

# Sexuality Education for Persons with Impairments

- General Remarks
- Definitions
- Disabilities as Life Experiences:  
Influence on Sexuality, Partnership  
and Parenthood
- Sexuality Education
- Determination of Target Audience
- Definition of Tasks
- Actions to Be Taken
- Conclusions



Concept

# Sexuality Education for Persons with Impairments

German Federal Centre for Health Education (BZgA)  
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# Table of Contents

<b>1</b>	General Remarks	5
<b>2</b>	Definitions	7
	2.1 Sexual Health and Sexuality Education	7
	2.2 Sexuality and Sexuality Education	8
	2.3 Impairments, Disabilities and Sexuality Education	8
<b>3</b>	Disabilities as Life Experiences: Influence on Sexuality, Partnership and Parenthood	11
<b>4</b>	Sexuality Education	17
	4.1 Basic Assumptions	17
	4.2 Goals	19
<b>5</b>	Determination of Target Audience	21
	5.1 Statistical Basis	21
	5.2 Categorizations of Target Audience	23

5.3 Definition of Target Audience	24
5.4 Disseminators	24
<b>6</b> Definition of Tasks	27
<b>7</b> Actions to Be Taken	33
7.1 Communicative Actions	34
7.1.1 Mass Communication Actions	34
7.1.2 Personal Communication Actions	35
7.2 Quality Management	37
7.3 Research	37
7.4 Cooperation and Networking	38
<b>8</b> Conclusions	41



## General Remarks

Germany's Pregnancy and Family Assistance Act (SchKG) assigns the German Federal Centre for Health Education (BZgA) the legal mandate to provide the nation with information on sexuality education. Together with the individual federal states and in cooperation with family counseling institutions throughout the country, the BZgA has the task of preparing the corresponding concepts and materials necessary to this end. These serve to provide health provisions to both avoid and deal with pregnancy conflicts; they are adapted to the various target audiences. In addition, the BZgA is committed to providing informational materials on living with a handicapped or disabled child and the life of the handicapped, and to provide them to a broad public audience.

This official mandate has been extended by the provisions contained in the [UN Convention on the Rights of Persons with Disabilities](#), as ratified by German Parliament. Art. 23 of this UN Convention<sup>1</sup> provides for the right to

- free choice of marrying and starting a family
- free choice concerning the number of desired children
- access to age-appropriate sexuality-education information
- educational and other information concerning reproduction and family planning.

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1 Bundesministerium für Arbeit und Soziales (Ed.): Unser Weg in eine inklusive Gesellschaft: Der Nationale Aktionsplan der Bundesregierung zur Umsetzung der UN-Behindertenrechtskonvention. See in particular Appendix, p. 212. Available under [http://www.bmas.de/SharedDocs/Downloads/DE/PDF-Publikationen/a740-nationaler-aktionsplan-barrierefrei.pdf;jsessionid=AAF110EC4B02633EC26EAE3015407224?\\_\\_blob=publicationFile](http://www.bmas.de/SharedDocs/Downloads/DE/PDF-Publikationen/a740-nationaler-aktionsplan-barrierefrei.pdf;jsessionid=AAF110EC4B02633EC26EAE3015407224?__blob=publicationFile) [from September 2011, accessed 17 April 2014].

These rights, considered basic human rights, are emphasized in the [Action Plan of the German Government for the Implementation of the UN Convention on the Rights of Persons with Disabilities](#). There we read: “The German government supports the rights of persons with disabilities to marriage, partnership and sexuality.”<sup>2</sup>

Obligations stemming from these rights are implemented by the BZgA as part of its overall mandate. The basis for this may be found in the [Conceptual Framework on Sexuality Education](#) developed by the BZgA in cooperation with the individual German federal states.<sup>3</sup> In addition, together with the World Health Organization (WHO), the BZgA has developed [Standards for Sexuality Education in Europe](#), which specially emphasize that sexual rights are basic human rights in all human beings.<sup>4</sup>

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2 Bundesministerium für Arbeit und Soziales (Ed.): Unser Weg in eine inklusive Gesellschaft: Der Nationale Aktionsplan der Bundesregierung zur Umsetzung der UN-Behindertenrechtskonvention. P. 62. Available online under [http://www.bmas.de/SharedDocs/Downloads/DE/PDF-Publikationen/a740-nationaler-aktionsplan-barrierefrei.pdf?jsessionid=AAF110EC4B02633EC26EAE3015407224?\\_\\_blob=publicationFile](http://www.bmas.de/SharedDocs/Downloads/DE/PDF-Publikationen/a740-nationaler-aktionsplan-barrierefrei.pdf?jsessionid=AAF110EC4B02633EC26EAE3015407224?__blob=publicationFile) [from September 2011].

2 Bundeszentrale für gesundheitliche Aufklärung (BZgA) (Ed.) (2011): Rahmenkonzept zur Sexualaufklärung. 17th ed., Cologne.

4 Cf. Bundeszentrale für gesundheitliche Aufklärung (BZgA) (Ed.) (2011): Standards für die Sexualaufklärung in Europa. Rahmenkonzept für politische Entscheidungsträger, Bildungseinrichtungen, Gesundheitsbehörden, Expertinnen und Experten. Cologne, p. 20.



