

Paper

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De-institutionalization of living conditions for persons with intellectual disabilities in Denmark from the decentralization of institutions for special care in 1980 until today

A paper trying to present a brief status on de-institutionalization of the every day life of persons with intellectual disabilities could start with a stipulation of the meaning of the concepts of institutionalisation and de-institutionalisation. A traditional understanding of the institutionalised life is formulated by the Danish Ministry of Social Affairs in the report: Evaluering af erfaringerne med institutionsbegrebets ophævelse på handicap-området, 1998 – 2002 (Evaluation of the Experiences with the Abolition of the Concept of Institution in the field of Disability, 1998 - 2002.) *"In the socio-political context, "institutions" have traditionally been understood as a common physical, structural, ideological and regulated framework for public support and education of groups of socially disadvantaged and marginalized people's lives under the supervision, treatment or care of professional staff."* (Socialministeriet, 2002, p. 33)

A somewhat different and more operational definition of the concept institutionalisation can be found in the report "Deinstitutionalisation and community living outcomes and costs, Volume 2: Main report", which says: *"For the purpose of the study, the European Commission defined a residential institution, as an establishment in which more than 30 people lived, of whom at least 80% were mentally or physically disabled."* (Mansell et al, 2007, Vol. 2, p. 6)

Based on these understandings of institutionalisation and de-institutionalisation, a brief status on the de-institutionalisation processes in Denmark will be carried out at two levels. The first level will consist of the development of the conditions which the political, legal and administrative intentions and decisions create in relation to de-institutionalisation processes and the second level will consist of some features of everyday life, as it is designed and takes place in the interaction between residents and professional staff.

Development of the political, legal and administrative framework and conditions

The concept of institution was abolished, but!!

With the commencement of the Social Security Act (Bistandsloven) in 1976 and with the decentralization of the special care system by transfer of authority from the State to the 14

Counties, it became possible to divide the huge central institutions in smaller units and to establish smaller independent housing facilities in regular living areas. In addition, the law from 1953 dealing with person with intellectual disabilities was abolished and the rights of people with disabilities became a part of the general Social Security Act, which then applied to all citizens receiving public support.

In the years after the counties took over the responsibility for the living conditions of persons with intellectual disabilities the development was marked of a dismantling of the central institutions by restructuring and relocation to smaller residential facilities in regular detached houses, in apartments or in newly build smaller institutions. Furthermore, in 1984 it also became possible for the municipalities to establish housing facilities for persons with disabilities. The period of the 1980'ties was, as Benny Lihme (1985) wrote, everywhere characterized by an atmosphere of breaking up and a mess of moving. In the counties and municipalities the talk was about removal, relocation, and bringing people home to own counties and municipalities. All seemed in some way to move. During a conference in 2005 on the occasion of 25 anniversary of the decentralization of the special care system, the then minister of Social Welfare Eva Kjer Hansen expressed the following about this somehow hectic period.

"Viewed in the light of belated wisdom, the development was, perhaps a little too fast for some of the persons with intellectual disabilities. It was based on the idea of normalisation that people with intellectual disabilities were moved out in small housing facilities in villa neighbourhoods or industrial areas. However, it didn't go as expected. They didn't become really integrated and some were isolated and could not find their feet in the new surroundings." (Kjer Hansen, 2005)

In 1998 the Social Security Act (Bistandsloven) was replaced by the Social Services Act (Serviceloven). With the Social Services Act became the concept of institution abolished and replaced by the concept of residence. The intention was to establish a separation between residence and social service benefits in such way that social service benefits were provided independent of the residence and according to the estimated needs of the individual.

The intentions regarding abolishing the concept and idea of institutions was only partly realized first of all caused by the remaining possibility of establishing housing facilities under two different Acts, namely the Social Service Act and the General Housing Act (Almenboligloven). Housing facilities established under the Social Service Act often had an institutional touch with small private rooms for the residents, large common rooms and office facilities for the professionals working there. This was combined with a lack of clear standards and regulations on how the residence should be arranged and furnished and often with a lack of consistent separation between the housing and the social service benefits of the residents. Opposite, housing facilities established under the General

Housing Act were characterized by a normalisation of the housing conditions, as the residents had a lease agreement and therefore ordinary rights in connection with lease termination and privacy. Housing facilities are as other facilities under this Act subject to standards demanding that the facility has bath, toilet, kitchen and running water.

