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NASJONALT KOMPETANSEMILJØ
OM UTVIKLINGSEMNING

Self-determination for persons with intellectual disabilities

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Roots and/or definitions

- Legal rights (Nationally)
- Human rights (Internationally)
- Normalization principles
- Social activism (social model)
- Self-advocate organizations (empowerment)
- Participation
- Power and control
- Causal agents



Legal rights and legal protection

- Legal rights involve values.
- Violations against the legal rights undermine the legal protection and challenge
 - the right to make one's own decisions, which in turn challenge your right to
 - 1) individual development and
 - 2) developing individual identity.
- Some are more affected by such violations.
- If the right to self-determination is not respected, it do not exist (Nirje)



Legal protection consists of

- Access to resources
- Legal requirements
which guarantee good and correct decisions
- Legal guarantees,
 - The principle of **legality**
 - Procedures for **executive** work
 - Supervision
 - Control
 - Access to file complaints
 - Possibilities for review



Universal Declaration of Human Rights

- Whereas recognition of
 - the **inherent dignity** and
 - of the equal and **inalienable** rights
 - of all members of the human family
- Is the foundation of
 - freedom,
 - justice and
 - peace in the world



Article 1

- All human beings are
 - born free and equal
 - in dignity and rights
- They are endowed with
 - reason and conscience and
 - should act towards one another
 - in a spirit of brotherhood



UNs Convention on The Rights of Persons with Disabilities

- **Article 3 – general principles**
 - (a) Respect for inherent dignity, individual autonomy including **the freedom to make one's own choices**, and independence of persons;
 - (b) Non-discrimination;
 - (c) Full and effective **participation** and inclusion in society;
 - (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
 - (e) Equality of opportunity;
 - (f) – (h)

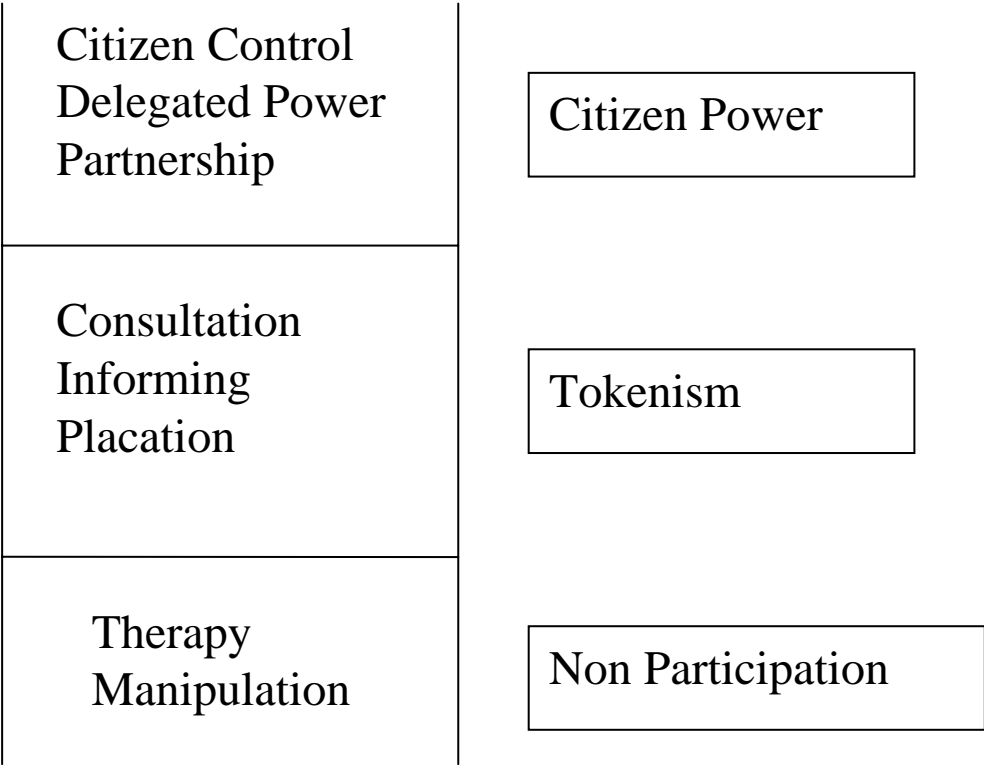


Participation

- Participation without redistribution of power **is** an empty and frustrating process for the powerless.
 - It allows the powerholders to claim that **all** sides were considered, but makes it possible for only some of those sides to benefit.
 - It maintains the status quo.



