



Sexuality and Disability

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When we first discussed the issue of “sexuality and disability” in the FORUM series (issue 2/3-2001), the Editorial discussed “admitting what you don’t know”: today the range of this issue remains extensive. In addition to the central and long-term issue of self-determined sexuality, the rights and wrongs of “sexual assistance” – a major issue at that time – were also discussed.

We are therefore extremely pleased to re-examine the issue of “sexuality and disability”, and to look at new themes, again discussed by excellent authors.

Sexuality as a human right – Ralf Specht provides an overview of recent discussions in academia and the prospects of a sex-positive future for everyone.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is viewed by many professionals in this field as a milestone in the history of the struggle for the self-determination of sexuality. It came into force in Germany in March 2009 and, for the first time, considers the issue of disability policy from the human rights perspective. Sigrid Arnade provides an extensive report on the content and significance of the UNCRPD.

The lawyer, Julia Zinsmeister, examines the law and legal reality with regard to sexual self-determination in assisted living facilities. Her article delineates the legal aspects in a clear and comprehensible way, applying these rigorously to the practical situation; this also involves consideration of structural problems. She investigates the extent to which the existing right to privacy is an applicable prerequisite for self-determined relationships.

Martina Puschke reports on the higher self-esteem of disabled women, their attitude towards sexuality and sexual assistance, their fight against sexual violence and other issues.

Many of our authors refer to the work of the self-help association “Mensch zuerst – Netzwerk People First Deutschland e.V.” This organisation is regularly mentioned in connection with the issue of “plain language” and the general use of language that people with learning difficulties can identify with. Stefan Göthling is Secretary of the association and has defined the tasks and duties of the association clearly and comprehensively (this is to be welcomed, and not only by the translators and copy-editors of this issue).

Aiha Zemp from Basel has focused on the prevalence and causes of sexual violence: according to international studies, women with disabilities are subject to this violence twice as often as non-disabled women.

The article by Beate Martin looks at concepts and successes in the world of continuing professional development (CPD) within the context of care for persons with disabilities. Sigrid Weiser from pro familia, the leading German NGO for sexual and reproductive rights, writes on the many years of commitment of the organisation to the area of sexuality and disability.

Finally, we have added a new section “Projects”: one-page presentations of the reality of existing practice: “In Sachen Liebe unterwegs” [On the road. Talking about love], based in the AWO advisory centre in Lore-Agnes-Haus in Essen, and “Liebe, Lust & Frust” [Love, desire and frustration] from Lebenshilfe Berlin, “Eigenwillig” [Independent], a project from the Familienplanungszentrum in Hamburg and “Liebe, Sex und Drumherum” [Love, sex and all that] from adult education services in Hamburg.

The editors of this issue can be contacted at the address below. We are always very happy to receive your proposals for publications, projects, conferences, etc. for the Infotheque section.

The editors

The right to sexuality for persons with disabilities¹

There has been a great deal of progress in the humanisation of the living conditions of persons with disabilities in recent decades; the issue of sexuality is no longer taboo for many institutions and services. Nevertheless, if sexuality for persons with disabilities is to be viewed as “normal”, then further efforts and a change in attitude to the right to sexuality and reproduction for persons with disabilities are required. This article reviews historical and current developments and examines what is required to create a sex-positive future.

From exclusion to normalisation

Until the 1970s – that is, up to forty years ago – persons with disabilities were not present in everyday life. This was due to the fact that they usually did not live independently and often spent their entire lives in large institutions or clinics. In these large institutions, persons with disabilities were perceived as patients. Basic care was provided primarily by doctors and care staff. Special needs support simply did not exist and self-determination was just not possible. Disabled people were excluded from society, often living in inhumane conditions.

The issue of sexuality was awarded even less attention. It was assumed that in the area of sexuality and relationships, persons with disabilities had fewer needs than, or, at best, needs that were different from, those of persons without disabilities. Furthermore it was presumed that genital sexuality and participating in relationships had no relevance due to physical, mental or intellectual impairment. Sexuality was a taboo subject, at least when communicating with the outside world, and sexual needs and expression were in effect prevented in institutions providing care for persons with disabilities. Given the reality of the living conditions of most men and women with disabilities, this was not difficult: shared

rooms, strict separation of men and women, physical immobilisation and pharmacological sedation and a monotone, unchanging daily routine lacking in stimulation were all typical of the restrictive structures that defined daily life in such institutions.

Thanks to media reports, publications by specialists and especially due to the greater number of awareness-raising activities carried out by a range of self-help and advocacy groups, the public became more aware of these lamentable conditions. Thus in the 1980s and 1990s, living conditions improved substantially. From the legal standpoint, it was above all the Custodianship Law [Betreuungsgesetz] of 1992 and the 1994 amendment to Article 3 of the Basic Law of Germany, which underlined the “normality” of persons with disabilities and their needs and wishes and supported the efforts of many activists and associations. This “normalisation principle” (THIMM 2008) helped to change the perception of persons with disabilities and the way they were supported. The most significant realisation was that persons with disabilities do not differ to any great extent from persons without disabilities, but rather in their capacity to meet their own needs.

Normalisation was expressed by the way that persons with disabilities began to receive more support, instead of being merely looked after. The same institutions continued to be responsible for care and support; however these underwent radical change. Large single-sex care homes were replaced by mixed-sex residential groups and six-bed dormitories and shared rooms were replaced by double rooms. Patients were treated as clients and medical treatment and care were replaced by pedagogical support.

The area of sexuality was included in the normalisation phase, albeit at a much slower rate of change. In the 1980s, sexuality became a subject of academic discourse; the need for action became ever more evident. The work of Professor JOACHIM WALTER was particularly important in this regard. In addition to his own research, he also collated information on sexuality education in German-speaking countries and made this information available to other experts (WALTER 2005).²

¹ The article discusses persons with disabilities. Given the range of differences in the type and degree of disability as well as the range and diversity of the living conditions of disabled people, it has been necessary to restrict our focus. Thus the following observations deal with adults living independently as well as with persons in assisted independent living or inpatient assisted living situations. Today, the terms “learners with special needs” or “intellectually disabled” are often used to describe these people. Many of the observations also apply to persons with physical disabilities and sensory disabilities; some also apply to persons with mental health disorders.

² In a previous issue of FORUM (2/3-2001), JOACHIM WALTER wrote a comprehensive article on the topic of disability: “Selbstbestimmte Sexualität als Menschenrecht – eine Selbstverständlichkeit auch für Menschen mit Beeinträchtigungen” [Self-determined sexuality as a human right – a matter of course for everyone, even people with impairments]. The issue is no longer in print but can be downloaded at: www.forum.sexualaufklaerung.de (editors’ note)

Furthermore, studies, especially those published since the middle of the 1990s, have documented an issue that was previously almost completely ignored: the fact that persons with disabilities, contrary to previous assumptions, were more often subject to sexual assault than persons without disabilities (ZEMP 1996, 1997) and became pregnant more often than previously assumed (PIXA-KETTNER 1996). According to the results of the studies, most pregnancies were not planned but instead were the result of non-existent sexuality education and sometimes the result of sexual abuse.

The knowledge gained from these academic studies was accompanied by the gradual removal of taboos surrounding sexuality in the institutional setting. Information on sexuality education was added to pedagogical support services in an increasing number of institutions. Following Scandinavian and Dutch models, German institutions provided more support for relationships between disabled people, for example, by creating a diverse range of residential models like smaller residential groups or flats for couples. In order to provide guidance for service providers for persons with disabilities, and guidelines on the issues of relationships, sexuality and dealing with sexual abuse, sexuality education strategies were developed and successfully trialled in some institutions. The issue of sexuality education was awarded more importance in schools and residential groups. Nevertheless, even today, only a small number of teachers and committed staff make use of the (few) suitable materials for sexuality education or attend training programmes.

Table 1 summarises the most important differences between the exclusion and normalisation approaches.

The steps leading from exclusion to normalisation have now been taken in most institutions providing services for persons with disabilities. However this does not apply to the issue of sexuality. The mistakes of the past and the treatment of sexuality as a taboo subject are still making their presence felt. Establishing procedures for dealing with sexuality within the framework of inpatient assisted living and assisted independent living has proved to be difficult and time-consuming.

It has not been possible to create uniform standards. Some institutions have only recently begun to view sexuality as an issue of concern and to provide support for sexuality education. Other institutions, for their part, have been providing sexuality education as a core focus of their services for many years. These deliver sexuality education programmes for institutional residents at regular intervals and provide guidelines on dealing with sexual assault. With regard to the institutional care of persons with disabilities in general, unfortunately, in practice sexuality is still not considered to be a normal and self-evident part of people’s lives. Yet some pioneers are currently working to remove existing taboos concerning issues like appropriate sexual assistance or positive support for persons with disabilities wishing to have a family.

“Normalisation” in the area of sexuality is an ongoing process. As the following observations illustrate however, normalisation is not the only response to the challenges faced

From normalisation to integration

The main focus of supportive work in the normalisation phase was to provide help and advice towards achieving normality. Yet this approach was based around the deficits

Tab. 1	
From exclusion to normalisation	
Exclusion	Normalisation
Single-sex living spaces in large institutions	Reduction in size and diversification of institutions
Medical treatment and care	Pedagogical support towards normality
Patient	Client
Basic care	Adaptation to standard provision of care
↓	↓
Sexuality	Sexuality
Taboo	Removal of taboos
Sexuality as problem	Sexuality as an issue of concern
Denial of sexual needs	Recognition of sexual needs

that shaped special needs education well into the 1990s: focusing on the limited cognitive abilities of persons with learning difficulties and the limited motor skills of persons with physical disabilities. The logic of this approach was that persons with disabilities ultimately could only participate in society to a limited extent.

A paradigm change has now taken place. The skills-focused approach to disability has become more and more commonplace; this emphasises society’s responsibility for creating the degree of disability (ARNADE 2009).³ According to this approach, individual disability is especially restrictive in a society that is not focused on integration. Therefore, supportive work pays particular attention to removing physical and social barriers and providing disabled people with equal opportunities to plan and live their lives as they see fit.

This approach is now enshrined in law. German Social Security Code (IX) [Sozialgesetzbuch IX], which came into force in 2001 and deals with the rehabilitation and participation of persons with disabilities, makes explicit the self-determination and participation of persons with disabilities. The General Act on Equal Treatment [Allgemeine Gleichstellungsgesetz, AGG], valid since August 2006, makes reference to the legal right to a “personal budget” (as of 2007) and above all it is the UN Convention on the Rights of Persons with Disabilities (UNCRPD), which came into force in March 2009 in Germany, that focuses on these issues.⁴

³ The definition of the World Health Organisation (WHO) is now authoritative. According to this definition, disability is considered as a restriction of a person’s economic and social participation in everyday life, and is created by the interaction between biological-medical disorders or functional limitations, restricted employment opportunities and unfavourable environmental factors. Environmental factors include both physical barriers and social factors, like kerbstones or non-accessible websites, as well as prejudices and marginalisation mechanisms in the labour market.

⁴ The article by JULIA ZINSMEISTER delineates legal aspects with regard to sexual self-determination; STIGRID ARNADE, also in this issue, examines the innovative potential of the UNCRPD.

Tab. 2

From normalisation to integration	
Normalisation	Integration
Reduction in size and diversification of institutions	Diversification of services
Pedagogical support towards normality	Support in carrying out own plans and goals
Client	Citizen
Adaptation to standard provision of care	Highest level of self-determination
↓	↓
Sexuality	Sexuality
Removal of taboos	Reinforcement
Sexuality as an issue of concern	Sexuality as a right
Recognition of sexual needs	Individualisation of sexual needs

This new approach to disability has, at least in part, had an effect on the lives of many persons with disabilities. For some years, services and institutions providing assisted independent living and inpatient assisted living for persons with disabilities have undergone an unprecedented process of modernisation and professionalisation (SPECHT 2008). New academic research and legal guidelines have been implemented. In this context, important concepts include promoting independent living and local community integration.⁵ Promoting independent living means that more opportunities for assisted independent living become available, thus providing an alternative and additional option to the current 24-hour care provided in assisted living institutions. Local community integration has the goal of creating diverse care services in the community for everyone and has been successfully established in services for young people, for example.

Table 2 summaries the main differences between the normalisation and integration approaches.

5 For those wishing to learn more, BECK/FRANZ (2007) provides an overview of new approaches and concepts.

6 For more on the term "plain language", see STEFAN GOETHLING's article in this issue (editors' note).

7 The articles by BEATE MARTIN and SVEN NEUMANN in this issue provide more information on continuing professional development in the field of sexuality education. The practical guide "Liebe(r) selbstbestimmt" [Love and self-determination, by and for ourselves] (AWO 2006), produced mainly by persons with disabilities from the organisation Mensch zuerst – Netzwerk People First Deutschland e.V., also deals with this issue (cf. STEFAN GOETHLING's article).

Building blocks for innovative sexuality education

What does the trend towards modernisation mean for sexuality and for the provision of sexuality education services for persons with disabilities? What sexuality education services can contribute to ensuring the statutory right to choice and to equal participation in society as well as the right to self-advocacy and co-determination in everyday life? A selection of current approaches will be presented in the following section.

Sexuality education (from the very beginning)

A basic knowledge of sexuality and bodily functions are required for self-determined sexuality. People with learning difficulties in particular often have very little knowledge of sexual matters, even as adults. Often, issues that arise during physical and sexual development are not explained or discussed. The link between inadequate knowledge and understanding of the body and unusual sexual behaviour is evident in certain cases. Sexual or physical processes can be threatening to people with disabilities, over the long-term or even during their entire lives.

Learning about the body and sexuality should be recognised as a basic human right and be implemented as such. This also includes the provision of information on respecting different sexual orientations, on sexual abuse and on the right to reproduce. Relevant educational programmes should be available for persons with disabilities throughout the course of their lives. Provision to date has been patchy and poorly coordinated.

As is also the case with persons without disabilities, education on bodily functions and sexuality can be provided in a range of different forms: in one-to-one discussions, via planned activities like women's groups in inpatient assisted living institutions watching films together, as part of teaching in schools or through the provision of books and other media, to name only a few. The content and form of this educational provision should be based on the experiences of the persons receiving support. Equally, the type and degree of disability must be taken into consideration. The following principles have proven to be useful:

- simplicity (e.g. using plain language),⁶
- attractiveness to learners (e.g. using games or similar methods),
- multisensory methods (e.g. using creativity),
- repetition (e.g. providing regular opportunities for discussion),
- ease of understanding (e.g. using visual media and models),
- hands-on methods (e.g. using objects for tactile learning).

Contrary to popular fears that dealing with the topic of sexuality would only "give people ideas", sexuality education programmes to date have had the opposite effect.⁷ Becoming more aware of yourself and your own wishes and needs can help you to differentiate between your own needs and those of other people and create a solid basis for recognising the difference between realistic and utopian wishes. In this respect, sexuality education also plays a significant role in preventing sexual violence.

Furthermore, there is a lack of suitable information on sexual issues; many institutions and services are not aware that materials exist or cannot access them. With regard to

persons with disabilities, some materials in plain language have recently been published, produced in collaboration with the persons concerned. However these are not well known.⁸ Informative materials must also be adapted to meet the needs of different disabilities, that is, should be available in Braille or in an aural medium. It is therefore important to be aware of the issue of accessibility.

Providing specialised training and qualifications for support systems

The reinforcement of the issues of sexuality and disability must be accompanied by increased professionalisation of support systems. Sexuality education cannot be organised as an “optional extra”. The success of such sexuality education initiatives – much more than in the case of people without disabilities – depends on the way they are taught. For example, when talking about sexual matters in a discussion on sexuality education, when providing advice, or when selecting a suitable methodology for a sexuality education project. Professional skills are required from the providers of sexuality education in order to support the process of sexual self-determination in a competent and appropriate manner:

- a high level of knowledge (professional competence),
- target-group-specific methodological and didactical skills (methodological competence),
- analysis of one’s own point of view and value systems (personal competence).

However, the persons delivering pedagogical programmes do not receive systematic and comprehensive training for sexuality education. Sexuality education modules must be a basic element of third-level studies. Furthermore, increased efforts to initiate, finance and implement short- and long-term continuing professional development programmes are required in order to provide support for professionals and other persons already dealing with these issues and to convince family members of persons with disabilities of the importance of this issue. Practice-based continuing professional development is now being delivered by certain institutions and organisations providing care for persons with disabilities, by pro familia [the leading German NGO for sexual and reproductive rights] and by the Institut für Sexualpädagogik (isp).⁹ The institutions and services providing care for persons with disabilities and insurance providers must ensure that in future these people are aware of these services and that when staff wish to participate in sexuality education training, this is not viewed as a private matter but a work-related one.

Diverse provision, topic-based and target-group-based research

There have been many positive changes with regard to sexuality in recent years. In many places, the issue is no longer about persons with disabilities being sexual beings, but rather is concerned with achieving the most self-determined experience of this sexuality. In all places where this issue is no longer taboo, it is time to develop or extend diverse target-group-based services.

Approaches for very different target groups and stages of life must be extended and disseminated in the case of estab-

lished topics like the knowledge of bodily functions and sexuality education, discussions about relationships and the prevention of sexual violence. Provision to date has been patchy and poorly coordinated. Yet it is essential that previously ignored aspects be integrated into existing provision and new topic-based media and services must be introduced and disseminated.

