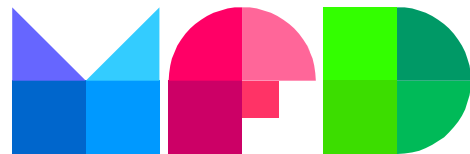


Sources of data on disability

Presentation on national experience by Sweden

Arvid Lindén



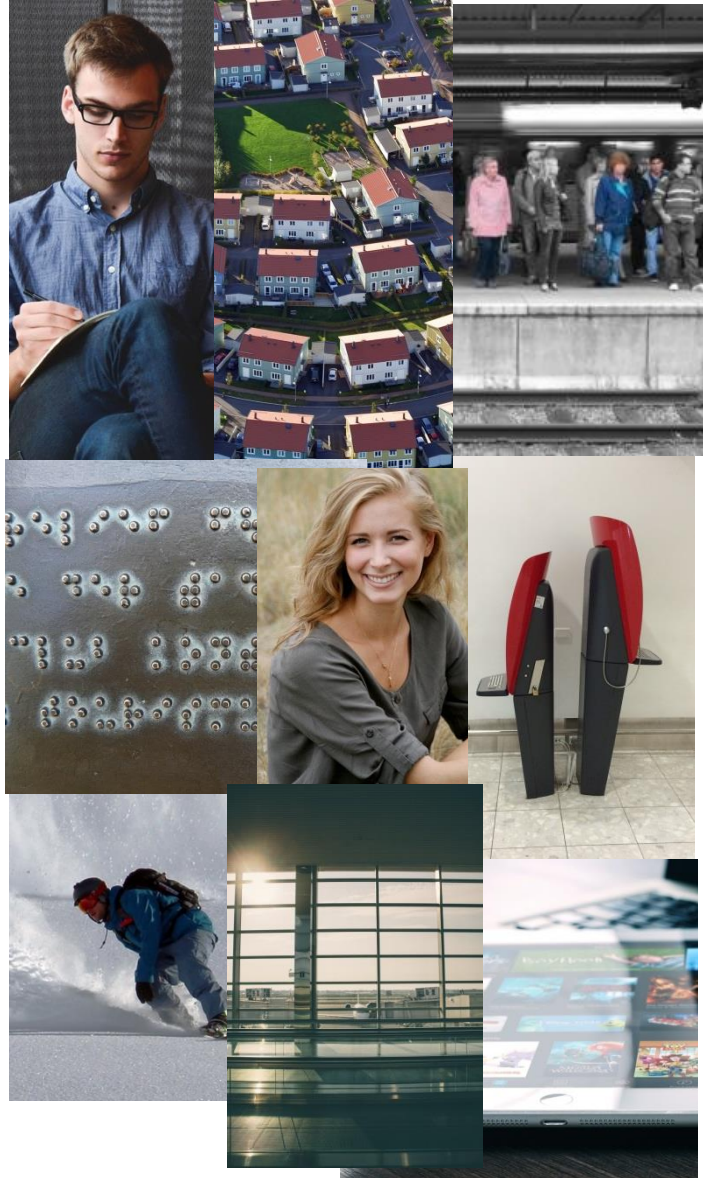
**Swedish Agency for
Participation**

The Agency for Participation

...established to take a more comprehensive, cross-sectoral approach with the task to stimulate and develop knowledge building in the area of

- rights of persons with disability
- participation, accessibility
- universal design
- digital technology
- living conditions and environment

...with the mission to accelerate the progress towards a society in which everyone can participate on equal terms, regardless of functional capacity



Swedish disability policy

- 2000: National action plan - "From patient to citizen"
- 2008: ratification of the CRPD
- 2011-2016: 5-year national strategy of Swedish disability policy
- 2018-2023 A disability policy inline with **CRPD** and **Agenda 2030** more efficient and systematic in the implementation and monitoring





A multidimensional system for follow up

Measure development

- Highlight inequalities
- Monitor implementation/action
- Create basis for targeting actions

Interdepartmental/sectoral

In different policy areas, such as the labour market, education, transport, public health etc.

