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The Challenge of Including and Organizing Special Support in Mainstream Services – A Swedish Perspective

Magnus Tideman

In this paper I will first give an introduction to the welfare system in Sweden in respect to persons with intellectual disability. Secondly, I will explain the policy, laws, responsibility and the definition of intellectual disability, including the question of mainstream and special services/support. This is followed by a discussion about concepts of disability and about responsibility, collaboration, organisation and competence.

Swedish government and disability policy

At a national level, the Swedish people are represented by the Riksdag (the Parliament), which has legislative power. The Government governs the nation, implements the decisions of the Riksdag and proposes new laws or amendments to legislation.

Sweden is, on the regional level, divided into 21 counties. Each county has a county administrative board, which is the Government's representative at the regional level. The county administrative board's responsibilities include supervision of the municipalities' traffic safety, environmental work and nature conservation, to name just a few. At county level there is also the county council, whose decision-makers are directly elected by the population of the county. By far the most important area of responsibility for the county council is health and medical services. Activities are financed primarily from taxation and to some extent from fees and government subsidies.

Sweden is, on the local level, divided into 290 municipalities. Each one has an elected council that has powers over most matters of local administration such as schools, preschools, care of elderly, social services, disability services, housing, roads, water supply etc. Activities at this level are financed primarily from taxation and to some extent from fees and government subsidies.

The cornerstone of the Swedish disability policy is the principle that every person is of equal value and has equal rights. General efforts to improve accessibility in the community are

central to achieving the goals of inclusiveness and equality. Persons with disabilities may be in need of individual support from the community. The state, municipalities and county councils are jointly responsible for this aid, which is intended to ensure good health and economic and social security.

The Social Services Act (1982) applies to all citizens and will assure a good life with reasonable living conditions, but in the early 1990's it was evaluated as not enough for persons with disabilities. In order to guarantee good living conditions for persons with disabilities, and to increase their levels of participation in society, a new law on rights in the area of disability came into force in Sweden in 1994, the Act Concerning Support and Service for Persons with Certain Functional Impairments. For persons with intellectual disabilities, this new law meant the right to certain defined individual measures, and the responsibility for support and service as well as for education was decentralised and passed over to the local municipalities, and that the dismantling of the institutions was to be complete. Actions such as housing with special services for adults, or daily activities for those who are inactive and not enrolled in education are regulated and municipalities have the main responsibility, in line with responsibility for people without disabilities. At the same time new legislation was introduced, societal development was dominated by economic problems for the public sector and the New Public Management (NPM)-inspired restructuring of the public sector with, among other things, increased levels of involvement from private enterprise within the areas of schooling, healthcare, disability care and care for the elderly.

Persons with intellectual disability – a growing group

The definition of intellectual disability is based on the administrative categorisation that is applicable in Sweden and for which society is responsible (Sonnander 1997). This means, apart from testing that indicates the existence of an IQ under 70, there is also the requirement for an investigated need for special support or education that cannot be met in another way, in order for a person to be categorised as intellectually disabled. This categorisation means that a large variation in intellectual ability exists within the group, and differences in the assessments performed exist at a local level. Traditionally the number of people with intellectual disability in total in Sweden has

been approximately 0.45 % of the total population. But the number of children and adolescents being categorised as intellectually disabled has increased significantly during the last 15 years (Tideman 2000, 2011). A large number of students in primary school have been categorised as such and have been moved over to the special form of schooling known as special programme (or "särskola" in Swedish). In the Swedish educational system, special programmes for children with intellectual disabilities constitute a form of instruction in their own right. Children that are deemed to be unable to complete mainstream primary school on account of their intellectual disabilities will, if deemed appropriate, be transferred to schooling in these special programmes. During the past 15 years, the number of children in such special programmes has more than doubled, a development that has meant an increase in the individual variation in abilities and learning conditions within the group. The reasons for the increased categorization can mainly be found in the increased theorisation in the primary school and coexistent inability in the primary schools to provide students with learning difficulties with adequate support due to reduced economic resources. We currently have limited knowledge about the categorisations' effects in the longer term of the transition into adulthood on living conditions and how young adults experience these effects. The increase in the number of referrals to the special programmes for children with intellectual disabilities raises important questions regarding the effects of this increase on individuals as well as on society, both in short and long term.