Arnstein's ladder of participation (1969)



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Hidden agenda

- Group therapy,
masked as citizen participation,
should be on the lowest **rung** of the ladder
because it is both dishonest and arrogant.

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Valued social roles/ not power over

- The power ideology appears to claim that having or not having power not only determines how one will be treated, but also whether one will get the good things of life.
(Wolfensberger 2002, p.254)
- Are people more likely to get the good things of life by occupying social roles that are valued by others, or by the exercise of power, autonomy, and self-determination in **and** over their lives, and of power over, or vis-à-vis, other people?

(ibid)



Social Role Valorization and, or Versus, "Empowerment"

- **If** the idea of "choice" and self-determination **in all** things were taken at full face value and **to its extreme**, it would de facto result in what has come to be called "**dumping**", that is, in handicapped people not only being **set into society** free from all constraints or supervision, but also **without the support** that they do need to live safely and decently (Wolfensberger 2002,p.255).



Empiricism or religion

- Some people will embrace empowerment and self-determination position as a religion –
 - and what they want is **power**,
 - and not **valuation** and **acceptance**
(Wolfensberger 2000, p.257).
- Thus, one would not be dealing with an **empirical controversy** over
 - what does and does not work,
 - but with a controversy at the level of
 - fundamental values and religious beliefs
(Wolfensberger 2000, p.257).

Research about self-determination

Wehmeyer et al. (1996)

- conducted a series of **structured interviews**
- with more than 400 individuals with intellectual disability,
- to examine **the contribution of essential characteristics** of self-determination behavior to the achievement of behavioral outcomes closely associated with self-determination.
- They used self-report measures of self-determined behavior, and measures of each of the essential characteristics

(Wehmeyer et al. 1995)

Four characteristics of self-determination behavior

Behavioral autonomy –

”from dependence on others for care and guidance to self-care and self-direction”

Self-regulated behavior –

”a complex response system enabling individuals to examine their environments and their repertoires of responses” (how to act, evaluate, and revise plans)

Psychological Empowerment –

”learned hopefulness”, ”problem-solving skills” and ”control”

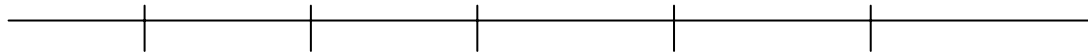
Self-Realization -

The self-knowledge and self-understanding influenced by evaluations of significant others, reinforcement, and attributions of one’s own behavior

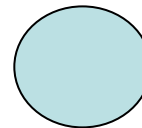
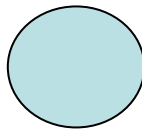
(Wehmeyer 1999, pp 58-59)



People were asked to score on a scale their degree of self-determination.



They were later divided into two, based on their scores;
High level/ grad Low level/ grade



- Whemeyer (1996) then compared the two groups in relation to the scores on measures from the four essential characteristics.

Findings from the research

- Measures of
 - Behavioral autonomy** (from dependence on others to self-care) and
 - Self-regulation** (a complex response system)was particularly potent predictors of self-determination status.
- The research also showed that self-determination status predicted membership in the higher quality of life group.



The impact of personal characteristics

In another study 301 individuals, identified as having intellectual disabilities, was recruited.

- 149 having mild intellectual impairment (IQ 56 – 75)
- 93 having severe intellectual impairment (IQ 55 or less)
- 59 with a developmental disability

(Wehmeyer and Garner 2003, p.257)

They used the ARC's Self-Determination Scale

(Wehmeyer & Kelchner 1995).

The scale was developed and normed with 500 **adolescent** with and without intellectual disabilities.

- The scale had **construct validity** and **internal consistency** (Cronbach's alpha =0.90)

(Wehmeyer 1996).



Findings

They found,
consistent with their earlier research,
that people **with** more severe intellectual
impairments were **less** self-determined.

However,
also consistent with their earlier findings,
the **correlation** between **IQ** and **self-determination**
scores

was **significant** but **relatively low** ($r=0,157$)
and of little practical significance

(Whemeyer & Garner 2003,p.262)



Surveys on self-determination II

An other study, this time from Norway, are based on studies on life conditions carried out by Tøssebro and Lundebj (2002).

- They found that closure of institutions (in 1991) led to a higher degree of self-determination, which in particular must be seen in relation to the removal of organizational obstacles.
 - The trend stagnated after 1994 (ibid,p.163).



