

Summary

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Housing provision and service delivery for persons with intellectually disability – 10 years into the Norwegian Deinstitutionalisation Reform

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Chapter 1. Project background and the normalisation principle behind the Deinstitutionalisation Reform

The Norwegian Institute for Urban and Regional Research (NIBR) performed this study on behalf of the Norwegian State Housing Bank. The Bank took as its starting point the rationale of the 1991 Deinstitutionalisation Reform (*Reformen i helsevernet for psykisk utviklingshemmede*, or abbreviated: *HVPU-reform*), enacted to promote normalisation, improve housing standards and service delivery in particular, and life chances more generally.

Steps were called for that fostered independent living and an active, meaningful life in the community. There was to be equity between living standards for the intellectually disabled and the majority population. The Housing Bank asked for a status report on housing and services for people with ID, and how far the visions of the deinstitutionalisation reform have been realised in practice.

Chapter 2. Selection, methods and research design

Four distinct sub-studies generated the data on which the report is based.

- Interviews with council officials in a representative sample of local authorities and city districts on housing and services for people with ID (NIBR)

- Housing conditions, use of local public services, consultation and participation, social contact and leisure activity of all registered users aged 20–66 in the same communities/city districts (NIBR)
- Case studies of six selected housing projects in three municipalities focusing on set-up, management and approaches (SINTEF)
- Analysis of data from a 2003 survey carried out by the Norwegian Board of Health Supervision of users of local care and nursing services, including intellectually disabled users (NIBR)

Target group – subject selection

Sub-studies 1 and 2 were conducted basically among intellectually disabled persons aged 20–66 living in their own home, with a formal diagnosis of intellectual disability.

3,292 individuals were included in the local authority study – in other words, a sixth of all intellectual disabled persons in Norway as per 1 January 2005. 1,784 of these lived in a home of their own. The study of individuals included a net sample of 1,430 persons.

Selection of local councils, data collection and response rate

The sample for both surveys was representative of the country as a whole. Some of the local authorities had been involved in the 2003 survey conducted by the Norwegian Board of Health Supervision. Postal questionnaires were distributed between November 2005 and February 2006. Response rate for the municipal survey was 88 per cent, and 82 per cent for the survey of individuals.

Chapter 3. Characteristics of people with intellectual disability – housing and housing tenures

Intellectually disabled by age and housing tenure

All

As of January 1 2005, there were 19,900 registered persons with intellectual disability living in Norway – 0.43 per cent of the population. 31 per cent were 20 years old or younger; 66 per cent 20–66; and 3 per cent 67+. 20 per cent are 50 years old and older.

Four in ten live with parents/relations. Most of these are children, though one in four is 20 or older. These account in turn for 15 per cent of all intellectually disabled persons aged 20+.

20–66-year-olds living neither with parents nor in an institution

65 per cent of all intellectually disabled persons aged 20–66 live in accommodation provided by the authorities or in an institution. 20 per cent live in a place of their own, owned or rented. The rest live with parents.

Persons aged 20–66 who were not living with parents or in an institution are the subject of this study, that is, 84 per cent of the 20–66 age group.

Key characteristics of intellectually disabled persons aged 20–66 living in their own home, and not with parents

Many suffer from speech impediments: 15 per cent have no speech, 30 per cent have only a partial ability to communicate verbally with their surroundings. Speech loss co-varies with increasing age, and is twice as likely among formerly institutionalised persons.

Coping with everyday living and practical support

The ability of people with ID to accomplish everyday tasks varies widely. Some cope well and have no need for practical assistance. Others are totally reliant on practical support. Only 5 per cent belong to the former category; 20 per cent receive help in the region of 1–5 hours per week. 40 per cent receive a total of 30 hours or more, including both support and supervision. These users lay claim in other words to the equivalent of one or more person-years. 10 per cent are unable to help themselves in any significant way. Support for these users can reach 100 or more hours per week, or about three person-years.

Intellectually disabled persons with a speech impediment receive three times as much support (no speech) or twice as much support (partial speech) as the average without speech problems.