Different levels of society

National, regional, local, individual

Intersectional

Disability, gender, age, ethnic diversity

Conditions and effects

I.e. assessability – living conditions



Agenda 2030 and the government

- In the SDG discussion the Swedish government are very ambitious. The important part now is to transfer the SDG:s into the Swedish context. Not only that we say that we already are taken care of it.
- Statistical Office has the main responsibility for disability statistics and also for reporting on the SDG:s both national and international.

Agenda 2030 in Swedish international disability policy framework

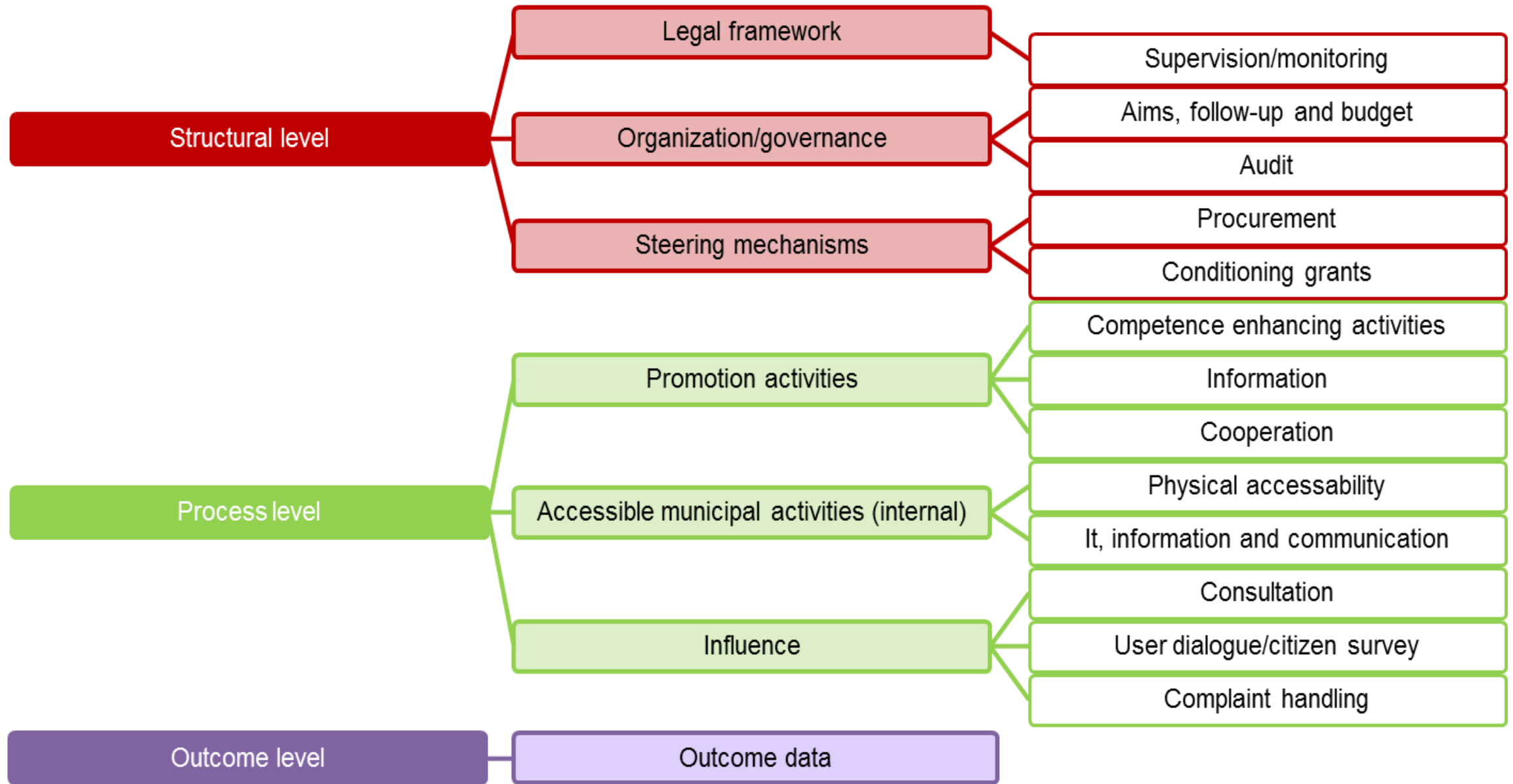
- The disability perspective needs to be included.
- Special attention in gender analysis.
- PWD as a priority group for global partnership.
- The knowledge and experiences of the civil society should be utilized
- That Sweden should take part in the development of methods for monitoring the implementation of Agenda