# Definitions

## 2.1 Sexual Health and Health Education

Based on a holistic concept of health that includes the mental and social background of individual well-being, sexual health is also an integral part of health.<sup>1</sup> “Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.”<sup>2</sup>

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1 This corresponds to the position of the WHO found in the following statement: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization (WHO) (2014): WHO Definition of Health. Available online under <http://www.who.int/about/definition/en/print.html> [Retrieved on 17 April 2015].

2 World Health Organization (WHO) (Ed.) (2006): Defining sexual health: Report of a technical consultation on sexual health 28-31 January 2002, Geneva. Geneva, p. 5. Available online under [http://www.who.int/reproductive-health/publications/sexual\\_health/defining\\_sh/en/](http://www.who.int/reproductive-health/publications/sexual_health/defining_sh/en/) [Retrieved on 17 April 2015].

Thus, as part of basic equal opportunity regarding health matters,<sup>3</sup> persons with impairments should enjoy the same opportunity to participate in holistic health education that has been adapted generally and specifically to the expressed needs of the target audience. Sexuality education is an integral part of health education; it fosters sexual health and thus serves the overall health of human beings.

## 2.2 Sexuality and Sexuality Education

The BZgA supports a broad understanding of the concept of sexuality. In this sense, sexuality is considered a basic existential need of all human beings. It is a central ingredient of personality development and personality identity. Sexuality comprises biological, emotional as well as psychosocial components. It is thus a central element in individual lifestyle and is experienced differently by individuals.

Correspondingly, it does not suffice to impart information on details concerning biological processes and techniques of contraception. Rather, holistic sexuality education has the goal of approaching people emotionally and respecting the various aspects involved in their relationships, lifestyles, life situations, values and mores as well as ethical involvements.

## 2.3 Impairments, Disabilities and Sexuality Education

The term “persons with disabilities” is defined in Article 1 of the UN Convention on the Rights of Persons with Disabilities as follows: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”<sup>4</sup> Thus, someone may be considered to have a disability with respect to sexuality when their physical, mental, intellectual

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3 „Chancengleichheit bezeichnet in modernen Gesellschaften das Recht auf eine gerechte Verteilung von Zugangs- und Lebenschancen. Gesundheitliche Chancengleichheit definiert dieses Recht gesundheitsbezogen, d. h. als Herstellung gleicher Chancen, gesund zu sein und gesund zu bleiben“ (Altgeld, Thomas (2011): Gesundheitliche Chancengleichheit. In: Bundeszentrale für gesundheitliche Aufklärung (BZgA) (Ed.) (2011): Leitbegriffe der Gesundheitsförderung und Prävention. Glossar zu Konzepten, Strategien und Methoden. Cologne, pp. 110-114, here p. 110).

4 See also Bundesbeauftragter der Bundesregierung für die Belange behinderter Menschen (Ed.) (2010): Die UN-Behindertenrechtskonvention: Übereinkommen über die Rechte von Menschen mit Behinderungen. Berlin, p. 12.

and/or sensory impairments confront them with barriers that put limitations on or completely hinder their sexual activity.

### Definitions Used in this Concept

- In this concept we speak of **disabilities** or persons with disabilities when sociocultural or social interests are present that lead to barriers for the affected persons and thus to disabilities.
- However, when **limitations** are involved (e.g., ambulation) which are inherent to a particular person or group of persons, then we speak of **impairments** (e.g., physical impairment) or of impaired persons.

Even when disabilities are viewed from this vantage point as cultural-social phenomena and are thus an integral part of human experience, under some circumstances medical diagnoses and the respective physical, mental, cognitive and/or sensory impairments may play a decisive role in the experience of sexuality. Thus, when designing holistic sexuality education for affected persons, the various aspects are of great importance. Holistic sexuality education for impaired persons is first and foremost general sexuality education that has been augmented with group-specific demands stemming from the context of the impairments as well as cultural/social disabilities.



Disabilities as Life Experiences

## Influence on Sexuality, Partnership and Parenthood

The ability of an impaired person to autonomously tend to their life, sexuality, family planning and parenthood depends on a number of very different prerequisites. Based on the idea that disabilities in the sense of the UN Convention reflect the life experiences of the impaired persons (cf. Chapter 2.3 above), there result a number of interactive circumstances that may severely limit the way impaired persons experience their sexuality and family planning.

### **Type and Severity of the Impairments**

Depending on the medical diagnosis – and parallel to that the type and severity of the impairment(s) – there may be major limitations (e.g., of bodily functions and/or communication) that have a significant influence on the realization and organization of social relationships – and thus of sexual experiences.

### **Gender Role Affiliation**

Impaired girls/women and boys/men repeatedly have the experience of being unable to fully experience and be experienced in their respective gender roles. Rather, they tend to be reduced to their role as disabled persons. This affects their self-awareness as well as their own experiences of sexuality.

### **Need for Assistance**

Impaired persons with a great need for assistance have only few, if any, times during which they are unobserved by others – times in which they can live out their own sexuality and have their own personal experiences. During puberty, when adolescents necessarily have a greater need for secret experiences, this can become a major problem.