Topics that have been neglected to date include:

- respecting different sexual orientations,
- reflecting on gender roles and identities,
- providing contraceptive methods other than three-monthly contraceptive injections,
- contracting sexually transmitted diseases,
- dealing with victims and perpetrators of sexual violence,
- using sexual surrogates and active sexual assistance, and
- discussing the desire to have a family and parenting.

Research needs to be carried out in all of these areas. Only research on the three last areas is available (e.g. FEGERT 2006; ZINSMEISTER 2005; PIXA-KETTNER 2006). Yet here too, the data available is very limited.¹⁰

In addition to the need for topic-based research, there is also insufficient knowledge of the target group. Very few studies on the subject of sexuality and persons with disabilities have been carried out (e.g. RITTBERGER 2000; LEUE-KÄDING 2004).¹¹ Even less information is available on the sexual needs and wishes of specific target groups, for example, persons who need a great deal of support or persons on the autism spectrum.

Community-based networks and creating inclusive structures

The integration of persons with disabilities requires the opening up and professionalisation of all social support systems. This cannot and must not be the task of existing disability-specific services alone. Today, many people with disabilities live alone or as part of a couple in their own home. They make decisions about how to run their own lives, what they would like to do and whether they need support for this or not. Many more community-focused support services are now available in their own community that are open to everyone and have an inclusive approach.

However, this often does not apply to the area of sexuality. In many regions, there is still no suitable public advice

8 Lebenshilfe [German federal association of people with intellectual disabilities] has put together a review of information brochures currently available at: http://www.bv.lebenshilfeweb.de/wDeutsch/aus_fachlicher_sicht/downloads/Leichtesprache08_doc.pdf

9 The article by BEATE MARTIN deals with the isp concept of continuing professional development (CPD) as well as detailing experiences to date. The services of pro familia in this area are presented by SIGRID WEISER.

10 In February 2009, a study was commissioned by the Bundesministerium für Familie, Senioren, Frauen und Jugend, [BMFSFJ, Federal Ministry of Family Affairs, Senior Citizens, Women and Youth] to research the degree and range of violence against women with disabilities. The project aims to collect representative data on this issue, which can no longer be ignored, as well as data on support needs and action required. The issue of sexual assault is examined in more depth in the articles by AIHA ZEMP and MARTINA PUSCHKE in this issue.

11 See ORTLAND 2008 for a general review as well as a comparison of research results.

provision on the issues of sexuality, contraception, sexual abuse or about starting a family and parenting. Very few counselling services are equipped to deal with the specific needs of persons with disabilities and their support workers. Often the centres are not even accessible. It is now time for institutions to extend their focus beyond the institution and to provide moral support and practical assistance to enable responsible action. Advisory centres can act on behalf of persons with disabilities, their family members and their support workers in a broad range of ways:¹²

- by providing specialised advice for teams,
- by setting up regular counselling sessions for persons with disabilities,
- by arranging inclusive courses on getting to know people,
- by organising evening information sessions for family members,
- by supporting women's and men's groups,
- by disseminating target-group-focused information.

Furthermore it is necessary that cooperation and coordination between existing sexuality education and counselling providers in each region is improved so that that these services can be coordinated and persons with disabilities become aware of them.

Nothing about us, without us – participation as an interdisciplinary task

In terms of their legal right to equal treatment, and bearing in mind the motto "Nothing about us, without us", persons with disabilities are increasingly participating in decision-making processes, for example in the creation and support of advisory committees in residential homes and workshops and by participating in assistance planning meetings.

Often the participatory principle does not apply to the area of sexuality. Persons with disabilities, for example, are often not asked whether they would prefer necessary personal hygiene assistance to be carried out by a man or a woman. The three-monthly contraceptive injection for women is very common. Yet, women are rarely informed of negative consequences for their health, and the injection is often used regardless of whether the women are in a relationship or even wish to have sexual intercourse. Self-determination can only succeed when people learn to participate in decision-making processes. Especially with regard to the topic of sexuality – an extremely personal issue – it is difficult to understand why persons with disabilities are excluded from decision-making and planning processes or why other people make decisions for them.

Mensch zuerst – Netzwerk People First Deutschland e.V., a self-advocacy group of persons with disabilities, first examined and commented on the topics of sexuality and

sexual violence many years ago, and developed a list of necessary changes.¹³ It is now time that these demands, formulated by the persons concerned, are finally accorded the attention they deserve and that other forms of discrimination of persons with disabilities with regard to the topic of sexuality also receive the attention they deserve.

Ralf Specht

¹² See the Projects section in this issue for details of other experiences.

¹³ Newer versions of the list of required changes can be found in the following conference proceedings on the Internet: http://www.saarland.de/dokumente/thema_soziales/MAF_S_u_Behinderung.pdf and <http://www.lvr.de/soziales/service/veranstaltungen/kuehnelo8o819.pdf>. For more on the current opinion of Mensch zuerst – Netzwerk People First Deutschland e.V on the topic of sexuality, see the article by STEFAN GOETHLING in this issue.



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Towards self-determination.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the sexual self-determination of persons with disabilities

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is the first international document to rigorously examine disability from a human rights perspective. Sigrid Arnade reports on the long history leading up to this Convention, its general significance and the consequences of this fundamental change in attitudes for the sexual rights of persons with disabilities.

The United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) has been hailed worldwide by disabled people as a milestone in disability and human rights policy.¹ The Convention on the Rights of Persons with Disabilities came into effect in Germany on 26 March 2009.

Even before the UNCRPD came into force, persons with disabilities in Germany had exactly the same right to sexual self-determination as any other citizen. The Convention reasserts this right and may even reinforce it, as disability and persons with disabilities are universally considered from a human rights perspective in the UNCRPD.

Looking back: towards self-determination

In the past, a life with disabilities was often considered "inferior" or even "unworthy of life". The terror perpetrated by the Nazi regime, its manic extermination of disability and illness, reached its gruesome pinnacle with the murder of roughly 100,000 people with disabilities and an estimated 350,000 forced sterilisations (ARNADE 2003, p. 3). According to the Nazis, people with disabilities were inferior and should not have any sexuality or be allowed to reproduce.

Immediately after 1945, the right to life of persons with disabilities was no longer challenged. Instead, they were protected by comprehensive social legislation. However, illness and disability were universally considered primarily from a medical, deficit-oriented perspective. As in the past, disability was considered as something different that was tainted by the stigma of inferiority. Instead of the threat of murder by the Nazi regime, disabled people faced disenfranchisement within the care system.

In his report on disabled people, the journalist ERNST KLEE proposed an image of the classic cripple as the "typical

disabled person": "grateful, nice, a little bit stupid and easy to manage" (KLEE 1976, p. 150). In this social environment, the sexuality of persons with disabilities was silenced in the truest sense of the word, by a phenomenon known as discursive discrimination. Parents and caregivers hoped that, if they did not broach the topic, persons with disabilities would then not express any sexual desire. No sexuality education was provided, with the result that, right up to the present day, pregnancies in women with learning difficulties (so-called "intellectual disabilities") are still often not discovered until the fifth month or later. Disabled men and women were also not entitled to any privacy where they could experience their sexuality. They shared rooms with others or slept in single rooms with doors they could not lock. Such conditions still prevail in some cases.

One aspect of the way in which the sexuality of persons with disabilities is determined by others was revealed in 1977 with the publication of a book entitled "Sollen, können dürfen Behinderte heiraten?" [Should, can, may disabled people marry?]. In this book, so-called experts presumed that they had the right to decide how people with disabilities should lead their lives. The book caused a storm of outrage among affected individuals, yet a second edition of the book was published in 1986.

A journey towards sexual self-determination

Persons with disabilities began to emancipate themselves in the late 1970s/early 1980s. They called for a fundamental change in perspective: disabled people no longer wished to be seen as objects of care but rather as autonomous subjects with full human rights.

With its criticism of the International Year of Disabled Persons in 1981, the disability rights movement in Germany became more politicised. A movement modelled on the US-American Independent Living Movement was subsequently formed. As the "last civil rights movement" (HEIDEN 1996, pp. 16, 28), activists were not looking for increased social

¹ The terms "disabled people", "persons with disabilities" and "people with disabilities" are used synonymously in this article.

protection but rather equality legislation akin to the anti-discrimination laws that had been enacted in the USA.

The main demands made by persons with disabilities in Germany were met by the 1994 amendment to the constitution, Social Security Code (IX) [Sozialgesetzbuch IX, SGB], the Equal Opportunities for Disabled People Act [Behindertengleichstellungsgesetz, BGG] and the General Act on Equal Treatment [Allgemeines Gleichbehandlungsgesetz, AGG].

At the same time, increasing numbers of not only disabled people but other groups in society adopted the change in perspective mentioned above. This had an impact on the sexual self-determination of disabled people. The right to a largely self-determined sexuality was increasingly viewed as a matter of course, particularly for persons with physical and sensory disabilities. They no longer discuss whether they are allowed to be sexual beings, but rather how they can construct their sexuality to suit themselves. How can the right to self-determined sexuality be realised if, for example, residences for adults only have shared rooms or if physical impairment makes masturbation more difficult? A German federal congress held in Nuremberg in 2000 entitled “Behinderte Sexualität – verhinderte Lust?” [Disabled sexuality – obstructed desire?] marked an important step in bringing such issues to the fore (MÖSLER 2002, p. 48).

Even people with so-called “intellectual disabilities”, who prefer to be known as “people with learning difficulties”, want to experience flirting, love, relationships, tenderness and passion just as much as their peers. After all, sexuality is part of each individual’s personality. This applies just as much to people with learning difficulties as it does to all other women and men (PRO FAMILIA 2006, p. 4).

Adults who have been diagnosed with “intellectual disabilities” have the absolute right to experience their sexuality as they see fit, without restriction or prohibition. Parents, institutional staff and legal guardians are frequently unaware of this right. The appropriate continuing professional development must therefore be provided. The lawyer JULIA ZINSMEISTER also suggests that the achievement of the right of disabled people to self-determination – including sexual self-determination – must be examined as a quality assurance criterion for institutions (ZINSMEISTER 2003, pp. 25–28).

Disabled people themselves demand that the issue of sexuality is no longer a taboo subject in any institution, but instead that they receive sexuality education and learn, for example, about HIV infection (ARNADE 2007, p. 101).

The long road to the UN Convention on the Rights of Persons with Disabilities (UNCRPD)

Germany is not the only country where the lives of persons with disabilities have frequently been characterised by the lack of self-determination and serious human rights violations. This was confirmed in 1993 in the report “Human Rights and Disabled Persons”, produced by UN Special Rapporteur LEANDRO DESPOUY. In this report, the author cites a great number of human rights violations suffered by persons with disabilities throughout the world on a daily basis. These include a ban on marriage and having a family, forced sterilisation, sexual violence and compulsory residential care.

Yet negotiations about the UNCRPD were a long time in coming. Support for the negotiations was provided by the

study “Human Rights and Disability”, published in 2002. Around the same time, the UN General Assembly established an Ad Hoc Committee to develop the UN Convention. A working group, consisting of government agencies, non-governmental organisations (NGOs) and national human rights institutions, developed a first draft in January 2004, which served as the basis for further negotiations.

The motto throughout the negotiations was “Nothing about us, without us”. Never before had civil society been so intensively involved in negotiations on a human rights convention. Many governments, including the German government, appointed persons with disabilities to their delegations. THERESIA DEGENER (a lawyer with a disability) took part in the negotiations in New York as a member of the German delegation (LACHWITZ 2007, p. 2).

The Ad Hoc Committee met for a total of eight sessions, extending over several weeks. At the end of the eighth session, the Committee adopted the draft text of the UN Convention and the Optional Protocol (governing the working methods of the Committee on the Rights of Persons with Disabilities).

The UN General Assembly adopted by consensus the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol on 13 December 2006. Both were available for signing and ratification from 30 March 2007 in New York. Germany was one of the first countries to sign the UN Convention on 30 March. At the end of 2008, the German Bundestag and Bundesrat passed legislation to ratify the UN Convention on the Rights of Persons with Disabilities and the UNCRPD came into force in Germany on 26 March 2009.

General significance of the UNCRPD

The UNCRPD is the first international document that addresses disability policy from a human rights perspective. Previous United Nations’ documents on disability-related issues tended to focus on concepts of state provision of care (HÄFNER 2007, p. 45). The medical model of disability traditionally prevails in most countries. This model considers disability from a medical perspective as being an individual deficit that is responsible for the lack of participation of the person concerned in all areas of society. In a further development of this model, many countries now see disability within the context of a social protection paradigm where the aim is to assimilate people with disabilities into “normal” society by means of rehabilitation.² The human rights approach goes beyond both of these models: from a human rights perspective “disability results from the interaction between persons with impairments and attitudinal and environmental barriers.” (UNCRPD Preamble, (e)).

This approach is based on the principle that disabled people do not simply need to be cared for or rehabilitated but are entitled to participate equally in a way that they determine themselves.³

2 Lecture by HORST FREHE (“Teilhabeconzepte: die Theorie der Anerkennung und die Belange behinderter Menschen – eine juristisch-politische Perspektive” [Ideas about participation: The theory of recognition and the concerns of disabled people – a legal and political perspective]) at a specialist conference organised by Interessenvertretung Selbstbestimmt Leben in Deutschland (ISL e.V.) in Berlin on 3 April 2009.

3 Ibid.

The UNCRPD gave voice to this change in perspective: persons with disabilities are no longer seen as patients but as citizens. They are no longer considered as problems but as individuals with inalienable human rights at all levels. Life with disability is thus affirmed as a normal aspect of human life and human society.⁴ The UN Convention speaks of the “valued [...] contributions” that persons with disabilities can make to the diversity of their communities (UNCRPD Preamble, (m)). At the same time, there is no attempt to deny the problems faced by disabled people. All existing human rights are specified in concrete terms with regard to the lives of disabled women and men and are tailored to their circumstances. The UNCRPD therefore did not create any new human rights for persons with disabilities. It does, however, emphasise that all human rights are just as valid for disabled people as they are for everyone else.

Sexual self-determination and the UNCRPD

“Sexual self-determination” is rarely mentioned in legislation. Nor does the UNCRPD allude directly to this term. Nevertheless, sexual self-determination is enshrined in German, European and international law, since it can be derived from other legislation, in particular, the protection of dignity, the protection of privacy and protection against discrimination (ARNADE 2009, p. 236). These are cited in legal provisions that are valid internationally, in Europe or in Germany and thus also in the UNCRPD.

All of the UNCRPD addresses the protection of dignity and protection against discrimination in relation to persons with disabilities. Particular weight is given to the protection of privacy, which is enshrined in a separate Article – Article 22 (Respect for privacy). Paragraph 1 of this Article states: “No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation.”

Article 23 (Respect for home and the family) in the UNCRPD, especially Paragraphs 1 and 2, should also be mentioned in relation to sexual self-determination:

- “(1) States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:
- a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
 - b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
 - c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

- (2) States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.”

These Articles unequivocally state the right of all persons with disabilities to sexual self-determination.

Sexual orientation

In terms of sexual orientation, people with a very diverse range of disabilities have the same rights as all other individuals. People with disabilities frequently describe the problem of the outsider role that often comes with multiple discrimination (TEICHERT 2007, p. 116). Lesbians and gays with disabilities find themselves on the fringes of the disability community due to their sexual orientation and are not always accepted in the lesbian or gay community because of their disability (BAZINGER 2007, p. 114). Paragraph (p) of the Preamble in the UNCRPD cites race, skin colour, gender, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth and other status as reasons for multiple or aggravated forms of discrimination. This list was not only included in the Preamble of the 2004 draft text of the UN Convention but also in one of the Articles in the UN Convention text, where it would have been legally binding, but was deleted following the intervention of a number of countries (BUNDESMINISTERIUM FÜR ARBEIT UND SOZIALES [Federal ministry of labour and Social Affairs] 2004, p. 56). The European Union advocated the inclusion of “sexual orientation” as a qualifying status and was supported in this by a number of other countries including Canada and New Zealand (SCHULZE 2009, p. 23). It was not included, however, as some Asian, and particularly Islamic, countries objected to the wording (BUNDESMINISTERIUM FÜR ARBEIT UND SOZIALES [Federal ministry of labour and Social Affairs] 2004, p. 60). Even if sexual orientation is not expressly specified in the UNCRPD, other provisions in the UNCRPD and German law prohibit discrimination on the basis of sexual orientation

Outlook

The rigorous human rights perspective adopted by the UNCRPD underscores the right of persons with disabilities to sexual self-determination. In Article 8 (Awareness-raising), the States Parties undertake to adopt comprehensive awareness-raising measures.

If Germany begins to implement the UNCRPD by adopting such measures, action plans and legislative changes, increasing numbers of citizens will perceive disability and disabled people from a human rights perspective. Hopefully, the time will then soon come when self-determined sexuality will be taken for granted for all persons with disabilities.

Sigrid Arnade

⁴ HEINER BIELEFELDT describes this view as the “diversity approach” (BIELEFELDT 2009, pp. 6–7).



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Sexual self-determination in assisted living facilities?

Law and legal reality

Self-determination in everyday life is a fundamental requirement for self-determined sexuality. In her article on the legal aspects of “sexuality and disability”, Julia Zinsmeister discusses how structural changes to the life situation of disabled men and women are required for this to be achieved.