Living conditions

During the past few decades, living conditions for persons with intellectual disabilities in the Nordic countries have undergone a number of changes, both legally as well as institutionally (see e.g. Tössebro et al, 2012). An objective shift within disability politics has occurred. The right to receive support in everyday life is now becoming a given priority, institutional care has been discarded and more active participation in society by this section of the population is being emphasised. The changes in Sweden from the beginning of the 1990s until today are characterised by a number of clear trends. Institutional living has been replaced by residential arrangements with staff service or the possibility for individuals to live in apartments of their own in ordinary residential areas. The level of variation in support and service depending on the city/town/area in

which individuals live has increased, and private companies are becoming increasingly involved within the disability care sector. At the same time, there has been, as mentioned above, a significant increase in the number of people being categorised as intellectually disabled, as well as an increasing level of resistance among young adults against being viewed as passive care receivers.

Since the middle of the last decade, questions about living conditions for persons with disabilities have become the subject of increasing attention among politicians, authorities, user organisations and social science-oriented researchers. Concrete examples of the increased level of interest in such questions include the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the European Disability Strategy (European Commission, 2010). In 2010 the European strategy was launched with the express aims of raising public awareness of disability, removing obstacles to inclusion and capacity building in order to ensure people with disabilities gain control over their lives. Persons with intellectual disabilities represent a group that is of special interest when it comes to knowledge, both nationally and internationally, since it is a group of people with a long history of vulnerability and marginalisation. Today the living conditions for the group defined as persons with intellectual disabilities are considered to be status quo, almost the same as they were in the 1990s. This means that, apart from the increased standard of accommodation due to deinstitutionalization, no significant changes have occurred since that time to reduce the difference in living standards for persons with and without intellectual disabilities. At the same time the present development we know points to an increasing level of variation of support within the group itself, something that is linked to, among other things, an individual's ability (or lack thereof) to negotiate on his/her own behalf. In line with the NPM this can be seen as an effect of the efforts to make a marketplace, where the well-informed and competent consumer is successful.

Power structures and discrimination

An important perspective when it comes to everyday life for adults with intellectual disabilities relates to the power structures that exist in society and the consequent risk of discrimination. Disability can be described as a social construct based on opinions of normality and deviation (Davis, 1995). Due to this, disability has long become a basis for discrimination in the form of

negative attitudes from the environment as well as the labour market, in both formal and informal social contexts. During the 1990s, legislation aimed at attempting to counteract discrimination against this group of people, was adopted. Many studies demonstrate, however, that disabled persons continue to be discriminated against in society and, in addition, are more socially isolated than other minority groups (Lindkvist, 2007). From this perspective one can see that there is an obvious power structure whereby disability can be viewed as a question of the distribution of resources rather than a given category (Söder & Grönvik, 2008).

Mainstream versus special services

In Sweden there has been a change in the disability debate from a focus on individual's shortcomings to changing of the society/environments. The Nordic welfare policy has traditionally focused on basic economic security and compensating individual support. We are proud of the physical standard in the field of disability and the standard of individual special support but focus and attitudes has changed during last year. The special services have been looked at more and more as a part of a discriminating society. Some say that we, via economic safety for people with intellectual disability, have "bought us free" from the real challenge, to create a society where all people, including people with intellectual disability, have the same conditions and prerequisites as others. One major part of an accessible society for all is that mainstream services include support to people with special needs. In the following I will give some illustrations from a number of fields to try to show the situation in Sweden today.