Housing for the intellectual disabled by living arrangement and coping capacity

50 per cent of intellectually disabled persons aged 20–66 live in *independent accommodation*. That is, either separate from other persons with ID and or in clustered housing schemes with other intellectually disabled persons or disabled/elderly persons. The other half reside in *community or congregate housing*. Congregate housing

and cluster housing predominate. All of 93 per cent of *formerly institutionalised clients* live today in cluster housing schemes with other intellectually disabled persons.

While disabled persons living on their own in their own home are helped 12 hours per week on average, those living in congregate or cluster housing receive 41 and 31 hours respectively. The latter figure works out at about one person-year input per person.

The amount of assistance provided varies considerably, both among people living in their own individual home, in cluster housing facilities or in a congregate arrangement. Coping capacity varies across the entire scale – *irrespective of type or category of housing* – from almost total dependency to almost total non-dependency. The residents of these housing alternatives exhibit many different types and differing levels of disability.

Housing tenure

Almost 80 per cent of Norwegian households own their home in one way or another. Among people with intellectual disability aged 20–66, 16 per cent own their home, the rest live in rented accommodation – 79 per cent in council housing. 5 per cent have other types of tenure. There are substantial differences between the intellectually disabled and people with other types of disability and, not least, the mainstream population. Only 10 per cent of former institution residents are *owner-occupiers*. The remainder live almost without exception in rented accommodation provided by the local council.

Nine out of ten persons with ID live together with other intellectually disabled persons (78 per cent) or in independent rented council accommodation (11 per cent). Only one in every ten lives apart from other disabled people in non-council housing, i.e., independent of a publicly structured housing regime.

Chapter 4. Housing options and housing provision

Key features of housing for the intellectually disabled

Most people with intellectual disability live in multi-unit buildings. That is to say, eight in ten live in buildings with three or more living units. Multi-unit housing means in six out of ten cases a high rise building or some other version of the multi-unit building. Only every seventh person with intellectual disability lives in Norway's dominant form of housing, the detached house. Normalisation of housing for people with ID has not, in other words, been achieved to any appreciable degree.

Private space

Of those living in independent accommodation in 2005, every fourth disposed of less than 50²m. Four out of ten had between 50 and 60²m. Only 3.5 per cent in this housing category enjoyed 80²m floor space or more. In multi-unit housing, about one in ten must make do with less than the recommended 40²m. The majority, or six in ten, dispose of 50–69²m.

Room types by housing category

Individual units include almost always a living room and a bedroom. And only 5 per cent of residents of congregate housing schemes lacks a separate kitchen. Virtually everyone has a separate own bathroom/WC. All have a bedroom to themselves. To conclude, nearly all multi-unit or congregate schemes offer living units with the basic room types.

Type of resident in housing schemes with intellectually disabled residents

Overall, seven in ten people with ID live in housing facilities used exclusively by people with ID. In addition, nearly two in ten live near other disabled people/senior citizens. Only 12 per cent live in housing where the other residents are not intellectually disabled, disabled in other ways or elderly. Living in multi-unit housing or cluster housing means most of the time living in a neighbourhood close to other intellectually disabled people or people with other care needs. People with ID are not generally found living in ordinary neighbourhoods. These factors tend to increase the likelihood of placement in a multi-unit or congregate housing scheme.

Accommodation in multi-unit housing co-varies most with language ability. A person with total speech loss is four times as likely to reside with other intellectually disabled people, all else being equal, and twice as likely if the speech impediment is partial, as people with no speech deficit. High disability levels also seem to lower an individual's chances of 'normalisation'.

Collectivist housing structure – main features

Housing for people with ID frequently falls into a collectivist mould. Half of our respondents live in multi-unit accommodation and from the outset are subject to a *collectivist structure*. In addition, almost all of these live with *other intellectually disabled people, disabled people or people with other care needs*. The tendency is reinforced by the fact that nine in ten residents live in *rented council accommodation*.

Eight in ten residents are supported in their daily life by the same people, that is, from the same service centre. Only 12 per cent live in their own home, that is, not with other intellectually disabled people, disabled people or in rented council property. Normal accommodation for people with ID in ordinary neighbourhoods in ordinary communities – housing normalisation in other words – clearly leaves much to be desired on the practical front.