10 years of experience

- Available statistical data actually do not give a true picture of the situation of the people on the ground.
- Great gaps of statistics in certain sectors, such as education.
- Persons with disability is a very heterogeneous group which will not be captured of national survey statistics.
- It's obvious that there are great differences in living conditions for some of the groups.
- Some groups are very small and is difficult to catch.
- Persons with certain psychiatric or intellectual disabilities

Monitoring and the Swedish Agency for Participation. Two main tasks on monitoring.

- Monitor the situation for people with disabilities compared to the rest of the population.
- The second is to monitor how the disability perspective is implemented in the society.



UNOHCHR model

	Structure	Process	Outcome
National surveys on the living conditions, i.e. health, labour			
Web panel 2500 PWD			
Municipalities work			
Governmental agencies work			
Qualitative studies on barriers, actions and living conditions			
Scientific research			

A welfare state with a lot of statistics from surveys and administrative data

- The information is not used as much as possible
- Restrictive regulations on the possibility to match and use information from different sources
- Restrictions on what personal data and information you are allowed to collect in surveys or registries. The integrity for the individuals.

The use of administrative data

- Primarily to describe living conditions also for more in depth studies of different groups of PWD
- Less useful to identify obstacles behind differences in living conditions
 - Such as causes of differences in living conditions due to that regulations or routines are not sufficient, not enforced or that different actors do not collaborate.

Examples of register studies on disability

- Ministry of Social Affairs - Economic conditions for people with disabilities.
- The Swedish Social Insurance Inspectorate - A study showing differences between families with children with disabilities and families with children without.
- The Institute for Evaluation of Labour Market and Education Policy - Studies on the effects of wage subsidies.

Economic conditions for people with disabilities

- Ministry of Social Affairs
- Sources: **Disability compensation, sickness- and activity compensation, total population income register and HURPID (research database Halmstad University)**

A study showing differences between families with children with disabilities and families with children without.

- The Swedish Social Insurance Inspectorate
- Sources: **National insurance data on childcare allowance.**

Study on the effects of wage subsidies

- IFAU - The Institute for Evaluation of Labour Market and Education Policy.
- Sources: **Register of jobseekers, Statistics Sweden's longitudinal databases LOUISE and LISA, Register-based labor market statistics (RAMS), Swedish Social Insurance Agency's register of sicknesses.**

The national monitoring system

- To satisfy the Committee on The Rights of Persons With Disabilities.
- Gives information both to the government and to the people.
- Gives information from all levels of the society, local, regional and national
- Last it's important to not just talk and describe the situation you also have to say how you shall deal with it.

Some points from a UN member state

- Both the CRPD and the Agenda 2030 states that information on the living conditions are needed. Also the disability organisations should be involved in the process.
- The UNSD has the mandate. Publish what you have and add what you can collect now. We need the data in the global partnership work.
- Focus on the advantage of using a human right functional approach such as the WG – skip parallel processes
- Plan strategies on how to convince the reluctant states

Thank you

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Living condition survey (ULF/SILC)

- The Survey has been the main source for national indicators on disability,
- In the living condition survey a lot of questions are set on the situation for people with disability. The identification of disability is made in a functional perspective based on the individuals own view on his or hers possibility to take part of the daily life in the society.

