

ANNEX VIII: GERMANY

BACKGROUND

(1) What definitions of Intellectual Disability are typically used in your Member State? Is there an 'official' definition?

There is no official definition of "Intellectual Disability" in Germany, but there are lot of definitions researchers and authors refer to in their work.

One definition which quotation can be found frequently has been elaborated by the German Advisory Council for Education (Deutscher Bildungsrat, 1974, S. 37): *"Als geistigbehindert gilt, wer [...] in seiner psychischen Gesamtentwicklung und seiner Lernfähigkeit so sehr beeinträchtigt ist, daß er voraussichtlich lebenslanger sozialer und pädagogischer Hilfen bedarf. Mit den kognitiven Beeinträchtigungen geben solche der sprachlichen, sozialen, emotionalen und der motorischen Entwicklung einher."* – "An individual, whose psychological/mental total development and learning aptitude is so much impaired that he/she probably needs lifelong social and educational help, is classified als being intellectually disabled. The cognitive impairment comes along with an impairment of the verbal, the social, the emotional and the motor development."

Another common definition combines physical, psychological/mental and cognitive disabilities in one statement: *"Als behindert gelten Personen, die infolge einer Schädigung ihrer körperlichen, seelischen oder geistigen Funktionen soweit beeinträchtigt sind, daß ihre unmittelbaren Lebensverrichtungen oder ihre Teilnahme am Leben der Gesellschaft erschwert werden."* (Bleidick, 1993, S. 5). – "People, whose directly daily tasks or whose participation in society become difficult due to their impairment of physical, mental/psychological and intellectual functions, are classified as being disabled."

A third well-known definition which also combines different kinds of disabilities is presented in §2 (1) of Book IX of the German Code of Social Law: *"Menschen sind behindert, wenn ihre körperliche Funktion, geistige Fähigkeit oder seelische Gesundheit mit hoher Wahrscheinlichkeit länger als 6 Monate von dem für das Lebensalter typischen Zustand abweichen und daher ihre Teilhabe am Leben in der Gesellschaft beeinträchtigt ist."* (Neuntes Buch Sozialgesetzbuch. In Bundesministerium für Gesundheit und Soziale Sicherung, 2005). – "People are disabled/handicapped when their physical function, their intellectual ability or their mental/psychological health deviates from the age-typical condition without much doubt for longer than six months and when therefore their participation in society is impaired."

The official definition of the American Association on Mental Retardation from 1992 is also often used or adapted in Germany as well as in a lot of countries (cp. European Intellectual Disability Research Network, 2003, p. 2).

(2) What is the historical context in which services have developed in your Member State?

The welfare work in Germany is composed of several supporting organisations inside of the free, the municipal and the state welfare work. The free welfare working organisations are:

The central associations of the free welfare work

- Die Arbeiterwohlfahrt (Labour Welfare, in the following called "AWO")
- Der Deutsche Caritasverband (Charity, Welfare of the Catholic Church, in the following called "Caritas")
- Das Deutsche Rote Kreuz (The German Red Cross)
- Der Deutsche Paritätische Wohlfahrtsverband (An on equal terms-working welfare association with independent social organisations, facilities and groups)

→ Das Diakonische Werk (Deacony, Welfare of the Protestant Church, in the following called "Diakonie")

→ Die Zentrale Wohlfahrtsstelle der Juden (The Central Welfare Center of the Jews)

The Churches and religious communities

→ The Catholic and the Protestant Church

→ Other Churches or religious communities

The self-help groups

→ Bundesvereinigung Lebenshilfe für geistig Behinderte (A very important service for people with intellectual disabilities, in the following called "Lebenshilfe")

→ Other self-help groups

Some other services are financed by foundations or private persons (Flierl, 1992).

Some of the most important representatives of the free welfare work regarding people with intellectual disabilities are the "AWO", the "Caritas", the "Diakonie", and the "Lebenshilfe".

The AWO, a honorary headed political pressure group and a service provider (Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege, 2001) with a free democratic basic order, was founded in 1919 at the end of the First World War in the course of the labour movement. The aim of the social democratic founders was not only to alleviate the misery of the people but also to remove the suppressive poor relief of the old German Empire and to integrate the idea of self-help and solidarity into a modern welfare-concept (Arbeiterwohlfahrt, 2000).