Public transport

The possibilities for mobility are of great importance for people today. The labour market, shopping and the social relations often presumes an ability to use public transport. In Sweden that is the first choice for people with intellectual disability, but when impairment consequences are more extensive there is a mobility service to complement it. In order to make public transport more accessible, there are some simple things to do. One recent personal example from Melbourne can be used as an illustration: as a person who is in Australia for the first time and English is not the mother tongue, it is a challenge to use the public transport system. The information about which tram or bus goes where, is impossible when

on the tram there is no information about which is the next stop. One way of making public transport services more accessible to people with intellectual disability (and to visitors) is to have accessible information, both verbally and with signs. In that respect the situation in Sweden is more advanced than in Melbourne. Nearly every stop has clear signs and verbal information and the metro, buses and trains provide verbal information ahead at each stop as well as legible signs which show the next stop and the next after that.

Education

In Sweden inclusive education has been a goal/vision for quite a number of years but we still have special programs for pupils with intellectual disability. The efforts during the last 20-30 years to make ordinary education more inclusive has lead to about 1/3 of all pupils with intellectual disability receiving their education today in the same classes as other non-disabled pupils. Two thirds are still in separate classes (although in the same school buildings as other pupils). We have had a long lasting debate about the advantages and disadvantages with inclusive and exclusive education. The new right-wing government has launched a policy which is friendlier to special solutions for pupils with disabilities. The research show that the variation is great among local authorities (who are responsible for education) which means that in some places nearly every child with intellectual disability is included in ordinary education and in some nearly none. This is an ideological question for politicians as well as for parents' organisations and the arguments are in line with the well known history of special needs research analysis of inclusion/exclusion.

Health

The point of departure is that people with intellectual disability, will use ordinary health services. Special medical doctors for special groups in primary care are no longer an option. If there is a health problem the individual will consult the general practitioner. This mainstream system is working well but when it comes to needing more special knowledge about certain impairments there will be a demand for expertise. Children's health services (CHS) can serve as an example. In Sweden all children and their parents are offered health services free of costs. CHS offers regular consultations with nurses and parent groups that discuss questions about bringing up children etc. This service is also for parents with children with

disabilities but when it comes to the needs of a special kind due to the child's impairment or the need for meeting other parents with the same experiences of disability, the general/mainstream service often can't fulfil this. Studies show (e.g. Broberg-Olsson 2006) that parents with children with disabilities need both the mainstream and the special services and that it is not likely that the children health services can manage that for all. The children's habilitation, managed by county council as a part of health services, offers expert knowledge and support for both the child and the parents when it comes to very special circumstances (like rare diseases).

Housing

The process of dismantling the institutions in Sweden was completed at the beginning of the 21st century. Institutional living has largely been replaced by various forms of residential arrangements with staff support in ordinary residential areas. This has happened at the same time that market solutions have made themselves significant within the area of disability. During the first decade of the 21st century an increasing number of residential arrangements and daily activities have been outsourced to private contractors. To some extent this has led to increased freedom of choice for the individual, although the picture is still largely dominated by limited opportunities for participation, self-determination and making one's own choices in everyday life. Persons with intellectual disabilities seldom receive real opportunities to choose their accommodation or workplace. Even if the residence's physical design and size has changed and improved, the types of routines and traditions that existed in the institutions are to some extent still to be seen today, like the isolating effects in the form of special measures and activities for persons with intellectual disabilities.

Accessible information

With respect to the nature of intellectual disabilities the question of information accessibility is a major issue. We are living in an "information society" where written information is substantial. This is however a problem, as most information is not easy to access for people with intellectual and/or literacy disabilities. People in common need access to news, literature and societal information and some need it in Easy to read or other adapted shapes. It is fundamental – democracy requires accessible information. In Sweden four years ago a

linguistic/language law was passed (SFS 2009:600) that states that it is the responsibility for authorities to use a simple and understandable language with respect to people with (and without) reading difficulties. This is in line with the definition of international Plain-language Association:

Plain language is communication designed to meet the needs of the intended audience, so people can understand information that is important to their lives.