### **Parents**

The parental home generally plays a major role in the sexuality education of children and adolescents. For many impaired persons the parents continue to be the most important persons in their lives beyond adolescence. Indeed, depending on the type and severity of the impairment(s), they may continue to live as adults with their parents, who are their constant caretakers. How parents deal with the sexuality of their impaired child can vary widely. Whereas some recognize the need of their child for own sexual experiences, foster this behavior and ensure proper sexuality education, others have difficulty dealing with this matter. In addition, the parents themselves may lack adequate information to ensure the proper sexuality education of their child. If the parents tend to overprotect their impaired child, this may lead to problematic or the complete absence of attempts to achieve independence. This makes it difficult for the persons with impairments to have their own experiences and to live out their sexuality. For this reason, the parents of an impaired child should receive considerable support in their endeavors.

## School

For many affected children and adolescents the school is the central place where they can enter into nonfamilial relationships. Sometimes in fact it is the only place they can have contact with peer groups, where the conversation often turns to matters of sexuality and where initial experiences can be made. Often such children and adolescents turn to their teachers as trusted persons to discuss such personal matters. On the one hand, the school has the official mandate to offer sexuality education and information, but experience shows that impaired children and adolescents do not receive adequate care in this regard. Besides receiving good teaching materials on sexuality education, school teachers need to be properly qualified to offer sexuality education that respects the special circumstances of the various forms of impairment.

## Institutional Living Arrangements for Impaired Persons

In most institutional settings matters concerning partnership and sexuality are difficult if not impossible. Thus, many impaired men and women fail to enjoy sufficient private and personal space, often having no room of their own. Most institutions are also not equipped to allow parents to live with their child or children.

Impaired persons living in such settings often have only limited or no ways of obtaining sexuality educational materials and suitable contraception of their own choice (e.g., because of the absence of internet access). The caretakers or employees of such institutions are often important contacts when it comes to sexuality education. But in order to provide good sexuality education and to properly react to the needs and concerns of the residents, they must be outfitted with the necessary skills.

## Living on Their Own

Most adult persons with impairments live independently on their own. They live either alone or in a relationship (with or without being married), with or without children. Their need for information concerning sexuality, contraception, parenthood and/or partnership can vary widely. The specific situation is a product of their type of impairment, age, educational status, present life situation, among other things.

### **Sheltered Workshops for the Disabled<sup>1</sup>**

For many impaired persons, in addition to the institutional home, the sheltered workshop is the only place they can experience the full range of social relationships. This includes of course sexual relationships. To meet the resulting needs, for example, with respect to sexuality education, the caretakers and employees at such workshops must be outfitted with the proper skills.

### **Legal Supervision**

Upon demand the guardianship court can assign adult persons with cognitive impairments someone else to be the legal supervision and their guardian for very specific areas. This person is often a member of the affected person's family (usually a parent). Where this is not the case, the court may appoint another, nonfamily member as legal guardian. Such situations often create uncertainties about the extent to which a guardian may intervene in the personal matters of the affected person, for example, concerning partnership and sexuality. To this end, information in the form of seminars of further education and informational materials are essential.

### **Sexual Orientation**

To date, homosexuality and bisexuality among girls/women and boy/men with impairments has not gained much attention. For example, support for affected lesbians and homosexual men (e.g., when coming out) is missing. On the contrary, they may become victims of both the general prejudices held against persons with impairments as well as those directed toward homosexuals. They may also be subjected to discrimination toward their homosexuality stemming from other persons with impairments. Thus, there is a need for informational materials specially prepared for the persons and groups who supply sexuality education to these persons.

### **Cultural Background**

Persons with impairments who have an immigrant background must cope with even further difficulties resulting from their impairment in combination with their cultural origins. With respect to their sexual activities, they are confronted with both the general discrimination addressed toward persons with impairments, but also with the prejudices stemming from their cultural background, while also being subject to the influences of their original culture. Such a convolution of circumstances as well

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<sup>1</sup> In contrast to the definitions set out in Section 2.3 above, in this concept we use the term "Sheltered Workshop for the Disabled" and not "Sheltered Workshop for Impaired Persons" since it is an established term.



as the difficulties encountered by persons with impairments from foreign cultures (e.g., divergent feelings of shame) may go unattended in the care of the disabled, for example, in residential care facilities. Special skills with respect toward sexuality education may often be necessary in order to meet the demands of persons with both impairments and an immigrant background.

In addition, there are overall social forces to consider which influence the sex life of impaired persons. For example, impaired persons are still subject to a number of discriminations concerning their sexuality and family planning. These may range from the statement that “the disabled have no sexuality” to the thought that “the mentally handicapped do not have their sexual drive under control.”

Even though sexuality today is in many respects widely discussed in the public forum, conversations with impaired persons concerning love, partnership and sexuality rarely take place. A number of various barriers have led to impaired persons having no or only limited ways of bringing their concerns and ideas on sexuality to the public’s attention.



