



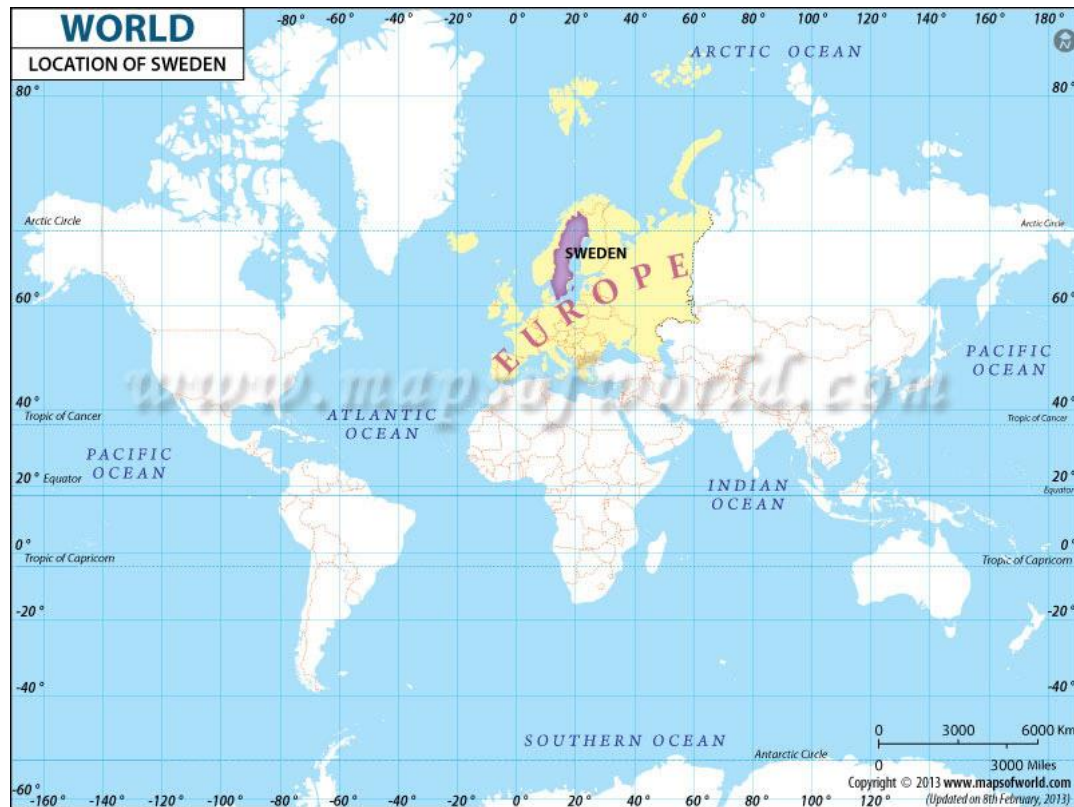
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# **PARENTS WITH INTELLECTUAL DISABILITIES: SOCIAL POLICY AND SUPPORT SERVICE PERSPECTIVES IN SWEDEN**

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# Location of Sweden





# Facts about Sweden

- Area:
  - 450,000 km<sup>2</sup>, the forth largest country in Europe
- Capital:
  - Stockholm
- Population:
  - 9.4 millions, 0,1 % of the world population



## .....more facts

- Form of government:
  - Constitutional monarchy, parliamentary democracy
- Life expectancy:
  - Men 79 years,
  - Women 83 years



# Education and research in Social Work

- BSW education at 12 universities
- MSW since 1980s
  - 7 percent of the social workers have a MSW
- PhD 1980–2009:
  - 252 doctoral dissertations in Social work
- Four scientific journals in social work



# Swedish Social Workers

- 30 000 social workers: 1 SW in 300 inhabitants
- Comparison:
  - United Kingdom: 1 SW in 600 inhabitants
  - Italy: 1 SW 1600 inhabitants
  - Uganda: 1 SW in 6500 inhabitants



# The lecture of today ....

- UN Convention on the Rights of Persons with Disabilities (UNCRPD).
- Different theoretical perspectives on disability
- The Swedish disability policy
- Implementation project for parents with intellectual disability



# The UN convention on disability

- Human Rights Convention
- The United Nation Convention on the Right of Persons with Disability (UNCPRPD)
  - equalization
  - participation.
- A guide for the national laws and regulation regarding support and services for individuals with disability.
- Sweden - one of the first countries that ratified the UNCPRPD in 2008.