The AWO was forbidden under the rule of the national socialists (1933-1945) and was reestablished in 1946 in West-Germany, West-Berlin and East-Berlin (only till 1961). Since 1990 the welfare association is also working in the newly-formed German states (ibid.).

In 2005 about 14.000 facilities and services with more than 330.000 beds/places are supported by the AWO. The establishments are used by children, adolescents and old people, foreigners and resettlers, women, unemployed persons, families and pregnant women, individuals with all kinds of disabilities and handicaps, people with psychological problems and persons who are looking for self-help groups, and at last invalid and chronically ill people (Arbeiterwohlfahrt, 2005).

The Caritas, the welfare organisation of the Catholic Church, was founded in 1897 in Cologne by a priest who thereby fulfilled the requirements of a lot of catholic-social politicians. The organisation had a lot of problems during 1933-1945 (Caritas, o.J. a).

The duties of the Caritas are to help people in time of need, to be actively involved in the development of social policy and to contribute to the qualification of social work (Caritas, o.J. c).

In relation to people with disabilities and handicaps the Caritas wants to stop the social exclusion of these individuals and to provide a reciprocal acceptance between persons with and without disabilities (Caritas, o.J.).

In the year 2005 the Caritas is the supporter of 790 inpatient facilities (basically residential establishments) with 39.297 beds/places, 773 day-care-services with 72.596 places, 26 basic and advanced training centers with 1.614 places and 467 services like information centers, early treatment centers, family support services or carpools for persons with disabilities (Caritas, o.J. b).

The Diakonie, the welfare association of the Protestant Church, emerged in 1848 as an inner mission ("Innere Mission") against mental and material poverty (ibid.) and had a lot of embarrassments under the national socialists (Flierl, 1992). After the end of the Second World War, the Protestant Church also founded a relief organisation ("Hilfswerk") to help all the displaced persons, the refugees and the uprooted young people. In 1957 the "Innere Mission" and the "Hilfswerk" were combined and in 1975 the two organisations were concentrated in the "Diakonisches Werk", short "Diakonie" (Diakonie, o.J. b).

The Diakonie pays attention to a lot of social fields: gerontological services, employee assistance programs, basic and advanced training for the members of staff, civilian service, disability services, family and children's services, services for people who got into special social difficulties, health, hospital and hospice care, youth services, nursing, migration care, psychiatry services, substance abuse services, crisis line etc. (Diakonie, o.J.).

Regarding persons with disabilities, the Diakonie goes along with more than 142.500 affected people in more than 2.700 facilities and favours participation instead of welfare, equalisation instead of pity and self-determination instead of paternalism (Diakonie, o.J. a).

Finally there is the Lebenshilfe, a friendly society, founded by parents of children with intellectual disabilities and specialists in 1958 in Marburg (Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung, 2006). The requirements and impulses of the Lebenshilfe with regard to the rehabilitation made an important contribution to better personal circumstances for individuals with intellectual disabilities in the academic, the occupational, the financial and the social area (Flierl, 1992).

On the one hand, the Lebenshilfe is a representative of people with intellectual disabilities and their relatives and on the other hand, the association is a supporting organisation (ibid.) of about 3000 services and facilities which supports and cares for 150.000 individuals (Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung, 2006a).

The aim of the Lebenshilfe is to help people with intellectual disabilities to live their lives as normal as possible in every age and to lobby for their social acceptance and self-determination. The Lebenshilfe regards disabilities as a polymorphy of the human life, which does not reduce the worthiness of life (Lebenshilfe Dortmund, o.J.).

(3) Are there specific legal rights afforded to people with intellectual disability? Education, disability specific service provision, etc. Situations where rights may be revoked on the basis of incapacity?

The Basic Law of the Federal Republic of Germany (Bundesministerium der Justiz, 1949/2002) assures people with disabilities in Article 3 – Equality before the Law – that they shall not be disfavoured because of their disability.

Individuals with (not only intellectual) disabilities have the same right to attend a regular or special kindergarden, a regular or a special school or a university according to their abilities.