Chapter 5. Housing location and community integration

Contrasting opinions about where to situate housing for intellectually disabled people

It is an accepted principle to promote the integration of people with ID into the community where they can live alongside ordinary people in ordinary neighbourhoods. Special interest organisations that for the intellectually disabled say that everybody has a statutory right to help where necessary, irrespective of living arrangement or geography. The authorities have sought in general to centralise and harmonise services in order to save money. The organisations, on the other hand, urge caution in this respect. If centralisation is taken too far, they say, and services aligned to accommodation units in the housing schemes rather than the individual service user, a new form of institutionalisation may be perilously close.

On the actual location of housing for intellectually disabled people

Location in relation to centrality and services

The location of disabled people's dwellings varies, with roughly equal proportions in various centres and outside the ordinary residential areas.

Location relative to institutions and homes for the elderly

Council owned and managed living units for people with intellectual disability are sometimes located on the same site as a nursing home or supported living arrangements for the elderly. All told, eight in ten accommodation units are situated in normal residential areas. In this case, then, there appears to be a high level of normalisation.

Location preferences of the intellectually disabled

Cluster versus dispersed housing

Almost all local councils irrespective of municipal size prefer the centralised option. Almost all believe that intellectually disabled people prefer not to live in dispersed housing.

Proximity to others in the same situation; multi-unit schemes occupied by other intellectually disabled persons

Almost all councils believe that intellectually disabled people want to live in near others in the same situation, and two in three councils believe intellectually disabled people want to live in the same building as other intellectually disabled persons.

What do local councils think about the location of housing for intellectually disabled persons?

Local councils are eager to pursue a firmer centralisation policy, siting accommodation for intellectually disabled people together with services.

Distinctive features of housing for intellectually disabled people by building type, housing scheme, living arrangement and resident category

Local councils tell us that six in ten dwelling units for intellectually disabled persons differ from the *surrounding built environment in terms either of size or architectural style*. Only a small number differ significantly, however. Nevertheless, a great deal remains to be done before practice can be said to conform with the vision of normalisation.

Living arrangement is more likely than other variables to predict architectural divergence from the surrounding built environment. For instance, congregate housing predicts divergence in 45 per cent of cases, while the figure for dispersed dwellings is 8 per cent. This impression is consistent not only with the architectural or physical layout, but also with a collectivistic management approach and resident typology. In housing where *the residents are exclusively intellectually disabled persons*, three in four schemes are likely to deviate in terms of architectural style relative to the immediate neighbourhood.

Disability level and behavioural profile are particularly important to an assessment of this question. The actual physical layout or architectural approach is in itself inadequate as a mechanism for promoting integration and normalisation.

Housing schemes and service centres

Two in three people with ID live in accommodation and housing facilities to which a dedicated service centre is attached. In congregate facilities, however, nine in ten people with ID are housed in schemes with a service centre. All told, 83 per cent of residents of congregate

facilities and housing clusters are connected to an on-site service centre. In the dominant housing arrangements, support for everyday tasks will most often be organised via the service centres. This does not mean, however, that services are linked to the living unit, or cannot be provided on an individual basis.

Although the majority of people with ID have access to on-site service centre, local councils would like to see improve the balance even more. In nominal terms, they are looking to get 22 per cent of users presently occupying dispersed accommodation closer to a service centre, leaving 1 per cent to live in dispersed housing. The opinions expressed are consistent and clear. Of those who today live without a service centre in their midst, four in ten should relocate. On top of this, councils would like to cut distances between service centres and residents for a sixth of those who *already* live close to one.

According to information provided by the local councils, the people in question are likely to cope better than most, whose accommodation is not out of keeping with the rest of the neighbourhood, and live in an ordinary neighbourhood with ordinary people. In other words, the tiny minority which appears to enjoy the highest level of normalisation as envisioned by the deinstitutionalisation reform.

Service centres are widely available in cluster housing schemes and congregate facilities. Services therefore co-vary fundamentally with living arrangement and housing type. Which as such is the opposite of what organisations for people with ID have been advocating. But the use of service centres is still not the same by any means as non-personalised, or one-size-fits-all type of service mentality.

Chapter 6. Housing provision and the needs of people with ID – how local authorities assess applications

Factors taken into consideration by local authorities in accommodation allocation decisions

Service delivery and *accommodation provision tend to be considered jointly*. Somatic and mental health problems and behavioural problems are also likely to be drawn into the decision making process. Four in ten local authorities always or often look at the client's need for social contact and mixing with people who are not members of his or her immediate family. The same proportion weigh the needs of exhausted parents and carers when allocating council accommodation.

