

# Report on the sexual education of Adults with Learning/Intellectual Disabilities

## Germany

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### 1. Brief history of services for Adults with learning/ intellectual disabilities

After the second World war, where a lot of people with learning/ intellectual disabilities were killed in “Mercy killing programs” of the Nazis, the bad situation of people with learning/ intellectual disabilities didn’t change for a long time. People with learning/ intellectual disabilities were held in big psychiatric clinics, together with psychiatric patients in all degrees. People were held like animals, had no education and possibilities of living a “normal” life. They were hospitalised for life!

In the late 60s and early 70s there was a major change in the living- situation for disabled people in western Germany. Student Organisations brought the terrible situations in these Clinics in the medias, and Parents-organisations like the “Lebenshilfe” started up programs, where special school systems and special living accommodations for people with learning/ intellectual disabilities were introduced and developed.

Slowly, the system started to be changed to values of normalisation and integration of people with learning/ intellectual disabilities in normal society.

In the eastern Part of Germany, the situation found after the opening of the wall after 1991, was horrible and on the level of 1930s. See: <https://www.youtube.com/watch?v=k0VLLaCjFVU> for a short view, but please hold your heart! This situation has changed a lot since then!

Sterilisation was allowed and often done until 1993. Today it is very difficult!

Today, the situation is, that there are various offerings of accommodation possibilities for people with learning/ intellectual disabilities in Germany. Some are still living with their parents, some in supported living groups, most with 8 to 10 persons. The intellectual fitter part of them live in their own apartments, partly integrated in society, with a necessary bit of professional support.

At the moment, the independent form of living is getting more pushed by the government, due to a lack of money following saving programmes in the social area. This is not only a positive change, a lot of young and older people are very little prepared for living on their own. Adults all have possibilities of working in sheltered workshops.

Germany has a very good system of special education for children with special needs. Schools slowly improve their sexual education, problem is often the poor education of the teachers and sometimes a

lack of interest of teachers and/or school leaders. Nevertheless, most of the adult people with learning/ intellectual disabilities are even now very little educated on the level of sexuality and partnership. Parents often forget to introduce sex education and the consequent learning about norms, values and speech of society, so young people are often badly prepared for individual living as an adult.

## **2. Current services**

In the last 20 years, a lot of services are offered, though these were often locally pointed, little consistent and often due to the inspiration of single people or organisations who were interested to do sex education for adults with learning/intellectual disabilities. Organisations like pro familia, AWO and Caritas finance projects, whether from own resources or project-money from special funds.

Pro familia has a national network of counselling offices, mostly in the bigger cities of the countries. They are specialised on family planning and sexual education and member of the IPPF. Most of the pro familia counselling offices in all Germany have sex- education offers for people with learning/ intellectual disabilities. Some of them also offer support for professional care systems and Parents of disabled people like Trainings, team counselling, information- evenings for parents, training for Teachers, etc.

Other organisation push projects here and there, but these are often reserved to some bigger city or limited in Time. Problem is, that not all the regions, especially rural areas have no such offers what so ever. Most of these offers are not financed by the German government.

Due to the last UN- convention for disabled people from 2009, also rectified by the German government, gave professional supporters support in argumentation why, in the stream of integrating disabled people to an independent way of life, government should support and pay for sex education to disabled people and their supporting systems.

We hope that in the future all people with special needs become the support in sex education they need, even when they live in the countryside!

## **3. Abuse and safeguarding of adults with learning/intellectual disabilities**

Due to the general lack of sexual education, the poor possibilities of defence, little knowledge about norms and values, lack of speech possibilities and lack of supporting systems for sexual abuse to people with learning/ intellectual disabilities, there is a big grey zone of sexual abuse, especially to women in Germany.

Slowly, care- organisations recognise the problem of sexual abuse and start organising systems where prevention of sexual abuse is integrated in the caring system. But until now, it is not a regular part of the work of organisations, again it is up to the initiatives of single persons.

Generally, the police is not schooled to handle people with learning/ intellectual disabilities when there is a suspect of sexual abuse. They know too little about the Intellectual and linguistic possibilities of these people. Often a case is not followed by a charge against a suspect. Caring professionals also often have no clear plan how to handle in cases of suspect on sexual abuse.

Often, in my sexual education groups of 7 women and 7 men, 6 of the women have been victims of sexual abuse. None of them have had a Therapy, because there are very little therapists that work with mentally disabled people!

#### **4. Current arrangements for sex education of adults with learning/intellectual disabilities**

Here I can only refer to the offerings of pro familia in our province, Northrhine Westfalen:

- Sexual counselling for people/couples with learning/ intellectual disabilities, their families, their teachers and professional supporters and caretaker-teams
- Sexual education offers for groups and single people with learning/ intellectual disabilities
- Courses for adult couples, flirt courses etc.
- Support in sex education for school classes
- Information days or evenings for parents
- Training courses in education centres for professional supporters
- Training for professional supporters
- Support for organisations who want to work out an institutional guideline
- Consultation hours in institutions

However, all of these offers are also made from our counselling- offices and some other institutions in other cities of the country too!

#### **5. Examples of current sex education for adults with learning/intellectual disabilities:**

a. Groups of people with learning/ intellectual disabilities.