Under the terms of Book IX of the German Code of Social Law people with disabilities have the legal right to make use of services concerning the (medical) rehabilitation, the participation in working life, the securing of subsistence and other supplementing benefits and at last they are entitled to benefits to participate and live in the community. Severely handicapped people have also some more rights like special protection against dismissal, additional leave or free public transport (Bundesministerium für Gesundheit und Soziale Sicherung, 2005).

The "Betreuungsrecht" (like "third party supervision", some years ago "guardianship") is true for people of full age and psychological diseases, mental/psychic or intellectual disabilities and for some people with physical handicaps. This means that people who are not contractually capable are assisted by a public appointed person (often a relative) for all or some legal fields of activity. The Betreuungsrecht has no influence on the legal capacity to act, but there are some cases in which a supported person is not always allowed to take part in legal relations (like "consensual caveat"), for example when there is the substantial risk that persons harm themselves or their capital (Bundesministerium der Justiz, 2006).

(4) What is the estimated prevalence figure for intellectual disability in your Member State? Both in terms of an estimated 1-3% of the population who have an IQ is less than 70, and in terms of known service users. Is there any published material on prevalence studies?

The German Federal Statistical Office (Statistisches Bundesamt Deutschland) declares a total population of 82.500.800 (as of: October 2005) for the Federal Republic. This means, with an underlying estimate of 1-3% of the population who have an IQ less than 70, that about 825.008 to 2.475.024 of the people living in Germany are affected.

Normally, the rough estimate is much lower in Germany, because researchers have to resort to prevalence studies of other countries. Material on prevalence studies of people with intellectual disabilities in Germany are not available. In addition a disability is not notifiable in the Federal Republic.

Haveman and Stöppler (2004) suppose that about 353.000 people with intellectual disabilities are living in Germany while the working committee of the offices for integration and of the main welfare offices (Bundesarbeitsgemeinschaft der Integrationsämter und Hauptfürsorgestellen, 2005) declares about 450.000 affected individuals. The "Bundesarbeitsgemeinschaft der freien Wohlfahrtspflege" (2001), a working committee which consists of six central associations of the free welfare work in Germany (excluding the very important "Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung") for example, register 12.449 facilities, 344.819 beds/places and 157.711 employees for the year 2000 in the field of their disability services.

Noticeably especially in Germany the number of older people with intellectual disabilities increases more and more. Haveman and Stöppler (2004) identify these people as the first generation who is able to grow old after the euthanasia program of the nazis. Furthermore health promotion and health services are much better than years ago. Wacker (2004) guesses that about 20.000 to 30.000 affected individuals living in residents are older than 65 years.

The official prevalence figure of severely handicapped or disabled individuals for the year 2003, published by the German Federal Statistical Office, (Statistisches Bundesamt 2005; 2005a) is a total of 259.165 persons with learning or intellectual disabilities who have a validated severely handicapped pass. Table 1 shows the age distribution.

<i>Age</i>	<i>n</i>	<i>Age</i>	<i>n</i>
> 4	1.866	45-55	41.204
4-6	2.444	55-60	10.989
6-15	21.987	60-62	4.293
15-18	11.482	62-65	7.264
18-25	30.141	65-70	9.232
25-35	43.355	70-75	5.506
35-45	63.065	75+	6.337

Table 1: Age distribution of individuals with learning or intellectual disabilities and a level of disability of 50% and more (Statistisches Bundesamt 2005; 2005a)

(5) What databases/sources are available in your Member State that might provide information on prevalence? Medical or social benefits; disability databases etc.

Databases that provide information on the prevalence of people with intellectual disability in Germany do not exist. It is important to keep in mind that there is neither an obligation to register for people with intellectual disability nor a specific database since the end of the nazi regime (Haveman & Stöppler, 2004; Wacker, 2004).

Well-known services have indeed published data on their benefits, but these information mostly concern their members of staff or the capacity of their residential establishments. They do not release prevalence figures and they also do not publish the number of their service users.