Plain language is language that is understandable. What is clear, or what is plain to your intended audience, can only be decided by the audience. Most people expect a definition of plain language that describes writing of a certain style. Plain language is more a process -- it has been described as a means to an end.

This means that all correspondence with citizens should be in accessible ways. Notifications, forms and verbal communication (via telephone, meetings etc) should be adjusted to the receiver and when it is needed the authority should offer personal assistance. There are recommendations for written information (about easy to read language, disposition, designing and alternative format) but also for telephone calls, meetings and conferences, movies, television and video and of course for the Internet and e-services. There are in Sweden easy to read books, a weekly easy to read newspaper, understandable news radio program (each day) etc. At libraries in Sweden there are resources of easy to read books and at museums, the mass media and other public spaces efforts are made to make information more accessible, but especially authorities at large are still slowly proceeding when it comes to these type of questions.

Accessible information is on the agenda but also a discussion among researcher and people in practice about the problems with easy to read. Current research shows that when making the text simpler it can be too simple and nearly without meaning/sense. The users who can't understand the context lose all interest when an easy to read text becomes too easy and without nuances. One good example of a recent publication is a easy to read version of the book "Zlatan – it's me". Zlatan Ibrahimovich is the most successful Swedish football player ever and his book became last year a bestseller. The easy to read version has succeeded in the ambition to tell his story in a shorter but not too simplistic way and it has been read by lots of people, both with and without disabilities. This shows an accessible way

of making mainstream literature responsive. But the lesson is that it requires competence to balance between a clear and understandable language and not making the text too vacuous.

Social work

Even people with intellectual disabilities can of course "be hit" by social problems like addiction, homelessness, isolation and criminality. Treatment for social problems is in Sweden often based on verbal support. It means that people with intellectual disability are offered social problem support which may not basically improve their skills. In a report from the Swedish County Administrative Board (2005) it is apparent that the level of support provided to persons with disabilities varies, not only from county to county, but also from individual to individual within a county. The degree of variation is connected to an individual's ability to claim his/her rights. It is also apparent from Szebehely's study (2009) that women, persons with lower levels of education and persons born outside Sweden do not receive support from society to the same extent as men, well-educated persons and Swedish-born persons. The first-named groups are instead often dependent on support from relatives. It can be pointed out that a person with an intellectual disability may need to have contact with a large number of professional helpers who are specialists in different aspects of that person's needs, such as disability care, home modifications, assistance in finding employment, etc. This line of argument is particularly relevant if the person in question has a number of social problems. There are deficiencies in the collaboration between different authorities when it comes to persons with intellectual disabilities who are in need of measures from several different authorities, for example with double diagnoses or addiction problems (Swedish National Board of Health and Welfare 2005). Studies show that professional helpers are important to persons with intellectual disabilities, although there have also been incidents of personnel subjecting such persons to violence and abuse, for example at sheltered housing (Barron 2008). In the field of treatment for social problems for people with intellectual disability the mainstream services have to develop special support inside their framework. In Sweden we are just in the beginning of this process.

Self-advocacy

The general development towards decentralisation and increased municipal freedom has opened up

for freer forms of activity within disability care and has also created conditions for increased individual influence. New activities have appeared and developed whereby young adults with intellectual disabilities are able to meet regularly in order together to strengthen their control over their own lives and exert influence over the local community in the direction of increased participation and changing attitudes to intellectual disability. An increasing number of persons with intellectual disabilities do not accept the traditional role of the disabled that is associated with daily activities and other forms of societal support and service. They are choosing to position themselves either entirely or partly outside society's welfare measures, and consequently new forms of fellowship are being developed. The growth of new forms of activity by and for persons with intellectual disabilities can be interpreted as those persons offering resistance to society's traditional treatment and means of offering special support and service (Svensson & Tideman 2007).