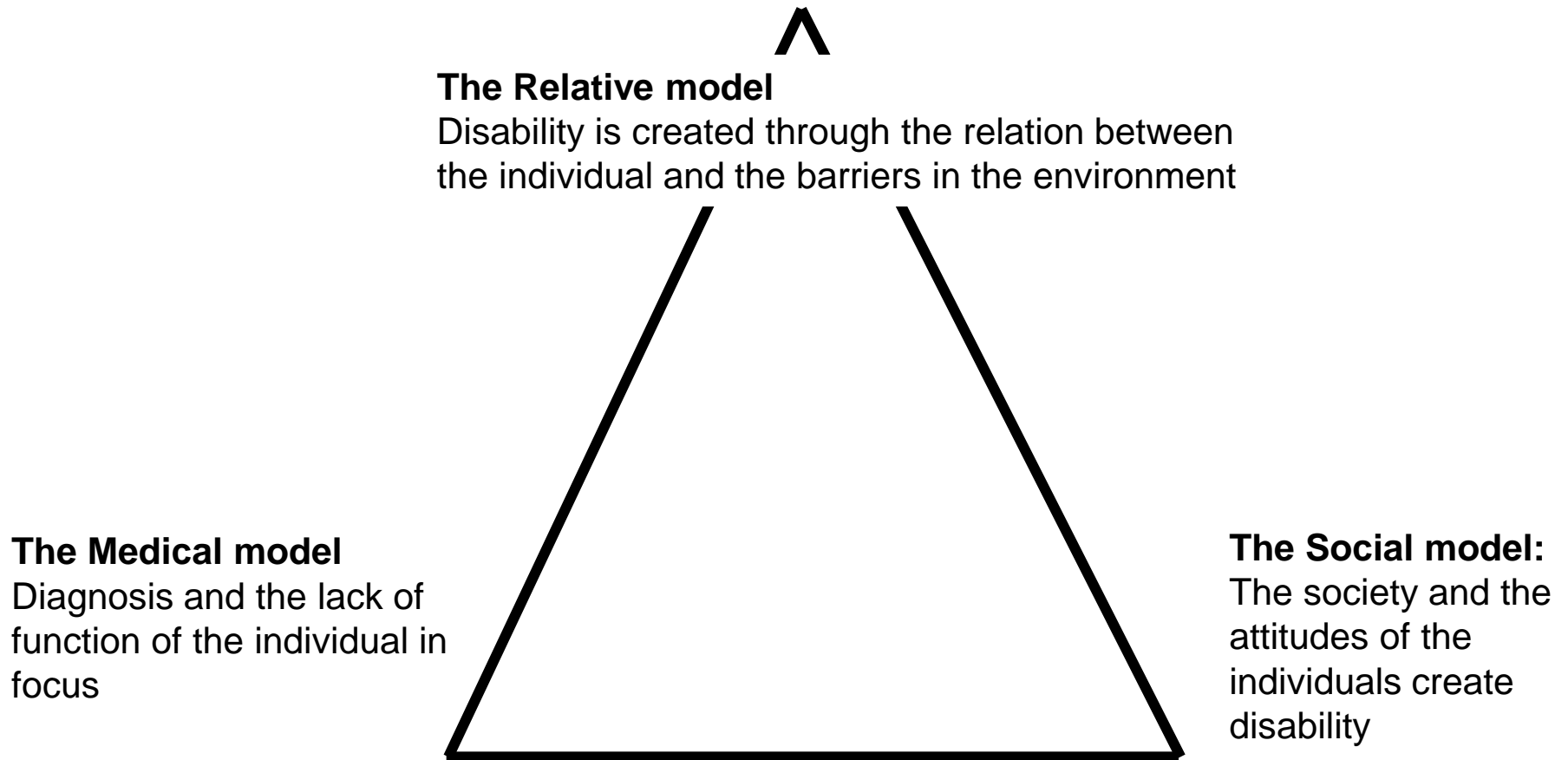


# Article 23 - Respect for home and the family

1 § States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others....