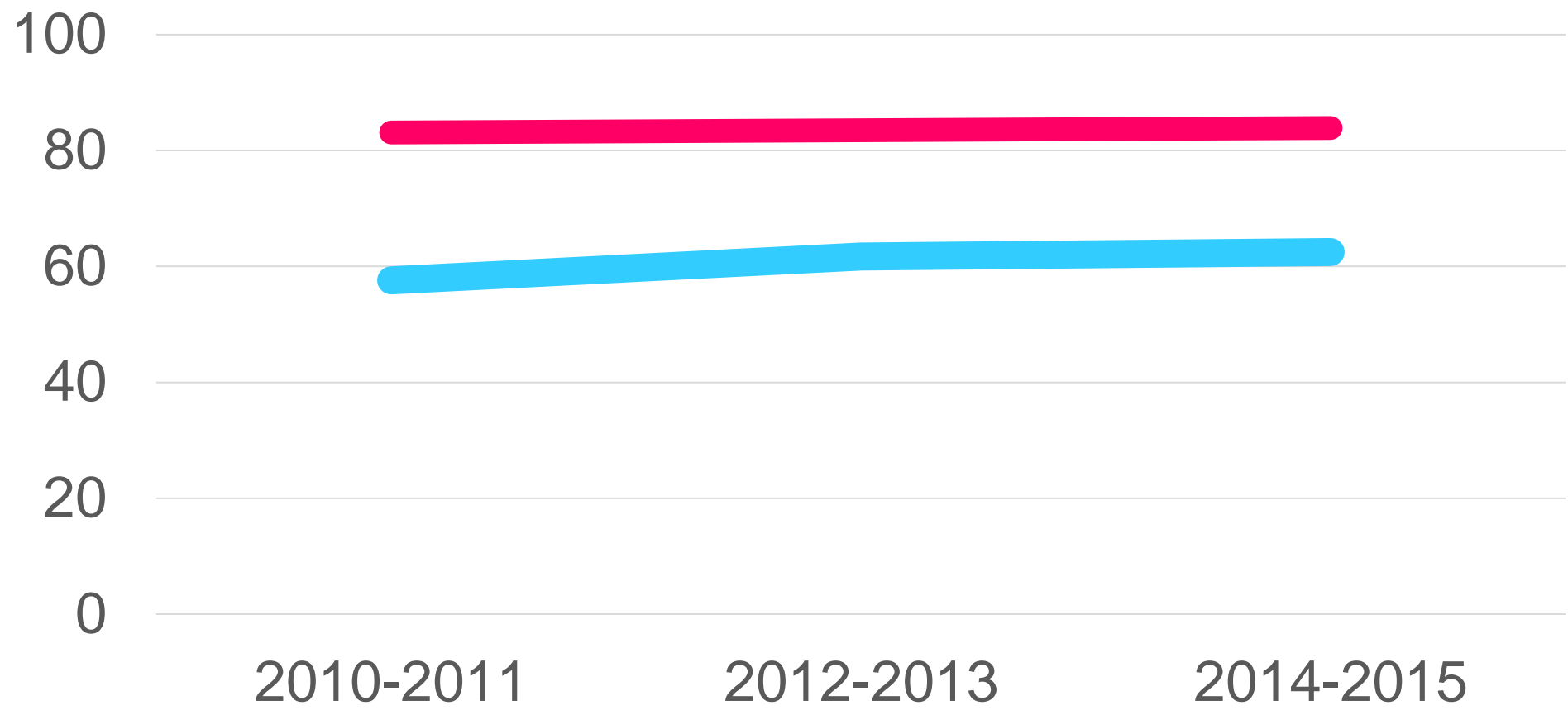
ULF/SILC definition of disability

- Impaired vision
- Impaired hearing
- Reduced mobility, Greatly reduced mobility
- Have severe problems with allergy and/or with asthma
- Severe problems of anxiety, worry, fear
- Severely reduced activity capacity
- Great trouble due to dyslexia and/or dyscalculia
- Neuropsychiatric diagnosis

Projects 2017 at Agency for Participation

- Monitoring living conditions (Survey, panel)
- Indicators and Key ratios
- In-depth studies
 - School to employment for persons with ASD
 - School to employment for persons with intellectual impairments
- Follow-up of community stakeholders
- Integrate childrens perspective in the society – pre. Convention of the children
- Men's abuse against women with disabilities

Employment % ages 20-64



Persons without disability

Persons with disability



Higher education % PWD per gender

