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***A non-institutional life for people with
intellectual disabilities in Northern Norway***

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Abstract:

A non-institutional life for people with intellectual disabilities in Northern Norway.

The foundation of Norway's shift from institutional care to complete reliance on home and community support for its citizens with developmental disabilities can be traced to the Norwegian welfare system. In May 1988, the Norwegian Parliament unanimously voted in support of the de-institutionalization reform.

The townships/municipalities gained full responsibility for care for people with developmental disabilities from the January 1991. As of 1992, people with developmental disabilities derived their rights through the ordinary Social Care Act and the Township/Municipality Health Care Services Act.

Ultimately, the goal of Norway's reform was to ensure that its citizens with intellectual disabilities live as fellow citizens. Normalizing living conditions, for example including people in all aspects of their daily life, and giving power back to people to take control over their own lives, are still the key challenges as far as care for people with developmental disabilities are concerned.

Even though physical and administrative normalization has progressed well in Norway, social normalization or inclusion that is true social integration has not yet been totally attained. For example, access to leisure and other activities is still dependent on the township/municipality economy and on the service providers' motivation.

The research project is to investigate the life conditions of people with intellectual disabilities in three municipalities/townships in northern Norway. Their social networks, care and support needs, daily living skills, communication skills, work and leisure will be examined. The target group for the investigation (N=100) includes people with developmental disability who live in their own rented house/apartment. Some members of the target group have lived in institutions, but the others have never been institutionalized.

A combination of structured interviews, unstructured interviews and observations will be employed in gathering information of relevance to the research. Caretakers of persons in the target group will be interviewed using structured questionnaires. Unstructured focus group interviews will be employed in obtaining information from five target group members (n=5) with verbal communication skills. Information on one target group member who has no verbal communication skills will be acquired through the use of participant observation. Information collected will be analyzed drawing inspiration from social network theory and research.

INTRODUCTION AND BACKGROUND

Western countries are steadily moving from institutional settings for people with intellectual disabilities to more community based living conditions. The change of policy was first articulated in the 1960s (Meyer, 2004; Bruininks, Kudla, Hauber, Hill & Wieck, 1981; Tidzard, 1960; Hatton, Emerson & Kiernan, 1995; Lakin, Prouty, Polister, & Smith, 2001).

In the 1950s and 1960s Norway built a number of small institutions for people with intellectual disabilities. The policy was primarily to provide residential services through institutional care. The largest institutions housed 300 to 400 persons compared with the thousands of people in some institutions in other nations at that time. These settings shared the sociological status of a “total institution”(Goffman, 1961) in which all aspects of people’s lives was controlled.

During this period (1950s and 1960s) new institutions were established primarily for people in Norway characterized as “noneducable” and could be admitted to one of these institutions. In 1950 some 0.025 % of the population in Norway was placed in institutional care. In 1970 it had grown to 0.18 % of the population. Between 1950 and 1970 there was an expansion of 300 institutional beds per year (Johansen, 1996).

In the 1980s the foundation for the “noninstitutional” society in Norway was laid. Groups of professionals and policy makers developed and submitted white papers to the Norwegian Parliament that stimulated discussions within Norwegian society and its political parties about recognizing and honouring the same rights to quality of life and welfare among people with intellectual disabilities as those for other people. Norwegian prosperity was also a reason for the attention to the question of what the society could do for people who were not a part of this prosperity.

Most of the institutions for people with intellectual disabilities before the reform were typically comprised of small and large group homes some of which other countries were using to achieve what they would call deinstitutionalization (Meyer, 2004, Cunningham & Mueller, 1991).

The home and community support for its citizens with intellectual disabilities lies in the health and welfare system that has been established for all Norwegian citizens. This system is predominantly publicly financed through taxation.

Nonworking spouses, students, unemployed persons, and other people, including people with disabilities who are without wages, are exempted from social security tax, but they retain the same right to assistance and medical treatment. This is the cornerstone of the Norwegian welfare state.