Only the German Federal Statistical Office (Statistisches Bundesamt Deutschland) collects data on people who have got a severely handicapped pass (level of disability: 50% and more) every two years following §131 of Book IX of the German Code of Social Law – "Rehabilitation and Participation of Disabled People" (Neuntes Buch Sozialgesetzbuch (SGB IX) – Rehabilitation und Teilhabe behindertter Menschen). This data concerns a) the prevalence figure of people with a validated severely handicapped pass, b) individual features like age, gender, nationality and residence, and c) the kind, the cause and the level of disability (Statistisches Bundesamt 2005; 2005a). On the basis of this investigation the German Federal Statistical Office has published some outcomes of a micro-census which refers to disability, circumstances and income (Pfaff, 2004; 2005).

SERVICE PROVISION

(6) What is the criterion for eligibility for intellectual disability services?

The criterion for eligibility for benefits and intellectual disability services is a diagnosed disability with a minimum level of 20 % loss of any function. Persons with a minimum level of 50 % have a status of severely handicapped or disabled individuals. It is possible but not obliged to apply for a handicapped ID or a severely handicapped pass at the local pension office (Versorgungsamt).

Making use of services does not basically require a determination of the individual level of disability in terms of a handicapped ID as a proof, but there are several benefits only for people with a severely disability (e.g. a special protection against dismissal or an additional leave). In this case and in order to use benefits like gratuitous conveyance on traffic it is essential that the level of disability has been determined and declared (Bundesministerium für Gesundheit und Soziale Sicherung, 2005).

These criterions do not only apply to individuals with intellectual but also with other disabilities.

(7) What type of service provision is currently offered to adults with intellectual disability? Educational, day service, residential, etc

Possible educational, day, support and residential service provision for adults in Germany include (Bormann, Häußler & Wacker, 1996; Consens Hamburg, 2003; Häußler, Wacker & Wetzler, 1996; Haveman & Stöppler, 2004; Wacker, Wetzler, Metzler & Hornung, 1998):

- special schools (possible until 25 years of age)
- special vocational schools
- sheltered workshops
- training groups inside of the sheltered workshops
- sheltered employment
- special care groups
- self-help firms
- integrated employment
- supported employment
- occupational training
- occupational rehabilitation
- work assistance
- family support service
- individual support for severely handicapped people
- adult education

mobile social services
 day care services
 residence for people working in sheltered workshop or other employees
 residence for people with other outlying occupation
 residence with integrated occupation
 nursing home
 outlying residence group
 boarding school
 community home
 living semi-independent/with a couple
 training living group
 village community

(8) What sources of income are available for people with intellectual disability? Benefits – provide some index of national minimum wage as a reference point

People with disabilities in Germany meet the mainly costs of their subsistence with the help of their pension (65,6%), their occupation (18,1%), their subsistence allowance (parents, husband, wife etc.) (8,4%) and other sources of income like unemployment benefit, social benefits, nursing care insurance or independent means (Pfaff, 2004).

A micro-census study from Pfaff (2005) results in some differences in the income of 1-, 2-, 3- and multi-person households with and without people with a disability.

	Without Income	Monthly Net Income < 700 Euros	Monthly Net Income 700-1.700 Euros	Monthly Net Income 1700-2.300 Euros	Monthly Net Income > 2.300
People with disabilities	4,3%	20,8%	53,6%	9,8%	6,9%
People without disabilities	23,9%	21,5%	34,8%	8,2%	7,7%

Table 2: Income of people with and without a disability in 1-, 2-, 3- and multi-person households (Pfaff, 2005).

The eligibility for benefits of the basic financial assurance ("Grundsicherung", German Code of Social Law, Book XII) is true for people who are older than 65 years or for people of full age with a reduction in their earning capacity. Both groups' precondition is no sufficient capital. Individuals who are working in a sheltered workshop belong to the second group.

When an applicant for assurance is living with his relatives, he is entitled to receive 276,00 Euro, when he is living on his own, he receives 345,00 Euro. Money for expenses like accommodation and heating is added. Under certain conditions it is also possible to get more money in form of additional requirements. Other benefits are once-only payments for furnishing the first flat and for clothes, the absorption of contributions of the health insurance and the nursing care insurance and facilities on subsistence in special exceptional cases (e.g. outstanding debts or imminent homelessness) (Lebenshilfe – Landesverband Schleswig-Holstein, 2004).