Introduction

Human rights are universal; they apply to all, regardless of gender, age, cultural background or disability. Nevertheless, it has been repeatedly necessary in recent years to refer to the requirement for equal treatment (Article 3 Paragraph 3 p. 2 Basic Law) in order to state why it is a matter of principle that disability does not restrict the right to sexual self-determination. The voices that made a serious attempt to question this are now finally silent. The paradigm of self-determination is well established in laws concerning social nursing-care insurance, rehabilitation and residential facilities as well in guidelines and concepts concerning services for disabled people. Yet these guidelines rarely mention the right of disabled people to self-determination, speaking only of their legitimate desire for self-determination. This slight lexical difference reflects the enormous gap between the law and legal reality: a person who can merely express his or her wishes, will (still) not be accorded authority to make his or her own decisions.

Therefore, from the legal standpoint, it is not only the actual content and scope of the right to sexual self-determination that is of interest, but also the conditions – following the stipulations of the new UN Convention on the Rights of Persons with Disabilities – that must be created in order to ensure that this right is put into practice to the greatest possible extent.¹

The right to sexual self-determination

The Federal Constitutional Court [Bundesverfassungsgericht] derives the right to sexual self-determination from the so-called “right to privacy” [Allgemeines Persönlichkeitsrecht] from the right of general freedom of action and the guarantee of human dignity enshrined [Allgemeine Handlungsfreiheit und der Garantie der Menschenwürde] in German Basic Law [Grundgesetz für die Bundesrepublik Deutschland]. The autonomy of a person is the source and expression of his or her dignity. It is to be respected, protected and supported, regardless of whether the individual wishes to or can take advantage of the freedoms accorded to him or her.² The right to privacy includes the autonomous area of private life, within which each person can develop and maintain his or her individuality.³ This scope of protection guarantees the right to sexual self-determination and the freedom of a person, to experience his or her sexuality according to his or her own wishes and ideas as well as the right to develop his or her own gender identity and sexual orientation.⁴ This refers especially to the protection of those persons whose gender identity is not located at the poles of “masculine” and “feminine” (intersexuality, transsexuality, transgender) or who experience social disadvantages and discrimination because of their homosexual or bisexual orientation. Historically, the expression “sexual self-determination” entered legal parlance in Germany in 1973 thanks to the influence of the women’s movement: The punishable offences in Chapter Thirteen of the German Criminal Code [Strafgesetzbuch] of the time – “Crimes and misdemeanours against morality” [Verbrechen und Vergehen wider die Sittlichkeit] – were summarised under the new heading of “Offences against sexual self-determination” [Straftaten gegen die sexuelle Selbstbestimmung]. Sexual self-determination includes the right to not be sexually exploited or harassed against one’s will. Finally, reproductive choice, that is, the freedom that women have to decide for or against pregnancy, is closely linked to sexuality and the right to sexual self-determination (BAER 2009, p. 93)

1 Law referring to the UN Convention of 13 December 2006 on the rights of disabled people. Bundesgesetzblatt 2008 II, p. 1419. The article by SIGRID ARNADE in this issue provides an introduction to this topic.

2 Federal Constitutional Court 39, 1 (41)

3 Federal Constitutional Court 79, 256 (268)

4 Federal Constitutional Court 121, 175–205

Of course, sexual self determination in the absolute sense does not exist in any community. Thus, the right of general freedom of action, including the freedom to experience one's sexuality according to one's own wishes, meets its moral and legal limitations with regard to the freedom and integrity of others. The opportunity for individuals to exercise their basic freedoms is also subject to practical limitations. Some people are single or childless against their will. Others do not find sexual fulfilment in their relationship. Low self-esteem or experience of violence can make it difficult to enjoy warmth, intimacy and eroticism with other people without fear. Other factors also influence gender identity and sexuality. If a person does not subordinate his or her self-image, appearance and actions to the heteronormative gender order, that is, the dominant conceptualisation of gender and "normal" sexuality, then he or she runs the risk of experiencing social exclusion and legal discrimination. If a person desires privacy and intimacy, then a private space and time are necessary in order to be alone or with other people. If a person would like to make use of commercial pornography and prostitution, then the corresponding financial means and practical access to these goods and services are required.

Autonomy in everyday life is essential for sexual self-determination

The autonomy of persons with disabilities is often limited by other impediments. These can be physical or mental in nature, but can also be determined by society. Some examples are the barriers to communication and the technical and structural obstacles that they often have to face and which make it much more difficult to have social contacts. As they are dependent on support in everyday life, their autonomy and privacy is further limited by the structures of the existing rehabilitation and care system. Many of the responsible bodies of institutions cannot meet the requirement to provide individual support and care for residents due to inadequate staffing levels. If, for example, residents with restricted mobility do not want to participate in communal leisure activities and would rather go to the cinema or go dancing, there is often no staff available to drive or accompany them there. The situation of people who would like to receive independent assisted living services is similar. Nursing-care insurance does not cover leisure activities; social assistance authorities provide this only to a very limited extent. People who have to organise their day, even when they get up or go to bed, according to the schedules of healthcare staff, have few opportunities to go out and meet other people – including potential sexual partners.

In an effort to find a solution to this situation, more attention has been paid to passive and active sexual assistance in recent years. "Passive" means that the assistant provides support without being personally involved in the sexual activity, by making condoms available or by organising a sexual surrogate, for example. Active sexual assistance is characterised by direct physical sexual contact. Although it is not the only aim, one of the objectives of active sexual assistance is to provide an alternative to a sexual partner. Many people understand and take this as an opportunity to find out more about themselves and to approach their body in a sensual way and to become more aware of their own sexual attractiveness. For people with extremely impaired physical movement, active sexual

assistance can be the only way for them to masturbate.

In order to receive active sexual assistance, persons with disabilities must access paid services from sexual surrogates or prostitutes. Their relationship with their caregivers does not permit support in any form of sexual activity. As long as disabled people cannot select and instruct their caregivers by themselves, and, if necessary, select a different caregiver, then they will continue to be in a situation of structural dependence and thus at risk of an abuse of power.⁵ Sexual contacts with caregivers can have consequences for caregivers with regard to labour and criminal law.

The law does not recognise the use of sexual services provided by sexual surrogates or prostitutes as a way of improving the integration of disabled people. In the view of the courts, therefore, the social assistance authority is not obliged to pay for the costs of these services. A home visit by a prostitute is not viewed as an appropriate way of improving integration (promoting everyday competence, involvement in the community). The satisfaction of sexual needs is one of the general basic needs that are covered by the payment of statutory social assistance benefits. Recipients of social assistance must thus spend their benefits accordingly, if necessary, resorting to other sexual practices or limiting the number of sexual contacts.⁶ People who are not able to resort to other sexual practices due to physical impairment are not likely to be persuaded by this reasoning. This was discussed in the legal opinion on sexual assistance commissioned by the pro familia federal association (ZINSMEISTER 2005, p. 17). However, it is correct that sexual assistance can only reduce to a limited extent the restrictions to participation that people with disabilities face in the area of sexual self-determination. It cannot adequately compensate for the lack of opportunities to make social contacts and build relationships or to create a private and personal space. Self-determination in everyday life is a fundamental requirement for self-determined sexuality, which, for its part, necessitates structural change to the life situation of disabled men and women.

Single rooms and bathrooms and shared living areas for couples are still not the norm in assisted living facilities. In shared assisted living facilities, the residents have much more privacy and freedom in comparison to inpatient assisted living facilities; nevertheless these are still involuntary arrangements as long as individuals cannot choose who they would like to live with according to the right enshrined in Article 19 a) of the UN Convention. The freedom to decide who will provide assistance is also an effective way of ensuring privacy. Even the legally regulated right of residents to choose a caregiver of the same gender (Article 2 Paragraph 2 p. 2, SGB XI) is not achieved by some facilities who claim that their staffing levels cannot meet this demand.

Living with a partner who does not require care or rehabilitation is only possible in individual assisted living facilities. Parents with high support needs often require

5 For more detail, see: Zinsmeister 2005, online at: <http://www.profamilia.de/shop/download/219.pdf> (as of 23. 2. 2010).

6 Thüringer Landessozialgericht, Decision from 22.12.2008 L 1 SO 619/08 ER, brief summary in: *Recht der Lebenshilfe (RdLH)* 2009, pp. 67–68; previously Bayerischer Verfassungsgerichtshof from 10. 5. 2005 Az.12 BV 06.320; on coverage of supplementary costs by statutory social assistance: Hamburgisches Obergerverwaltungsgericht from 21. 12. 1990 BF IV 110/89 and Verwaltungsgericht Ansbach, Judgement from 5. 3. 2004 Az. AN 4 K 04.00052.

additional assistance from youth and social services in order to care for their children appropriately. However they are often confronted with deficiencies in the social care system that have dramatic consequences. Many cannot assert their legal right to receive the required services or only receive them to a limited extent.⁷ Mothers and fathers with learning difficulties,⁸ that is, who have been diagnosed with an intellectual disability, have particular problems in attaining independent assisted living support in their own homes. The majority of (expectant) mothers are referred to specialised mother and child facilities. However these facilities are few and far between in Germany and do not meet demand. The women are thus faced with the choice of leaving their social network behind, in some cases also their partner and the father of the child, and living in an unknown facility and environment, possibly in another part of Germany, or of giving their child to foster parents.

In order to achieve the highest level of independence, despite support needs, physically and sensory disabled persons developed the care concept of “personal assistance” many years ago.⁹ In the case of the employer model, the person with the disability (“assistance user”) is the employer of his or her caregivers (“assistance providers”) and thus has the freedom to decide who will provide the care, as well as when and how. Some disabled assistance users have organised themselves into assistance cooperatives. The employer model and assistance cooperatives are without doubt the organisational forms most likely to maintain and promote the self-determination of persons requiring care and to guarantee their private sphere. Yet, even though the declared goal of social nursing-care insurance is “to help the person requiring care, despite the need for support, to live the most independent and self-determined life possible, corresponding to the dignity of the human being” (Article 2 Paragraph 1 p. 1, SGB XI), persons requiring care who select such a model receive significantly reduced services from their insurance provider than people with the same needs in inpatient assisted living facilities. Put in figures: persons requiring care at care level II, who are supported in their own home by caregivers they have organised by themselves, receive a monthly allowance for nursing care of 430 euros, while persons in residential facilities with the same care needs receive 1,279 euros. If care for independent assisted living is provided by a nursing care service, nursing-care insurance will pay up to 1,040 euros each month.

7 ZINSMEISTER, J.: “Staatliche Unterstützung behinderter Mütter und Väter bei der Erfüllung ihres Erziehungsauftrages” [State support of disabled mothers and fathers in carrying out their parental duties]. Legal opinion commissioned by the Netzwerk behinderter Frauen Berlin e.V [Network of disabled women, Berlin]. Online publication at www.elternassistenz.de with more details on “Gesetzesänderungen” [legislative changes] (research from 22. 2. 2010).

8 Mensch zuerst – Netzwerk People First Deutschland e.V., the advocacy group set up and run by people who have been diagnosed as intellectually disabled, rejects the term “intellectually disabled” as discriminatory. In line with their own definition, the term “people with learning difficulties” is used in this article.

9 STEINER, G.: Wie alles anging. Konsequenzen behindertenpolitischer Selbsthilfe. [How it all began. Consequences of politicised self-organised care for disabled persons]. Online publication at http://www.forsea.de/projekte/20_jahre_assistenz/steiner.shtml (research from 12. 2. 2010).

The allowance for nursing care is neither designed nor suitable for the coverage of daily care needs. Persons requiring care, who organise and coordinate their support by themselves and are neither dependant on the staffing schedule of professional service providers nor wish to move into a residential facility, must either have a sufficient level of income to pay for their nursing care (in part or in full) by themselves or must find voluntary carers (in particular, family members) to cover their care needs. If they cannot do this, then, for all intents and purposes, they are forced by the different levels of nursing care benefit payments to apply for social assistance and/or move into a residential facility. In the light of Articles 19 and 22 of the UN Convention, this is problematic (DEGENER 2009). According to these Articles, disabled people are not obliged to live in specialised housing, but instead must have equal opportunity to choose their place of residence and to decide where and with whom they live. They shall not “regardless of place of residence or living arrangements [...] be subjected to arbitrary or unlawful interference with his or her privacy, family, home (...)”. (DEGENER 2009, p. 34). Not only, but especially in inpatient assisted living facilities, they are at risk from interference. The following section will discuss this risk.

A personal budget can make it easier for persons (also) receiving rehabilitation benefits to organise assistance by themselves. According to the law introduced in 2001, personal budgets have the goal of facilitating disabled people in “buying” necessary care services. However, to date, very few disabled people have made use of this opportunity. As long as nursing-care insurance providers only participate in these budgets via nursing-care vouchers then this budgeting will not provide the desired and necessary flexibility for many users. Furthermore, there is also the risk that the agreed budget will not be sufficient, since unforeseen needs and staff and financial administration costs (“budget assistance”) are not adequately considered in these calculations. And finally, the inflexible structures of the governing bodies are causing the failure of current implementation.

The objection can be made that assistance that is “bought” and organised by the users is not a suitable form of support for everyone. This demands a high level of organisational and management competence, which many people – disabled or not – do not possess. People who cannot express their needs, or who are not aware of time constraints, will not create a staffing schedule for their assistants or cooperative.

For many people, living in assisted living facilities is the only residential option available, apart from living with their parents. However, for many people it is impossible to experience their sexuality when their parents are in the next room. Moving into assisted living facilities is thus linked with the hope and expectation of having more space for personal expression.

Example: Rules in residential facilities and communities

Relationships and sexuality are no longer a taboo subject in assisted living facilities; diverse providers deliver sexuality education programmes or assertiveness and self-defence training. A few counselling services and responsible bodies of institutions also organise contact with sex surrogates and prostitutes. Nevertheless the autonomy of residents remains

limited. This is not only due to space constraints and inadequate staffing, but also to support concepts that continue to be shaped by paternalism.

Thus the rules of many residential facilities and communities include regulations that forbid residents to receive guests in their rooms after lights-out. These regulations constitute interference to the freedom of the residents to decide who they invite into their private residential space, and when. In reality, they also reduce the opportunity for residents to have private sexual contacts with others to zero. The regulations must be classified as unlawful due to the reasons listed above.¹⁰ The responsible body of a residential facility is in principle not authorised to regulate the social contacts of its residents. Such authority can only be exercised if an invited guest causes a serious and repeated disturbance to the other residents. In such cases, the right of the other residents not to have to experience this disturbance overrides the right of the person receiving the guest, if the situation cannot be resolved through less invasive means.

The effect of visiting regulations on the sexual self-determination of the residents is evident. Further unwritten and written rules usually exist in assisted living facilities that violate the right of residents to privacy, without actually intending to do so. Examples include regulated meal- and bedtimes or the rule that meals are to be eaten communally. For residents sharing a room, mealtimes can be the only times during the day when they have the opportunity to be alone in their room. Regulations with the declared goal of promoting the ability of the individual to live in a community by integration in a shared assisted living facility are problematic from the legal viewpoint with regard to autonomy and the protection of privacy. This also applies to regulations that stipulate whether and for how long adult residents can leave the residential facility.

Does the risk of being a threat to oneself or to others people justify the limitation of a person's autonomy?

Adults with learning difficulties are usually inadequately informed of their rights. Many accept the care regulations applied by their legal guardians and care workers without discussion. Yet is it really possible, putatively in their own interest, to stipulate when adults can go out and meet other people? Do parents as legal guardians have the right to be informed by residential facilities about the private activities of their adult children? Can potential dangers to the putative well-being of a disabled woman or the child she would like to have justify the prescription of contraceptives to disabled women against their will?

When they reach the age of majority, people are, in principle, responsible for their own well-being. This freedom includes the freedom to do harm to themselves. In order to be able to make decisions for another person, one must either be nominated to represent this person or, due to other legal grounds, be appointed to act on their behalf. The view that legal guardians or care workers – more or less automatically – have the legal responsibility to supervise assisted persons, and can make decisions on their behalf, putatively in their interests, is as widespread as it is legally invalid. Instead, their role is to facilitate self-determination, that is, not to limit the opportunity to make decisions, but instead to develop it. They should provide advice and support so that

people, can, where possible, make decisions by and for themselves, or at least be able to formulate their wishes and interests. These wishes and interests constitute the guidelines for anyone acting on their behalf.

Support must have the goal of strengthening the self-protection skills of assisted persons. This also applies to protection from sexual violence and harassment. Effective violence prevention includes information and (sexuality) education, assertiveness and self-protection training and other types of empowerment. In addition, the structural causes of violence must be recognised and dealt with. In specialised care institutions for people with disabilities there is a higher risk of disabled residents experiencing violence and violations of personal space. In such instances, the responsible bodies are required to take organisational precautionary measures (ZINSMEISTER 2003; 2010). According to Article 16 of the UN Convention, in future, independent authorities must effectively monitor all precautionary measures taken to prevent exploitation, violence and abuse in specialised care institutions and programmes. In addition, Article 16 requires that disabled victims of violence attain unrestricted access to the legal system and protective services, both at national and state level.

Wherever assisted persons are personally capable – or can be helped to become capable through information, advice and support – of making decisions, then there is no place for their legal guardians to do so on their behalf. In order to make self-determined decisions, the following is required: understanding of the need for the decision, awareness of the different possible courses of action and the consequences that arise from these, as well as the ability to assess these consequences in light of one's own attitudes and outlook on life. Furthermore, the ability and opportunity to communicate with others is necessary. The ability to make decisions is gauged via the process itself and not via the results achieved. Thus a decision is not based on lack of will, just because third parties think that the result will be unreasonable.