Findings from the study

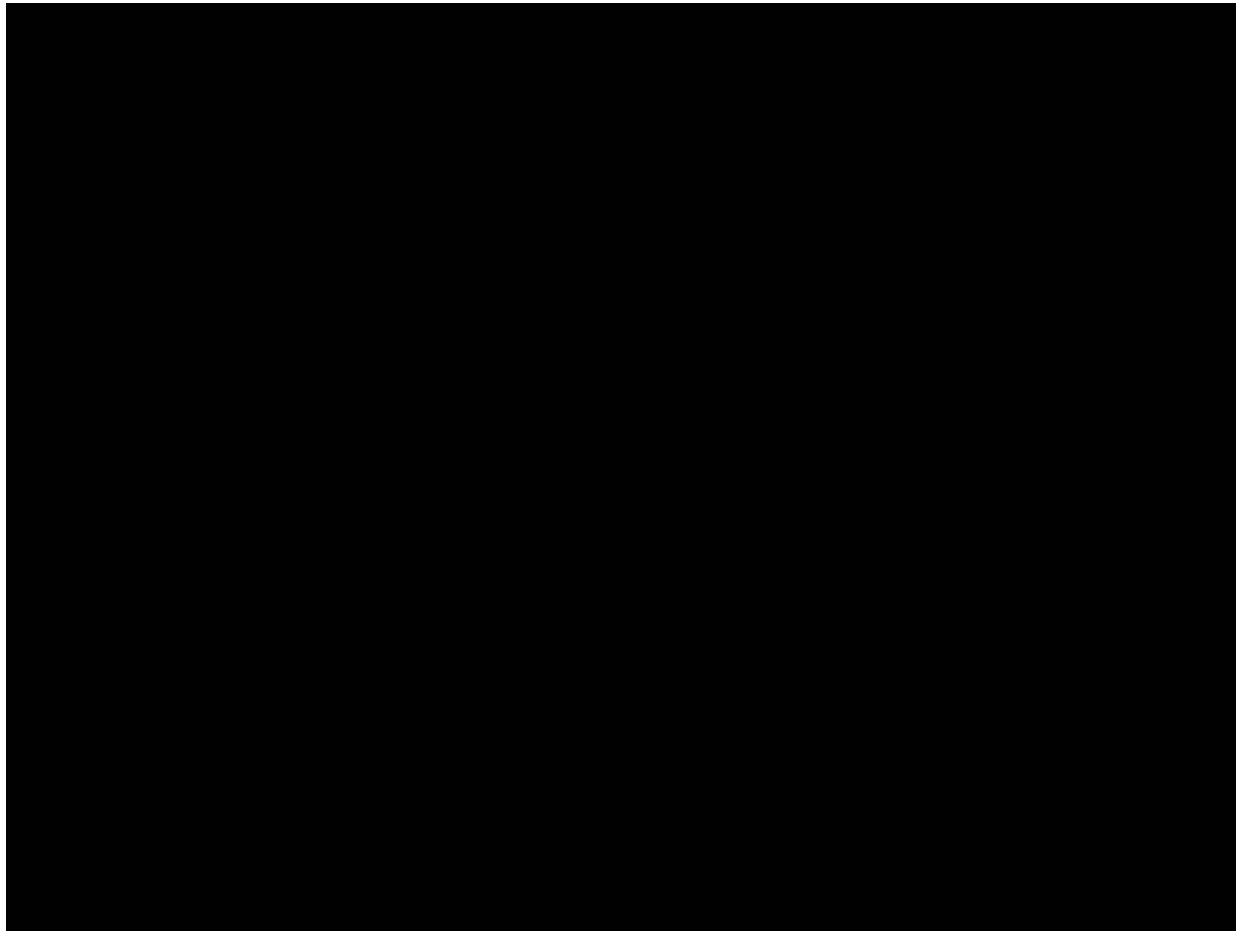
Data was collected In 1989, 1994 and 2001.

With focus on **who** “decide” or “participate in decisions”,
And looking at the period of closure 1989 (n=775) to 1994
(n=550), data shows –

- Decide **who is employed** (? in 1989 / 1% in 1994)
- Decide **whom to live with** (5% in 1989 / 16% in 1994)
- Control over income - (? in 1989 / 38% in 1994)
- Choice of furniture - (34% in 1989 / 54% in 1994)
- Diet and meals - (44% in 1989 / 66% in 1994)
- Choice of clothes - (71% in 1989 / 77% in 1994)



Atempo – Nueva - Users asking users



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Many words but what do they tell

- Participate
- Influence
- Control
- Contribute
- Determine
- Agree to
- Decide



Many concepts - what do we wish to achieve

If we wish to participate in decisions, what are we actually looking for, what do we want ?