Except for the construction industry, there is no national minimum wage in Germany.

HEALTH SERVICES & UTILISATION

(9) What health services are currently offered to adults with intellectual disability?

Health services for adults with intellectual disabilities include health promotion (q.v. question 12) and medical rehabilitation where it is required. Medical rehabilitation services are: medical attendance like visit to the doctor, treatment in a hospital or in a rehabilitation institution physical treatment methods like passive or active exercises in the air or in the water, relaxation exercises, massages, respiration and inhalation therapy, exposures and electrotherapy speech therapy and occupational therapy adjuvants like prostheses and orthoses, hearing aids, wheel chairs, orientation guides for blind persons and services like modification, repair, replacement and instructions in using the adjuvants exposure providing and building up of skills for the occupational rehabilitation rehabilitation sports (Bundesministerium für Gesundheit und Soziale Sicherung, 2005).

(10) Is there a body of research in your Member State on the health of adults with intellectual disability? Cite main researchers and areas of research they investigate (not the specific studies themselves – just direct the reader to where the information can be found)

Deutsche Gesellschaft für seelische Gesundheit bei Menschen mit geistiger Behinderung e.V. (German association for the mental health of people with intellectual disabilities)

→ Contact: <http://www.dgsgeb.de/>

→ Research includes workshops which broach the issue of dementia, growing old, maladaptive behaviour, addiction and psychotropics

Bundesarbeitsgemeinschaft Ärzte für Menschen mit geistiger Behinderung (Federal working group of medical practitioners for people with intellectual disabilities)

→ Contact: Diakonie Stetten e.V., Schlossberg 2, 71394 Kernen im Remstal

→ The society acts for the health interests of people with intellectual disabilities and multi-handicaps, organises advanced trainings, develops quality standards and guidelines for the medical care for people with intellectual disabilities

→ First conference in 2001, online: <http://www.mamh.net/Countries/Germany/Overzicht.htm>

Univ.-Prof. Dr. rer. soc. Elisabeth Wacker, University of Dortmund

→ Contact: <http://www.fk-reha.uni-dortmund.de/Soziologie/Homepages/Wacker.html#4>

→ Main research among others: ageing and disabilities, conceptual designs of prevention and rehabilitation

(11) Is there any data on life expectancy among this population in your Member State?

Due to the fact that there is no obligation to register for people with intellectual disabilities, data on life expectancy among this population are not available.

Haveman and Stöppler (2004) report on an increased life expectancy for these individuals relating to studies of Haveman himself inside the Dutch population and to studies of other countries. Reasons for a longer life-span are better health services (preventive medical check-up and medical treatment). The authors explain that there is not much of a difference in life expectancy between people with or without intellectual disabilities, only individuals with Down syndrome or with additional severe physical diseases or epilepsy are an exception.

A life-table (Table 2), published by the German Federal Statistical Office (Statistisches Bundesamt Deutschland, 2005b) shows the further anticipated average life of people living in Germany:

Further anticipated average life (in years)					
Newborns	Men	75,89	45 years of age	Men	32,75
	Women	81,55		Women	37,69
1 year of age	Men	75,24	65 years of age	Men	16,26
	Women	80,86		Women	19,77
15 years of age	Men	61,39	75 years of age	Men	9,83
	Women	66,99		Women	11,93

Table 3: Life table 2002/2004, German Federal Statistical Office (Sterbetafel 2002/2004, Statistisches Bundesamt Deutschland, 2005b)

The average life-expectancy in Germany for the year 2001 based on data of the World Health Organisation (2006) amounts to 78,76 years of life for newborns.

(12) Can you provide comparative information on the following for both people with intellectual disability and the general population – prevalence of epilepsy, forms of health promotion such as screening for blood pressure, blood cholesterol, breast screening, cervical screening, testicular cancer screening. Are there other forms of health promotion screening available to people with intellectual disability (such as medication use, oral hygiene, contraception etc.) and how is this information available – in written form, pictures, television adverts etc.