In the context of sexual self-determination, in practice, it is often not recognised that the regulation of social and sexual contacts (“access regulations”) are neither the task of the family members of adults,¹¹ nor is this one of the duties of their legal guardians and care workers. This is applicable only in a situation where comprehensive legal guardianship of a person (“guardianship”) has been authorised, which also covers the right of access. Legal guardians, who have been awarded right of access, can only exert this right without or against the will of their clients if this is required for their protection due to a specific mental or physical threat. Examples from law are the refusal of access to persons who have repeatedly placed the assisted persons under severe mental pressure and frightened them, but

10 HÖFLING, W.: Hausrecht in Heimen – Zur Regulierung der Außenkontakte von Heimbewohnerinnen und Heimbewohnern – Rechtslage und rechtspolitischer Reformbedarf – Rechtsgutachten erstattet im Auftrag des Bundesministeriums für Familie, Senioren, Frauen und Jugend [House rules in residential facilities – Regulation of visitors to persons in residential facilities – Legal situation and legal basis for political reform – Legal opinion commissioned by the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth (BMFSFJ), September 2004, Online publication at www.bmfsfj.de/BMFSFJ/Service/Publikationen/publikationsliste, did=02^6.html (research from 12. 2. 2010); ZINSMEISTER 2005, p. 17 (51 ff.).

11 Bayerisches Oberstes Landesgericht Decision from 28.12.2001 Az.3Z BR 267/01, in: FamRZ 2002, 907–908.

where the assisted persons themselves do not wish to end contact with such persons.¹²

Within the context of family planning, the contrast between the treatment of non-disabled women and the extreme methods used in regard to contraception for women with learning difficulties is striking. Women with learning disabilities are more likely to use contraception, even if there is no concrete possibility of them becoming pregnant, and take contraceptives that are rarely used by non-disabled women because of the serious side effects (e.g. the three-monthly contraceptive injection). Numerous individual cases provide grounds for assuming that many of the women receive medical treatment without receiving an appropriate medical explanation beforehand. The treatment of a patient without her informed consent is normally a punishable offence. Legal guardians may only give consent on behalf of the patient, if, after adequate explanation, she is still not aware of the connection between sexual contact and pregnancy or does not understand how contraception works and its (side) effects, and thus make a decision based on this knowledge. If the legal guardian of a woman unable to give consent has to consent to treatment with hormones on behalf of the woman, then he or she must act according to the wishes and family planning goals of his or her client. If disabled men and women wish to have a family, then according to Article 23 Paragraph 1 b) of the UN Convention and the stipulations of Custodianship Law, it is the duty of their legal guardian to counsel them in an open way and, in particular, to inform them of the options available (e.g. state support) to parents.

In summary

The respect for the autonomy of a person is required before the right to sexual self-determination can be exercised. This also applies to people who are only partially able to make their own decisions. They must have the opportunity to state their wishes and interests, and these must form the guidelines for any action on their behalf by their legal guardians and care workers. Sexual self-determination requires autonomy, not only regarding issues of sexuality, but fundamentally in the way people live and plan their life and in their interaction with the world around them. The UN Convention safeguards the opportunity for disabled people to have the equal right to choose their place of residence, and to decide where and with whom they live. The Convention protects their right to live in a relationship and to have a family. In assisted living facilities, this right is often met with restrictions that must be removed. This demands the removal of structural limitations and the overcoming of paternalist concepts of support. Put simply: the courage to change.

Julia Zinsmeister

12 Bayerisches Oberstes Landesgericht Decision from 18. 2. 2004 3Z BR 5/04, in: FamRZ 2004, 1670–1671; Bayerisches Oberstes Landesgericht Decision from 26. 2. 2003 Az.3Z BR 243/02, in: BtPrax 2003, 178–179; Bayerisches Oberstes Landesgericht Decision from. 23. 10. 2002 Az.3Z BR 180/02, in: BtPrax 2003, 38–39 and FamRZ 2003, 402–403.



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Sexuality – experiences and hindrances.

Current discussions and projects from the perspective of women with disabilities

The sexuality of women with disabilities has long ceased to be the taboo subject it was in the past, even as recently as the 1980s and 1990s. The theory that women with disabilities grow up as sexless beings is no longer universally accepted. A wide variety of educational materials, recent seminars and the experiences of self-confident young women prove that the opposite is the case.

Yet, even in the new millennium and despite the end of the taboo, many women with disabilities like us are still prevented from enjoying a life of positive and self-determined sexuality due to a variety of social and structural barriers. Girls and young women who need a great deal of assistance, from their parents, for instance, may find it difficult to buy and read popular teen magazines like *Bravo* or *Mädchen* without drawing attention to themselves. Meeting boys and girls their own age outside of school – with whom they can chat, explore their own bodies, have a first “kiss and cuddle”, and so on – is difficult if they attend a special school and their school friends do not live nearby or if visiting their peers in general tends to be a rare occurrence because they are so dependent on their parents. As their children get older, parents are often concerned that their disabled daughter will become pregnant. As a result, they decide on the form of contraception that their daughter will use (in many cases a three-monthly contraceptive injection) or prevent her from having close physical contact with the opposite sex. Even girls and women who require little or less assistance and can therefore get around more freely without parental “supervision” find that, due to their disability, or, more precisely, due to the prejudices associated with their disability, they generally experience their first sexual contacts with others later than young people without disabilities. For some, this experience represents a common theme throughout their lives. The result is often unfulfilled sexual longing, culminating in unwanted childlessness.

In institutions providing care for persons with disabilities, structural conditions determine how and to what extent sexuality can be experienced. Are staff open to the issue of

sexuality? Are there single or double rooms? These are just some of the issues that can affect sexual self-determination.

It is clear even from this introduction that the sexuality of women with disabilities covers a broad spectrum. The purpose of this article is primarily to provide a selective overview of current debates on the issue and to incorporate the views of some women with disabilities.¹ It does not address other issues that are often dealt with in other contexts, e.g. sexuality education, contraception and the desire to have a family.

You are beautiful to me...

“I was denied everything that was essentially feminine, everything associated with becoming a woman. all of this simply erased from the agenda. rebellious longing and a desire not to allow myself to be classified and labelled as an asexual being meant that I fought for the smallest things: lipstick, pink nail polish, a short skirt, a first kiss. I never got a bra. ‘you don’t need one!’ – the devastating response sank into my consciousness. why did I not need one?” (MIELKE 2004)

Yes, why not indeed? Why does a young woman have to fight for a bra, just because she is in a wheelchair and her body does not conform to socially accepted ideas of what constitutes beauty? ANDREA MIELKE finally won her battle. She was eventually able to say to her reflection in the mirror: “‘you are beautiful the way you are!’ with my body’s deformities, the constant immobility of all my limbs and my dependency on others.” (Ibid.)

Beauty, attractiveness, aesthetics and sensual charm are closely connected to eroticism and sexuality. Women with disabilities have been addressing these issues since the inception of the disabled women’s movement, if not earlier. In the early 1980s, women with disabilities completely rejected the prevailing beauty ideal, yet the first modelling contest for physically disabled women took place at the beginning of the new millennium and proved to be a very

¹ As a disabled woman myself and someone who is deeply involved in the disabled women’s movement, I do not write objectively about women with disabilities but instead take the insider’s view and include several testimonies from women in our movement.

popular event (cf. FABER/PUSCHKE 2007). This was an issue that triggered a controversial debate in the magazine EMMA in the early years of the disabled women's movement (EMMA 2004).

Meanwhile, a number of photographic exhibitions and films have featured erotic images of beautiful, self-confident women with disabilities, including women with a wide range of impairments. This move into the public sphere is good for us as women and also for everyone else. It shows that it is time to challenge the old clichés that associate disability predominantly with negative attributes.

Controversial debates among women with disabilities seldom arise in relation to photographs and films unless they cross the line into pornography or even acrotomophilia.² A recent public discussion centred on a film and series of photographs by GERHARD ABA in 2007. ABA photographs only female amputees but rejects the accusation of acrotomophilia.³

What do women think about sexual surrogacy and sexual assistance?

When the debate on "sexual surrogacy" for people with disabilities began in the late 1990s, Weibernetz e.V. and our associated regional disabled women's networks assumed that this issue was relevant almost exclusively to men with disabilities. To us, the concept seemed too close to prostitution.

It was also clear that these services were used overwhelmingly by heterosexual men (PRO FAMILIA 2005). One of the reasons for this was that this form of eroticism – a 45-minute "session", virtually at the push of a button – suited men better than women. Nevertheless, we discussed the issue of sexual surrogacy at a Weibernetz e.V. meeting in September 2006, held to commemorate the 25th anniversary of the disabled women's movement. One participant had the following to say: "It's fine if a woman does not need these services because her sexual needs are being met or if she compensates in some other way. I have never had a boyfriend. For me, sexual assistance and sexual surrogacy are the only ways in which I can enjoy some erotic hours of sex."

In fact, women with various disabilities are very interested in sexual surrogacy. However, interest cannot be equated with use of this service because, in reality, only a small number of women actually avail of it. Furthermore, the difference between facilitated sex and prostitution is an issue that is still debated and viewed critically by many women.⁴

A frequently neglected issue: lesbians and disability

Today, just about every soap opera features a lesbian (or at least gay) couple and in major cities in particular lesbians and gays have a high media profile. This acceptance by the media is not reflected in all areas of life however. Unfortunately, as in the past, homophobia and discrimination are part of everyday life for lesbian women and gay men as well as transsexual and intersexual individuals.

And where do we see lesbians with disabilities? They are not represented in the media at all – it seems that it would be too drastic to portray so much stigmatisation in one person. However, the real answer is that they are every-

where: living on their own, in couples, in their own homes, in assisted living facilities, in residential homes, etc. Frequently, however, there is no awareness of their sexuality; in some cases it is not taken seriously or is even a taboo subject.

To give one example: in a residential home for persons with learning difficulties, two women share a room and have sex together. Staff members turn a blind eye; they do not react. In one way, the two women are lucky, but, in another, it is unfortunate if they have questions about their sexuality and the only answers available relate to heterosexual sexuality. Added to this is the lack of acceptance (and the associated discrimination against the lesbian lifestyle) displayed by the institution in ignoring the situation. In most cases, if a man and a woman were to share a room in a residential home in order to have sex together, it would be handled differently. Their sexual needs would at least be raised as an issue, regardless of the outcome.

Many years ago, lesbian women with disabilities joined forces to form the German Krüppel-Lesben-Netzwerk [cripple-lesbian network]. Krüppel-Lesben groups or groups of lesbian disabled women now exist in a number of cities. In some cases, lesbians and gays also meet up together. Some advocacy groups representing disabled women include the words lesbians (and girls) in their name to make it clear that the life situations of lesbian women and girls with disabilities must also be taken into consideration.⁵

Lesbian and gay sexuality is also discussed in more recent brochures on the sexuality of people with learning disabilities (cf. FEGERT et al. 2007). However, most published articles on the subject of "sexuality and disability" still tend to exclude homosexuality.

A small number of lesbian advisory centres also cater for lesbians with disabilities.⁶ Another source of support worth mentioning is the annual *Lesbenfrühlingstreffen* [lesbian spring gathering, taking place in 2010 in Hamburg] as a meeting place for lesbians with disabilities.⁷

2 Acrotomophiles are (mostly) men who find female leg amputees particularly sexually attractive and frequently seek them out in the "lonely hearts" columns or at specialist trade fairs, e.g. the *Rehacare* trade fair. This can (but does not necessarily) lead to assaults and prosecution. Some women notice that when they enter a relationship they are reduced to their amputation in the other person's eyes.

3 The film "Vom Charme des Makels" [On the charm of the flaw] was produced in Austria in 2005 and part-financed by the European Social Fund. It is based on an exhibition of photographs. In May 2007, a number of photo models, the artist, TERESA LUGSTEIN from *make it – Büro für Mädchenförderung* [an organisation promoting the advancement of girls] based in Salzburg, Austria, and Martina Puschke from Weibernetz e.V. became engaged in a controversial debate about this film. Many questions remained unanswered, such as why only amputated women were photographed and whether a photo in which the blade of a circular saw is held against an amputated leg stump glorifies violence.

4 For more on sexual surrogacy, see the website of the Institut zur Selbst-Bestimmung Behindert, ISSB [an institute promoting the self-determination of persons with disabilities]: www.sexualbegleitung.org/was.htm

5 For a list of groups and advisory services for lesbians with disabilities, see also the Weibernetz e.V. website at www.weibernetz.de/lesben.ht

6 Cf.: RuT – Rad und Tat e.V. Offene Initiative Lesbischer Frauen e.V. in Berlin, www.lesbischeinitiativerut.de and www.lesbenfruehling.de

7 Cf. www.lesbenfruehling.de

Impact of sexual violence on sexual experience

Sexual violence is not sexuality. Sexual violence is violence. Violence where power is exercised. Nevertheless, we must digress briefly in this article to discuss sexual violence. Experiencing sexual violence can significantly impair a person's future sexual life. Fear of experiencing further assaults, including violence, can reduce the desire for closeness and intimacy with sexual partners or make it difficult or even impossible for the victim to achieve intimacy with another person.

Traumatisation can occur many years after the violence has been perpetrated, affecting the woman's own body awareness, her ability to achieve intimacy with other people and her own sexuality. We know in particular of elderly women in care situations who are "re-traumatised" in old age as a result of rapes that occurred during the Second World War. The huge effect that this has on their experience of their body is just one of the adverse effects that they suffer. It is important therefore that, in addition to good sexuality education and the creation of constructive conditions for experiencing sexuality, we explore the prevention of violence and the provision of help after violence has been experienced.

Women with disabilities frequently experience (sexual) violence. An Austrian study carried out in 1996 proved that 60% of women who live in institutions experience violence (ZEMP/PIRCHER 1996). To date, no representative figures are available for Germany. That is about to change however. The Bundesministerium für Familie, Senioren, Frauen und Jugend, BMFSFJ [Federal Ministry of Family Affairs, Senior Citizens, Women and Youth] has commissioned a study entitled "Lebenssituation und Belastungen von Frauen mit Behinderungen und Beeinträchtigungen in Deutschland" [Life situations and pressures on women with disabilities and impairments in Germany]. As part of this study, researchers from the Interdisziplinäres Zentrum für Frauen- und Geschlechterforschung, IFF [an interdisciplinary centre which conducts research on issues relating to women and gender] at the University of Bielefeld are currently working with colleagues to investigate the extent of violence suffered by women with disabilities in Germany based on representative data collected by the researchers. The results of the study will be available in 2011.

Action is vital if we want to prevent violence and provide assistance to women who experience violence. In recent years, a number of services and projects have been specially tailored to meet the requirements of women and girls with disabilities. The following section contains some examples.

To protect themselves from violence, women with disabilities worked with Wen-Do trainers in the 1990s to develop assertiveness and self-defence courses especially for women with various disabilities. Since then, these courses have been conducted by different providers, although no nationwide network of services exists.

In 2001, "Übungen für behinderte oder von Behinderung bedrohte Frauen und Mädchen, die der Stärkung des Selbstbewusstseins dienen" [Training to increase self-confidence for disabled women and girls or women and girls who are at risk of being disabled], were enshrined in legislation.⁸ These exercises are based on the courses described above but are taught as part of rehabilitation sports. Once they have been prescribed by a doctor, the relevant rehabilitation fund (e.g. statutory health insurance fund or pension insurance institution) covers the cost of the training. As most regional disability sports associations, and branches of these associations that provide rehabilitation sports, are represented in all German federal states, activists had reason to hope that suitable courses could soon be provided in all federal states for women and girls. However, they are still waiting in vain for this training. Nine years after German Social Security Code (IX) came into force, this training is still not being provided as part of rehabilitation sports.

Since the training involved a whole new service that providers had never had to provide before, the BMFSFJ first commissioned a three-year research project entitled "SELBST – Selbstbewusstsein für behinderte Mädchen und Frauen (§ 44 SGB IX)" [SELF – Self-confidence for disabled women and girls (Social Security Code (IX) Article 44)]. Under the auspices of this project, conducted jointly by the Evangelische Fachhochschule Rheinland-Westfalen-Lippe [Protestant University of Applied Sciences Rhineland – Westphalia – Lippe] and the Deutscher Behindertensportverband, DBS, [German federation of disability sport], a curriculum of self-confidence-raising training and a train-the-trainer curriculum were developed. The curriculum for the training was evaluated as successful, which meant that both curricula have been available since the project finished in December 2006.⁹

The DBS has not yet implemented the results of the SELBST project. In 2006, one woman with learning difficulties (or rather her father, who acted as claimant) succeeded in obtaining funding for this training: the woman's statutory healthcare insurer was forced to reimburse her for the cost of engaging a private trainer to provide an assertiveness course and a self-defence training course because there was no appropriate rehabilitation sports service in the area where she lived.¹⁰

Women with disabilities initiate Action Plan to combat violence

The German federal government's 2007 Action Plan II to combat violence against women cited women and girls with disabilities as its target group and established specific projects in this regard.