# Sexuality Education

## 4.1 Basic Assumptions

Sexuality education should be understood as a holistic act, that is, it proceeds from the following basic assumptions in accordance with the needs of each specific group:<sup>1</sup>

- Sexuality education must meet the needs of the persons being addressed with respect to their age and developmental stage. It respects the biological, gender-specific, social and cultural background as well as the specific impairments and disabilities. Sexuality education must be adapted to the particular situation of impaired persons.
- Sexuality education derives from the demands inherently contained in human (sexual and reproductive) rights. With respect to impaired persons, the stipulations of the UN Convention on the Rights of Persons with Disabilities are given special consideration.<sup>2</sup>
- Sexuality education is based on a holistic concept describing human well-being, in particular health. With respect to impaired persons, special consideration is given to matters stemming from their impairment or disability.
- Sexuality education is oriented toward the clear equality of the sexes, the recognition of the diversity of humans and their right to self-determination. With respect

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1 Cf. Bundeszentrale für gesundheitliche Aufklärung (BZgA) (Ed.) (2011): Standards für die Sexualaufklärung in Europa. Rahmenkonzept für politische Entscheidungsträger, Bildungseinrichtungen, Gesundheitsbehörden, Expertinnen und Experten. Cologne, p. 31.

2 See Chapter 1

to impaired persons, this means that they should be perceived primarily in their social roles (which in turn result in part from their gender roles) and not with reference to their impairments.

- Sexuality education is oriented toward individual self-determination in choosing to consent to or reject physical and emotional proximity. This is particularly the case for impaired persons who are dependent on others.
- Sexuality education is a life-long process. Regardless of the type or severity of the impairment, this is also true for all impaired persons.
- Sexuality education can contribute to a strengthening of the overall equity and empathy in society by demanding respectful dealings among all citizens. With respect to impaired persons and their very diverse life circumstances, it can also contribute to eliminating prejudices.
- Sexuality education is based on state-of-the-art, scientifically based data. Any research done on sexuality education in impaired persons should inherently be interdisciplinary in nature.
- Sexuality education does not view persons with impairments from a deficit-oriented perspective, but rather is aligned to the strengths and abilities of affected persons.

Generally speaking, sexuality education should reflect the idea of life skills in order to correspond to the specific circumstances and needs of impaired persons.

## 4.2 Goals

Impairments can result in people experiencing only a limited range in their sexuality. The goal of sexuality education is to support people with impairments in accordance with their specific needs. It should enable them to have a sophisticated, self-determined (and responsible) relationship to their own sexuality. Sexuality education should be directed toward providing information as well as promoting motivation and communication. The challenge of designing sexuality education is to reach all persons with impairments, to give them the feeling of being addressed and cared for.

This, however, cannot succeed without the support of personal communication. Thus, the task is to provide anyone dealing with impaired persons with the ability to implement adapted sexuality education. Assistance should take the form of enabling them to feel comfortable with the theme of “sexuality and disability” in their everyday (and professional) life, and to support impaired persons by providing an open-minded, tolerant and emancipatory sexuality education.

In addition, the distribution of information to the broad public on the theme of “sexuality and disability” can enable the elimination of existing prejudices toward impaired persons.



# Definition of Target Audience

## 5.1 Statistical Basis

### Explanation of Statistics

The German Federal Statistics Office regularly prepares statistics concerning “severely disabled persons.”<sup>1</sup> However, these statistics do not provide information concerning the actual number of disabled persons in accordance with the definition of disability stated in the UN Convention on the Rights of Persons with Disabilities, but rather how many people have which medically diagnosable impairments. The reason for the impairment does not include cultural and social circumstances, but rather “among other things, congenital disabilities, diseases, accidents, injuries sustained as part of war, military or civilian service.”<sup>2</sup> Thus, the terminology employed for the statistical data does not correspond to the definitions spelled out in this concept.

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1 Statistisches Bundesamt (2014): Statistik der schwerbehinderten Menschen 2013 – Kurzbericht. Wiesbaden, p. 4. Available online at [https://www.destatis.de/DE/Publikationen/Thematisch/Gesundheit/BehinderteMenschen/SozialSchwerbehinderteKB5227101139004.pdf;jsessionid=57C3453FE6E51A90F0034EC0B1960C49.cae1?\\_\\_blob=publicationFile](https://www.destatis.de/DE/Publikationen/Thematisch/Gesundheit/BehinderteMenschen/SozialSchwerbehinderteKB5227101139004.pdf;jsessionid=57C3453FE6E51A90F0034EC0B1960C49.cae1?__blob=publicationFile) [retrieved on 17 April 2015]

2 Statistisches Bundesamt (2014): Statistik der schwerbehinderten Menschen 2013 – Kurzbericht. Wiesbaden, p. 4. Available online at [https://www.destatis.de/DE/Publikationen/Thematisch/Gesundheit/BehinderteMenschen/SozialSchwerbehinderteKB5227101139004.pdf;jsessionid=57C3453FE6E51A90F0034EC0B1960C49.cae1?\\_\\_blob=publicationFile](https://www.destatis.de/DE/Publikationen/Thematisch/Gesundheit/BehinderteMenschen/SozialSchwerbehinderteKB5227101139004.pdf;jsessionid=57C3453FE6E51A90F0034EC0B1960C49.cae1?__blob=publicationFile) [retrieved on 17 April 2015]

Because comprehensive data are missing encompassing the definition proposed in the UN Convention on the Rights of Persons with Disabilities, this concept must resort to the data collected by the German Federal Statistics Office in order to estimate the actual needs for sexuality education among impaired persons.