Under political pressure, the Minister of health and Social Services appointed a committee composed of parents, politicians, public administrators and scholars in the field. Their task was to conduct an evaluation of institutional care for people with intellectual disabilities. They visit institutions throughout Norway.

The committee concluded its work in 1984-85. The committee used four factors in considering its standards of quality assessment: (1) the ideological tenets of the principle of normalization, (2) the government's commitment to decentralization of services, (3) the goal of the integration of persons with disabilities, and (4) moving toward a broader definition of developmental disabilities as a target group for services.

Most significantly, the review committee concluded that institutional care should be ended in Norway.

The specific findings contributing to the conclusions of the review were:

- The circumstance of life and standard of living of persons with developmental disabilities in institutions was unacceptable by basic human, social, and cultural standards.
- There were no rational reasons to send people out of their neighborhoods to specialized facilities because of a developmental disability.
- The special-care organizations for persons with developmental disabilities provided poorer medical, pedagogical, social, and cultural service in the institutions than what was available in the local community.
- The politically accepted goals of normalization, inclusion, and decentralization could only be realized through local (township) responsibility. Special-care organizations, whether small (e.g., eight persons) or large (e.g., 150 persons) worked in opposition to the realization of the accepted goals for people with developmental disabilities.
- The township (municipality) responsibility for people with developmental disabilities would limit the extent to which people would fall between the cracks or find themselves in the "grey areas" of responsibility of direct government entities.
- Continuing to pour money into institutional care would yield only marginal effects on the living conditions of people with developmental disabilities, but similar investments in services within townships could contribute to significantly better lives for people (NOU nr. 34, 1985).
- The committee further recommended that the complete dismantling of institutional care in Norway be accomplished within a period of 10 years, from 1985 to 1995. It was recognized that the townships needed both time and money to close the institutions.
- Because the goal was so important, it was recommended that the process should start as soon as possible. It was recommended that the money to achieve these goals would come from the national government.

In May 1988 the Norwegian parliament debated the basic premises and recommendation of the white paper and in June 10 the temporary Act about dismantling the institutions.

One section of the Norwegian Reform Act provides guidelines on housing. It provides that all people with developmental disabilities who rent or own their apartment or the house in which they live can do so in their own names. It assures that they are the ones paying the rent from their social security benefits or earnings. The Act provides for special loans to individuals for these purposes, and a special financial program called Norwegian Housing Bank was required to provide loans to the townships for creating the new housing needed. Rules promulgated based on the Act established the following criteria for individual housing:

- The individual would rent or own his or her own house/ apartment.
- The contract or mortgage for that housing would be in the name of the person.
- The apartment would be part of the ordinary housing stock of the community with appropriate consideration for access to public offices, work, leisure, and buses that were near the area.
- The quality and character of housing should be similar to that of other citizens of the township.
- If purchased, the apartment should have relative marketability for resale.
- The apartment must be barrier-free and accessible for people using wheelchairs or having other physical impairments.

The law further provided that persons with developmental disabilities would own everything in their apartments. They would pay for food, clothing, electricity, travel, and fees associated with their recreation/leisure activities from their own.

Ultimately, the goal of Norway's reforms was to ensure that its citizens with developmental disabilities could live as fellow townspeople. Normalizing lives, including people, and giving back power to people over their own lives are still key challenges for people with intellectual and developmental disabilities. The closure of institutions for people with developmental disabilities leads to new public policies, including an evolving concept of how communities could integrate people with intellectual disabilities within their fabric. These new care/services remain as the girders of Norwegian social goals for people with developmental disabilities.

As it is evolving, the contemporary view of normalized services has a number of aspects. First, normalization includes the idea of people with disabilities having access to, and participating in the same programs, activities, and services as the other citizens of their township. Normalization also means making the neighborhood normal by acknowledging and celebrating that it is "normal" for a neighborhood to have people with developmental disabilities. It is normal for people who are 20 years old to choose a neighborhood and to choose a home. It is normal to have friends in one's neighborhood. It is also normal for people to fear other people who they seldom see, do not know and who have strange behavior. It is normal to not understand or be threatened by people who are different. The goal of

“normalizing” communities and neighborhoods can only be accomplished when people not only live in the community, but when they live as visible, active members of it.

