

Intellectual Disability

Situation and Developments in Switzerland

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Overview

- **Epidemiology**
- **Care for people with intellectual disability**
 - „Geburtsgebrechen“
 - Differences between childhood and adulthood
 - Non-medical care
 - Psychiatry
- **Developments**
 - Engagement of the Swiss Academy of Medical Sciences (SAMS)
 - Legislation („Behindertengleichstellungsgesetz“, „Sterilisationsgesetz“, NFA“)
 - SAGB (Swiss Organisation of Doctors for People with Intellectual and/or Multiple Disabilities)

Epidemiology

- **Switzerland:** about 7.6 million inhabitants , 21,5 % foreigners, federalistic structure with 26 „Kantone“ with 15.000 – 1.3 million inhabitants, 4 different languages
- No epidemiological assessment of intellectual disability in Switzerland
- **WHO:** 3 % with any form of intellectual disability (i.e. 210000 persons), 1/3 with IQ < 70 (70 000 persons)
- **Statistics of Invalidity Insurance (IV):** about 60 000 persons meet certain criteria as "Hirn- und motorische Störungen", "Störungen geistiger Art", "Mehrfach geistig und körperlich behindert“, which point to intellectual disability
- Future: a **national research program** "Sozialstaat" aim to work out basics for a statistical assessment of the prevalence of intellectual disability in Switzerland (www.sozialstaat.ch)

Care – “Geburtsgebrechen”

- For historical reasons (obligatory health insurance since 1996, invalidity insurance (IV) since 1960) **IV** cover costs of **medical care** for many congenital (not necessarily genetic) physical and mental disorders (“Geburtsgebrechen”) until the person reaches his or her 20th birthday. After that time the costs are overtaken by the obligatory **health insurance system**.
- Federal Council (Swiss government) established a **directory of congenital disorders**
 - Updated on an annual basis
 - Covers more than 200 diagnoses or groups of diagnoses.
 - Listed in order of anatomical criteria, ranging from simple diseases like inguinal hernias which require a single operation up to highly complex diseases like congenital metabolism disorders and cerebral palsy which require sophisticated medical treatment over many years.
 - A disorder has to be treatable: while many syndromes like Trisomy-21 are excluded, some of its treatable symptoms, such as congenital heart defects are included in the directory.
 - Epilepsy or psychiatric symptoms are included if they are caused by an congenital disorder.
- **Services** include medical treatment, if necessary in hospital, and medical measures prescribed by a doctor (drugs, physiotherapy, occupational therapy and psychotherapy). These therapies must be scientifically validated, appropriate and cost-effective.

Care – Children and Adults

- **Children**

- Medical care provided by (neuro-)pediatricians with a sophisticated knowledge of syndromes, neurological, neuro-orthopediatric and psychiatric aspects
- (Neuro-)Pediatricians usually care for their patients until the age of 16, in case of disabled patients they also take care for adult persons, since patients and their families are afraid of a lesser degree of competence of the doctors for adults (GP, neurologist)
- In case of „Geburtsgebrechen“ payment of costs für medical care changes from IV to health insurance at the age of 20
- Increasing tendency to live at home with parents
- Costs for non-medical care (i.e. residence, support at home) are usually covered by IV („Rente“ = pension, „Ergänzungsleistungen“ = complementary pension, dependent on economic situation, „Hilflosenentschädigung“ = complementary pension dependent on degree of helplessness)

Care – Children and Adults

- **Adults**

- Most adults (around 70%) with intellectual disabilities live in institutions or in assisted accommodation, the rest lives with their parents or independently (Heer S, International Psychiatry 2008; 5: 9 – 12)
- Institutions usually do not employ doctors, psychologists etc. →
- Residents choose their doctors (usually GP working in the same village/town)
- GP are the „gate keepers“ to specialised doctors (Psychiatrists, Neurologist etc.)
- No specialised physicians for disabled patients
- Costs for medical care by health insurance
- Costs for non-medical care (i.e. residence, support at home) are usually covered by IV („Rente“ = pension, „Ergänzungsleistungen“ = complementary pension, dependent on economic situation, „Hilflosenentschädigung“ = complementary pension dependent on degree of helplessness)
- In case of an accident as cause for the disability a special insurance covers costs for medical and non-medical care