Discussion and conclusions

In summary, the development that has taken place for persons with intellectual disabilities in Sweden from the beginning of the 1990s until 2012 can be described, partly as a process from relative homogeneity to increased levels of variation in support and service as well as education, and thus even increased variation in living conditions, and partly as a process whereby shrinking normality has resulted in increased categorisation. As I see it, there is in Sweden at the same time reason to derive much satisfaction from, among other things, the fact that the process of dismantling the institutions has been completed, and that persons with intellectual disabilities are creating resistance against being treated as passive care receivers, outside the mainstream society.

The development raises questions about accessible and responsive mainstream services as a way to counteract the variation in living conditions and services, and support for a more inclusive society and questions about concepts of disability and about responsibility, collaboration, competence and organisation.

The relational disability concept (Söder, 1982) positions itself, as I see it, between the individual and society-based (social model) views of disability. The approach signifies an affirmation both of the fact that people can have individual impairments and that society can in various ways

obstruct, oppress and discriminate against people. Disability is seen as a relational phenomenon, where disability can occur in the meeting/at the meeting point between the individual and the environment. This means that the surrounding environment, not merely in its physical aspect but also in the shape of social relations and meetings, decides whether a person in a certain situation becomes disabled or not. The same person with impairment can become disabled when encountering a non-adapted environment/situation, while in another environment/situation no disability occurs. Disability is thus shifted from referring only to the individual or to the "qualities" of society, to referring to the relations between the individual and society. Both the individual and the social level are needed in order to understand disability and how it is construed. According to the relational approach, both individual and general efforts are important in order to minimise disability-inducing situations.

Using the relational approach to disability, the increase in special programmes for pupils with intellectual disability can be seen as the result of an encounter between individual shortcomings and the school's failings. When the environment, in the shape of the school's resources and approach, is not adapted to the backgrounds and prerequisites of all students, the school becomes an environment that creates disability for some pupils. Disability becomes a question of the relationship between individual factors, such as the pupil's prospects and ability, and environmental factors. In addition to the potential of the individual pupil, factors such as the parents' educational background also play a role. For example, the parents' ability to look after the interests of their child and negotiate in order to gain access to support services is one factor. Other influencing factors include the local government's financial commitment to the school, attitudes of the school management and teachers to children's learning difficulties and how they should be dealt with, national demands for grading systems and theoretical knowledge, and so on. Disability can therefore be seen as a relational concept, where the relation between different factors can create disability. Since it is possible to influence this type of relation, it can be said that disability primarily is what society, through its actions, decides to call disability (cf. Bury, 1996). As I understand it the relational approach is possible to translate into the discussion about mainstream and special services. The key question is about the relation between them. Mainstream and special services are interconnected vessels. If mainstream works

well the need for special services will be limited and vice versus.

In Sweden we have guiding principles about responsibility for disability accessibility where the basic principle is that the sector in society who is responsible for e.g. transports also has the responsibility for disability issues related to transports. This is a way off trying to do services more mainstream and there has been some success, but it also initiates the question of collaboration between sectors. The research about collaboration in the field of disability show results that indicate for example the presence of power conflicts (Danermark 2005). When it comes to different opinions about which kind of adaptation that will be required or the balance between mainstream and special support, appears the question of preferential right of interpretation. It often also comes to an argument about money. To make services accessible and responsive is seldom for free. In discussions about priority with limited resources, many years of experiences in Sweden shows that disability concerns with varying success. It often ends up with the fact that disability issues are important but with respect to other bigger or higher social status groups there are not enough resources. The question of collaboration is not easy, besides power and money it is also about competence and attitudes.

From Swedish point of view one main problem for speeding up the implementation of mainstream services is the low level of staff education in disability care. Unlike other human service organisations there is no demand for staff to have post secondary education. Staff with none or low education are more likely to work in special services. They have concerns for their own jobs but also have an attitude that people with disabilities are served best via segregated social services. The special becomes security for both staff and service users. And the same goes for part of the disability movement. Many disability organisations in Sweden in their rhetoric advocate for a society for all and mainstream services. But when it comes to practical questions and implementation some of them promote special knowledge and special services. As a disabled person, or a parent so a disabled child, we want to meet the most skilled expert when there is need for health consultation or negotiations with the administrator of individual support. And, not to forget, there is among some parents a strong view that special services means security, which is their first priority.