In Norway, there is a system of public support within the township that promotes normalized relations between support providers and persons with disabilities. A system of housing has been created in which conditions are normalized. However, although physical and administrative normalization has progressed well in Norway, social normalization (or inclusion) that is true social integration has not yet been totally attained. For example, access to leisure and other activities is still dependent on the township economy and on the service providers’ motivation.

Sandvin (1992) has written about the concept of statistical normalization as a way to bring attention to the living conditions and the welfare of people with developmental disabilities. Statistical normalization is achieved when measures of standard of living, earnings, and other statistical signs of well-being are achieved by people with developmental disabilities at rates common for all citizens of the local society. On many social measures, Norwegians with developmental disabilities have lives that are not normalized, despite the commitment to normalization (Johnsen, 2002; Rustad, 1999; Sandvin, Söder, Lichtwark, & Magnussen, 1998; Sundet, 1997).

Relative deprivation is a concept that examines quality of life experience as it compares to others in a comparable position. In evaluating the lives of people with developmental disabilities there is an effort to identify a group of people that are in a relatively worse position. It seldom happens that we identify such a group (Jensen, 1996).

As part of this analysis one looks for the barriers to people’s possibilities for a normal life. Part of the value of the process is to study the role of special services in limiting or assisting in ideal normalization. It allows attention to be given to the role of the service act in helping the service user to reach certain personal standards of living.

Of course there are human values more basic than being “normal.” One may not wish a life that is common. Often in Norway it is the township-employed health and social worker who makes the decisions for people with developmental disabilities. There are conflicts between the township staff and relatives, and there are conflicts between relatives (and the township) and people with developmental disabilities. Conflicts are mostly based on different attitudes concerning how people are (or should be) living their daily lives. Conflicts are often based on differences in understanding cultural factors. Increasingly conflicts derive from increased opportunities and expectations for people with developmental disabilities (Johnsen, 2002; Rustad, 1999; Sandvin et al., 1998; Sundet, 1997). For many relatives and others involved in the person’s life, normalization represents a new reality.

Normalization as an ideology is mainly a discussion among scholars; it has had limited effect in evaluating and improving the daily support of people with developmental disabilities. Some instrumental evaluating tests have been developed, for example Wolfensberger’s PASS (Wolfensberger & Glenn, 1975), and Solum and Stangvik’s NOTIS (Solum & Stangvik, 1987). But in daily life support, providers make their decisions based on common sense or on their own notion of what normalization means. Part of the conundrum is that the concept of normalization is difficult to translate into a template that guides daily life when interactions are often fast-paced and decisions have to be made with little or no reflection. Under these conditions, people with developmental disabilities are seldom consulted and asked about their

own experiences or preferences (Johnsen, 2002; NOU nr. 34, 2001; Rustad, 1999; Sandvin et al., 1998; Sundet, 1997; Tøssebro, 1992). Their choices are limited, and their daily activities are often based on the structures and patterns chosen by their carers. Despite intentions to the contrary, the goal for people with developmental disabilities to become fellow townspeople based on respect, citizenship, and a commitment to “normal” self-determination has not been achieved. Among scholars in Norway there have been numerous discussions about the meanings and applications of the Scandinavian normalization tradition, the independent living movement, empowerment concept, and Wolfensberger’s notion of social role valorization. In part, Norwegian scholars have been influenced by all of these notions, but the concepts as used among the scholars often result in different meanings and interpretations (Kristiansen, 1993; Solum, 1993; Stangvik, 1987).

These discussions have led to new perspectives on the evaluation and design of community services for people with developmental disabilities. Methods are being developed to attend to the individuals’ needs and preferences by helping the individuals develop the competency to express their own views and make their own well-founded decisions. The perspective of self advocacy is part of this new trend to try to let people with developmental disabilities establish their own agenda, or at least to be recognized as having an important role in defining it.

