

Study on the Specific Risks of Discrimination against People in Situation of Major Dependence or with Complex Needs



SELF-ADVOCACY FOR PERSONS WITH DISABILITIES

SELF-ADVOCACY

Conclusions of the Study

progress in terms of self-advocacy and empowerment has been made in all European countries in the last decade

Persons in situations of major dependence or with complex needs are:

- included in law but excluded in practice from exercising their rights
- not a target group for full integration and inclusion in many relevant policy areas

Early Childhood & Family Support

Parents & Services

- medical and therapeutic orientation
- harassing application procedures
- little information, coordination of support, counselling
- parents rarely considered 'Experts' of their child
- lack of awareness of the life situation of families



Sweden, the Netherlands – Individual Plans, Germany – Respite

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Education & School

Paradox

inclusive kindergarten but special schools from primary level
or home schooling

Children's Leisure

Time - greater awareness
but limited access to mainstream
leisure time activities



Italy – 'school for all': inclusive mainstream education from pre-school to university, individual education plan

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Self-Advocacy in Childhood

- lack of communication with, or awareness of, the life situation of families
- segregated education and leisure time activities in childhood

= no voice

= no choice

= no participation

SEGREGATION IN ADULT LIFE

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Vocational Training, Employment & Leisure Time for Adults

General assumption

complex support needs = incapacity to work

no valued adult roles or economic independence

less self-determination, greater dependency

- unemployment
- little or no access to open labour market or mainstream leisure activities
- sheltered workshops, day care centres, exclusive leisure activities



Germany – self-advocacy groups in large private enterprises and civil service

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Housing for Adults

Independent Living & group houses

on principle promote self-determination, empowerment and participation but are normally offered to persons with low support needs



**living at home or in residential care
is the norm**
with limited possibilities to choose,
control daily life or develop a positive self concept

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Exercising Civil Rights

- few opportunities for self-advocacy or full citizenship
- lack of support in exercising civil rights, including the right to vote
- no or limited civil rights for persons with severe disabilities and/or under legal guardianship



United Nations Convention on the Rights of Persons with Disabilities (2006)
Articles 12 & 29 – legal capacity, participation in public affairs

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Ageing & the End of Life

- lack of awareness of, or advocacy for, the needs and rights of older people in situations of major dependence or with complex needs
- often no-one to represent their rights and interests
- passive, inactive life
- highly vulnerable group



Italy – 'During our Lives and When We are Gone' - Parents' Movement to guarantee adequate care, support and a home for adult children with complex dependency needs throughout their adult life.
Associations have an active advisory role in policy making through the National Disability Council and government committees

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Self-Advocacy in Adult Life

The ability of adults in situations of major dependence or with complex needs to choose, take their own decisions and control their lives *on an equal basis to others* is not generally recognised or supported

VOICE

- self-advocacy skills training and support from childhood for the person and their family

CHOICE

- professionals, personal assistants who act with – and not for - the person in everyday situations involving choices and decisions

PARTICIPATION

- supported decision-making in exercising civil rights

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The Social Model of Disability

UN Convention on the Rights of Persons with Disabilities (2006)

recognises that

*'disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others' **

and

*'the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices' ** (Preamble e), n)**'*



'Nothing for us without us'