This parallel legislation in the field of housing gave rise to criticism partly because housing facilities established under the Act on Social Service not clearly separated residence and individual social service benefits, for instance should recipients of early retirement pension from before 1. January 2003 according to the rules pays a service charge and partly because the parallel legislation gave different terms for the residents, according to the law under which their housing facilities were established and managed. This criticism was raised in the report:

Persons with Disabilities in Denmark: *“It is the view of the Institute that the use of the Social Service Act § 92 for allocation of housing facilities for persons with disabilities results in discrimination caused by disability..... Residential facilities under the Service Act § 92 will often be of significantly lower quality than residential facilities under the General Housing Act. The residents under the Social Service Act do not have status as lease-holder and have to pay service charge if they are recipients of incapacity benefit according to the rules of before 1st January 2003”.* And further: *“The institute recommends furthermore, that all residential facilities that today are functioning under the Social Service Act, are up-to-date renovated and transferred to the General Housing Act.”* (Institut for Menneskerettigheder, 2005)

The criticism had consequences. The service charges for all residents of housing facilities under the Social Service Act were repealed in 2008 as well as the legal position in relation to the residence was improved with the right to a residence document and 3 months written notice before termination. However, residential facilities under the Social Service Act are still not subject to quality standards as the facilities under the General Housing Act.

The Challenge of the Municipality Reform

A new local administrative structure *came* into force on 1. January 2007. With the structural reform of municipalities and counties became 271 municipalities and 14 counties merged to 98 municipalities and 5 regions. The reform was followed up by changes and amendments in the Social Service Act as the municipalities were given the overall responsibility for ensuring that all citizens in the municipality got relevant service offers and for the referral to and financing of these offers.

The five regions got operational responsibility for the offers within the fields of social security, social psychiatry and special needs education, which the municipalities were not obliged to take over or did not want to manage.

Besides this, decentralization of responsibilities for social affairs from the former counties to the new municipalities the reform implied some changes in the Social Service Act. An annual agreement between each region and the municipalities in the region should be elaborated in order to ensure that the region would establish and manage housing facilities to the extent, which the municipalities assessed as necessary. Moreover, municipalities and regions became obliged to report information regarding their residential offers to a " www.portal" (See www.tilbudsportalen.dk) in order to create openness and transparency in relation to users. Furthermore, in April 2006 Disability Councils were established in all municipalities in order to advise the municipality councils on disability policy issues and finally an national knowledge and specialized counselling organization (VISO) was established to assist municipalities, citizens and residential accommodation with guiding elucidation and special *advice* on cases, where local expertise was not likely to be present.

Now it is just a little more than one year ago that the new municipalities took over responsibility for the housing facility area and it is therefore a little premature to take stock of what the reform will have of consequences for the further de-institutionalisation of the lives of persons with disabilities. Many of the 98 new municipalities are still trying to gain an overview of the housing facility area and how they can build the necessary capacity and arrange with neighbouring municipalities and regions, in order to create relevant offers to the citizens of the municipality. With this in mind, the following will nevertheless be an outline of some current trends and issues.

First, the municipalities have taken over a number of housing facilities, which are very different from each other. Some housing facilities are specialized for a particular diagnostic category of users. Some housing facilities are managed under the Social Service ACT and some are established under the General Housing Act and fulfil the relevant standard requirements demanded by this law. Some housing facilities are worn down and have structural characteristics of an institution with hospital-like corridors, large common rooms and small private rooms for the residents and some are new and operate largely as private housing residents and homes. Some are located as small entities in public residential areas and some are located as major cluster buildings in the outskirts of cities. Some consist of a small number of residents in a stairway or in a house and others are larger and consist of well over the 30 residents and can thereby be defined as an institution according to the definition in the report : "*Deinstitutionalisation and community living – outcomes and costs*" (Mansell et. al., 2007). This variegated picture makes it a challenge for municipalities and local Disability Councils to formulate the future disability policy on housing facilities.

Second, there is now a tendency that new residential facilities are built under the General Housing Act as cluster facilities in the outskirts of cities and often with accommodation possibilities of

between 16 to 24 residents. However, still some municipalities are building cluster facilities planned to accommodate up to 40 to 50 residents. This is justified partly by economic considerations and partly by the argument that residential accommodation should have a certain size in order to be able to provide adequate technical expertise and professional support to the residents in the housing facilities. Moreover, it is common in this discussion on size and location of new residential facilities to refer to bad experiences with moving residents into facilities in ordinary residential areas. See for instance the quotation above of Eva Kjer Hansen, former minister of Social Affairs.