Care – Non-medical care

- There is no legal right to a place to live
- Residential units for 6–10 people with professional assistance and care
- Bigger institutions usually not only offer a place to live but also a place to work
- In residences nurses and so-called „agogen“ care for disabled persons →
- Nursing and psychosocial needs (esp. increase of autonomy) of disabled persons are managed by different professions with different self-understanding
- Usually there are no specialised psychologists
- In a few cantons there are *Wohnschulen*, where adults have training to allow them to live independently.
- In three cantons social security is running a pilot scheme („Assistenzbudget“) (2006–08), where individuals have their own budgets to buy the assistance they need. Just a few adults with intellectual disabilities are involved, probably because there is no service available to help organise the assistance.
- **Finding a place to live is often very difficult for those with additional behavioural disorders**, there is a risk that these individuals are passed on from institution to institution.

Care – Psychiatric Aspects

- For historical reasons psychiatry in Switzerland is not very much interested in psychiatric symptoms due to brain diseases or brain damage
- No special education in mental health problems of disabled persons within the psychiatric curriculum
- Little cooperation between psychiatrists and „Agogen“ in residences
- Public health services are largely unable to respond to the needs of individuals with intellectual disabilities and mental health problems, partly because of accessibility, partly because of a lack of appropriate structures or simply because there is no knowledge of how to deal with this group.
- Even psychiatric clinics are often not prepared or are simply unable to care for individuals with intellectual disabilities.
- Exceptions:
 - „Fachstelle“(BE) offers counselling for behavioural disorder
 - Psychiatric centre in Geneva (Galli Carminati)
 - Some of the institutions employ psychologists/psychiatrists (Swiss Epilepsy Center)
 - Specialised psychiatric outpatient services (LU)
 - A few psychiatrists work with individuals with intellectual disabilities in their own practice

Developments – SAMS*

SAMW

WEITERE ORGANISATIONEN UND INSTITUTIONEN

Medizinisch-ethische Richtlinien und Empfehlungen

Medizinische Behandlung und Betreuung von Menschen mit Behinderung

* Swiss Academy of Medical Sciences

Developments - SAMS

- Rationale and aims behind/of the guidelines and recommendations
 - The right of all people with disabilities to appropriate treatment and care
 - Good medical treatment and care as a condition for supporting people with disabilities striving for self-determination and social participation
 - Help for the medical, nursing and therapeutic treatment of people with disabilities and their families
 - Recommendations to politics and society for favorable conditions for a good medical treatment and care for people with disabilities

Developments - Legislation

- „Behindertengleichstellungsgesetz“ (2004)
 - Promotes the integration and equalisation within society of people with disability
 - Includes public transport, education, public services, housing and public buildings
 - Its impact cannot be estimated so far
- „Sterilisationsgesetz“ (2005)
 - Sterilisation of individuals who do not have the capacity to consent is allowed only where the person is at least 16 years of age and where no other contraception is possible
- „NFA = Neugestaltung des Finanzausgleichs und der Aufgabenteilung zwischen Bund und Kantonen“ (2004)
 - Determines the distribution of tasks and financial commitments between the federal government and the cantonal governments
 - Residences are now under the control of the cantonal governments and no longer under supervision by the federal government
 - Differences concerning resources and standards for care, residences etc. among the cantons will grow
 - Accessibility for specialised services will be more difficult for disabled persons from smaller cantons with limited resources and facilities (comparable to the problems emerging from the also cantonal controlled health insurance system)

Developments – SAGB*

* „Schweizerische Arbeitsgemeinschaft von Ärzten für Menschen mit geistiger oder Mehrfachbehinderung = Swiss Association of Physicians for People with Intellectual and/or Multiple Disabilities

- Founded on November 3rd, 2007 at Swiss Epilepsy Center
- Members at present: **80**
- Aims:
 - Enhancement of cooperation of physicians with different specialisations
 - Education/training of physicians
 - Definition of quality standards
 - Information for patients, their families and caregivers
 - International contacts
- Activities:
 - Annual meetings with talks about different medical topics
 - Working groups (e.g. management of somatic and psychiatric crisis, financial aspects of medical care for disabled persons)
 - International contacts

Schweizerische Arbeitsgemeinschaft von Ärzten für
Menschen mit geistiger oder mehrfacher Behinderung
SAGB

**Aus der Praxis
für die Praxis**

Jahrestagung 2008



11.9.2008, 14.00 – 17.30 Uhr
Congress-Hotel Olten