Customized accommodation and services – local authorities’ judgement of own performance

Only half of the local authorities in this study believe that most people with ID have a clear idea of their accommodation and service needs and wishes. A majority do say they could have done more to map users’ needs. *Consultation* procedures have not been good enough.

Harmonising housing provision with the needs and wishes of people with ID – performance ratio

Accommodation provision is today unsatisfactory for every sixth person with ID aged 20–66 living in a place of their own. And two in three people with ID in the same age group who currently live with their parents would like to move out in the short or medium term.

Housing provision capacity and assessment of individual needs – local authorities’ judgement of own performance

Only every third local authority or city district authority provides housing for *all* adult people with ID. There appears to be a considerable shortfall in certain municipalities. Pending applications or waiting lists account for 13 per cent of all 20–66-year-olds living in their own homes.

Opportunities to move to better accommodation and actual moves

All or the majority of people with ID living at present in a council owned and managed property could move into new council accommodation if necessary in 10 and 30 per cent respectively of all municipalities. Conversely, people with ID in six out of ten municipalities effectively lack this option.

Every eighth person with ID would themselves like to move, or their carers/guardians would like them to move to new accommodation. According to the local authorities, in the majority of cases, congregate living arrangements are preferred, i.e. the dominant arrangement, and the one which conforms least with what the deinstitutionalisation reform laid down as “normalised” accommodation.

Housing demand exceeds supply

There is a unmet demand for about 4,500 living units for people with ID whose current accommodation is inadequate or who live with their parents. At the same time, almost as many live in council accommodation with little or no chance of obtaining a new, more suitable place, not when they want to move, but *if and when it is*

necessary. In light of the present shortfall, there is an urgent need to step up the pace of housing provision for people with ID.

Chapter 7. Chapters 3–6 in summary

This report sets out the empirical data to emerge from those parts of the project that concern mainly the housing situation and service delivery for people with ID. Chapter 7 offers a synopsis of the findings summarised here.

Chapter 8. Deinstitutionalisation Reform: Are housing and services for people with ID normalised and integrated as envisioned? Some reflections

In this final chapter we take stock and discuss what local authorities have done over the past fifteen years to promote accommodation and services for people with ID consonant with the deinstitutionalisation reform's normalisation and integration ideals.

The analysis covers five themes. We take issue 1) with the fact that most people with ID live in collective housing owned and managed by local authorities. We ask 2) whether accommodation is normalised architecturally and in terms of location within the built environment. We explore 3) the use of service centres in connection with housing facilities, before 4) looking at housing for people with ID in relation to the immediate neighbourhood, i.e. whether there is architectural consistency with the neighbourhood, and whether people with ID are segregated from or integrated into the community. The final theme 5) reviews the demand for new housing and need for increased flexibility in the use of existing council housing for people with ID.

We refer the reader to Chapter 8 in its entirety.

Part II. Case studies – housing for people with ID

Part II presents the results of a case study of six housing schemes for people with ID in three communities. Suggestions and lessons derived from the case study were fed into discussions about and approaches used in the project's quantitative surveys. The case study is important in itself, showing the complexity of the options and considerations facing local authorities. Requirements of service delivery play a role in the choice of architectural solution.

The study also reveals the extreme diversity of housing needs of people with ID. Experiences with housing schemes implemented in connection with the deinstitutionalisation reform are, say officials in

the case municipalities, largely positive. Our interviews with these officers would suggest that efforts to provide housing have generally resulted in reasonable standards and services that are sensitive to the individual's dignity, personal needs and wishes. The picture is of one in which the majority of residents are involved in a job and pursue activities in their spare time in the local community (with or without assistance). Some of them say that efforts to implement the reform were somewhat inflexible in some cases, and the housing needs of the individual service user could have been canvassed better. And that some of these housing schemes would involve a relatively large workforce was also partly overlooked.

The study discovered a need for a raft of solutions, including,

- Individual homes in harmony with the wider built environment
- Clustering housing together to bring services and users closer together and ease care provision
- Community schemes for residents who need help and support to socialise, to structure and enrich their daily lives

The provision of housing for people with intellectual disability will remain a constant challenge for local authorities.