medical diagnoses. Thus, we find countries where one organisation, for example the Muscular Dystrophy Organisation, works for personal assistance but not the Spinal Cord Injury Association or any of the other organizations of the country. As if people with Cerebral Palsy, rheumatism, autism, sight impairment, Downs Syndrome, etc. would never need personal assistance! Would not our fight for personal assistance be more successful, if more organisations, more people were pushing the issue?

National organisations for Personal Assistance

I suggest we start ad-hoc one-issue organisations in our countries – national organisations for personal assistance. Anybody who wants to support or work for the goal is highly welcome regardless of their medical diagnosis or affiliation with other organisations.

Coalitions with the organisations of retired and older persons

Having worked for personal assistance for the last 40 years, I realise that we make a big mistake when we do not build coalitions around personal assistance with the organisations of retired and older persons. If our movement could get these often very large, rich and politically influential organisations to support our cause, lawmakers would pay more attention to us. How can we get these organisations on board?

Let us join organisations of retired and older persons

One of the ways is that those of us who are old enough join them and try to climb up in their ranks. We need these organisations to realise that their members are not only old but also prone to become disabled sooner or later, with a high probability of needing assistance by others with the daily activities of living. We have to convince their leadership that to live in the community with personal assistance is a hundred times better than being warehoused in an institution.

Our motto: We are profoundly ordinary people

We must double our efforts in making everybody – most importantly ourselves – understand and identify with our position: Though we may look, walk, or behave different, we are profoundly ordinary people because, like everybody else, we need to be seen for who we are, we need to be respected, we need to be loved. These needs we share with everyone, these needs make us truly human. To meet these needs, we need to live, love, and work among our friends and family in the community – with personal assistance.

As SEAMUS HEGARTY ELABORATED: 'IN AN IDEAL WORLD THERE WOULD BE NO SPECIAL SCHOOLS SINCE EVERY CHILD WOULD RECEIVE AN APPROPRIATE EDUCATION IN A LOCAL COMMUNITY SCHOOL. NO COUNTRY IS NEAR ACHIEVING THAT GOAL, APART PERHAPS FROM ITALY, AND IT HAS TO BE ASSUMED THAT SPECIAL SCHOOLS WILL FEATURE ON THE MAP OF SPECIAL EDUCATION FOR SOME TIME TO COME. BUT THAT DOES NOT MEAN THEY CAN CONTINUE UNCHANGED. SPECIAL SCHOOLS HAVE MANY ADVANTAGES — CONCENTRATION OF EXPERTISE IN TEACHING PUPILS WITH VARIOUS DISABILITIES, MODIFIED CURRICULA AND PROGRAMMES OF WORK, ADAPTED BUILDINGS AND EQUIPMENT, TRAINING OPPORTUNITIES FOR STAFF, AND LINKS WITH LOCAL EMPLOYERS AND POST-SCHOOL TRAINING AGENCIES. THESE ARE THE VERY THINGS WHOSE ABSENCE FROM ORDINARY SCHOOLS MAKES THEM INEFFECTUAL IN EDUCATING PUPILS WITH DISABILITIES. THE CHALLENGE TO SPECIAL SCHOOLS THEN IS TO FIND WAYS OF SHARING THEIR EXPERTISE AND RESOURCES, AND OF EMBEDDING THEM IN A WIDER EDUCATIONAL CONTEXT. SOME SPECIAL SCHOOLS HAVE ALREADY BEGUN TO DEVELOP OUTREACH PROGRAMMES. THIS CAN ENTAIL SETTING UP WORKING LINKS WITH NEIGHBOURHOOD ORDINARY SCHOOLS WHERE STAFF AND PUPILS ARE SHARED.'