Therefore, since the spring of 2009, women with learning disabilities are being trained as part of the "Frauenbeauftragte in Einrichtungen" [women's representatives in institutions] project to work as women's representatives in sheltered workshops and residential homes. One topic that is comprehensively covered during training is violence against women in institutions. In eight training units, the participants are prepared for their role as a contact for the women in "their" institution. They are supported in their new role as women's representatives by another person in the institution. In some cases, this is an employee in the sheltered workshop; in others, an external facilitator is

8 Cf. German Social Security Code (IX), Article 44 Paragraph 1 No. 3

9 The final report can be downloaded at www.bmfsfj.de/BMFSFJ/Service/Publikationen/publikationsliste.did=i2izi4.html

10 Cf. Social Court [Sozialgericht], Konstanz, AZ.: S 8 KR 1641/05, Judgement from 29. 6. 2006

involved. The Weibernetz e.V. project will be conducted in cooperation with Mensch zuerst – Netzwerk People First Deutschland e.V. until the middle of 2011 and will be sponsored by the BMFSFJ.¹¹

The “Laut(er) starke Frauen” project [Women with Voices], which aims to prevent violence against women and girls with disabilities or chronic illnesses, has also been established as part of the Action Plan. In this initiative, which is run jointly by the BAG Selbsthilfe [the German task force charged with assisting persons with disabilities and chronic illnesses], the LAG Selbsthilfe NRW [a member organisation of the German task force, working at state level in North Rhine-Westphalia] and the Netzwerkbüro Frauen und Mädchen mit Behinderung/chronischer Erkrankung NRW [a network for women and girls with disabilities/chronic illnesses in North Rhine-Westphalia] and funded by the Bundesministerium für Gesundheit [Federal Ministry of Health], projects relating to this issue will continue to be integrated into the Action Plan until the summer of 2010. By getting to know one another and sharing information and experiences, the aim is for women with disabilities to have improved access to support services.¹²

In addition to nationwide projects, other services have been initiated by individual agencies or on a cross-agency basis. The Caritasverband für das Erzbistum Paderborn e.V. [an association of Catholic welfare organisations in Paderborn] and the Sozialdienst katholischer Frauen Paderborn e.V. [Paderborn-based organisation providing counselling and information for women, single parents and families] formed a network to combat sexual violence against people with learning difficulties and intellectual disabilities. For several years now, the Bundesvereinigung Lebenshilfe e.V. [German federal association of people with intellectual disabilities] has been providing seminars on the issue both for women with learning difficulties and employees. In the AWO Bezirksverband Niederrhein e.V. [workers’ welfare association based in the Lower Rhine area], the Lore-Agnes-Haus in Essen offers advice on preventive measures against sexual violence as part of its project entitled “In Sachen Liebe unterwegs” [On the road. Talking about love] (cf. ANNETTE WILKE’s article, pp. 40 ff., editors’ note). Pro familia is another organisation that has been addressing sexuality and sexual violence for many years. These are just some of the projects that show that the taboo surrounding sexual violence against women and girls (and in some cases against boys and men) with disabilities is being overcome.

Support system still not accessible

The positive examples shown here should not disguise the fact that, as in the past, the support system available for victims of violence is not always accessible. Only about 10% of women’s shelters have limited accessibility for persons with disabilities and even women’s emergency helpline and advice centres are only slowly opening up for individual target groups by becoming wheelchair-accessible, encouraging staff to learn sign language or developing materials in plain language, for example. Individual women’s advice centres such as Wildwasser e.V. offer a special advisory service for girls and women with disabilities, in some cases in collaboration with disabled women’s networks (such as those established in Mainz and Berlin).

In Summary

This brief discussion shows the dynamic nature of the issue of the sexuality of women (and men) with disabilities. One positive development is that activities are emerging from a variety of sources. Women with disabilities are gaining self-confidence, showing themselves to the public in a positive light by posing for erotic photographs and demanding their right to self-determined sexuality. No researchers (hopefully) would now dare to ask whether people with disabilities can, should or are allowed to marry. Educational material is produced for disabled young people as a target group. The German federal government funds relevant projects. The issue is gradually becoming less of a taboo subject within services for persons with disabilities and more and more women’s projects are catering for disabled women.

But there is no room for complacency. Despite all the positive and diverse representation, we must not forget that self-determined sexuality, relationships and parenthood are human rights. These rights were formulated with special consideration for persons with disabilities in the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Each individual case in which these rights cannot be exercised represents a human rights violation.

Martina Puschke

¹¹ Information available at: www.weibernetz.de/frauenbeauftragte

¹² Information available at: www.bag-selbsthilfe.de/news/1880/projekt-lauter-er-starke-frauen



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Nobody's perfect.

The tasks and goals of the association “Mensch zuerst – Netzwerk People First Deutschland”

At Mensch zuerst, we demand that people with disabilities and people without disabilities have equal rights in all areas. This also applies to the areas of sexuality, relationships and family.

Mensch zuerst – Netzwerk People First Deutschland e.V. is an association organised by and for people with learning difficulties. The People First movement came to Germany from the USA at the beginning of the 1990s. Our association was founded in 2001 and has around 250 members who come from all over Germany, Austria and Italy. There are also 23 People First groups in Germany, who work in a network with us.

We are people who do not like to be described as “intellectually disabled”. We reject this term, as do many other people. Who has the right to say: “You are intellectually disabled and you are not”? Who decides where the bar is set? How is intellectual ability measured? Perhaps we are simply people with different strengths and abilities?

We use the term “people with learning difficulties” because we experience difficulty in learning. People with learning difficulties like us may learn differently and sometimes need support or more time.

What do we do?

- self-determination and self-advocacy of people with learning difficulties
- plain language
- political work
- PR work
- training for advisory committees in residential homes and workshops
- training for women with learning difficulties with regard to equal treatment in residential homes and workshops
- personal life planning.

Why do we do this?

Self-determination and self-advocacy are important for all people – everyone would prefer to make decisions about their own lives as much as possible when it comes to issues

like: “Where shall I live?”, “Where shall I work?” or “Who would I like to live with?”

Plain language is a language that everyone can understand. Unfortunately, many people in Germany believe that “when I use complicated language or ‘dictionary’ words, then I know a great deal”. However, this makes life difficult for people with learning difficulties and many other people.

At Mensch zuerst we translate difficult texts into plain language. This means avoiding “dictionary” words; writing short sentences; explaining words; using images to assist understanding and using easy-to-read large print.

We have submitted a petition to the German Bundestag and hope that plain language will become a right. More than 13,500 signatures were collected.

We hope that applications, letters and laws will soon be written in plain language so that everyone can understand them.

We deliver training for people with learning difficulties so that they can learn about their rights. We often find that advisory committees in residential homes and workshops take their work very seriously, but that they are not always aware of their rights and duties. We work with Weibernetz e.V. in order to deliver training to women’s representatives in residential homes and workshops. Weibernetz e.V. is a nationwide political advocacy group by and for women with disabilities (cf. article by MARTINA PUSCHKE in this issue, editors’ note).

There are women’s representatives in many companies in the formal employment sector. This is a right. Yet why are there so few women’s representatives in residential homes and workshops today? In cooperation with Mensch zuerst, Weibernetz e.V. demands that there be women’s representatives in all residential homes and workshops. Women with learning difficulties are confronted more often with sexual violence and harassment: it is easier to ignore them when they say “NO!”.

Many women in residential homes are dependent on their care workers and on other people with learning difficulties. This makes it even more difficult to say “No”.

People with learning difficulties very often need different kinds of support throughout their entire life, for example, when taking a shower or using the toilet, they are usually assisted by people that they did not choose themselves. People with learning difficulties often have only two choices: either they accept the care worker present or they cannot use the toilet or take a shower. People with learning difficulties are also dependent on their care workers when it comes to leisure activities. Many of them have to rely on the good will of their care workers in order to spend their leisure time as they would like. We do not think this is a self-determined way to live one's life. However, this applies not only to people with learning difficulties. This also affects many older people or persons requiring care.

People with learning difficulties and sexuality

Another difficult issue for people with learning difficulties is sexuality. At Mensch zuerst we believe that it is time for the taboo surrounding sexuality and disability to be removed. We would like all advisory centres dealing with the issues of sexuality, bringing up a child and the desire to have a family to advise and support people with learning difficulties.

Relationships must be accepted in workshops and residential facilities. However, this is often not the case. Care workers and parents often still make decisions for people with learning difficulties and say: "You cannot have a relationship or experience your sexuality!"

We believe that everyone has the right to decide for him- or herself about a relationship, even if other people, for example, care workers and parents say: "This relationship is not good for you because you are not good for each other". Yet we often observe relationships between people without disabilities that work very well, even though outsiders said: "That will never work". But in this case, outsiders do not interfere.

People with learning difficulties are often forbidden to do things by laws made by persons without disabilities. But such laws are only necessary when a person is not able to deal with an issue by him- or herself. Openness towards people with learning difficulties is necessary; this openness must also be proactive.

Relationships can also begin in the workplace. However, this issue is treated differently inside and outside sheltered workshops. Relationships are not particularly welcome outside such workshops, but are accepted. They are not forbidden in principle by their employer. Why are things different in workshops? Couples are prevented from seeing each other, for example. This is not the equal treatment that applies to everyone that is stated in the German Basic Law.

We believe that if two people are in love with each other, then they should be allowed to have sex. The issues of sexuality and relationships must be dealt with in an open way in residential homes and workshops. Known contact points must be available for and accessible to people with learning difficulties, where they can receive advice on this issue.

Contraceptive methods and illnesses must also be properly explained in a way that is easy to understand. Everyone must be able to choose which doctor he or she would like to see.

The desire to have a family

Some people with learning difficulties also have the natural desire to have a family. Nobody has the right to forbid them to do so. We are well aware that some people with learning difficulties need support in looking after and bringing up their children. But people without disabilities need this too.

Parents with learning difficulties, in particular, are kept under much closer observation by their parents, their residential home, the social services and society. This intense observation creates a great deal of pressure. And when parents are placed under pressure, then mistakes can be made that are judged in a certain way by society because the parents are people with learning difficulties. Yet when we observe parents without learning difficulties, there are situations where we would like to voice our opinion. But we are not allowed to do this. We do not believe that people with learning difficulties make worse parents. People with learning difficulties can also look after their children well, if necessary, with help and support. The statement – "Nobody's perfect" – is very relevant here.

Nobody has the right to force parents to give up their children for adoption because they are people with learning difficulties. Support services should be found that enable the children to stay with their biological parents.

We often become aware in discussions that the prejudice exists that parents with learning difficulties will also have children with learning difficulties/disabilities. This shows us that society itself still has a lot to learn about the issue of disability and children. Today, people with disabilities and people without disabilities live in two different worlds. This needs to change.

Previously, women with learning difficulties were often forced to terminate their pregnancy. Today, pregnant women with learning difficulties face pressure from all sides: "You will not be able to bring up a child". In this way, women are indirectly forced to terminate their pregnancy.

Both of these approaches are an infringement of human dignity and can have negative effects on the mental health of these women for the rest of their lives. It is also not acceptable that men and women are sterilised against their will.

We need to change the way we think

Ultimately society needs to change the way it thinks. This can take place with the support of counselling services, brochures and public information activities. However this work must use a language that all people with learning difficulties can understand. And so, we return to the issue of plain language. What is the point of brochures on sexuality, talking to doctors or counselling services if they use difficult language that people with learning difficulties cannot understand? It is important that doctors and care workers use plain language so that people with learning difficulties can also understand what is being said. A good example of plain language is the informational leaflet by AWO [workers' welfare association] "Liebe(r) selbstbestimmt", [Love and self-determination, by and for ourselves] (cf. Infotheque, editors' note). This discusses the issues of love, relationships, sexuality and the desire to have family in plain language. More material like this needs to be developed, and it must be made available to many people with learning difficulties.

Peer counselling – people with disabilities counselling other people with disabilities – is an area that we believe should be developed. People with learning difficulties, who already have children, for example, can work in counselling services in order to counsel other people who would like to have children.

The UN Convention on the Rights of Persons with Disabilities strengthens the rights of people with learning difficulties in the areas of relationships, sexuality and health. Germany has also signed the UN Convention. Now it is time to also implement the Convention so that people with learning difficulties receive equal treatment in all areas and can live their lives in a self-determined way – like everyone else.

The UN Convention exists on paper; unfortunately it has not yet been implemented in society. People with disabilities and people without disabilities must be open to each other. We can only change things if we work together.

Stefan Göthling



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“I will decide myself!”

Preventing sexual violence against people with disabilities

People with disabilities are particularly at risk of falling victim to sexual violence. Based on studies carried out in the USA, Austria and Germany, experts believe that people with disabilities are twice as likely to be affected by sexual violence than people without disabilities.

What is sexual exploitation?

Sexual exploitation occurs when one person is used by another as an object to satisfy certain needs and the perpetrator of this action does not have the free and informed consent of the other person. Sexual exploitation is the manifestation of an unequal power relationship. A power asymmetry exists for disabled people when it comes to the power to decide on how resources are allocated, the power to articulate, informational power, positional power and the power to organise. Sexual exploitation always involves secrecy.

Extent of sexual violence against people with disabilities

A total of 130 women and men aged between 18 and 78 were surveyed in the two studies “Weil das alles weh tut mit Gewalt – Sexuelle Ausbeutung von Mädchen und Frauen mit Behinderung” [Because everything concerning violence

hurts – sexual exploitation of girls and women with disabilities] (ZEMP/PIRCHER 1996) and “Sexualisierte Gewalt im behinderten Alltag – Jungen und Männer mit Behinderung als Opfer und Täter” [Sexual violence in the everyday life of people with disabilities – boys and men with disabilities as victims and perpetrators] (ZEMP et al. 1997). We made a distinction between sexual harassment and sexual violence in the types of behaviour surveyed.

According to our data, 26% of women had been raped at least once; the figure for men was 7%. It is always important to include the gender aspect in such studies.

Background to sexual violence against people with disabilities

We live in a culture that defines people with disabilities according to deficits: non-functionality must be compensated for as much as possible. There is a lack of resource-oriented thinking, which looks at what is possible and provides the appropriate maximum support. With a deficit-oriented approach, the child – consciously or unconsciously – perceives a particular message: “There is something wrong with me; they want me to be different”. This perception is often reinforced by the many therapies that children and young people with disabilities must endure. The question we must ask is whether these therapies really benefit the child and alleviate his or her limitations or conditions or whether they are an attempt to “normalise” the child. Everyone, including people with cognitive impairments, perceives this basic attitude very clearly in their own way. Given this prevailing attitude, girls and boys, women and men learn all too rarely that their body deserves love and protection, even if it is different.

People with disabilities are subject to particular risk factors, including:

- greater dependency on others,
- a dependency on care and a great need for support in everyday life,

Tab. 1		
Sexual harassment/sexual violence		
Women	Sexual harassment	Sexual violence
Yes	62,3	63,8
No	37,7	36,2
Total	100,0	100,0
Men	Sexual harassment	Sexual violence
Yes	38,4	50,3
No	61,6	49,7
Total	100,0	100,0

Source: Zemp/Pircher 1996; Zemp et al. 1997; figures in %

- cognitive inferiority,
- social isolation,
- limited communication skills (some people cannot communicate verbally; for some, physical contact may be their only way of communicating),
- medical examinations and therapies that make it difficult for people with disabilities to perceive their body in a positive light and to know their own limits (people with disabilities therefore find it difficult to understand transgressions of boundaries),
- lack of a process-based and individually tailored sexuality education programme.

Who are the perpetrators?

The perpetrators come from the disabled person's immediate environment: family, sports organisations, institutions. Some perpetrators systematically seek out institutions where they can work – as managers, care workers, workshop supervisors, etc. Care workers are often dismissed from an institution because they are suspected of assaults and sexual violence but no definitive proof can be obtained. Sometimes an institution is aware that assaults are taking place but no action is taken to prevent this behaviour. Other grounds are stipulated for the dismissal. This means that such incidents do not appear in the perpetrator's CV and he or she is hired by another institution.

Unfortunately, sexual violence among people with disabilities themselves occurs much more frequently than was previously assumed. In the study conducted on violence against women, men with disabilities were the third most likely perpetrators; in the study on men, they were the main perpetrators. Preventive work regarding perpetrators must be increased and continued. Sexuality education represents a vital component in this process. Our findings show that, particularly where violence against people with disabilities takes place, the offenders have generally not received any sexuality education and their actions are based on a lack of knowledge. In most cases they are simply perpetrating what they themselves have experienced because they believe that this is how sexuality is experienced. Many of them have experienced sexual violence at the hands of men without disabilities and therefore think that this is the way in which men without disabilities experience sexuality.

Victims send out clear signals

Sexual violence can lead to huge physical and mental health problems for victims and causes a great deal of suffering.

People with disabilities who are affected by sexual violence draw attention to their experiences in their own way. For example, they present with behavioural or perceptual disorders, behave aggressively towards themselves or others, or exhibit regressive behaviour. Affected individuals may suddenly begin to suffer from dizzy spells. When tested for epilepsy, the results are negative. Regardless of the negative result, they are prescribed medication for the condition, despite the well-documented and serious side effects. Administering this medication divests victims of their survival strategy because the dizzy spells occur when a noise, an image, a smell, etc., reminds them of the violent experience. In such cases, the dizzy spell helps to temporarily suppress

the traumatising images. These types of signals are very often prematurely ascribed to the disability. This can prevent affected children, young people and adults with disabilities from receiving the necessary help that could be provided.