### Statistics

At the end of 2013 there were some 7.5 million persons registered in Germany as being severely disabled, corresponding to about 9.3% of the general population. The number of men in this group was 51% and thus slightly more than that of women. Statistically speaking, the number of impairments increases with increasing age.<sup>3</sup>

If we combine the various types of medically diagnosable impairments into groups, we get the following distribution of persons officially accredited as being severely disabled:

- Physical impairments 61.9%
- Impairments of inner organs or organ systems 24.8%
- Impairment of the function of arms and legs 13.9%
- Impairments of the spine and upper torso 12.0%
- Blindness or visual impairments 4.7%
- Deafness/hearing loss, equilibrium impairments or speech disorders 3.9%
- Mental or emotional impairments 11.5%
- Cerebral impairments 9.0%
- Not otherwise specified impairments 17.6%<sup>4</sup>

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3 Cf. Statistisches Bundesamt (2014): Statistik der schwerbehinderten Menschen 2013 – Kurzbericht. Wiesbaden, p. 5. Available online at [https://www.destatis.de/DE/Publikationen/Thematisch/Gesundheit/BehinderteMenschen/SozialSchwerbehinderteKB5227101139004.pdf;jsessionid=57C3453FE6E51A90F0034EC0B1960C49.cae1?\\_\\_blob=publicationFile](https://www.destatis.de/DE/Publikationen/Thematisch/Gesundheit/BehinderteMenschen/SozialSchwerbehinderteKB5227101139004.pdf;jsessionid=57C3453FE6E51A90F0034EC0B1960C49.cae1?__blob=publicationFile) [retrieved on 17 April 2015].

4 Cf. Statistisches Bundesamt (2014): Statistik der schwerbehinderten Menschen 2013 – Kurzbericht. Wiesbaden, p. 5. Available online [https://www.destatis.de/DE/Publikationen/Thematisch/Gesundheit/BehinderteMenschen/SozialSchwerbehinderteKB5227101139004.pdf;jsessionid=57C3453FE6E51A90F0034EC0B1960C49.cae1?\\_\\_blob=publicationFile](https://www.destatis.de/DE/Publikationen/Thematisch/Gesundheit/BehinderteMenschen/SozialSchwerbehinderteKB5227101139004.pdf;jsessionid=57C3453FE6E51A90F0034EC0B1960C49.cae1?__blob=publicationFile) [retrieved on 17 April 2015].



## 5.2 Categorizations of Target Audience

In light of the many different types of impairments possible, it would seem wise to first approach the matter of sexuality education with fewer categories. To this end, the following stipulations for special education priorities seem suitable:

- Learning and performance
- Speech
- Emotional and social development
- Mental development
- Physical and motoric development
- Hearing
- Vision<sup>5</sup>

When drawing up such distinctions in the target audience, however, it is not always possible in all cases to clearly delineate the various impairments. Some people are afflicted with combinations thereof. This factor must be kept in mind when drawing up plans for sexuality education. Further, persons with impairments do not comprise a homogeneous group; rather, preparation of a list of possible target audiences must differentiate based on the following characteristics:

- Age
- Sex
- Type of impairment
- Social background
- Cultural background
- Sexual orientation
- Sexual identity and
- Present life circumstances.

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<sup>5</sup> Cf. Sekretariat der ständigen Konferenz der Kultusminister der Länder in der Bundesrepublik Deutschland (1994): Empfehlungen zur sonderpädagogischen Förderung in den Schulen in der Bundesrepublik Deutschland. Beschluß der Kultusministerkonferenz vom 06.05.1994, pp. 10 ff. Available online at [http://www.kmk.org/leadadmin/veroeffentlichungen\\_beschluesse/1994/1994\\_05\\_06-Empfehl-Sonderpaedagogische-Foerderung.pdf](http://www.kmk.org/leadadmin/veroeffentlichungen_beschluesse/1994/1994_05_06-Empfehl-Sonderpaedagogische-Foerderung.pdf) [retrieved on 17 April 2015].

## 5.3 Definition of Target Audience

Because persons with cognitive impairments often have considerable difficulty, or find it impossible, to procure informational materials on sexuality education, and because they are sometimes unable to fully understand the materials presented to them, it seems appropriate to specially consider this group of cognitively impaired persons in their varied life circumstances. This, however, should not imply that persons with other impairments should not receive our full attention.

## 5.4 Disseminators

Persons with impairments (often) are afflicted such that their sex life is restricted as well, thus also impeding or wholly preventing their sexuality education. Whether and how best to provide sexuality education to this group and in what manner they can experience a fulfilled sex life often depends on persons or groups in their immediate social surroundings. These comprise, among others,

- Parents and other family members
- Personnel in nursery school
- Teachers
- Personnel in residential care facilities
- Personnel in sheltered workshops
- Personal assistants
- Legal guardians
- Personnel in prenatal counseling centers
- Physicians
- Midwives
- Personnel in family counseling centers
- Church personnel
- Other persons with impairments

Especially the role of other persons with impairments in their support of this group should be carefully considered. Both they and the respective interest groups play an important role in the sense of peer support<sup>6</sup> because of the counseling and support they can offer other persons with impairments.

