

# Growing up with Down Syndrome in Norway

The Transition to Adulthood

# Aims



- To present a longitudinal PhD study undertaken in Norway, focusing on Transition to adulthood.
- To share information that could be useful for further research in this field.

# I will talk about three areas from my research

- Transitions from school to work life
- Transition from living at home with parents to sheltered residence
- Transitions from youth to young adults: Quality of life and well-being

# Background: Norway's policy on disability

- Closing down of institutions for people with disabilities from the early 1990s
- Communities took over the care of people with disabilities
- Important perspectives in policy and society are *normalization, inclusion, participation, CRPD and WHO's ICF-model*
- Despite a society that is based on these principles, we have discussions in Norway regarding the implementation of normalization and the CRPD (work, education, living conditions, etc)



# In 1996/97 in Norway...

- 62 children born with DS, 43 were included in the first study in 2001
- Several studies were undertaken in this cohort, between the ages of 5 and 25 years



# The longitudinal study:

## Data collected at ages 5,7,10,14,17, 22 and 25 years old

Age	Theme
5 (n=43)	Functional performance/ capability– school entry. Using PEDI (self care, mobility and social function)
7 (n=43)	Functional performance/ capability (PEDI) - postponed school entry

Age	Theme
10 (n=6)	Inclusion and social participation: Peer interaction and support in mainstream schools
14 (n=38)	Participation in leisure activities - parent perspectives
14 (n=38)	Functional performance/ capability (PEDI)

Age	Theme
17 (n=22)	Friendships and patterns of social leisure participation among Norwegian adolescents with DS
22 (n= 20)  (n=8)	<ol style="list-style-type: none"> <li>1) Academic progress</li> <li>2) Process from school to work</li> <li>3) Thoughts of emerging adults with DS on quality of life</li> <li>4) The process of moving out of home</li> </ol>
25 (n=8)	Students with DS in the Norwegian Folk High Schools – 1) parent perspectives 2) young adults perspectives

# PhD project



Main research question:

*How do young adults with Down Syndrome and their parents experience the young adults possibilities and capabilities for agency within structures in their daily life in the transitions to adulthood?*



# Participants

Participants: 25 parents representing 20 young adults

Eight young adults (from the same cohort)

- Data collected in 2017/ 2018
- Four articles published
- Survey and qualitative comments (study 1) and qualitative interviews/ analysis (study 2, 3 & 4)



# Qualitative Interviews

- Capture the young adults subjective experiences about their life
- Semi-structured interviews (Johannesen et.al,2006)
- The young adults own photos from their everyday- life (Aldrige, 2007)
- Interviews with the parents
- Ethical considerations, the parents' involvement

# Transitions to where and to what?

- From children to young adults (in this longitudinal study):  
Several transitions

Kindergarten- school, primary school – secondary school, secondary school- upper secondary school)

- As young adults:

Transition from school to work

Transition from living at home to independent living

Transition from youth to young adults



# Perspectives on Transitions

## Theoretical Perspectives:

Emerging adulthood (Arnett,2007)

Isolation and Exclusions (Côté & Bynner, 2008).)

Recognition, identity and status (Kittelsaa & Kermit, 2015)

# Other research on Transitions: Some findings

Young adults with disabilities want to have influence in their transitions, to have the possibility to be agents in their own lives and construct their identity as adults (Midjo & Aune, 2018)

For young adults with Down Syndrome, transitions between different structures are challenging (Foley et al., 2012)

Some studies related to young adults with Downs Syndrome point out that parents have the intention to protect their children, this has impact on the young adult's autonomy and feeling of independence (Carr, 2008; Scott et al., 2014; Terrone et al., 2014).



# 1. The Transition from School to Worklife

- Transition to worklife starts at school
- A critical period...
- Defined as not capable to work?
  
- Parents describe themselves as guardians
- Variations in how prepared the different work-places are
- The young adults want to have opportunities in worklife and work based on interests





## 2. The Transition from moving out of parental home to independent living

- From the parents' perspective
  - Manage practical skills
  - To be prepared and ready
  - To be given help, the staff «close on»
  - To live independently
- From the young adults' perspective
  - Manage practical skills
  - To be prepared and ready, but not fully prepared ...
  - Ask the staff for help – when they need it
  - To live independently - with help and support

(Jevne, 2023)

# 3. The Transition to an adult way of living

The overall Goal: Quality of life and well-being

To achieve this:

Work based on interest and capability

Having an active and social leisure life

A safe place to live

The use of information and communication technology



# Some (new) important theoretical perspectives

A tension between structures in the society and the young adults as Agents in their own life

Critical Realism: What inhibits the young adults to be agents in their transition-  
PROCESS? (Bhaskar 2016, Danermark et al. 2018)

Independency in Adult life

Relational perspective on Vulnerability (Mckenzie 2019, Lid 2023)

# Some (new) important theoretical perspectives cont.

New perspectives on the ICF/ Relational Model on disability:

The Capability Approach (Nussbaum 2007, Mitra 2006)



# Reflection and Discussion?

- Involve the young adults as agents also in their Transition process
- Are the structures made for the young adults to become Agents in their own life?
- New perspectives on help and support
- The Ideal of Normalisation.. Is this the best?

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Thank You!!



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