- to be the one who decides?
- to be the one who controls the process?
- to fulfil our objectives?
- to make sure we get the services we require?
- Influence (speak our mind/tell what we wish)?
- to be present



Chester Finn - Be that change



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Self-determination – a causal agent

- Self-determination refers to the attitudes and abilities required
 - to act as the primary causal agent in one's life and
 - to make **choices** regarding one's quality of life **free** from undue external influence or interference

(Wehmeyer 1992)



Causing things to happen

- Being self-determined is not a function of how much you can do for yourself, behaviorally, but instead is a function of how much you can make or cause things to happen in your life

(Wehmeyer 1998)



Of importance

- I find it meaningful to emphasize that choices regarding one's quality of life, is first of all about the things that are important in one's life
- Furthermore - studies shows the self-determination and Quality of life correlates (significantly)



User involvement

- User involvement is linked to democratic principles like representation on boards, advisory bodies and committees (at a systemic level).
- User involvement have two objectives:
 - the right to **information** and to be **heard** in cases where one is affected
 - contribute with information to public decision-makers about the users experiences

(White paper no. 40 (2002-2003), p.36)



An important distinction

1. By using the term **user involvement instead of self-determination**, there is a danger that the existing rights and sovereignty of each individual is reduced to involvement.
 2. Similarly, the significance of **user involvement in democratic processes** can be reduced if we conclude that user involvement is protected through individual involvement in cases that affect us.
- By clearly distinguishing between the two concepts, we help reinforcing both the right to self-determination and the democratic rights embedded in user involvement.





Can everyone decide for themselves?

- No one doubts that greater personal autonomy, self-determination, and having more choice and control over one's life is important.

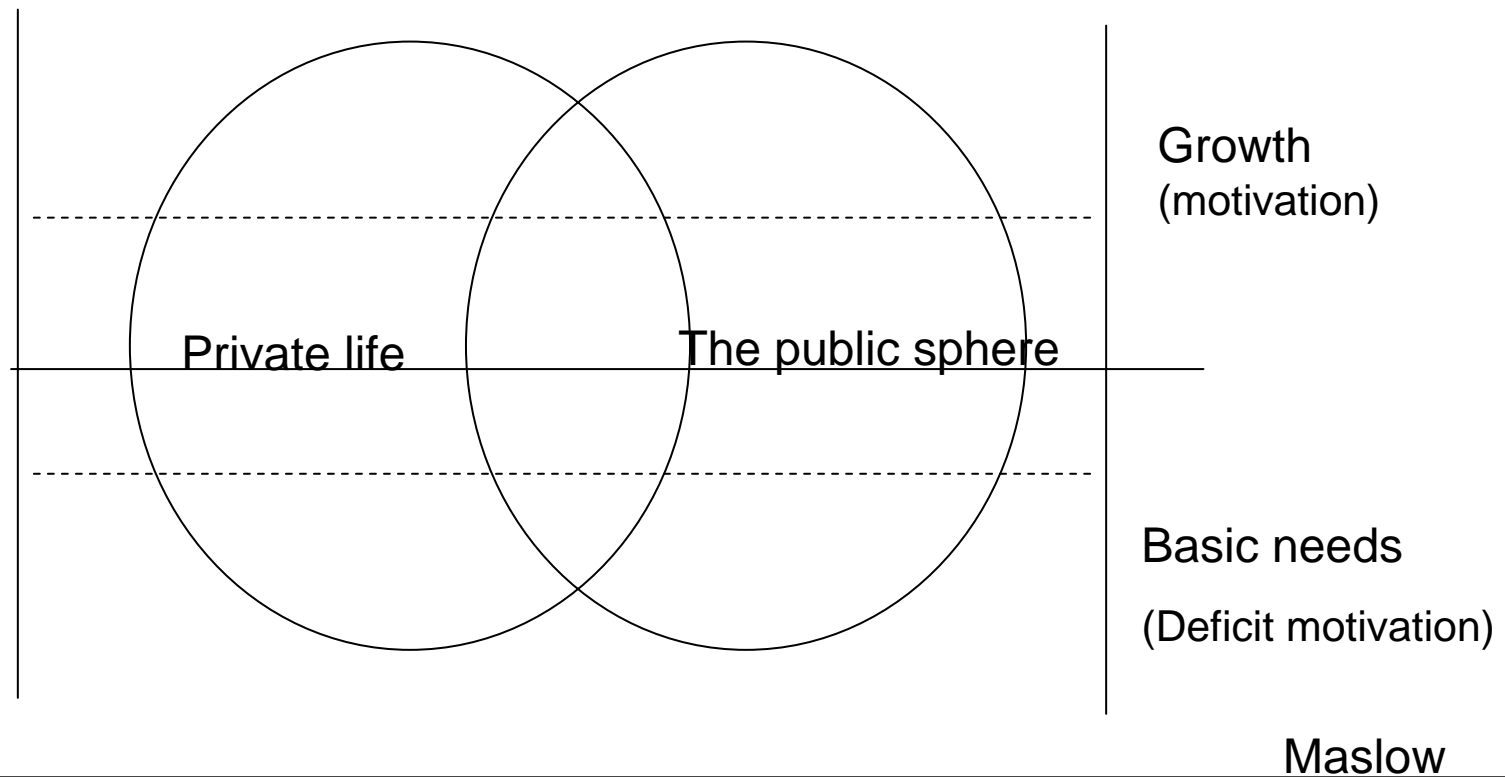
But it is then also essential to remember that most of us have also received support and assistance in learning how to make choices, what to consider, and have some sort of way that we have learned to weigh alternatives and possible consequences.