Third, the possibility of the users to choose residence depends on the facilities available and an often long waiting list. This makes it unusual and difficult for a user to thank no to a proposed residence or move to another housing facility, and it puts it under the question whether there really is the free choice of residences in Denmark as confirmed by an executive order of the Ministry of Welfare in 2002 and as expressed in the UN Convention on the Rights of Persons with Disabilities: *"Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement."* (Article 19, 2006)

A very recently published study carried out by SL (The National Federation of Social Educators) presents the following figures on the present housing situation of persons with disabilities living in residential facilities.

- 17.000 adults with disabilities are living in housing facilities.
- Out of those 17.000 one third lives in residences with living space below 20 square metres
- Six out of ten are living in residences with living space on or below 30 square metres
- 5.900 don't have own bathroom
- 5.300 don't have kitchen or own cooking facilities. (Holm, 2009)

Institutionalisation of the lives of persons with disabilities depends not only on the conditions which the law, the administration and the design of buildings represent. The interaction between residents and professional staff is maybe more important as this interaction is essential for the structuring of every day life and for the possibility of the residents to be a citizen with the right to participation, autonomy and privacy.

The every day life in the residence

Based on results and experiences from the research and development project: "Der skal to til en tango" (Perlt, et al., 2006) and Erving Goffman's (1967) characteristics of a total institution this final

part of the paper will discuss institutionalization and de-institutionalization of the every day life in the housing facilities of persons with intellectual disabilities.

It should be stressed that the research and development project: "Der skal to til en Tango" (It takes two to dance a tango) was carried out in 7 housing facilities, which all were quite large facilities under the Social Service Act and with residents, who had problems with verbal communication and a profound need for care. The results and the experiences of this research and development project can therefore not be used to say something generalized about the present situation in Denmark. However it can be used to point out problems and tendencies, which still exist in at least some of the Danish housing facilities.

The institutionalized life in a total institution was described by Goffman (1961) as characterized by the following:

- *Segregation and isolation*; the institutionalised life is influenced by barriers to social relations and interactions with the world outside the institution.
- *Classification*; the residents of the institutions are divided according to typologies, criteria and categories (diagnoses, sentences, age, gender, etc.) This classification is decisive for the expectations to the residents and for imposing opportunities and needs of the residents.
- *Single framework for life*, all life activities (sleeping, eating, leisure, work) are carried out within the framework of the institution.
- *Standardisation and predictability*; life is based on chronology; it is framed by time and activity schedules together with fixed routines. It is not the needs of the residents, but the patterns and standards of the institution that determine life-expressions.
- *Homogenisation*; with due regard to the classification of residents, equal treatment is attempted
- *Residents and staff*, the residents are living in the institution and have limited contact with the outside world while the staff are professionals, who work at the institution and are socially integrated with the outside world.

Structuring of every day life

If we look at the results and experiences of the study: "Der skal to til en tango" (Perlt, 2005), the following can be claimed:

No doubt the 7 project participating housing facilities can not be characterized as total institutions. The everyday life of the residents has been de-institutionalised since the decentralisation of the special care system in 1980. However, when this is told, it is still important to analyse and consider, in which degree the planning and structuring of everyday life in the housing facilities promotes or constrains opportunities for residents' self-determination and participation in regular every day life activities. A number of structured observations on the everyday life of the residents

were carried out during the research and development project. The following example on a daily activity cycle has been chosen because it represents a typical scenario, where daily routines are usually only interrupted by events like the celebration of anniversaries or necessary activities, such as visiting a medical doctor and so on.

Example of a typical course of a weekday

Time	The resident will usually be here at this time of the day	The resident is occupied with an activity carried out many times before.	Number of person, who are together with the resident or in the same room as the resident S: Staf (Professionals) R: Other residents O: Others
08.30	Yes	Yes	S: 1
09.00	Yes	Yes	S: 2; R: 8
09.30	Yes	Yes	S: 1; R: 6
10.00	Yes	Yes	S: 2; R: 5
10.30	Yes	Yes	S: 1; R: 4
11.00	Yes	Yes	S: 1; R: 4; O: 1
11.30	Yes	Yes	S: 1; R: 4
12.00	Yes	Yes	S: 1; R: 3
12.30	Yes	Yes	S: 2; R: 8
13.00	Yes	Yes	S: 2; R: 8
13.30	Yes	Yes	S: 1
14.00	Yes	Yes	S: 2; R: 2
14.30	Yes	Yes	S: 2; R: 6
15.00	No (celebrates birthday)	Yes	S: 3; R: 3
15.30	Yes	Yes	
16.00	Yes	Yes	
16.30	Yes	Yes	
17.00	Yes	Yes	
17.30	Yes	Yes	
18.00	Yes	Yes	S: 3; R: 8; O: 2
18.30	Yes	Yes	
19.00	Yes	Yes	
19.30	Yes	Yes	S: 2; R: 5; O: 2
20.00	Yes	Yes	
20.30	Yes	Yes	
21.00	Yes	Yes	R: 1