All of these groups function as disseminators in the spread of sexuality education among persons with impairments. Thus, they and the respective interest group organizations they are active in form important contacts for ensuring the successful implementation of sexuality education.

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6 Cf. Miles-Paul, Ottmar (1992): Wir sind nicht mehr aufzuhalten – Behinderte auf dem Weg zur Selbstbestimmung: Beratung von Behinderten durch Behinderte - Peer Support: Vergleich zwischen den USA und der BRD. Munich: AG Spak.



## Definition of Tasks

One of the basic tasks of sexuality education lies in creating an atmosphere that is conducive to openly speaking about the subjects of sexuality and sexuality education. This is especially true for the entire area of “disability and sexuality,” which is subject to a number of prejudices.

The concrete tasks involved in the sexuality education of persons with impairments depend on the respective target audience in question<sup>1</sup> as well as the respective goals set for this group. It is in any case important that ways be found to promote sexual self-determination among persons with impairments.

This includes conveying the contents of the various themes of sexuality education both generally and with particular reference to the aspects of “impairments and disabilities.” If necessary, the way this information is presented and conveyed must be adapted to the specific communication and learning challenges present in the respective groups of persons with impairments.

The following list does not make claim to completeness but is rather in need of continual updating. However, it may serve to point out the basic contents of sexuality education. Regardless of the type of impairment or disability, the following list must be viewed and conveyed both in its totality and specifically with respect to the necessities of the respective target audience of persons with impairments.

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<sup>1</sup> See Chapter 5.2 for a list of the factors that define the respective target audience.

## Information Brokerage, Behavioral Motivation and Skills Promotion – Relevant Topics

### Acquiring Knowledge Through Information Brokerage

#### **Sexual Development**

- Physical-biological development
- Courses of sexual development
- Emotional coping with physical and mental changes in the various phases of life
- Physical and mental development against the backdrop of the various forms of impairment

#### **Sexuality and Fertility**

- Fertility and fecundity
- Pregnancy and development up to birth
- Sexual behavior in various phases of life
- Contraception and contraceptive methods, their proper use and procurement
- Access to contraception
- Counseling services on sexuality, contraception and pregnancy
- Family planning
- Pregnancy conflicts, e.g., the entire matter of prenatal diagnostics

### **Sexuality and Health**

- Body hygiene
- Sexually transmitted diseases (STIs, HIV), risks, transmission and protection
- Successful sexuality and sexual relationships, masturbation
- Relationship between positive sexual experiences and physical and mental well-being

### **Sexuality and Lifestyles**

- Identity and sexual orientation (heterosexual, homosexual, transsexual, bisexual), cultural identity, gender roles, dating, partnership
- Variations in lifestyles and life designs
- Family planning
- Social determinants of sexuality
- Various cultural values and sexual value systems as found in the parental home, school and other place of socialization
- Sex-specific differences in norms and moral attitudes
- Taboos and violence
- Media and sexuality, communication on the subjects of sexuality, language and sexuality

## Acquiring Knowledge Through Behavioral Motivation

### **Sexual Development**

- Dealing with both the physical and mental changes that take place in the various phases of life
- Becoming aware of one's own corporeality
- Accepting one's own physical appearance
- Developing one's own sexual identity and sensuality
- Sexuality and lifestyle

### **Sexuality and Lifestyle**

- Taking up relationships outside the family
- Establishing independent relationships
- Dating and partnership

### **Social Discourse on Sexuality**

- Becoming aware of the role and influence of the media
- Becoming aware of the facts of fertility, fecundity and means of family planning
- Experiences of power and powerlessness



## Acquiring New Behaviors Through Skills Promotion

### Sexual Development

- Coping with reactions in one's immediate environment to physical, mental and emotional changes
- Developing one's own identity

### Sexuality and Fertility

- Dealing with the themes of family planning and parenting (role of mother and father), also by working through the ambivalences of one's own experiences with parents
- Unwanted childlessness
- Developing the ability to communicate in a partnership about the themes of contraception and the desire to have children
- Developing ways to actively seek out assistance
- Strengthening self-awareness when coping with and dealing with conflicts
- Developing the ability to deal with and act upon conflicts with both one's institutional and personal environment

### Sexuality and Lifestyle

- Developing the ability to communicate and act on subjects such as contraception, partnership, family planning, sexuality, protection against STIs, HIV, etc.
- Dealing constructively in a relationship with conflicts and seeking solutions to problems
- Redefining one's relationship to the social environment
- Experiencing one's own body and reacting to closeness and affection
- Establishing one's own value system with respect to sexuality, friendship, partnership, family planning and love
- Developing the ability to deal with conflicts stemming from the ramifications of sexual interactions



## Actions to Be Taken

The actions to be taken to ensure sexuality education generally correspond to the principles of health promotion. They are thus not directive in nature, but rather serve to strengthen individual skills. They are also evidence-based, that is, they conform to the state of the art of the research in this field. They reflect the fact that sexuality education is concerned with sensitive and taboo-laden matters as well as dealing directly with personal and intimate areas of life. Generally speaking, actions of sexuality education are not limited to providing information, but also serve to promote motivation and skills. These actions must also be adapted to the respective target audience. That is, they should be:

- Age appropriate
- Sex appropriate
- Impairment appropriate
- Level of education appropriate
- Culture appropriate
- Directed toward the needs of the various types of sexual orientations

The various actions are conceptually related; they are linked by the principle of holistic sexuality education and thus complement each other.