Persons who have been controlled by others up through adult life, and been excluded from ordinary life experiences, often simply do not know how to make decisions (Kristiansen, Söder og Tøssebro 2000, s. 422).

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Legal framework



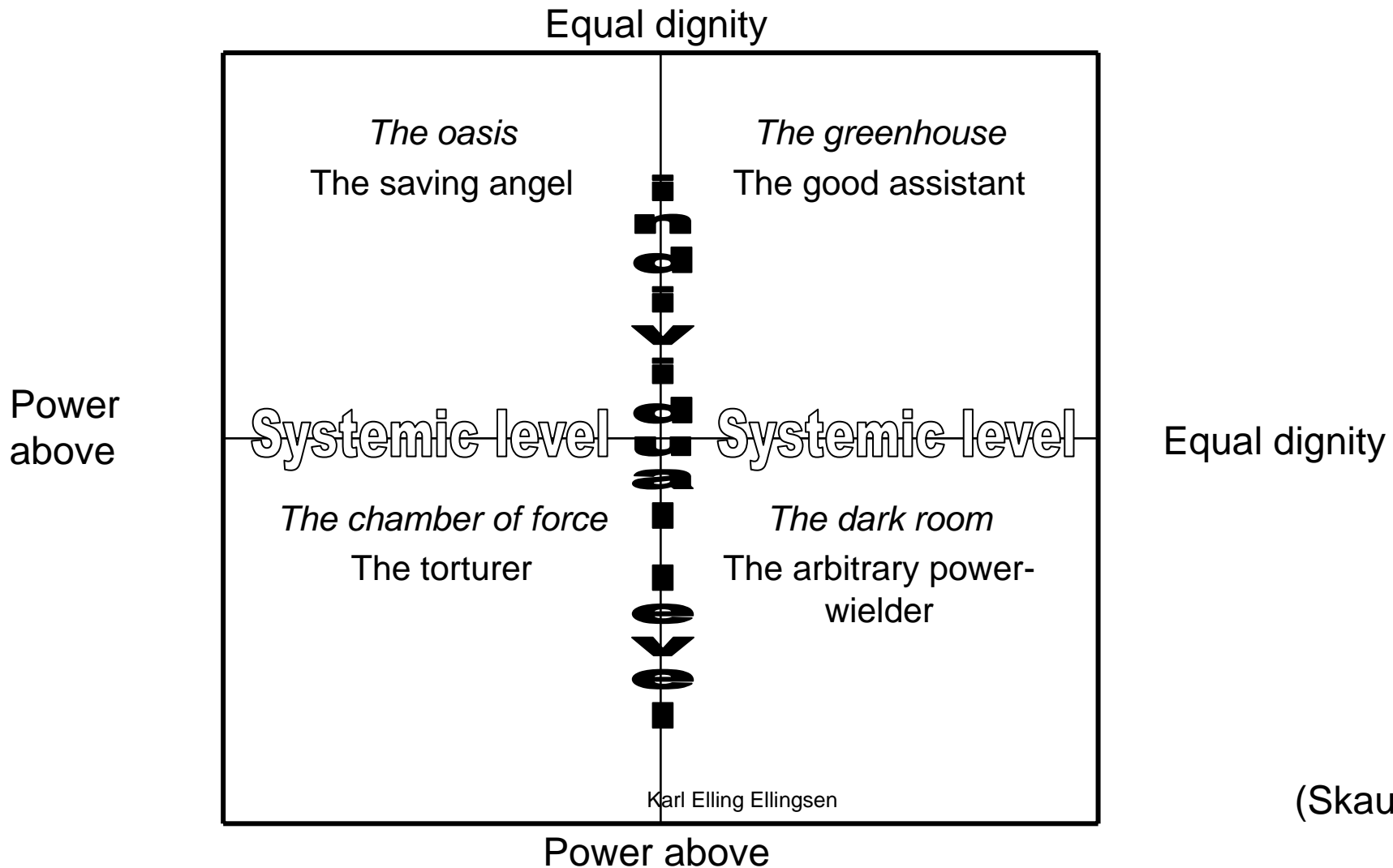


Four dimensions of power

- **Direct power** is "When person A gets person B to do something person B otherwise would not have done"
- **Indirect power** is non-decisions, or preventing problems from reaching the decision-making process
- **Consciousness controlling power** is when one influences how others conceive their interests in order to make them correspond to one's own. This is achieved through authority, manipulation, blocking certain cases, preventing identification of power by transferring it to collective entities
- **Institutional power** is of the kind "the world takes it for granted"/ things are just how they are

(Christensen & Daugaard Jensen 2001)

Power above or equal dignity orients?



(Skau 2003)

In what situations and with what justification?

- Coercion most often occur in
 - Demanding/ requiring situations and in situations involving scheduled tasks (a total of c. 35% of all cases)
- Often justified in situations where
 - The individual causes him-/herself injury (20%)
 - The staff is being attacked (30%)
 - The individual refuses (20%)

What do we know about research on the existing practice?

- According to a survey carried out in Trondheim, Norway - from 1999 to 2002, 106 intellectually disabled persons out of the total population (550) were subjected to coercion.