Between 500.000 to 800.000 of the people living in Germany have an epilepsy (Bundesministerium für Gesundheit, 2003), but there is no German data available on individuals with intellectual disabilities and epilepsy. Schädler (2002) cites some studies and comes to the conclusion that 21% of the individuals with intellectual disabilities without any other cerebral impairment are affected while about 50% of the people who have an additional cerebral palsy develop an epilepsy. The frequency of occurrence of an epilepsy correlates with the severity of the intellectual disability.

A lot of health promotion services are offered to the general population including people with disabilities (Bundesministerium für Gesundheit, 2005; Deutsche Angestellten Krankenkasse, 2004; Techniker-Krankenkasse, 2006):

- examination of the female genitals and cancer screening: annual for women from 20 years on
- examination of the prostate and the male genitals and the dermis and cancer screening: annual for men from 45 years on
- examination of the breast and the dermis/mucosa and cancer screening: annual for women from 30 years on
- examination of the large intestine and the rectum and screening for occult blood in the stool: annual from 50 years on
- check-up on occult blood in the stool: annual between 50 and 55 years
- two colonoscopies and cancer screening: at intervals of 10 years from 55 years on ; or alternatively, when no colonoscopy is done with 55 and 65 years: check-up on occult blood in the stool every two years
- mammogram cancer screening: every two years for women from 50 to 69 years
- health check-up on cardiovascular diseases, renal diseases, diabetes mellitus, physical check-up including screening for blood pressure, blood screening for total cholesterol and glucose, urine screening for proteins, glucose, red and white blood cells and nitrite: every 2 years from 35 years on
- screening for diseases of the teeth, the mouth and the jaw: twice a year
- dental clearance: annual
- inoculation for adults against tetanus and diphtheria: every 10 years

- inoculation against influenza and pneumonia: from 60 years on
- other inoculations for people with an increases risk or for members of special age and risk groups
- preventive medical check-ups and ultrasonic testing for pregnant women
- (- preventive medical check-ups for children and adolescents)

Other health promotion services for special risk group including people with intellectual disabilities are also scheduled (Brucker, 1998).

There is no data available on other forms of health promotion for people with intellectual disabilities. Probably residential members of staff have some individual material to explain contraception e.g. to the residents.

(13) Is there any disability specific training for health professionals – such as modules on undergraduate programmes etc? GP, Dental, Psychiatry -

The web page of the "Bundesärztekammer" (2006), the federal medical association of Germany, does not factor out people with disabilities. The regulation on further education of this association includes in the area of:

ophthalmology: rehabilitation of visual impaired people
 medicine for children and adolescents: developmental disorders of babies
 child and adolescent psychiatry and psychotherapy: diagnosis and therapy concerning individuals with intellectual disability
 psychiatry and psychotherapy: identification and treatment of mental-health problems of people with learning and intellectual disability
 forensic psychiatry: ethical and legal questions concerning the interaction with mentally ill, disturbed and disabled people
 flight medicine: principles of the primary and secondary transport of ill and disabled people in planes and helicopters
 geriatrics: symptomatology and functional meaning of age-related changes, diseases and disabilities of older people
 rehabilitation: effects of disabilities in different age-groups projected onto the social reference fields
 social medicine: assessment of the type and extend of health disturbances on the performance in the occupational and social environment in consideration of [...], disability and healthiness, [...].

This list shall not conceal the fact that the medical care for people with intellectual disabilities in Germany is not the best. Physicians are not very well prepared for the belongings of these people. The undergraduate and postgraduate studies of doctors do not point out relevant information on the health of individuals with disabilities nor do future doctors meet any affected person in the studies (Bundesarbeitsgemeinschaft Ärzte für Menschen mit geistiger Behinderung, 2001).

Diseases of people with intellectional disabilities are often diagnosed much later than the same diseases of the general population. Sometimes because of the untypical symptoms or the incompetence of affected individuals to verbalise their problems and pains, and mostly because professional health staff and disability service staff do not recognise health problems of people with intellectual disabilities, and therefore cut off the supply, although the health care in Germany is very capable and effective. (Brucker, 1998; Bundesverband Evangelische Behindertenhilfe, 2001; cp. Gembris-Nübel, 2005).

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