## 7.1 Communicative Actions

Generally speaking, we distinguish between mass communication and personal communication actions. Because of the different reach these two types have, they are located on different levels.

### 7.1.1 Mass Communication Actions

Actions of mass communication – examples are print media, audiovisual media and the internet – are appropriate for making others aware of certain themes, for distributing basic information and for stimulating discussion about a particular topic. In this way, persons with impairments as well as their social environment can be stimulated to deal with the subject of sexuality (and disabilities). Moreover, they can contribute to reducing the number of public prejudices toward persons with impairments and their sexuality.

Persons with impairments can generally use the same media as persons without impairments. However, the concerns of persons with impairments, particularly with respect to the subject of sexuality, are not well covered by the various forms of media. In addition, the individual means of accessing this information and the user behavior of disabled persons can vary widely.

Various different media may be employed depending on the type and severity of the impairments, the educational level and the respective life situations. For this reason, there must be an abundance of media to ensure that the differentiated information transfer corresponds to the respective needs of persons with impairments (easy language, Braille, sign language, etc.). Examples of such suitable media are as follows:

- Brochures
- Internet
- Film
- Social media

Because of the broad range of needs among persons with impairments, both the thematic content of sexuality education as well as the pertinent media employed must be adapted to the respective target audience. Thus, the media chosen should be appropriate to both the impairment and the age group. Subjects should be presented not only for all groups, but also differentiated according to the respective group. This is possible, for example, by preparing brochures in which the concerns of the respective target audience are treated which stem from the peculiarities of particular forms of impairment.

### 7.1.2 Personal Communication Actions

Personal communication actions are communications in dialogue form. Personal communication is best suited to discussing themes with individuals or groups of individuals and fostering thought processes among them. Individualized communication can be adapted to the special concerns and questions of the persons present and react to personal experiences and life circumstances. As part of an empowerment strategy it can also raise the level of autonomy and self-determination among persons with impairments.

Personal communication plays a central role for persons with impairments particularly in light of their impairment (e.g., in communicating). This is important not only in reproductive and family counseling centers, but also plays a major role in the offers extended in other settings (e.g., in residential care facilities) to persons with impairments.

Schools are important places for sexuality education – whether we are dealing with the sexuality education of adolescents or of young adults with impairments.<sup>1</sup> The mandated sexuality education in the curricula of the individual federal states in Germany is carried out by teachers, supported in part by specialists who have received special training in sexuality education.

Personal sexuality education needs local, well-qualified disseminators to assume these tasks. Not only must they possess the necessary expert knowledge, they must also

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<sup>1</sup> Cf. Bundeszentrale für gesundheitliche Aufklärung (BZgA) (Ed.) (2013): *Jugendsexualität und Behinderung: Ergebnisse einer Befragung an Förderschulen in Sachsen* von Sabine Wienholz, Anja Seidel, Marion Michel, Martina Müller. Unter Mitwirkung von Monika Häubler-Sczepan, Christina Schiller. Cologne, pp. 75 f.

have at their disposal the requisite communication skills, such as conversation techniques and didactic skills. Moreover, they must have positive personal characteristics such as empathy, sensitivity, perceptivity, and the ability to make contact and deal with conflicts – all of which are important in engaging with persons with impairments and supporting their dealings with love, partnership and sexuality. Special attention must be paid to persons with impairments who, in the sense of peer support, themselves act as disseminators within their respective group. Their own experiences as persons with disabilities can often provide new ways of reaching other persons with impairments.

Disseminators are dependent on the availability of good qualification measures. In the focus of such measures should lie, first, the conveyance of information and, second, the strengthening of communication and conflict skills. This can best be achieved by creating a comprehensive and broad access to training as well as continuing and further education. This can be done as part of professional training directed toward working with persons with impairments or in special courses on sexuality education among persons with impairments.

Moreover, concepts that reflect the state of the art in scientific research, applied practices and existing sexuality-education materials will have a positive effect on the resulting educational offers. A further cornerstone of continuing qualification lies in long-term exchanges of information and experiences and the networking of both organizations and individuals who are concerned with the theme of “sexuality education for persons with impairments.”<sup>2</sup>

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2 See also Chapter 7.4 below.

## 7.2 Quality Management

High-quality sexuality education is based on practices that have a proven track record, such as scientific surveys and evaluations. These practices must reflect the various types of target audience, that is, they must be adapted to the different forms of disability (e.g., in the type of communication chosen) and the overall life circumstances of the persons being studied. Generally speaking persons with impairments should be viewed and involved as “experts of their own accord” with respect to both research and evaluation.

Quality management also includes the evaluation of media and existing measures, drawing up market overviews regarding the national media and existing measures, the joint development of recommendations on indications and standards as well as their dissemination in training as well as continuing and further education. Persons directly involved in sexuality education play a special role here.