The increased interest for universal design will probably mean that the physical environment and technical devices become more accessible and responsive to people with intellectual disability. The rapid development of inside information technology (like appropriate apps for smart phones and more accessible Internet) is promising from a disability perspective. But technique can't replace the need for human assistance. The development is promising but raises two related problems, the first is, will intellectually disabled people get smart phones and iPads etc as technical aids? The second is to strengthen competence about these kinds of facilities amongst staff members (remembering the low level of education). In Sweden we have seen that ability improving technical aids for people with intellectual disabilities is present but not in use to some degree. What we see instead is that people, particularly with mild intellectual disabilities, use computers, and smart phones without any special adjustment. Facebook and other social Medias are for instance very popular.

Even if the legislation is kept within bounds for different areas (like education, social services and public transport) making mainstream is mainly about how we organize. There is always a risk that special laws (like the Swedish Act Concerning Support and Service for Persons with Certain Functional Impairments) will lead to special services organized in separate ways. But it is possible, even with specific legislation, to organize the support inclusively, mainstream. We need then to make the difference between the administrative and the practical.

More accessible mainstream services will reduce the need for individual special support but never totally. The challenge is to make mainstream services accessible and at the same time manage to give those who need it, special support inside the mainstream area. This sounds quite easy but it is an issue. One perspective is that for some special support (e.g. alternative communication skills) you need special knowledge that is unlikely for everyone to have (like every bus driver or GP). When it comes to judgement, who decides where the limit for mainstream is and on what premise. The experiences from Sweden are as follows. We have in law and prescriptions a clear mainstream directed ambition. But when it comes to practice and implementation the level of ambition is decreasing. To explain that phenomena the research show how unstated economical aspects result in decisions that goes in a mainstream direction but just goes part way.

One example is the very mainstream rhetoric "From Patient to Citizen: A National Action Plan for Disability Policy" (1999). It contains a lot of very radical ambitions for creating a "society for all", but in the implementation, when it came to the question of resources, the politicians decided to take some minor steps in that direction. They do it without saying that the goals in the plan were too ambitious and without any public debate. It is done in a kind of consensus silence. This shows how disability issues nearly always are non-political (Sand'en & Tideman 1996) in that sense that they have low status in the political discussion and seldom cause different political standpoints. All political parties are eager to support people with disabilities but not to take the time or costs for doing the implementation in full. In addition many politicians share the view that special services are safer than mainstream and have problems to defend other solutions. A couple of years ago the left-wing government decided to close down special services for children with intellectual and physical disabilities but regretted it after a very small minority of parents and staff caused a mass media storm about letting vulnerable children down. Few politicians can cope with being accused of harming weak groups.

Special support efforts can brand and separate, but at the same time it is obvious that avoidance of special efforts can contribute to individuals not receiving the support they need and therefore risk even greater segregation (Söder, 1989). The most important question for the future is not whether there is a need for special support efforts for pupils with difficulties in school or for people with intellectual disability in the society, but on what grounds and in what manner special support should be handled in the mainstream schools and in the society of today and tomorrow.

From a Nordic perspective (Tossebro et al 2012) we can notice a need for revitalization of the ideological and political debate in the field of intellectual disability. There is a lack of strong stakeholders today if we compare it with 20 - 30 years ago. We need drivers for change. If we are able to develop mainstream services which includes special services it will be a way to tear down barriers for people with intellectual disability in the society. And it will mean that fewer with impairments will be disabled in their daily life and many with impairments will be disabled in fewer situations. In other words, steps towards a society for all, where the mainstream society is tolerant of people with different abilities.

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- Professor Magnus Tideman was a visiting Professor at La Trobe University during 2012/13, and is Professor of Disability Studies with focus on social work at Halmstad University, Sweden. Magnus.Tideman@hh.se