Girls and boys with disabilities are hardly in a position to independently acquire the relevant information and to avail of support services. A key caregiver generally determines whether children and young people with disabilities require counselling. This key caregiver is very often a special needs teacher or therapist and is someone who should be integrated more fully into neuropaediatric practice. Such individuals are important and are often the only key caregivers outside the family who the children can trust or confide in and who can take any relevant action.

Crisis in sexuality education

One of the theories that motivated our study was the connection between the level of sexual violence and lack of education. More than half (52%) of the female respondents and two-thirds (66%) of the men stated that they had not received sexuality education or could not understand the questions.

The women were most likely to know the difference between men and women and half of them understood the connection between the sexual act and the conception of a child; for men, the figure was just under 40%. Around 46% of the women knew something about ejaculation while only 28% of the male respondents knew about menstruation. Only 18% of men knew how to use a condom. Among the respondents, 43% of women, but only 30% of men, knew about contraception. The different levels of knowledge among women and men with disabilities indicate that women with disabilities tend to be more knowledgeable due to the risk of pregnancy.

However it was not possible to verify this theory. We could not find any relevant connection between the extent of sexual violence and the level of sexuality education. However, the study did reveal that women who had experienced sexual violence were aware of individual aspects of sexuality but women who had not experienced violence were hardly aware or were aware to a much lesser extent. This implies that for most women with learning difficulties, an experience of sexual violence is often the only sexuality education that they receive – a shocking fact that urgently needs to be addressed.

Contraception

Another theory that motivated our study was that many women who do not have a partner use contraception, or rather are forced to do so, with or without their knowledge, for fear of a possible pregnancy resulting from rape. For the women, however, the threat of sexual violence increases because they are at risk of being seen as "fair game".

This theory – that many more women use contraception than are actually in a relationship – was confirmed. If we include (compulsory) sterilisation as a means of contraception, the percentage of women who use birth control is almost as high as the percentage of women who do not use it (43.8% compared to 43.1%), even though at the time of the survey only 13% of the women were in a relationship. Of the

Tab. 2

Level of knowledge about sex**Women**

Level of knowledge about sex	Yes	No	No answer/ don't know
Difference between women and men	64,6	26,2	9,2
Menstruation	48,5	38,5	13,0
Ejaculation	32,3	46,2	21,6
Sexual intercourse	47,7	36,9	15,4
Conception	51,5	32,3	16,1
Contraception	43,1	36,2	20,2
Birth	46,9	33,1	20,0
Sexual violence	46,2	28,5	25,4

Men

Level of knowledge about sex	Yes	No	No answer/ don't know
Erections	41,9	5,1	53,0
Ejaculation	40,2	6,8	53,0
Masturbation	41,1	6,0	52,1
Homosexuality	25,6	19,7	54,7
Heterosexuality	41,0	6,0	53,0
Conception	39,3	4,3	56,4
Menstruation	28,2	17,1	54,7
Contraception	30,8	13,7	55,5
Petting	29,1	15,4	55,5
Sexually contracted diseases	23,1	21,4	54,7
Using a condom	17,9	20,5	61,5
Being able to say "no"	41,9	2,6	55,5
Respecting a person's right to say "no"	38,5	2,6	58,9
Sexual violence	35,0	7,7	57,2

Source: Zemp/Pircher 1996; Zemp et al. 1997; figures in %

women who were protected against pregnancy, 62.5% were sterilised.

Sustainable prevention

According to CAPLAN (1974), the objectives of prevention can be subdivided into three time-related categories. Primary prevention aims at reducing or preventing the occurrence of sexual violence against children throughout society as a whole. The objective of secondary prevention is to identify and put a stop to violent situations at an early stage. Tertiary prevention involves treating victims of trauma and preventing perpetrators from reoffending.

The preferred strategy for preventing sexual violence against children begins with sexuality education and upbringing. Effective prevention takes into consideration the fact that most sexual assaults occur within the family or the local community. Sexuality education increases children's self-confidence and encourages their independence. It also informs girls and boys about sexual exploitation and provides them with specific options as to the action they can take. Children who have received sexuality education and who feel strong and secure can identify sexual assaults more easily

and are more able to protect themselves against them. However, responsibility for protecting themselves against sexual assault must never be delegated solely to the children – responsibility lies first and foremost with adults. Sustainable prevention requires an educational strategy that is effective on an ongoing basis and strengthens children's resources and rights. This latter point is extremely important for children with disabilities as it creates an environment that assumes a resource-based concept of humankind and does not focus on deficits. Those responsible for education must themselves address the issue of sexual violence, reflect on the way they deal with sexuality, power and boundaries and set the children an example of how prevention works on a daily basis.

Three principles must be observed in order to demonstrate to persons with disabilities that prevention can be effective:

1. The isolation and exclusion of persons with disabilities must be reduced.

Studies show that the more isolated disabled people are, the more likely it is that sexual violence will occur. It is important therefore to integrate children and young people with disabilities into all areas of daily life and not separate them from other people.

2. Powerlessness must be eliminated and independence must be promoted.

The guiding principle favoured by Italian doctor Maria Montessori – "help me to do it myself" – is one of the most important educational principles for children and young people, including those with disabilities. They are neither stupid nor incapable. Any support that they are given to assist them in doing as much as possible for themselves also boosts their self-confidence. Preventive education reduces their feeling of powerlessness and promotes a feeling of being able to achieve something and assert themselves. This begins with quite ordinary, everyday matters.

3. Preventive education must provide access to information about the body, sexuality and sexual violence.

Lack of knowledge and dependency make people with disabilities "ideal" victims. In order for them to be able to defend themselves against sexual assaults and obtain help, the appropriate language and information are required. Sexuality education is therefore an important element of prevention. It is important for young people to be aware of their own bodies and how they work and know about their genital organs in order to experience self-determined sexuality and to be able to recognise and repudiate any transgressions of these boundaries. This applies also to disabled people who cannot communicate verbally or can only do so to a limited extent.

The sexuality education of people with cognitive limitations must be an ongoing process, from early childhood to old age: it is not enough to simply explain things to them once at the age of 15 and then assume that they will remember it for the rest of their lives. Sexuality education therefore cannot be delegated to a group of key caregivers – everyone must address the issue of sexuality in the course of everyday life.

We must not restrict ourselves to simply responding to what is asked explicitly because people with cognitive

limitations in particular often do not ask and often cannot ask because they do not have the words required.

It is worth emphasising once again that, with all preventive work, responsibility must never be shifted onto the dependent individuals. Responsibility for the prevention of sexual violence lies with the people who live and work with people with disabilities.

Prevention can also foster a culture of disclosure. If the issue is addressed in school, then children are encouraged to speak out about specific incidents and report more frequently about their own experiences of violence following such programmes. As a result, sexual violence against children and young people can be identified at an earlier stage and stopped (secondary preventive effect). However, this requires teachers to have a basic knowledge of dealing with the issue and to be aware of support services that affected children and young people can access. If prevention is to be effective in the long term, it needs not only committed teachers and motivated parents but also structural measures whose long-term objective is to permanently prevent sexual violence in the school, institution and family.

Self-determined sexuality as an important preventive measure

Sexual violence is always a violation of the victim's self-determination. The two issues of sexual violence and sexual self-determination are therefore closely related. Nevertheless, sexual self-determination must not be seen only in this context. Fortunately it also exists independently of the phenomenon of sexual violence, namely when sexuality can be experienced according to a person's own wishes and needs. Staff in institutions often oppose sexual contact between residents because such relationships show signs of sexual exploitation (cf. FEGERT/JESCHKE/THOMAS/LEHMKUHL 2006, pp. 250 ff.). This raises the question of the staff's ability to teach sexuality education. Staff must be trained to not only permit but also encourage the sexual self-determination of residents. This in turn requires them to reflect on their own standards and values in relation to sexuality and to engage in a self-critical analysis of how they themselves deal with power. Every relationship of dependence is simultaneously a power relationship. If, for example, a care worker is uncomfortable with the concept of homosexuality, it does not give the care worker the right to use his or her power to proscribe or suppress the homosexuality of a dependent person. Both staff and parents generally feel a great need to monitor and control their disabled residents/family members, particularly their sleeping arrangements and contraceptive measures. Staff and parents are more fearful of losing control over sexuality-related areas than any other area.

Self-determined sexuality also requires privacy. This includes the right to personal decisions and behaviour in relation to intimacy, provided that these do not affect the sexual rights of others. As in the past, there are very few institutions in which residents can lock their own rooms. In many cases, (even if a disabled person is living at home with his or her parents), people do not knock before they enter the room or they knock while coming into the room (a "token knock"). At "peak times" in institutions, such as mornings and evenings, the bathroom resembles a busy railway station: someone is having a bath but care workers

go in and out to wash out hand basins or to perform some other task.

The right to experience our own sexuality is part and parcel of the basic right of personal freedom and applies also to people with disabilities. Basic rights in relation to sexuality include the following:

- the right to privacy,
- the right to freedom from harm,
- the right to sexuality education,
- the right to sexual services,
- the right to have children,
- the right to a sense of self.

Aiha Zemp



Dr. phil. Aiha Zemp is a psychotherapist who has run her own practice since 1997. She was appointed by the Austrian Minister for Women to conduct the world's first-ever study on the subject of sexual violence against persons with disabilities. She set up fabs – Fachstelle Behinderung & Sexualität [fabs –office for disability & sexuality] and has been its Director since it opened in May 2006.

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Supporting and promoting sexual self-determination.

Continuing professional development (CPD) in the context of services for people with disabilities

Since 1989, the Institut für Sexualpädagogik (isp) in Dortmund has regularly provided specialised training and qualifications in sexuality education for persons working in the social work field. Since 2003, the isp has also delivered a CPD programme for people working full-time – “Sexuality and disability”. This article looks at the ideas behind this, the need for this programme, how it is taught and also outlines the experiences of some participants and the effects of the programme on their professional practice.

The understanding of sexuality education as a lifelong process

Sexuality education is now established as a major issue in institutions providing services for people with disabilities. Since sexuality education has been debated and developed in Germany as a consequence of many years of work in the area of sexuality education with children and young people, and since adults have long been included as a target group of this education, it is astonishing that the general prevalence of this issue in institutions providing services for people with disabilities is progressing at such a slow pace and is beset with such difficulties. In their introduction to the textbook “Sexualpädagogik und sexuelle Bildung” [Teaching and learning sexuality education] UWE SIELERT and RENATE-BERENIKE SCHMIDT write: “There are clear signs that society’s awareness of sexuality education has increased in recent years. The need to provide children and young people with sexuality education is being articulated more clearly; there are more opportunities for training and continuing professional development; the legal framework has been extended and the results of research projects and theoretical concepts are being published.” (SIELERT/SCHMIDT 2008, p. 11)

Yet what does this mean for adults, who due to disability, require support and advice on issues relating to sexuality and relationships that is similar to that which is provided for children and young people, but the social framework for this does not exist or the necessary support is not available?

The social dimension of sexuality education

In 1983, the social psychologist JOACHIM WALTER in particular, began publishing books and essays in journals on a regular basis that highlighted the particular situation of people with disabilities, who have the same right as anyone else to experience self-determined sexuality. In his definitive work “Sexualität und geistige Behinderung” [Sexuality and

intellectual disability] WALTER and his co-authors highlight the connection between the importance of sexuality and integration in society. In his article, REINHART LEMPP emphasises that integration in society is not necessary in order to experience a sexuality accepted by society. Instead, it is the experience of sexuality that is the prerequisite for integration in society (LEMPP 1996). This statement is exemplary for many other contexts that restrict the lives of people with disabilities, not only in the areas of relationships and sexuality.

Social, economic and biographical factors restrict the normality of the sexual diversity of people, who, for a range of different reasons, have a greater need for support as adults, but also as children and young people. The following socially imposed restrictions create particular obstacles in this context: limited or even non-existent provision of education about the body and sexuality, the lack of (unsupervised) spaces for learning and experiencing, an institutional framework that complicates the issues of relationships, intimacy and privacy, the dependence on care and support from third parties and the interference of family members and institutional care workers.

Many dedicated people are well aware of these issues, and an increasing number of these people now work in institutions providing services for people with disabilities. The far-reaching taboo regarding the sexual needs of people with intellectual or physical disabilities seems to have been replaced with the view of sexuality and sexual self-determination as a basic right; yet when we look at the issue in practice, the picture is very different. The situation is characterised by uncertainty on the part of care staff, lack of knowledge of legal stipulations with regard to sexuality and of how to provide the corresponding sexuality education, how to help couples and how to provide sexual support as part of everyday life.

Furthermore, as was previously the case when working with children and young people, the desire to protect overrides any liberating or invigorating energies when it comes to developing concepts and practical measures for

couples counselling and sexual surrogacy. SIELERT and SCHMIDT write: "However if we wish to develop a new sexuality education, then this must stop being defensive, or to put it more positively, it must stop focusing on potential dangers, but instead 'naturally' also focus on the 'cultivation' of sexuality, on 'sexual desire and knowledge'." (SIELERT/SCHMIDT 2008, p. 11). This is a fundamental concept that could also become a guiding concept in institutions providing services for people with disabilities and could complement in a meaningful way the normally reactive small programmes already in existence.

The idea

Far-reaching changes normally only take place if supported "from the outside", if enough time is made available and if specialised training and qualifications are involved. Continuing professional development (CPD), concepts relating to sexuality, supervision and the opportunity to reflect on one's own actions all have a supportive effect. This is why the isp set up a one-year CPD programme focusing on "sexuality and disability" in Germany.

The isp is the leading professional institute for teaching and learning about sexuality education in German-speaking countries. Since 1989, the institute has regularly provided specialist training and qualifications in sexuality education for people from heterogeneous, psychosocial fields within social work. The experiences of these CPD programmes prove the effectiveness of general sexuality education training and qualifications as well as the long-term significance of embedding this issue in the institutional context. Staff from institutions providing services for people with disabilities are increasingly taking advantage of these programmes. The CPD programme delivers a great deal of information and ideas that stimulate critical analysis, reflection and suggestions on how the information can be implemented in everyday life. However, on repeated occasions it became clear that both parallels and significant differences exist with regard to other professional areas, meaning that it is necessary to specialise in specific thematic areas (e.g. sexual support and sexual assistance). For this reason, and after discussions with experts in this area like Joachim Walter as well as with persons working in this field, the idea came about to develop and establish an additional CPD programme focussing on "disability" in Germany. This will be delivered in 2010/2011 for the fifth time (cf. Infotheque). A further programme could be delivered in Austria and in Germany (as in-house training for a large institution). We can look back with some pride on these programmes that run parallel to sexuality education programmes. In this way, it is not only staff in institutions providing services for people with disabilities who have the opportunity to attain qualifications and pass on this knowledge within the institutional framework, the isp is also creating a new social focus. People, who due to disability are dependent on others in order to experience their sexuality, be it completely, partially or throughout their entire life, have the right to receive comprehensive help and support from trained and qualified persons. Thus in future it will be necessary to train caregivers and to focus on research and empirical knowledge in these thematic areas.

isp: need and services

Even if issues like sexuality and relationships and the concept of sexuality educational intervention in institutions providing services for people with disabilities are no longer new, the embedding of the CPD programme was an innovative step forward, which, according to the isp, was long overdue in Germany. Even if the definitive work "Sexualität und geistige Behinderung" [Sexuality and intellectual disability] (WALTER 1983) was published some years ago, it has lost none of its significance or relevance today. In addition to Walter's work, a great number of other publications have appeared recently, which emphatically illustrate one issue: despite the increasing normalisation of living conditions and ongoing efforts at integrating people with disabilities, sexuality is still not an "everyday" part of their lives. The worthwhile goal of sexual self-determination for everyone as well as sex-positive conditions in residential homes and workshops is being achieved in institutions at a very slow pace.

Many home and workshop staff do not feel adequately trained for the complex challenges faced when carrying out appropriate sexuality education work. They express both great need for continuing professional development and high personal interest. This is also demonstrated by the increased number of CPD seminars on sexuality education delivered by a range of providers and training institutes; nevertheless so far these have only been short-term in nature. In order to establish long-term and solid competence in the field of sexuality education in institutions providing services for people with disabilities, then "teachers" must be trained to disseminate knowledge to diverse target groups. The isp has been successful in filling this gap in the provision of CPD programmes for people working full-time. With the support of JOACHIM WALTER and the Institut für Weiterbildung der Hochschule Freiburg [Institute of continuing education, Protestant University for Applied Sciences] the first programme was established in January 2003. Due to this CPD programme, the cooperating institutions were able to respond to a need, regularly expressed by professionals working with people who require very high levels of support on a daily basis, which had been clearly stated in many meetings of experts over the years, in debates between specialists and by diverse professional organisations. The goals of discussing issues relevant to daily practice, developing and strengthening practical competence, presenting sexuality and disability as key issues for professional practice were achieved using results-based didactic approaches, multisensory methods, and great dedication on the part of the concept team.