The Norwegian Welfare System has made important changes to improve the lives of people with developmental disabilities, but there is still more to do before the goal as articulated in the original national plan is attained. NOU (2001) is a guiding work to create strategies for breaking down the barriers to achieving national goals. It continues to show a gap between the political goals and reality. A major component of that gap is a lack of equal power and equal possibilities for people with developmental disabilities in planning and making decisions about their support and about their lives. Tøssebro and Lundeby (2002) concluded that there is still a struggle for parents to get the services they need from their local townships. But, it also appears that most of the parents who have obtained services from their townships are satisfied with the services, from the kindergarten and school, to the assistance they receive in their daily living (Tøssebro & Lundeby, 2002).

The next stage of Norway’s reform strategy is to find the mechanisms to close the gap between goals and reality of equality.

Decentralization and devolution of authority to townships/ municipalities in Norway has resulted in large part in normalization of services for people with developmental disabilities.

Removing the “special services” for people with developmental disabilities, outside typical community service for all people, was a large step toward normalization. But this step was not without its problems because it also resulted in a loss of differentiation and a loss of special entitlements and specialized expertise that may often have been necessary. Decentralization means that decisions have to be made in a township where local human services priorities include helping other groups, such as elderly adults, children, drug abusers, and other differentiated populations.

Decentralization can also pose a risk for people with severe disabilities because such individuals are much more dependent on service providers who may not always listen to wishes of service users.

Norway's experience with deinstitutionalization and devolution of services can offer us many lessons. We certainly recognize that the way in which measures and services are organized and provided for in the townships will have a great impact on the extent to which it will be possible to meet the objectives and values of the national reform policy. One lesson is that township service administrators and staff, under this type of reform, need to understand the dynamics of social life and have the resources and ability to stimulate and arrange for integrative social processes.

The research project

The research project is to investigate the life conditions of people with intellectual disabilities in three municipalities/Townships in Northern Norway.

There social networks, care and support needs, daily living skills, communication skills, work and leisure will be examined.

The target group for the investigation (N-82) includes people with intellectual disabilities who live in their own rented house or apartment. Most members of the target group have lived in institutions, but some have never been institutionalized.

First part:

First part is a quantitative structured interview of careproviders who knew members of the target group. Structured questionnaires were used relevance to the research.

There were 82 persons (N-82) in the target group. 66 of them come from one township/municipality. The other comes from the two other townships (7 + 9).

The target group are as follow:

- The youngest is 18 years old	
- Under 30 years old	6 persons
- Between 30 – 40 years old	14 persons
- Between 40 - 50 years old	15 persons
- Between 50 – 60 years old	23 persons
- Between 60 – 70 years old	21 persons
- <u>Over 70 years old</u>	<u>3 persons</u>
	<u>N 82 persons</u>

Everyone is living alone in their apartments as the reform said.

Communication

In the group I investigate there performance in communication. I grouped as follows:

- Verbal Communication			
Normal language		30 persons	
Longer sentences, but often repeated		8 persons	
One and two words sentences/difficult to understand		18 persons	
One word sentences. Sign from Norwegian Sign language		11 persons	
			67 persons
- <u>Nonverbal kommunikasjon</u>			<u>15 persons</u>
	<u>N-81</u>	=	<u>82 persons</u>

There are 30 persons who can communicate normal without any problem. They are understood and they understand “everyday” language.

15 persons have no language.

Work

There are three who is working outside the work shelter. He is employed by the municipality. Ten in the target group is working at a shelter workshop. Eleven are at a activity daily center more then 2 days a week. Five are home and have no organised activity.

Lesure

I will lecture about that and the lack of inclusion.

Other factors

Daily living skills and care and support needs.

Unstructured interviews and focus group interviewed will employ in obtaining information relevance to the research. This will come later as a second article. It was not time to do it now.

Humans are social individuals. Some people have different ways of relating, for example those with autism spectrum disorders. But most human beings seek company, recognition and acceptance, and without them life can be bleak, tedious and lonely (Pahl, 2000).