If the structuring of the every day life in the 7 project participating residential facilities is assessed against Goffmans (1967) characteristics for the organization of life in a total institution, the following overall picture can be found, although the 7 participating residential facilities in many ways are different regarding the planning and structuring of the residents' everyday life. Everyday Life in the 7 residential facilities is quite strongly influenced by a predictability established by fixed routines and standardised daily activity schedules. In this context it still appears reasonably to state that somehow the institution elf moved out of the large central institutions together with the residents. Also the classification of the residents can be found in several of the 7 residential facilities in the form of referral criteria to become a resident and in the form of specialisation of houses or departments within each housing facility. Houses or departments in the

residential facility was often specialised to accommodate certain types of residents such as residents with psychiatric problems, residents with Prader Willi's syndrome, elderly care demanding residents, mobile and non-mobile residents etc. In varying degree the characteristics of the institutionalized life can be found in terms of predictability, standardisation and classification, but hardly in terms of homogenization as the social pedagogical support of the residents in many ways has been individualized during the last decades.

Professional orientation between care and management

While various development and research activities were being carried out in the seven housing facilities, it became clear that staff were experiencing some increased, and somehow contradictory, demands in their work. These demands played a part in creating dilemmas for staff in terms of their professionalism, and affected their daily work and the time they spent with residents.

In recent years, staff members have experienced an increasing demand for documentation, planning, efficiency and goal orientation in the daily work. Looking at an annual report from a housing facility, written according to standards laid down by the county authorities, it is apparent that staff have to describe the status of development and service goals previously recorded, as well as the mandatory benchmarks. Moreover, they also have to account for levels of activities, target groups, work partners and focus areas for future work. On top of this, they have to prepare written plans for cooperation with each resident, meetings with relatives and other people involved as well as ongoing revisions of existing individual programme plans and reports on the use of coercion, etc.

In connection with the demand of documentation and visibility many of the housing facilities have developed a project culture. Projects are planned and implemented targeting the entire housing facility, single departments in the housing facility or individual residents. Some of the 7 participating housing facilities were involved in seminars in which ongoing projects were presented and discussed. (Holst, 2005)

Here, as example, some excerpts from the program for a 3-day project delivery seminar which was held in 2004 for a number of housing facilities

Tuesday 4 May

09.10 - 10.40: Peter 38 years: Development of methods for the purpose of increased user influence

11.00 - 12.00: Ida 28 years: "How to use the clock"

13.00 - 13.50: Jens 52 years: "Support to shaving"

14.10 - 15.10: Line 20 years: "Eye contact training"

Wednesday 5 May

10:25 to 11:40: Ulla 6 years: "Language stimulation of a child with Down's syndrome"

12.30 - 13.30: Lars 31 years, "Laying a table"

13.50 -14.50: Vibeke 57 years: "Departure from home and arrival to day centre"

15.00 - 16.00: Helle 19 years: "What should I be able to do"

Thursday 6 May

09:10 to 09:55: Jesper 52 years: "Jespers clothes "

10.10 - 11.10: Child, 5 years: "Establishing of social relationships through structured play situations"

11:20 to 12:20: Willy, 7 years: "To play games"

13.10 - 14.10: Ole, 56 years: "Getting cleaning detergent "

14.30 - 15.30: Karsten, adult: "Clarity , days and nights"

(Excerpts from a program of a 3-days seminar in which housing facilities discussed ongoing projects, 2005)

The increased demands on documentation, visibility and efficiency have the effect of diverting staff's understanding of their work and profession from a care and development perspective towards a management perspective. While ethics, empathy, recognition and dialogue are the core of care work, management is about planning, control and efficiency. Although staff handle the demands of documentation and management in different ways, these demands still affect the development of the support relationship between staff and residents. The residents' lives are subjected to careful planning. The needs of the residents are scrutinized and described. Strategies for meeting these needs are determined and tested. The efficiency of the chosen strategies is evaluated based on the development and efficiency perception of the authorities and professional support bodies. Furthermore, the resident becomes involved in the demands for dynamism, development and flexibility by becoming the target of a number of – not always coherent – projects. The question is whether there is an incongruity between the intentions of the Service Act and the managerial measures used to implement the Act, - an incongruity between the visions of normalization, deinstitutionalisation and self-determination and the managerial attempt to organise and systematise the life of persons with disabilities living in the housing facilities. (Holst, 2005)

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