## 7.3 Research

Although the theme of “sexuality and disability” has played a greater role in various research areas in the recent past, resulting in a great number of scientific contributions, the available empirical data, for example, concerning the sexual behavior of persons with impairments in various life situations, remain incomplete. Moreover, much information is still missing regarding sexuality education among persons with impairments. For example, empirical studies have failed to address the following themes:

- The situation of girls with impairments and the sexual behavior of women with impairments
- The situation of boys with impairments and the sexual behavior of men with impairments
- The situation of lesbians and gay men with impairments with respect to partnership, family planning and sexuality
- The situation of persons with impairments from an immigrant background with respect to partnership, family planning and sexuality

- The vantage point of persons with cognitive impairments toward partnership, family planning and sexuality
- How sexuality is treated in residential care facilities for persons with impairments
- The implementation of the mandate to teach sexuality education in both special and mainstream schools
- Sexuality education of children and adolescents with impairments in the family
- How persons with a high need for assistance experience sexuality
- Sexuality education with special consideration of the respective impairment, sexual orientation and cultural background
- Relevance of (mass) media in the sexuality education of persons with impairments

In light of the incomplete database, it is presently not possible to provide exhaustive information on the situation of persons with impairments. Corresponding scientific studies are necessary.

## 7.4 Cooperation and Networking

Developing and maintaining cooperative structures between different organizations and individuals concerned with the sexuality education of persons with impairments is absolutely necessary. Against the backdrop of the many different circumstances and environments of persons with impairments, there is a great need for networked communication structures that enable the respective target audience to be reached with the proper type of sexuality education.

To this end, the cooperation of the federal states and the providers of family counseling centers mentioned expressly in the pertinent laws is necessary as well as that of the other protagonists in order to ensure access to persons with impairments. The following partners from various levels of involvement should be included in such cooperative efforts:

- Self-help organizations of persons with impairments
- Parents' organizations



- Organizations of legal guardians
- Residential care advisory boards
- Management of the relevant residential facilities
- Employees of the relevant facilities
- Residential care managers
- Teachers
- Sheltered workshops
- (Personal) Assistants
- Counseling services for persons with impairments
- Sexuality-education counseling services
- Physicians' organizations
- Institutions of continuing and further education
- Political advocacy groups
- Churches (as providers)
- Welfare organizations

In order to ensure proper sexuality education, these institutions and organizations should be networked for the purpose of establishing personal communication measures at both the regional and local level. Such cooperative measures at the national level should be expanded to include the regular exchange of information and experiences at the international level.



## Conclusions

Any form of support directed toward the establishment of self-determined sexuality and family planning of persons with impairments demands the full recognition of the individuality and autonomy of persons with impairments – as well as self-reflection with regard to one's own sexuality. With respect to sexuality education this means that

- People with impairments should not be viewed as a homogeneous group.
- Disability itself should not be treated as a special theme, but as a cross-sectional topic from sexuality education.

Seen from this vantage point, sexuality education is directed toward respecting the variations in human life – present both in people and their life circumstances – and approaching the themes that result from these variations. This also includes the theme of sexual violence and abuse: Proper sexuality education is always also a contribution to the prevention of sexual violence.

Correspondingly, attention should be directed toward the following characteristics:

- Age
- Sex
- Social background
- Cultural background
- Sexual orientation and
- Present life circumstances

In situations involving persons with impairments, in the end the goal is to enable people to develop a responsible, healthy and self-determined approach to sexuality and family planning in the broadest sense possible.

The German Federal Centre for Health Education (BZgA) adheres to these principles. This concept and the tasks emerging from it in the future serve to improve the lot of persons with impairments. This is especially apparent in the informational materials and the media appearances as well as in the research and evaluation of sexuality education it produces or sponsors.

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Executive Director: Dr. med. Heidrun Thaiss

Maarweg 149–161

D-50825 Köln

Phone: +49 221 8992-0

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[www.sexualaufklaerung.de](http://www.sexualaufklaerung.de)

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Dr. Karsten Exner, BZgA

Angelika Hessling, BZgA

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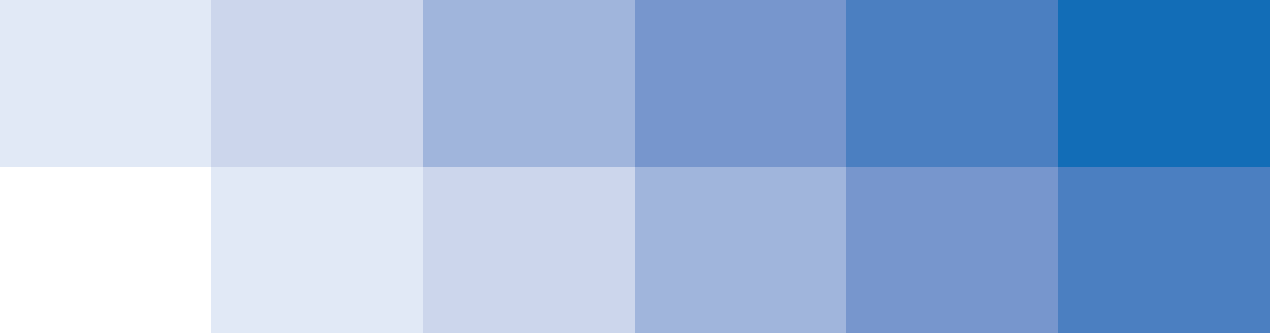
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