Communities and networks are important. Networks play a number of functions. Friendship makes people happy and connected, gives emotional support, instrumental aid, evaluating problems or solutions and monitoring.

Disable people are often in a greater need of friends, they are less likely to be integrated into networks and friendship circle.

This investigating shows a lack of social network. The people in the target group who has little of verbal communication have now other contact than the care provider and the person who are in the day care facilities.

People in the target group who has normal verbal language has a greater opportunity to make friends and are doing that. Their closest friends are other with disabilities.

Under such devolution, townships are being asked to design and affect social engineering to benefit one group of their citizens. Yet, in reality, the public services in townships can only provide for a realization of the objective of the reform, and not always meet them. Social inclusion and acceptance, social community, and the establishment of spontaneous friendship or more intimate relations are all values lying outside the scope of “public management.” The dilemma is that when implementing the mechanics of such a public policy (i.e., the reforms), attempts to exceed such borders might represent an instrumentalism of social life, or an “invasion” of social and life activity areas where measurable and rational social service management could do more harm than be supportive. It can be said that the reform in itself is a result of such recognition. The emphasis on the need for integration in a normal school, working life, and in more informal traditional communities is based on the recognition that the objective of the reform cannot be realized by the public service alone (Sandvin, 1993).

While the goals of community integration are worthwhile and laudable, realities often tell of the inherent problems in achieving social integration. For example, data provided by Hem, Aas, and Piene (1997) on living conditions for people in Norway in 1987, 1991, and 1995, show that people with various disabilities attend fewer cultural events and participate less in leisure activities than persons in the general population. In a study conducted at Harstad University College, 120 service providers were interviewed about leisure and activity in the afternoon and evenings for people with developmental disability (Meyer, 2004). The study indicated that the majority of adults with disabilities living in their own apartments do attend special activities set up for adults with disabilities (e.g., discos, boccia), but they very seldom attend ordinary community cultural events. The data also revealed that adults with developmental disabilities needed help to be able to go to community cultural events, but that this help was not available from service providers, and the township economy did not give this activity a priority.

The tendency within today’s social policy thinking is to interpret physical nearness and contact as an analog to integration and involvement in one’s community. However, attending a normal school is not the same as being part of a school community.

Living in a normal housing community is not the same as being integrated in a neighborhood. Söder (1979) commented on this misunderstanding:

The normal life, to which mentally retarded people are introduced, is not in itself integrating. Instead the “normal” reality is segregation. Segregation and social degradation is all the time present in our community; both in working life and at our work place. By disregarding this, it is easily believed that all “normals” represent one unit where mentally retarded people can be integrated by physically placing them there. This represents an obvious risk of romanticizing reality. [Author’s translation from Swedish].

Although physical nearness between human beings is normally a good prerequisite to developing closer social contact, physical integration can also be a source of conflict or social distance. Research shows that many people have a tendency to shield themselves from social

contact with neighbors and the local environment because they fear that such contact can be bothersome and reduce their individual freedom (Ehn, 1978). Goffman (1982) noted that fear of nearness may create a need to protect one's own territory and mark borders both physically and socially. Nearness can also make the differences between people more visible and create a need to isolate the factor that can threaten the social stability.

The political process in Norway based on the latest work of NOU (2001) is proceeding. Yet, it will be of interest to see if the political focus will shift given the realities of organizing services for people with developmental disabilities in the future. It is hoped that the experiences of changing the nature and structure of services in Norway can benefit others as they wrestle with the difficulties inherent of moving from a segregated, albeit specialized system of services, to one that involves people with disabilities within the fabric of their natural community. Further, in those nations where institutional care never existed, it is hoped that this examination of devolution will aid in anticipating the problems – and thus solving them before they become barriers – when creating a broader network of support and specialized aid to people with developmental disabilities living within the framework of their family and kinship networks.

This research project will be ended in January and the fully analyzed report will be made in to an article in a Journal with referee.

The next article with the focus group interviews will come in 2008.