

Inclusion and Daily Life for Adults with Intellectual Disabilities in Norway

Ideology and Reality

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Ageing and Health

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‘At school he was in a group of kids with special needs. There was not much of integration in the playtime when they were out in the schoolyard. (...). The others outgrow them. They never get friends. They don’t. Among the others – the normals.’

(Mother)

The 'responsibility reform' 1991

- Normalization
- Inclusion in society

The reform

- closed regional institutions and returned the persons with ID to the home municipalities
- transferred responsibility for persons with ID from government to municipalities

(cf. Nirje 1985)

Norwegian welfare system for adult persons with ID

- public support to live a life independent of family's care
 - private flat
 - individual help

Today's topic

- Inclusion
 - housing
 - friendship
 - leisure activities

Project 'The Double Ageing'

Life Course, Living Conditions and Quality of Life
for Persons with Intellectual Disabilities
and Their Elderly Parents

- 'dual ageing'
 - both elderly parents and their adult children may experience age related health reduction at the same time

Research questions

- What are the life courses, living conditions and quality of life for elderly parents and their grown up intellectually disabled children?
- What are the wishes and needs of the parties?
- How can care and support be optimally planned and organized, both for today's needs and as well as preparing the family members for future changes?

Method and sample

- in-depth interviews with a life course perspective with twenty elderly parents (62-86 years old)
- interviews with five adult children with ID
 - sixteen of the twenty children (30–51 years) have their own home
 - thirteen in flats next to others with ID
 - one in an ordinary flat in an apartment block
 - two in shared houses
 - Four still live with their parents

The interviews are transcribed verbatim and analyzed in the perspective of life course theory

— covering past, present and future prospects

Findings

- All parents' stories centred almost exclusively about their adult children's lives, not their own
 - parents' lives seem to be thoroughly dominated by concerns for the children even if the children have their own flats

Regarding housing

Parents satisfied with

- quality of flats
- specific locations

What is often missing

- social activities in common living room (not all persons with ID have access to such a room)
- company with others
- adjusted individual help and activities

A common living room for social contact is of great value

‘Yeah, we are so happy about that! Even if it was against the reform. We are really very happy for that, *everybody* is so happy about this common living room! Nobody wants to be there for the whole day, but they can get together there on Saturday night and when ever it might be.’

(Mother)

Lack of continuity – a major problem

- Large staff *discontinuity* in the homes becomes a problem for persons with ID
 - many different people are coming and going
 - part time positions
 - lack of education
 - lack of engagement
 - makes every day life unpredictable
 - help is not individualized and social relations are unstable
 - the persons' identities are not supported

Structural neglect in the homes for adults with ID

- lack of training of staff
- lack of dependable information systems
- lack of sufficient information
 - lack of knowledge about the individual among staff, about
 - health situation
 - illness
 - life history
 - interests and wishes

Social life

- at day centre
- at work
- in the neighbourhood?
- at home?
 - persons with ID need arrangements

A trip to the grocery store as integration in local environment

Ideal

- involvement in ordinary activities
- knowledge about neighbourhood
- sense of belonging to the place
- training in localization and recognition

Reality

- staff order food and household articles online
- person with ID stays at home
- world of experiences gets no expansion
- segregation

(cf. Christie 2005)

Social contact in neighbourhood

- little personal contact with neighbours
(cf. Walker, Ryan & Walker 1993, Walker, Walker & Ryan 1996)

‘There is nobody ringing her door bell!’

(Mother)

Informal social life

- support is necessary for participation
 - by parents
 - by support contacts and leisure contacts

(cf. Helsetilsynet 2008)

Support contact as a door opener

‘Mike mostly goes for a walk with old ladies! Therefore I am so happy that he’s got a support contact once a week. Then I have a young gentleman and I am so happy about that. (...). Today they’re going to the cinema. (...). Otherwise he has a dog and they go hiking with the dog. They have been in the forest cooking dinner on a camping stove. They go swimming in the lake. They visit museums. And sometimes they go for a barbeque in his garden. When the baby arrived, he took my son to the hospital and visited them, and Mike was allowed to hold the baby right away.’

(Mother)

Difficult to find a support contact for persons with severe disabilities

‘There is no point in applying for a support contact! Because there is nobody who wants to be a support contact for him.’

(Mother)

Lack of activities makes holidays empty

‘There is no program for him in the weekend on what to do in the house or what they shall do with him there – or for activities outside the house. I mean one trip here or there in the weekend or so – *no way*, there is nothing! He therefore remains seated in the wheelchair, stranded in the flat with his music cassette. Because the *only* thing he can do is to reel forward and backward. *That’s it*. From Friday to Monday.’

(Mother)

System failure

- Parents take action
 - they undertake responsibility to improve their child's wellbeing
 - to prevent isolation, decline in skills, aggression / self injurious actions

Continuity

- parents are the main persons representing continuity during their intellectually disabled children's life course
 - siblings are often busy with their own life
 - others?

(cf. Atchley 1989)

Ordinary leisure activities – a central gate for inclusion in society

- lack of support contact often obstructs persons with ID to take part in ordinary activities
- lack of qualified staff in the homes also has a negative effect on the possibility of taking part in ordinary activities
- economical limitations become a hindrance for holidays

Parents take care of activities for their adult children

- visiting the parents' home in weekends
- family gatherings in siblings' houses
- trips
- holidays

The study shows that

- parents act as organizers to give their adult children with ID a varied every daily life – beyond fixed daily activities
- most leisure activities are meant for persons with ID

Conclusion

- Inclusion is failing
 - especially in informal life
- Apart from contact with their families, persons with ID are often segregated
 - they are together with either staff or others with ID
 - According to the parents, it is mainly their responsibility
 - to include their adult children in informal social life
 - to secure continuity in living conditions
- Parents are tired and wish stable and dependable services to their children to secure continuity when parents pass away

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Livsløp og hverdagsliv med utviklingshemning

Livsberetninger til personer med utviklingshemning
og deres eldre foreldre



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