Implementation: Content and development of specialised training and qualifications

The focus of the theme-based seminar modules is to reflect on their relevance to the daily practice of the participants. In order to ensure optimal practical utilisation, in addition to self-reflection and specialist theoretical knowledge, the transfer of methodological and didactical competence is an integral part of the various CPD modules. The content of the individual modules is based upon the fundamental principles of emancipatory sexuality education; its guiding

principles are self-determination and respect for life. The methodology of the seminars follows the premise of “active learning”, which facilitates the practical and self-reflective transfer of information. Additional work on the part of the participants taking part in CPD leading to qualifications is necessary: this includes self-study, taking part in an inter-visit group as well as analysis, implementation and reflection on the sexuality education practical modules. Within the framework of the CPD programme, the work context is reflected upon with regard to sexuality; information and specialised knowledge are conveyed and the implementation of methods and ways of providing sexuality education and sexual surrogacy are tested.

The CPD programme contains seven seminar blocks with a total of 220 teaching hours. The content focuses on: sexuality throughout our lives and the influence of sexuality education, teaching sexuality education and the options for sensual and body work, sexuality education training for everyday life, sexual violence, prevention and challenges to sexual self-determination. These include the special themes of sexual support, passive and active sexual assistance, dealing with pornography and prostitution, the desire to have a family and parenting.

Sexuality education certificate – what comes next?

As in all CPD programmes, practical implementation occurs in a variety of different ways. At the beginning, there is often a feeling of euphoria; in most cases this is followed by a return to reality. In order to make best use of this energy, it is crucial that institutions support their staff during the CPD programme and are themselves interested in implementing the knowledge in practice. Sexuality education strategies must be established in institutions to ensure their long-term effectiveness. This provides not only guidelines for staff but is also of great benefit to residents. When several colleagues take part in specialised training leading to qualifications over a certain period of time, this increases the chances of putting together a team that will take on responsibility for implementing established goals. We often hear from participants that they began full of enthusiasm, but over time began to feel restricted or frustrated because they were forced to take on the role of “pioneer” or “sex expert” within their institution. Both roles generally tend to be unsatisfactory for all parties involved. A team with no prior sexuality education training normally cannot follow someone with specialised knowledge and training. Without institutional support, the specialised training and qualifications will, for the most part, remain in the areas of personal continuing professional development and personal development. Equally, it is extremely difficult to embed primary goals, motives and content within institutions. Nevertheless, examples of a great number of successful programmes exist. One large institution providing services for people with disabilities financed a CPD programme for two members of staff and used this opportunity to establish an in-house counselling team, working with the two staff members and with external support. In future, this will provide support in the area of sexuality for colleagues in teams in different residential groups. Other participants continue to meet at irregular intervals after completing the CPD programme, in order to exchange information and/or reflect upon the

sexuality education work being implemented. During the course of the CPD programme, some practice-based projects looked into creating appropriate materials particularly for adults with cognitive limitations; in this regard some initiatives are continuing this goal of adapting suitable material so that it can be published and made available for others to use in everyday practice.

The isp supports and advises the participants in the CPD programme on all areas of sexuality education during and after attaining their qualifications. The goal of the CPD programmes delivered by the isp is to disseminate practical competence, linguistic and communicative skills and sexuality education in institutions providing services for people with disabilities. Our aim is to convey the fact that sexuality is a social issue and a lifelong process, one that is experienced and shaped by everyone in different ways. The institutional implementation of sexuality education must assist, support and embed this goal.

Beate Martin



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Pro familia's commitment to people with disabilities

One in four pro familia advisory centres currently offers special services for people with disabilities. This article outlines the background to the provision of these services, documents considerations affecting the implementation of accessibility and describes some model case studies.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has been binding since 26 March 2009. Germany has undertaken "... with respect to the international community and also to its citizens, to observe and implement the Convention on the Rights of Persons with Disabilities and in particular to observe and to protect the rights formulated in the Convention and to strive to implement them in full, as quickly as possible using the available resources." (AICHELE 2008; editors' note: cf. SIGRID ARNADE's article in this issue).

While it is not legally binding in the same way that it is for the State and its institutions, the UNCRPD is still a valuable instrument for NGOs such as pro familia for directing and evaluating the human rights aspect of its work in terms of representing the interests of and advocating for its stakeholders. In the 1990s, the pro familia federal association committed itself to being an organisation that upholds human rights and incorporated the objective of implementing the sexual and reproductive health and rights of individuals into its constitution. Sexual and reproductive health and rights relate directly to the international human rights movement and its institutions. In 2004, the Bundesmitgliederversammlung [meeting of federal state members] called on the federal association and the regional associations of pro familia to work more closely with human rights organisations.

The Programme of Action agreed to follow the United Nations International Conference on Population and Development in Cairo in 1994 has provided the greatest support to improving sexual and reproductive health and rights of recent years. Following on from the Cairo Programme of Action, the international family planning movement, under the auspices of the International Planned Parenthood Federation (IPPF), the umbrella organisation of pro familia, made sexual and reproductive health and rights the focus of its work. "The conference in Cairo changed the work of family planning organisations around the world. Linking the theme of the conference to the issue of human rights led to greater complexity, which necessitated not only

an examination of existing structures but also presented us with the ongoing task of reflecting on and dealing with our own areas in a wider context," says Elke Thoß, Director of the pro familia federal association, which helped to drive and shape this paradigm shift at a national and international level from the very beginning (THOSS 2009).

Taking its cue from the IPPF Charter on Sexual and Reproductive Rights, which explicitly cites people with disabilities, pro familia had already intensified its work at all levels with and for people with disabilities even before the UN Convention on the Rights of Persons with Disabilities came into force. Twenty years ago, a number of local pro familia centres began to provide counselling, medical assistance and sexuality education. Today, one in four pro familia advice centres offers specialist services for people with disabilities.

The pro familia federal association has supported this development with continuing professional development (CPD), informative material for clients, expert reports and – in terms of association policy – a number of decisions. In its programme for the future "Parcours 2002", it put the spotlight on sexuality and disability, and in 2003, European Year of People with Disabilities, the Bundesmitgliederversammlung decided to continue its focus on this area for the following five years (Schwerin Decision).

Accessibility and "reasonable accommodation"

The UN Convention on the Rights of Persons with Disabilities, which, like pro familia's concept of sexual and reproductive health and rights, is based on an empowerment approach and emphasises the importance of accessibility and "reasonable accommodation". The second term, in particular, was not very familiar to us previously, but its implications are momentous. In calling for reasonable accommodation, there is a huge potential for social change. This was pointed out by the Deutsches Institut für Menschen-

rechte [German Institute for Human Rights] at a specialist conference in December last year (AICHELE 2009).

But first, we need to address accessibility, an extensive and fascinating concept from which everyone can benefit. Accessibility manifests itself in the way that people make themselves understood; in the way that individuals display courtesy to the person they are dealing with, in even seemingly incidental ways; in the ease of access to premises so that there is enough room for wheelchairs but also for prams and buggies and so elderly people can move around safely; in cherishing slowness; in plain language, which can be easily understood by both non-proficient readers and people whose mother tongue is not German; in the use of the gynaecological chair for disabled women; it manifests itself in the correct door colours for visually impaired people and Internet access. Accessibility is a human right, a quality that makes life more humane for everyone.

It means the removal of hindrances that preclude the right to equal participation because they hamper or completely block access to counselling, medical examination, treatment, and many other services. An analogy can be drawn with the call for universal access, one of pro familia's five strategic objectives in association with the IPPF.

While accessibility is related to groups of people and their disabilities (such as wheelchair users and visually impaired people), the right to reasonable accommodation can be claimed by individuals who have specific needs. Examples of such needs include sexual counselling, information on contraception, care during pregnancy, etc.

Reasonable accommodation is therefore crucial in enhancing and extending accessibility. The basic concept paves the way for considerable potential for innovation and new instruments for asserting the rights of persons with disabilities. To give one example: granting sexual assistance can constitute a reasonable accommodation for a man who is paralysed since this is the only way that he can exercise his right to a self-determined sexuality.¹

The UN Convention on the Rights of Persons with Disabilities stipulates reasonable accommodation and accessibility as necessary prerequisites for inclusion and the establishment of participation on an equal basis – people with disabilities are entitled to both of these rights. An absence of these rights constitutes discrimination (cf. AICHELE 2009).² The following section examines three expert initiatives launched by the pro familia federal association and considers their link to the UN Convention on the Rights of Persons with Disabilities.

Approaches to accessible advisory centres

An underlying dynamic understanding of disability is key to the UN Convention on the Rights of Persons with Disabilities. According to the UN Convention, disability exists in an interactive relationship with society and frequently only arises through barriers that are placed in the way of people, preventing them, for example, from availing of services relating to sexual and reproductive health (cf. AICHELE 2008).

To identify and eliminate the barriers that make it difficult for people to access counselling services, experts from pro familia centres, on the invitation of the pro familia federal association, consulted with advisors from disability organisations. The following recommendations and considerations for implementing accessibility were formulated by participants at the expert meeting (cf. PRO FAMILIA 2007):

- The implementation of accessibility is a process that can only be successful with the support of the relevant organisation/association.
- Organisations offering counselling services should include accessibility as one of their objectives.
- The objectives should be formulated and codified, e.g. in an advisory centre's quality assurance manual.
- Accessibility must relate to all types of disabilities.
- Achieving accessibility is a process consisting of many small steps.
- Once achieved, accessibility must be continuously maintained and monitored.
- People with disabilities should be employed in the advisory centres.
- Motivation and joint efforts are required on the part of everyone involved in the advisory centres. Sensitivity and training are vital for all employees.
- The barriers that exist in the minds of those who work as professionals or volunteers in the advisory centres or associations must not be ignored.
- Cooperation and communication about accessibility are crucial in associations. The appointment of working groups or of staff members responsible for accessibility may be appropriate in this regard.
- The involvement of people with disabilities as experts on their own behalf is essential to the success of the process.

Implementation in practice

People with physical disabilities often do not have access to locations such as car parks and entrance areas of buildings or to locations within buildings themselves (e.g. lifts, stairs, toilets, waiting areas, consulting rooms, group rooms).³

In many instances, little attention is paid to the rights of people with visual or hearing impairments. Greater efforts must be made to dismantle the barriers that they face when accessing services in advisory centres.

For example, high-contrast colours on the doors of advisory centres, induction loop systems, sufficient light, signs and tactile lettering in lifts are necessary for people with visual impairments. For people with hearing impairments, the option to communicate in writing (by fax, email, Internet) is extremely important.

While the barriers for people with physical disabilities are often apparent, it is generally more difficult to pinpoint the barriers faced by people with so-called intellectual disabilities

¹ Reasonable accommodation in the UN Convention on the Rights of Persons with Disabilities is limited in cases where it would impose an undue burden on the State.

² The author is referring to the translation of the UN Convention: A "shadow translation" was produced by Netzwerk Artikel 3 e.V, which was an adapted version of the translation agreed by Austria, Germany, Liechtenstein and Switzerland. www.institut-fuer-menschenrechte.de

³ For more information on this issue, recommended reading includes checklists such as "Bauen für alle! Barrierefrei – eine Checkliste für barrierefreies Bauen" [Building for everyone! Accessibility – a checklist for accessible building] produced by the city of Münster, www.muenster.de/komm.

or learning difficulties or even mental health disorders.

Various skills and different impairments at a neuro-psychological level demand different approaches on the part of the institutions providing advice and counselling. The concept of accessibility can also help people with such disabilities if it is linked to their skills and there is recognition of these skills in the required preparations, facilities, communications methods and the way these are dealt with.

The use of plain language is crucial. It should be used in almost all areas in the advisory centre: the way in which the first meeting is conducted and appointments are arranged can indicate that the person's right to access is being respected.

Essentially, the situation calls for calm and patience, time for both parties to ask questions and respect for each person's way of expressing themselves and their language. Appointment cards should be available in plain language. It may be useful to include the name and a photograph of the counsellor on the card; this helps to allay fears in advance as, after all, the client should be able to build up trust in the service at an early stage. Other useful measures include incorporating directions for getting around the advisory centre on the appointment card ("Always follow the yellow line to the advice centre"), having a central and conveniently situated location (many people with so-called intellectual disabilities or learning difficulties have restricted mobility), having directions for finding the advisory centre in plain language (e.g. distinctive buildings, photographs).

Certain quality standards must also apply to the counselling itself:

- focusing primarily on the client, not on their assistant or the person accompanying them,
- addressing different senses (e.g. a combination of verbal explanations and materials to touch and look at),
- using plain language, allowing enough time, speaking calmly, remaining patient, showing respect for the client's personal integrity, special needs and skills,
- gaining the best possible understanding of the client's personal life situation
- displaying sensitivity, for example, when questioning the client to determine whether he or she has correctly understood the issue at hand,
- taking into consideration possible limitations in the client's ability to remember (repeat information, do not provide too much information all at once),
- ensuring that the counselling is ongoing (information written in plain language to read at home).⁴

The requirements of people with autism or mental health disorders when visiting advisory centres have not yet been documented in scholarly discourse.

Access to gynaecological services for women with disabilities

Article 25 of the UN Convention on the Rights of Persons with Disabilities states the following with regard to health: "States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-specific ..." (cf. footnote 2)

Very few accessible services exist for women with physical disabilities who need gynaecological care. Many of them, therefore, cannot avail of preventive check-ups, for example, which should form part of everyone's healthcare routine. The scandal of this unmet medical need is scarcely mentioned in public debate (to date, no precise figures are available). This is a clear case of discrimination as defined by the UN Convention on the Rights of Persons with Disabilities and the State has an obligation to remedy this situation.

The pro familia advice centres in Frankfurt am Main and Berlin have been providing gynaecological clinics for women with disabilities for several years. They developed a women's health programme, which does not focus exclusively on deficits and a notion of providing care but rather on equality, ability, participation and a self-determined life. The success of this initiative has been due to the many years of ongoing cooperation with disability organisations.

The pro familia federal association is campaigning to have these (rare) good examples of healthcare provision replicated in the mainstream care provided by gynaecologists in private practices, with the aim of improving services for women with disabilities. To this end, an expert meeting entitled "Qualitätsstandards für die ambulante gynäkologische Versorgung von Frauen mit Behinderung und rechtliche Grundlagen für ihre Durchsetzung" [Quality standards for the outpatient gynaecological care of women with disabilities and a legal basis for their implementation] took place in November 2008 (PRO FAMILIA-BUNDESVERBAND 2009). In addition to requirements for accessibility, which were already formulated for advisory centres and in most cases could also be transferred to medical practices, there are ongoing requirements in the way in which medical practices are furnished and equipped. These include hoists for women with physical disabilities, height-adjustable examination chairs that can be adapted to the seat height of wheelchairs, hydraulic examination couches, small examination instruments and ultrasonic probes and special devices on the examination chairs that allow physically disabled women to adopt the correct position as independently as possible. Specialist knowledge about different types of disabilities and their ramifications is vital for a thorough medical consultation, diagnosis and treatment. Student gynaecologists should acquire the appropriate training during their studies.

Up until now, the scholarly debate on meeting such demands has been reduced mainly to the costs of accessibility, for which nobody can, or wants to, pay for. The UN Convention on the Rights of Persons with Disabilities represents a powerful international legal instrument that opens up promising new opportunities to assert the right of women with disabilities to broad access to gynaecological care.

4 Mensch zuerst – Netzwerk People First Deutschland e.V. and Lebenshilfe Bremen e.V. provide translations, training and advice for employees.

Sexual assistance

The reasonable accommodation called for in the UNCRPD focuses attention squarely on the individual and what he or she needs to be able to exercise his or her right to equal participation and inclusion. Dr. JULIA ZINSMEISTER produced a legal opinion on behalf of pro familia entitled “Sexuelle Assistenz für Frauen und Männer mit Behinderungen” [Sexual assistance for women and men with disabilities], which examines the legal basis for sexual assistance (cf. PRO FAMILIA-BUNDESVERBAND 2005). If a person cannot experience his or her sexuality without the support of other people due to a disability, he or she may need sexual services, which can range from help in looking for a private space and procuring contraceptives to paying for sexual intercourse.

For many people, such services, which are known as sexual assistance, may be the only opportunity that they have to experience self-determined sexuality and yet it is currently an extremely controversial subject for various reasons.⁵ Individuals now have the backing of the UN Convention on the Rights of Persons with Disabilities in seeking the required reasonable accommodation that will allow them to assert their right to sexual assistance as part of their right to exercise self-determined sexuality.

In terms of accessibility and reasonable accommodation, the full implications of the UN Convention on the Rights of Persons with Disabilities are far from being manifest. They offer many opportunities to welfare services, professional organisations and their funding bodies to focus on the human rights aspect of their work. The UN Convention on the Rights of Persons with Disabilities represents a major step forward. The role of NGOs like pro familia is to work persistently and passionately to ensure its implementation.