'SOME SPECIAL SCHOOLS ACT AS RESOURCE CENTRES, PROVIDING INFORMATION AND CONSULTANCY TO LOCAL SCHOOLS, ORGANIZING SUPPORT SERVICES FOR FAMILIES AND CONTRIBUTING TO IN-SERVICE TRAINING ACTIVITIES. DISCHARGING THESE FUNCTIONS SUCCESSFULLY REQUIRES CONSIDERABLE CHANGES WITHIN SPECIAL SCHOOL STAFF. NEW SKILLS MUST BE DEVELOPED AND NEW ATTITUDES FOSTERED. TRANSMITTING A SKILL TO OTHERS IS NOT THE SAME AS EXERCISING IT ONESELF, AND OPERATING ACROSS SEVERAL SCHOOLS OR IN THE COMMUNITY IS VERY DIFFERENT FROM WORKING IN THE CLOSED CONFINES OF A SINGLE SPECIAL SCHOOL.'

'THE MOST IMPORTANT CHANGES REQUIRED ARE ATTITUDINAL: STAFF WHO ARE JEALOUS OF THEIR AUTONOMY AND INTENT ON MAINTAINING LINES OF PROFESSIONAL DEMARCATION WILL NOT SET UP EFFECTIVE COLLABORATION. THERE MUST BE A WILLINGNESS TO MOVE BEYOND EXISTING INSTITUTIONAL BASES AND ANY STATUS THAT MAY GO WITH THEM, AND

TO WORK CO-OPERATIVELY IN WHATEVER NEW STRUCTURES MAY BE ADVISED. THE UPSHOT OF ALL THIS IS THAT SPECIAL SCHOOLS OF THE FUTURE COULD BE VERY DIFFERENT FROM NOW. EMPHASIS WOULD MOVE AWAY FROM EDUCATING LIMITED NUMBERS OF PUPILS IN RELATIVE ISOLATION TOWARDS ACTING AS RESOURCE CENTRES. THE LATTER COULD ENCOMPASS CURRICULUM DEVELOPMENT, IN-SERVICE TRAINING, THE COLLECTION AND EVALUATION OF EQUIPMENT AND COMPUTER SOFTWARE, AND SPECIALIST ASSESSMENT, AS WELL AS ADVICE AND CONSULTATION ON ALL MATTERS RELATING TO THE EDUCATION OF PUPILS WITH DISABILITIES. THESE RESOURCE-CENTRE FUNCTIONS ARE IMPORTANT IN IMPROVING THE STANDARD OF SPECIAL EDUCATIONAL PROVISION REGARDLESS OF WHERE IT IS PROVIDED. BY CAPITALIZING ON AVAILABLE EXPERIENCE AND ESTABLISHING A BANK OF INFORMATION, MATERIALS AND EXPERTISE, THIS OFFERS A POWERFUL MODEL FOR MAKING BEST USE OF FREQUENTLY LIMITED RESOURCES. IF SPECIAL SCHOOLS HAVE TO MAKE CHANGES, ORDINARY SCHOOLS HAVE TO UNDERGO REVOLUTION. ORDINARY SCHOOLS HAVE GENERALLY FAILED PUPILS WITH DISABILITIES AND MAJOR SCHOOL REFORM IS NECESSARY BEFORE THEY CAN MAKE ADEQUATE PROVISION FOR THEM.'