# Different models or perspectives of disability





## Some consequences of the relative model

Swedish disability policy:

The disability policy is especially focused on identifying and removing barriers in order to create and support full participation in society, preventing and combating discrimination, and providing people with disabilities to have an independent and autonomous life



# The Swedish Agency for participation

- Responsible to overlook that UNCRPD and the disability policy to have an impact throughout the country, guided by the objectives and strategies for disability policy



## The Act concerning Support and Service for Individuals with Certain Functional Impairments

- To ensure the right for support for individuals with disability and to reinforce the opportunities of individuals with disability to live an independent and autonomous life.
- Applies to individuals with intellectual disability, autism, and individuals with physical impairments and persons with mental impairments:
  - respite care,
  - individual assistance,
  - transportation,
  - contact person
  - daily activities



## The Act concerning Support and Service for Individuals with Certain Functional Impairments

- Provides an example of a combination of models:
  - Support depends on a medical diagnosis
- Consequences
  - The amount of individuals that receive a diagnosis increases
- Provides examples of attitudes toward individuals with disabilities
  - Issues about parents with disability are not paid any attention in this Act



# Parents with intellectual disability

- Relatively small population
- Overrepresented in support by the social services and foster care of the children
- Professionals indicate a lack of knowledge and lack of strategies and tools



# Parents with intellectual disability

- A Swedish review about parents with intellectual disability was carried out at the National Board (2005, 2007)
  - parenting programs for parents with ID have been developed with good results – however no such program in Sweden
- Parenting Young Children (PYC) developed by Dr Mildon & Dr Wade
- Imported to Sweden 2010:
  - social pedagogic methods and ethical values
  - consistent with Swedish law and regulations
  - promote empowerment, respect and collaboration.



# Parenting Young Children

- Aims to improve the child care and positive parent-child interaction skills of parents with intellectual disability
- Evidenced informed parent education program
- Social learning theory
- Parents with intellectual disability
- Children aged 0 to 6 years
- Home-based
- Individually tailored
- Moore information see  
<http://www.healthystart.net.au/images/resources/05-Education-and-Development/PYC%20Information%20Sheet.pdf>



## Current publications from the project

Starke, Wade, Feldman & Mildon (2013) Parenting with disabilities: Experiences from implementing a parenting support programme in Sweden *Journal of Intellectual Disabilities* 17(2) 145–156

Mc Hugh & Starke (2015). Understanding professionals' competence development in working with parents with intellectual disability To be published in *Journal of Intellectual Disabilities*



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# **Professionals perspectives of the program - providing a new approach**

- Responding to the parents
- Working alliances with the parents
- Structure



## Parents' voices

- *Sara says: "I think that many parents should have this ...because it is so good and you learn so many things ... and you feel so talented"*



# Parents' experiences of changes

- The parents described that they have developed their parenting competence through PYC. They have:
  - strengthened their parenting skills
  - increased their ability to meet the children's needs
  - strengthened their self-esteem
  - received more knowledge about child care and parenting
  - less worries and are less stressed
  - developed their communication with the other parent
  - developed interaction with the child



# In summary the interviews with the parents shows

- PYC:
  - stimulates the parent
  - influence the parents' collaboration with the support workers
  - helps the parents to identify the responsibilities and expectations of their parenthood
  - motivates the parents to receive support
- The results show that the parents are satisfied with the experience of:
  - being able to influence
  - collaboration with the support workers
  - learn skills



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