Time: Varies, in my case most of the time 4 or 5 times 2-3 hours, 10 – 15 people. Possible themes:

- knowledge of your own body (with many visual materials)
- how to get a partner?
- What to do together?
- possibilities to have sex
- Sex and porn
- Sexual diseases
- Possibilities of contraception
- Questions and answers (mostly integrated in the workshop)
- Sexual abuse
- Men's/ woman's hour (separate themes with men and woman)

The themes vary a bit; I always make up the Themes with the people on the spot!

b. Training for professional supporters, themes:

- Norms, values and speech about sexuality in our society
- Sexual rights – UN- Convention
- Self-reflection on your own sexual education and biography
- general attitude in working with clients
- sexual development from children/ children with learning/ intellectual disabilities
- Discrepancy in the personal structure of people with learning/ intellectual disabilities
- Dependencies of adult people with learning/ intellectual disabilities
- How to start a conversation about sex- related themes with Clients
- Possibilities of sex education in daily work situations
- Sexual abuse
- Desire to have children
- Pornography
- Work with parents
- Sexual Helpers, prostitution (???)
- The importance of institutional guidelines
- Literature
- Support from Professionals

I Think, both education possibilities are equal important. Without good Sex education, people/couples with learning/ intellectual disabilities will have difficulties having a joyful sexual life, and professional supporters have to know how to support their clients where they need it!

Parents and professional supporters are the only lobby for people/couples with learning/ intellectual disabilities, we are the only ones who can make things better, let's do it!

## **Results of the interviews**

The Interviews with parents, caring persons and persons with mental disabilities did not give a clear picture. It seems that in Germany the situation regarding sexual education depends totally on the conditions of the family and the commitment of the institution.

The sexual education varied in an immense extend from "nothing" to "I could ask everything and received all answers I needed".

One of the extremes is a young man, living in a home of the "Lebenshilfe" in Wittenberge who regards himself as gay. He said that his mother accepted his homosexuality though he never received any information about becoming a man and his sexuality. His dream is living together with a boyfriend. He had his "coming out" during a visit in Hamburg. He was never interested in girls, never has had a boyfriend and the small city he is living in there is little chance to find one.

Quite the contrary represents Tanya, a young woman living at the "Lebenshilfe" in Northrhine-Westfalia. In her sexual education no questions were left open, she has a fiancée since many years, spends the nights in his flat and loves to have sex with him.

Contraception is realised by pill and condoms. They would like to marry but there is not enough money.

All the other interviewed persons with disabilities ranged between – in some families sex is still a taboo and the institutions are more or less motivated and capable to organise sexual education.

The problem is that the caring persons in the centres are mostly not trained in performing sexual education and the situation in the NGOs is different as well.

A very important NGO in this field in Germany is "profamilia", an organisation which offers partnership and family counselling as well as counselling in case of pregnancy.

In some areas of the country profamilia is very strong and has a close co-operation with the Lebenshilfe and other organisations for persons with disabilities but in other regions – specially on the country side and because of lack of trained staff – there is no or only weak co-operation.

The caring persons are aware of the problem and the lack of training and materials. They know that the use of internet for watching pornographic movies is high and – specially young men – are often masturbating. Some of them would appreciate if there was a possibility of receiving prescriptions for going to a prostitute. They think this would lower feelings and actions of aggression.

The caring persons would be happy as well if there was more material for sexual education and many of the interviewed persons with disabilities would appreciate seminars at their living or working places.

One important side effect of the the project and the interviews performed was that in the institutions the awareness of the importance of sexual education rised – they noticed that they should do more in this field.

The situation in the families varies a lot: from tabooing everything concerning sexual education and sexuality to an open and supporting atmosphere where everything seems possible.

Of course to talk with tabooing parents was not possible but e.g. to a very supporting mother (Misses P.) of a 24 years old young man with trisomie 21. The reported facts varied a bit between the mother and the son. He did not understand my question for masturbation (or he did not want to). His mother thinks he does

not know the word but I asked him more concrete. She confirmed that he learned something about that from a friend and he practises it the way that he is lying on the belly and moving that he ejaculates in his trousers. After that he seems to be more relaxed. She would like that her son could have the opportunity to learn more comfortable ways of masturbation because sometimes he hurted himself during this practise. She would like somebody could give him "a hand". The father does not regard that as one of his main responsibilities and when I asked the young man whom he would like to ask more about sexuality he said after some thinking: "My mom". In the interview I asked her if she could imagine to help her son literally to get in in case that he can have sex with a girl. She thought as well before she answered that she would. She said that sexualitiy has to be learned like eating and drinking and she would do a lot to make her son happy. I showed all my inteview partners an easy-read brochure from "CHANGE" ("Safe sex and contraception") which they all liked and even without knowing English understood. There should be more of that – e.g. on themes like puberty, homosexuality, how to please oneself etc. There should be material for different ages dependent on the capability of understanding.

Sexual miseuse seems to be a common fact – of the persons with disabilities among themselves and of caring persons (mostly male) mistreating persons with disabilities. There seems to be more misuse then thought and of course there is a broad zone of grey – specially in the field of caring. For example even washing a person with disability who cannot do it himself might be regarded as a pleasure or exitement of the caaring person. So it should be insured that it is done by two of them.

But even a good willing caring person might provoque feelings of missing estimation towards persons with disabilities in case that he or she is trying to stop a action of tenderness between two persons during worktime - it might be understood as a preventing act of sexuality in general.

So it is important that the caring persons are always clear and transparent in their interventions.