'THIS REFORM MUST OPERATE AT TWO LEVELS: THE ACADEMIC ORGANIZATION AND CURRICULUM PROVISION OF THE SCHOOL AND THE PROFESSIONAL DEVELOPMENT OF STAFF. THE FORMER REQUIRES RETHINKING THE WAYS IN WHICH PUPILS ARE GROUPED FOR TEACHING PURPOSES, THE ARRANGEMENTS THAT SCHOOLS CAN MAKE FOR SUPPLEMENTARY TEACHING AND THE MODIFICATIONS TO THE MAINSTREAM CURRICULUM THAT TEACHERS CAN MAKE SO AS TO GIVE PUPILS WITH DISABILITIES ACCESS TO IT. ALL OF THIS FORCES MAJOR CHANGES IN TEACHER BEHAVIOUR. ATTITUDES, KNOWLEDGE AND SKILLS MUST ALL BE DEVELOPED TO CREATE AND SUSTAIN A NEW KIND OF SCHOOL WHERE THOSE PREVIOUSLY DISENFRANCHISED ARE GIVEN AN EQUAL SAY AND NARROW CONCEPTS OF NORMALITY ARE DISCARDED.' (HEGARTY, 1994, 16). HEGARTY CONTINUES: 'PREPARING PUPILS WITH DISABILITIES FOR ADULT LIFE IS A PARTICULAR CHALLENGE FOR ORDINARY SCHOOLS THAT RUN INTEGRATION PROGRAMMES. MANY SPECIAL SCHOOLS HAVE DEVOTED GREAT EFFORTS TO THIS AREA AND HAVE WELL-ESTABLISHED LEAVERS' COURSES. THEY ALSO BENEFIT FROM THE GREATER CONTROL THEY CAN EXERCISE OVER PUPILS' ENVIRONMENTS AND EXPOSURE TO THE OUTSIDE WORLD. ORDINARY SCHOOL STAFF HAVE TO FIND WAYS OF ENSURING THAT PUPILS DO NOT MISS OUT ON THE SYSTEMATIC PREPARATION THEY WOULD RECEIVE IN A GOOD SPECIAL SCHOOL, AND THEY MUST OFTEN DO SO WITH FEWER RESOURCES AND IN CONTEXTS THAT ALLOW FOR LESS CONTROL.' (HEGARTY, 1994, 45)

THE DEBATE PERSISTS AND HAS GAINED NEW IMPETUS FUELLED BY THE CONTROVERSIAL FINDINGS OF FOLLOW-UP RESEARCH CONDUCTED ON CURRENT EXPERIENCE OF INTEGRATION IN SCHOOLS. A UNICEF INNOCENTI INSIGHT STUDY OF 2005 HIGHLIGHTS THE SITUATION IN CEE/CIS COUNTRIES AND THE BALTIC STATES: 'THE EDUCATION DEBATE IS STILL VERY ACTIVE. THERE ARE ARGUMENTS THAT INTEGRATION OF CHILDREN WITH DISABILITIES INTO MAINSTREAM CLASSROOMS CAN BE A DRAWBACK FOR SOME STUDENTS, BOTH DISABLED AND NON-DISABLED PERSONS. THAT MAY BE A QUESTION OF ADEQUATE RESOURCES — A PERSISTENT AND IMPORTANT ISSUE. THERE IS A CASE IN THE CEE/CIS REGION FOR LINKING SPECIAL EDUCATION SCHOOLS WITH LOCAL MAINSTREAM SCHOOLS TO HELP TO BREAK DOWN THE TRADITION OF SEGREGATION.'

'IN SOME WESTERN COUNTRIES, THERE IS A TREND TO CO-LOCATE SPECIAL SCHOOLS ON THE SAME SITE AS MAINSTREAM SCHOOLS IN THE BELIEF IT PROVIDES THE 'BEST OF BOTH WORLDS'. SERIOUS EFFORTS TOWARDS INTEGRATION ARE BEING MADE IN SOME COUNTRIES, NOTABLY BULGARIA, HUNGARY, ROMANIA AND MACEDONIA.

'WHERE INTEGRATION HAS OCCURRED, IT IS LARGELY ACCOMPLISHED BY BEING AT THE SAME LOCATION AS AND/OR MIXING WITH MAINSTREAM STUDENTS, RATHER THAN INTEGRATED OR INCLUSIVE CLASSROOMS. CURRICULAR INTEGRATION, WHERE CHILDREN WITH DISABILITIES LEARN TOGETHER IN THE SAME CLASSROOMS WITH THE GENERAL STUDENT POPULATION, IS STILL SELDOM SEEN IN THE REGION — AND WHERE IT IS, IT IS OFTEN UNPLANNED AND, THEREFORE, UNSUPPORTED. IN ALBANIA IN 1996, AS THE COUNTRY REPORT NOTES, FOR THE FIRST TIME 'THE INTEGRATION OF PUPILS WITH DISABILITY IN REGULAR SCHOOL' BECAME A DECLARED POLICY GOAL — ALTHOUGH THE DETAILS OF HOW TO DO THIS WERE NOT SPECIFIED. A RECENT SURVEY BY THE ALBANIAN DISABILITY RIGHTS FOUNDATION FOUND THAT THE INTEGRATION OF CHILDREN WITH DISABILITIES WAS QUITE LIMITED AND DONE LARGELY IN RESPONSE TO PRESSURE FROM PARENTS OF CHILDREN WITH MODERATE DISABILITIES. IN HUNGARY, WHERE THE SPECIAL SCHOOL SYSTEM WAS RETAINED, ENROLMENT OF CHILDREN WITH