- Numbers from The Norwegian Board of Health Supervision (2008) show that c. 10 % of all persons with intellectual disability have experienced coercion.
 - A high connection between receiving public services and being exposed to coercion.



”Vulnerable situations”

In the survey from Trondheim, illegal use of coercion were reported in the following contexts:

- Norms and expectations from the local environment
- Injury caused to oneself or others
- Meals
- Pressure generated from expectations from colleagues
- The precautionary principle
- Personal care and hygiene
- Planned activities
- Taking other users/residents into consideration
- Preventing the relevant person from destroying furniture/possessions





Cross communication

- Believing one is talking about the same issue as another party
- Talking past each other because:
 - Concepts are understood differently
 - One pretends to have equal status, when attempting to dominate and influence the other party

Divergent understandings of concepts

- Do we know the exact meaning of a concept, and does it mean the same?
- What do you understand by the following concepts?
 - Safety
 - Security
 - Control

 - Danger
 - Risk
 - Freedom

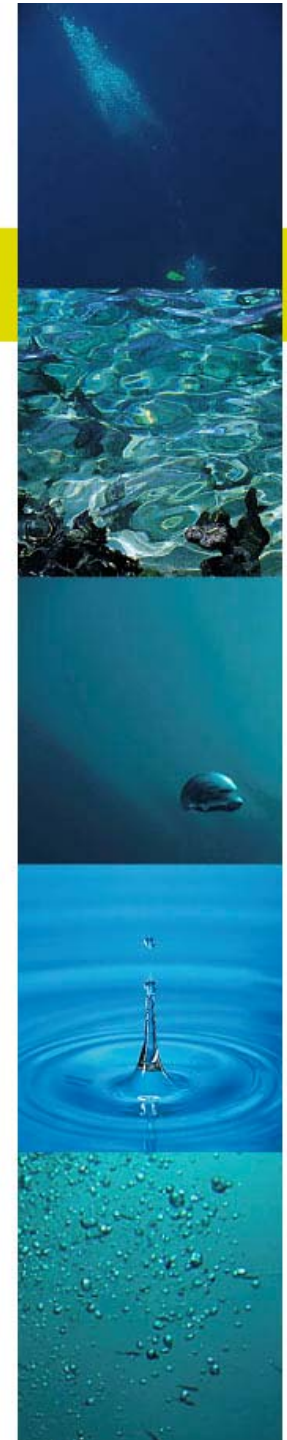
Control

- What is control?
- Is control avoiding risks?
- Is it a feeling?
- Is it control over your fears for what you perceive as dangerous?



Risks

- Is it possible to have freedom free from risks?
- Is freedom risktaking?
- Is it possible to avoid risks?
- Is it possible not to take any risks?
- How do you calculate risks?