DISABILITIES IN MAINSTREAM SCHOOLS STARTED SPONTANEOUSLY IN THE MID-1990S. HOWEVER, SCHOOLS 'DID NOT HAVE THE TECHNICAL, PEDAGOGICAL AND CONCEPTUAL CONDITIONS NECESSARY FOR THE INTEGRATED EDUCATION' OF CHILDREN WITH DISABILITIES.

'THE RESISTANCE OF ATTITUDES AGAINST THE INTEGRATION OF CHILDREN WITH DISABILITIES IN MAINSTREAM SCHOOLS CANNOT BE UNDERESTIMATED. IN ECHOES OF THE 'CHARITY' TREATMENT OF CHILDREN WITH DISABILITIES, PARENTS AND OTHERS MAY SUPPORT INTEGRATION ONLY CONDITIONALLY, E.G., THE PROVISIO THAT INCLUDING CHILDREN WITH DISABILITIES IN A REGULAR CLASSROOM DOES NOT DETRACT RESOURCES FROM NON-DISABLED STUDENTS. ADDITIONALLY, THERE IS SUBSTANTIAL PASSIVE RESISTANCE INCUMBENT IN EXISTING EDUCATION SYSTEMS AND OTHER SOCIAL SERVICES.' (UNICEF, 2005, 20).

IN THE LITERATURE WE CAN FIND SEVERAL EXAMPLES: 'ALTHOUGH PARENTS WERE HAPPY WITH THE PROGRESS OF THEIR CHILD AT THE SCHOOL, THEY WERE DISAPPOINTED ABOUT SOCIAL OUTCOMES. THIS WAS IN PART DUE TO THE FACT THAT MANY CHILDREN WITH DISABILITIES CAME BY BUS FROM OUT OF CATCHMENT: THEY HAD TO MAKE A NEW FRIENDSHIP BASE, AND AN OPPORTUNITY FOR CARRYING IT ON OUT OF SCHOOL HOURS.' (AVRAMIDIS, BAYLISS & BURDEN, 2002, 150)

THE UNICEF STUDY CONTINUES WITH A QUOTE FROM THE LITHUANIA COUNTRY REPORT OF 2002: 'POLICY, LAW AND PRACTICE HAVE BEEN LINKED IN LITHUANIA TO MAKE STRONG PROGRESS IN MEETING SPECIAL NEEDS EDUCATION. THE 1991 LAW ON EDUCATION RECOGNIZED THE RIGHT OF CHILDREN WITH SPECIAL NEEDS TO BE EDUCATED IN SCHOOLS CLOSEST TO HOME. SINCE 1991 SCHOOLS STARTED USING MORE RESTRICTIVE CRITERIA FOR ACCEPTING CHILDREN INTO SPECIAL SCHOOLS — A CRUCIAL GATEKEEPING FUNCTION. AMENDMENTS IN 1998 SET OUT DEFINITIONS OF THE ROLE OF PEDAGOGICAL-PSYCHOLOGICAL SERVICES IN ASSESSING SPECIAL EDUCATION NEEDS AND GAVE PARENTS AND CHILDREN THE RIGHT TO CHOOSE THE FORM AND PLACE OF EDUCATION. THE LAW STRESSES INTEGRATED EDUCATION AND THE RIGHT OF PERSONS, EVEN THOSE WITH COMPLEX OR SEVERE DISABILITIES, TO BE EDUCATED.' THE UNICEF STUDY THEN REFERS TO STAFFING ISSUES: 'THE LACK OF TEACHERS WHO ARE ADEQUATELY TRAINED TO WORK WITH CHILDREN WITH LEARNING