Categorizing the concepts

- The six concepts are interconnected in several ways.
- They may represent contrasting categories
- They may have similarities



What concepts represent similar and contrasting phenomena?

safety

danger

security

risk

freedom

control



Risks

Security

Danger

Safety

Freedom

Control





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Risks

Danger

Freedom

Security

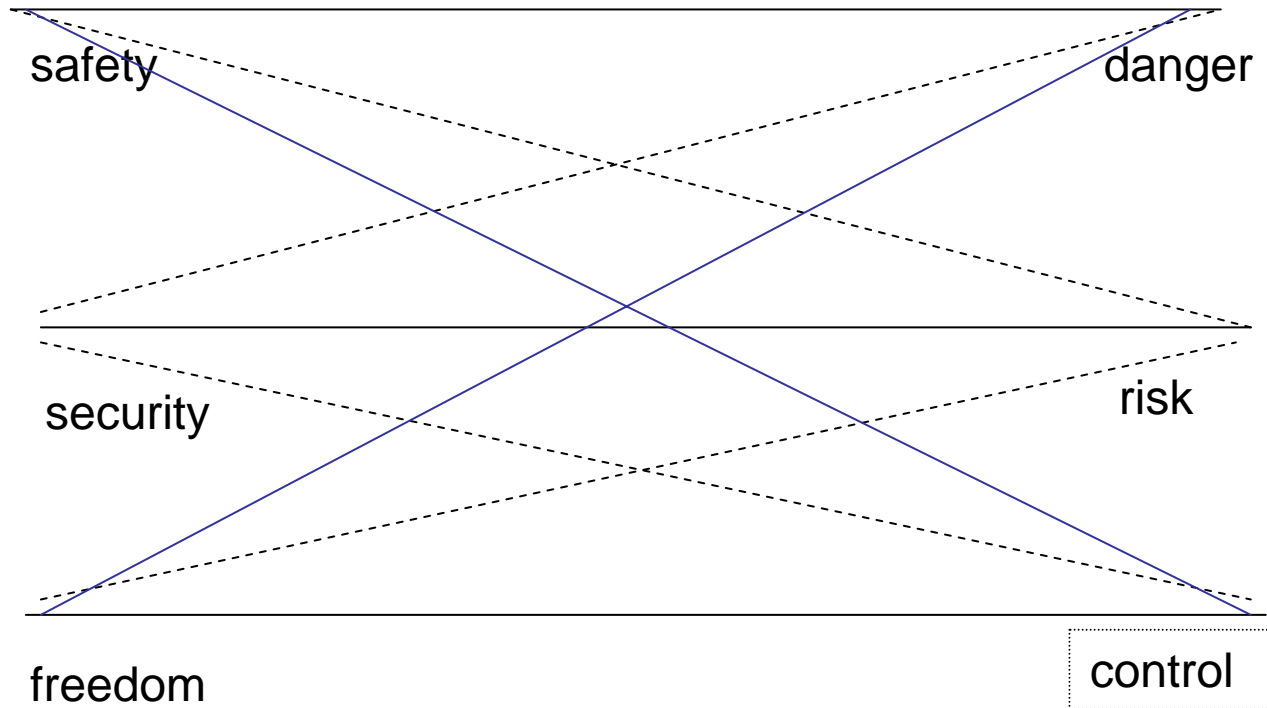
Safety

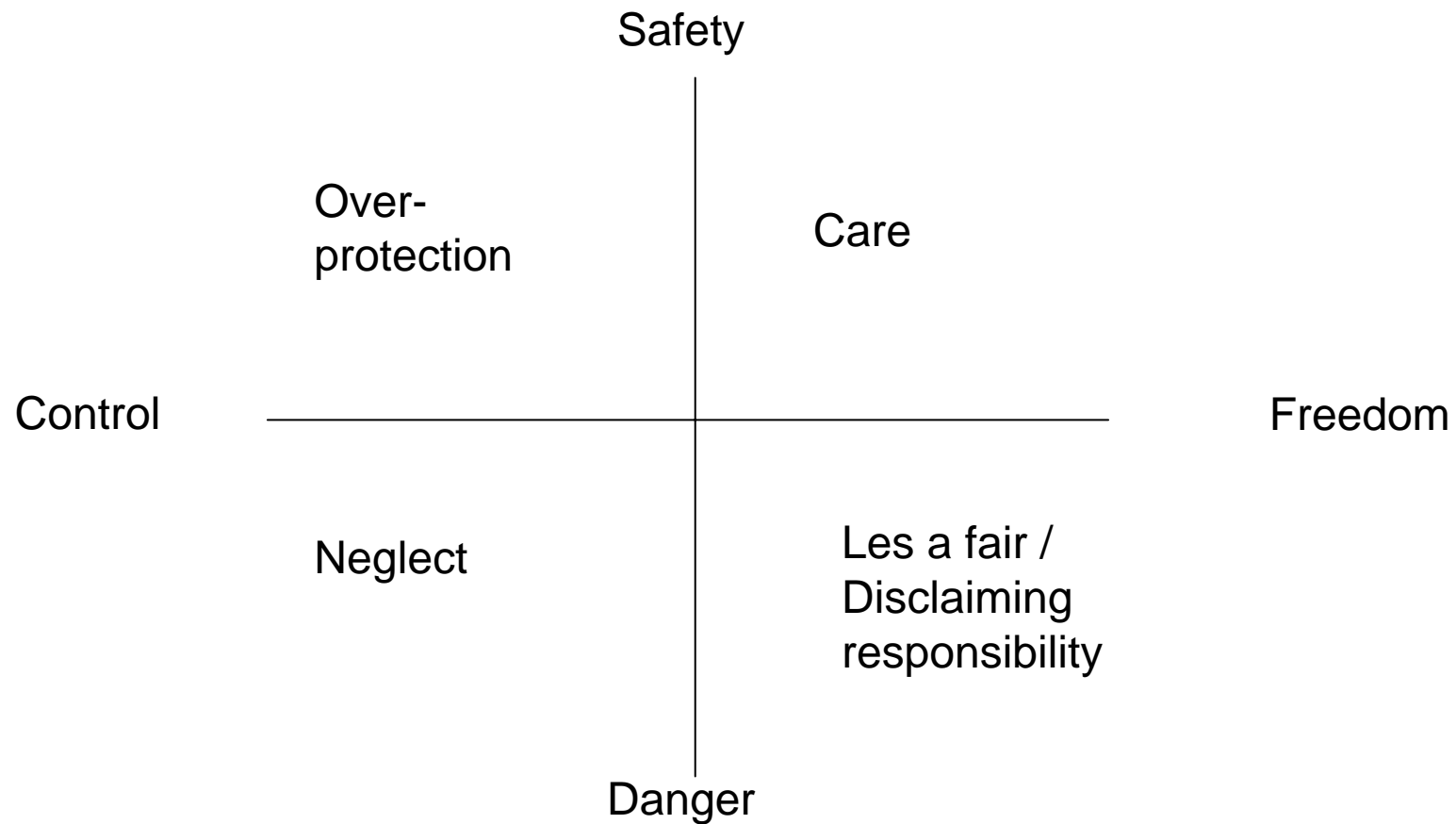
Control

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Kryss-kommunikasjon







A book about self determination

The book opens with the poem
"Human dignity" by Hanne Mathiassen
and ends with the poem "
Star Heaven" by Geir Brekke.

The main theme is that self-determination
implies that people are interconnected,
share the same human rights and human dignity
and are equipped with
the same reason and consciousness.



Human Dignity – by Hanne Mathiassen

Human Dignity has a child with Down's syndrome.

It is just as **valuable** as other people,
even if it has a chromosome more than others.

Human Dignity is important for all of us,
even if we have different handicaps; Down's syndrome, cerebral palsy,
or injured in traffic.

We are important because we are capable of caring,
thinking and feeling for other people.

This is what gives us compassion, care, light and happiness in our lives.

Human Dignity is profound love, friendship and trust
in other people with handicaps like me.

We all need Human Dignity. We are all of the same value.

Let us take care of one another and help those who are in trouble,
those who need care, compassion, confidence, love and happiness in their lives.

Human dignity is important for all of us.

When Marte Wexelsen Goksøyr says:

”All I want is that you believe in me, I want you to believe that I can”,
she challenges all the doubters, the know-it-alls

She challenges us to realize that what we understand by good
judgement and reason, subjects her to injustice.

Kjell, a fictional name of a man who lived in an central institution, asks
for a confirmation of that regardless of what he tells from his
experience, he will not be denied a ”free exit”.

He challenges us in our role as service-providers to be responsible for
our own and other people’s action, and not to defence ourselves
claiming we was not there

Our own or other people's decisions and values?

Especially two aspects of the texts, poems, narratives and contributions from intellectually disabled people I find intriguing.

- One is the silent and modest form in which the demands are presented.
- The other is the trust in other people.

Compared with other battles and movements, they are often marked by the opposite, loud protests and a strong distrust of other people's intentions.



Steve Dowsen – Seattle 2000



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STAR HEAVEN

Dark night
Clear heaven
Tropical night
30 degrees
Romantic journey
Beautiful girl
My gem
Sweats and the kiss from a girl
A family
A dream

By Geir Brekke

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