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Downloads available at www.profamilia.de

⁵ Cf. first FORUM issue 2/3-2001 Sexualität und Behinderung [Sexuality and disability] (no longer in print). It can be downloaded as a PDF file at: www.forum.sexualaufklaerung.de (editors' note)

**AWO Beratungszentrum
Lore-Agnes-Haus:
“In Sachen Liebe unterwegs”
[AWO Advisory Centre
Lore-Agnes-Haus: On the road.
Talking about love]**

Annette Wilke

The AWO advisory centre Lore-Agnes-Haus in Essen has been a contact point dealing with issues of sexuality, relationships, pregnancy and pregnancy counselling and family planning for more than 25 years. The foundation for its work is Germany's Pregnancy and Family Assistance Act [Schwangerschaftskonfliktgesetz, SchKG], Article 2 of this Act guarantees the legal right, also of persons with disabilities, to counselling on issues of sexuality education, family planning, pregnancy and birth. The reproductive rights of persons with disabilities, the right to organise their lives as they see fit and, above all, the right to self-determined sexuality is unequivocally stated in the German Social Security Code (IX) and the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

Disabled people still have to overcome many barriers before they can access counselling in the areas of sexuality and family planning. Their lives are still determined to a great extent by the support and influence of third parties. The majority of persons with disabilities have received noticeably less sexuality education than persons without disabilities

**“Liebe(r) selbstbestimmt”
[Love and self-determination,
by and for ourselves]**

In 2005, the Lore-Agnes-Haus began the two-year project “Liebe(r) selbstbestimmt” and has made contact with more than 1,000 people with disabilities as well as family members and specialists. In order to support specialists in the area of sexuality education, “Liebe(r) selbstbestimmt”, a practical guide for psychosocial counselling and sexuality education work with disabled people, was published in 2006 in cooperation with the federal association Arbeiterwohlfahrt e.V. (cf. Infotheque).

Results

In order to meet the needs of disabled people, their family members and specialists providing services for dis-

abled people, advisory centres must create individualised counselling and sexuality education programmes and schedule flexibly to meet the needs of the target groups.

People with so-called intellectual disabilities need support in issues relating to their personal life and sexuality and this support must be available, where required, throughout the course of a person's life. To do this requires knowledge of their daily life and the reality of their world.

It is helpful to make use of the expert knowledge of family members and specialists and to aim for cooperation, while always remaining focused on the wishes and concerns of people with disabilities.

A need exists for one- and three-dimensional media and materials, which deal with issues from “first love” to the “birth of a child” and discuss the complex aspects of the issue of sexuality using clear, realistic and comprehensible language.

Also helpful are: thematic series, constant repetition, rituals, working with photographs and pictures instead of texts. Young people and adults with disabilities need pictures, drawings and photographs that relate to their lives and their age group.

Sexuality education must take their lives and experiences into consideration, for example, their disability, gender roles and all the other usual thematic areas. Issues like the desire to have a family and the presentation of concepts like “assistance for parents”, the prevention of sexual violence and the examination of aspects of intimacy/distance in the context of sexuality must all be included.

**“In Sachen Liebe unterwegs”
[On the road. Talking about love]**

In June 2007, benefiting from these experiences, the Lore-Agnes-Haus initiated the project “Mobiles Kompetenzzentrum – In Sachen Liebe unterwegs” [Mobile competence centre – On the road. Talking about love], which is also supported by Aktion Mensch e.V.

All over the Düsseldorf region, the mobile project delivered one-to-one, couples, peer and specialist counselling, sexuality education group and information events as well as continuing professional development training on the issue of “sexuality and disability”, not just for persons with disabilities, but also for their family members, specialists and other interested parties.

Proactively providing these services where needed meant that groups of schoolchildren or teams in various institutions providing services for people with disabilities could take part, without the need for travel, which is usually difficult and sometimes impossible.

The Lore-Agnes-Haus acts as a knowledge centre, collating and disseminating information. Its networking and cooperation with responsible bodies and advisory centres for persons with disabilities and other specialist advisory centres is indispensable.

Some numbers and a lot of work
From June 2007 to December 2009, 1,200 counselling sessions and around 250 group events – around half of these for persons with disabilities – took place. Care workers or family members took part in a quarter of the around 260 one-to-one and couples counselling sessions. The clients themselves decided whether to take part as well as the extent of their involvement. The initial contact was usually made by specialists or family members, also known as support systems. Since 2007, the Lore-Agnes-Haus has organised large events for men and women with intellectual and multiple disabilities, like: “Flirten lernen – leicht gemacht” [Getting to know people – the easy way], 2008: the first Essen summer school “Liebe leben, wie ich will. Wie geht das?!” [Learning about love. How?], 2009: “Leben von A bis Z – von A wie Alltag meistern bis Z wie Zungenkuss” [Life from A to Z: from daily life to French kissing], always working closely with advisory centres for persons with disabilities.

Since 2005, requests for events have steadily increased: these include sexuality education, conflicts in relationships, questions about psychosexual development or legal aspects as well as several sexuality education CPD programmes for staff who go on to transfer this knowledge to their colleagues.

Contact:

*Beratungszentrum der Arbeiterwohlfahrt
Bezirksverband Niederrhein e.V.
Lore-Agnes-Haus für Familienplanung,
Schwangerschaftskonflikte und
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Lützowstraße 32
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Liebe, Lust & Frust. Eine Beratungsstelle für Menschen mit einer geistigen Behinderung [Love, desire and frustration. An advisory centre for people with intellectual disabilities]

Matina Sasse

The “Liebe, Lust & Frust” project, an advisory centre that focuses on issues of sexuality and relationships for people with intellectual disabilities, began in 2001. The advisory centre has existed for nine years, and is now an integral part of the advisory services of Lebenshilfe Berlin [an association for people with intellectual disabilities and their relatives].

How it all began

Since the middle of the 1980s, Lebenshilfe Berlin has been placing more focus on the issues of sexuality and relationships, much discussed by society in general, and has been taking the needs of their assisted clients in regard to this area more seriously.

After the two-year lead time, in 1994, the working and advisory group “Liebe, Lust & Frust”, known as “Lilufu”, was started. From 1995 to 1998, the advisory team, consisting of staff from residential care facilities, completed training as experts in sexuality education/sexuality counsellors. In the years following, the team delivered a great number of one-to-one and couples counselling sessions as well as team-based continuing professional development for colleagues from services for disabled people. In January 2001, the working group received funding for the project from the Deutsche Behindertenhilfe Aktion Mensch e.V. and became an official advisory centre. The project funding has now ended and the advisory centre now employs one person full-time.

The issue at hand

Relationships, love and sexuality are important issues in the lives of young people. The disadvantageous biography of people with intellectual disabilities and their corresponding psychosexual and social sexual development can cause difficulties that necessitate support in the form of education and advice on sexuality.

There are very few suitable advisory services available for people with intellectual disabilities within the framework

of general sexuality and relationship counselling.

Objectives

Based on the guiding principle of self-determination, the advisory centre “Liebe, Lust & Frust” provides people with intellectual and/or mental impairments with one-to-one and couples counselling as well as training on the questions and issues regarding their own individual sexuality.

The guiding concept is to encourage and facilitate clients to access and accept their sexuality, to discover their own individual sexuality and to experience this as natural and fulfilling.

The general objectives are the development and acquisition of social and sexual behavioural and practical competence as well as the assumption of personal responsibility for the experience of sexuality.

The counselling work follows the following objectives:

- becoming aware of one’s own needs
- differentiating between one’s own perception and that of others
- improving one’s perception of the body
- integrating individual sexual needs
- acquiring the ability to set personal boundaries
- extending one’s repertoire of behaviours in interpersonal relations (achieving one’s needs)
- increasing one’s level of information/knowledge

Target groups

The advisory and training services are directed towards people with intellectual and/or mental impairments, in so far as it is possible for the counsellor to communicate with these persons. Naturally, the advisory services are also available for family members, care workers and interested parties. Furthermore, the advisory centre delivers practice-related continuing professional development training on the themes of sexuality, relationships and intellectual disabilities for all persons working with intellectually and/or mentally impaired people.

Content and methodology

The counselling activities focus on promoting independent and autonomous action when it comes to developing one’s own sexuality.

The counselling work is client-focused; the CPD training is client-focused and theme-based.

The methodological elements include:

- talking to clients
- role plays
- working with visual representations and/or theme-based worksheets
- demonstrating contraceptive methods
- using audio-visual media
- discussing case studies
- exercises to increase sensitivity
- using the imagination
- physical exercises
- relaxation exercises
- creating collages/models of the body
- using diverse, specific materials and aids

All discussions and information in the counselling services and training are confidential.

Content of counselling services
People who make use of an advisory centre have a broad range of very different questions and problems. Common themes when counselling people with an intellectual disability are: sexuality education, contraception, communication problems in a relationship, jealousy, dealing with frustration and sadness after separations, sexual problems in a relationship, sexual orientation and sexual violence. The problem of the difficulty of finding a partner is a very common theme.

In summary

Creating counselling services in sexuality education for people with intellectual impairments is an important step towards autonomy and self-determination. In my function as a counsellor, it is very satisfying to know that I have made a small contribution to this aim.

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www.lebenshilfe-berlin.de

Das Projekt EIGENWILLIG im Familienplanungszentrum Hamburg e.V. [The EIGENWILLIG project in the Hamburg e.V. Family Planning Centre]

Maria Gies

Ms B. is eight weeks pregnant and would like to have counselling on the topics of pregnancy and parenting. Ms F. has a new partner and is wondering which method of contraception is most suitable for her. Two normal situations in the daily routine of the counsellors at the Familienplanungszentrum (FPZ) in Hamburg.¹ With one difference: Ms B. and Ms F. are women with learning difficulties.²

Are there any special requirements for reaching out to and successfully counselling people with learning difficulties? And what can an advisory centre do in order to become more accessible to this target group?

Since October 2008, the FPZ has been running a project called EIGENWILLIG,³ which is targeted specially at people with learning difficulties.

For more than 25 years, the FPZ has been a contact point for all questions concerning the topics of sexuality, contraception, pregnancy and sexuality education. The provision of such an accessible infrastructure means that the FPZ particularly reaches people from socially disadvantaged backgrounds or who are viewed as being difficult to reach and who do not take advantage of general care facilities. People with learning difficulties are also utilising

the FPZ with increasing regularity. The counselling service had neither the required target-group-specific expertise nor experience with existing aids that enable and facilitate easier communication. There was no systematic cooperation with the responsible bodies providing services for disabled people.

In accordance with the inclusion model, the FPZ has not created EIGENWILLIG as a special project for people with learning difficulties. Instead it provides a framework where special requirements of the advisory centre could be analysed, suitable media and materials could be developed, and, where necessary, structures could be improved. In addition to the project team, consisting of one female and one male expert in sexuality education and a female gynaecologist, the entire interdisciplinary counselling team is involved in the project.

Key experiences

The needs of people with learning difficulties are diverse and no different from the issues that concern the other clients of the FPZ. Nevertheless, there are some differences in the requirements for medical, psychological and social rights counselling.

Communication is often the greatest challenge at the first meeting and throughout the counselling: a great range of communication options are available, ranging from the non-verbal to very differentiated levels of language. In addition to the competence of providing counselling in plain language,⁴ a broad spectrum of aids, openness, process-based methods and, above all, practice are required.

Furthermore, counsellors and service providers must be aware of the particular socialisation of people with learning difficulties. Many issues that are obvious from the point of view of the advisory centre are understood in a different way by people with learning difficulties. The principle of confidentiality and the option of one-to-one counselling are often new experiences. It is still the case that people with learning difficulties are often spoken about and all too rarely spoken to. Especially when decisions must be made, the caregivers generally become involved. Their interests can be different from those of the clients; therefore separate counselling sessions are occasionally necessary.

As little or no education on sexuality and family planning has been delivered,

gaps in knowledge often exist and these must be taken into consideration during counselling. These deficits apply both to specialist and general knowledge of the body and sexuality as well as to knowledge of the right to sexual self-determination.

What has changed for Ms B. and Ms F.?

Today, flyers detailing services, the website and the answering machine have all been translated into plain language, making it easier for people to inform themselves in an independent and self-determined way and to make contact with the service.

It is now easier to navigate the advisory centre: text used in signage has been replaced by symbols. The toilet is now accessible to wheelchair users. A new rolling staircase allows access for wheelchair users via the steps leading to the entrance of the 100-year-old building. Brochures and books in plain language directed at this target group, as well as models, visual aids and films are available to facilitate medical, sexuality education and psychosocial counselling. Materials required for special areas have been determined, developed and trialled.

Ongoing continuing professional development of the entire team means that the staff of the FPZ are sensitised to the special requirements of providing counselling for people with learning difficulties. Strategies for structural changes, like extended opening times for counselling services, are developed jointly.

The establishment of a regional network on the issues of sexuality and family planning that can adequately provide counselling for people with learning difficulties is a further support. A guide with the relevant contact points will be made available online when the project is complete.

The EIGENWILLIG project enables the FPZ Hamburg to make a significant contribution to implementing the right to participation in society, to information, counselling and self-determined sexuality.

Contact:

Familienplanungszentrum
Bei der Johanniskirche 20
22767 Hamburg
gies@familienplanungszentrum.de
www.familienplanungszentrum.de

1 The Familienplanungszentrum (FPZ) has no political or religious alliances and is a non-profit organisation, based in the Altona district in Hamburg. The range of services offered meets the legal requirements of Germany's Pregnancy and Family Assistance Act [Schwangerschaftskonfliktgesetz, SchKG] Articles 2, 5 and 6.

2 The term "people with learning difficulties" corresponds to the requirements of Mensch zuerst – Netzwerk People First Deutschland e.V., who would like to "not" be referred to as "intellectually disabled", see article by STEFAN GOETHLING in this issue and www.people1.de

3 The EIGENWILLIG project is funded by Aktion Mensch, the Hamburg Spendenparlament and the Andrea-Brudermüller Stiftung.

4 Netzwerk People First Deutschland e.V. has produced criteria that define plain language. Recommended reading: Das neue Wörterbuch für leichte Sprache, Kassel 2008

Liebe, Sex und Drumherum – ein sexualpädagogisches Erwachsenenbildungsangebot für Menschen mit Behinderungen [Love, sex and all that – a sexuality education service for adults with disabilities]

Sven Neumann

If we tried to describe the sexuality of persons with disabilities, we would be faced immediately with two problems: there is no such thing as disabled people who can be summarised and described as one group. Persons with disabilities are individuals with a diverse range of skills, interests and characteristics.

And is there one sexuality? Sexuality is a fundamental part of life and an energy that can inspire us during the different stages of our life. Sexuality is closeness, relationships, contact, attention, intimacy, experimentation, etc.

Until very recently, the orthodoxy prevailed that people with intellectual disabilities should not explore their sexual needs. It was feared that an uncontrollable, instinct-driven sexuality would be the result. Today, experts still disagree as to whether the sexual development of people with intellectual disabilities is as significant as that of everyone else. Society has the obligation of enabling the participation of people with disabilities. This includes providing the opportunities and space to enable a person to live a self-determined life.

Today, the ability of people with learning difficulties to learn and to develop as adults is no longer questioned (THEUNISSEN 2009).¹ The space where new experiences are possible is to be found in adult education. Here it is important that a large enough range of services are provided so that people can choose freely and in a self-determined way.

There has been a coordination group for adult education in Hamburg for more than 20 years. The five largest responsible bodies providing services for people with disabilities have merged and provide over 100 courses every year

for people with and without learning difficulties. These are delivered throughout the city of Hamburg. These services are funded by the Behörde für Schule und Berufsbildung [Schools and vocational education authority]. This means that the cost for participants is relatively low.

Sexuality education courses with the title "Liebe, Sex und Drumherum" have been delivered since 2005. Currently, these are delivered monthly on Saturdays for four hours in the accessible rooms of an assisted independent living service in a central location, with good public transport connections. The mixed-sex group has between eight and twelve participants. Couples often come to the seminar. Each series has six seminars.

The participants are usually adults with learning difficulties who live with their parents, in residential facilities or in their own home.

Experience has shown that they have a very diverse range of questions, have a large pool of knowledge, strengths and previous knowledge that can be shared with the group. During the first seminar, people not only get to know each other in a pleasant atmosphere but the wishes and expectations of the men and women for the rest of the course are also discussed.

Each individual seminar focuses on a specific issue. In addition to discussions, many creative elements, methods and media are used. Sessions on perception of the body and relaxation are also included. Excursions (to special exhibitions, etc.) are also undertaken.

The following is a sample seminar programme:

Introduction

- Welcome
- Deciding together on rules for the seminar
- Getting to know each other
- Wishes and expectations
- What do I like, what do I think is good?
- Sexuality and language

Our body I

- What do I know about my body (inside and outside)?
- General: What organs do I know, why are they there?
- Differences between men's and women's bodies

Our body II

- Genital organs (consolidation)

- Contraception
- Pregnancy

Sexual identity

- I am a woman
- I am a man

Feelings, relationships, life with a partner

- Where can I meet someone?
- How do I get to know someone?
- Intimacy – distance
- How far can I / should I go?
- What can I experience and where?
- What should I try to avoid?
- Feelings in a relationship: Love, arguments, jealousy, making up, etc.
- The ideal partner

At the end of the course, participants reflect on what they have learned and experienced. Care is taken to examine whether the wishes and expectations of the participants were met to their satisfaction during the seminars.

The demand for these seminars is very high. There is interest in sexuality education in the narrow sense. Equally, the need to discuss issues not only in an informative way but also talking personally about sexuality is very evident. The use of plain language throughout is of great significance!

Contact:

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Course Director
Liebe, Sex und Drumherum
Barbara Adden and Sven Neumann
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¹ THEUNISSEN, G. (2009): Empowerment und Inklusion behinderter Menschen, 2nd edition, Freiburg

All BZgA media and materials are available as PDF files:
www.sexualaufklaerung.de

BROCHURES

Barrierefreie Medienbildung auf einen Blick [Accessible media literacy – at a glance]

It is very important for people with physical or intellectual disabilities to be able to use media (literacy) tools easily to ensure their equal participation in the information society. This four-page brochure, produced by the mekonet project office [German portal for media competence] contains many useful links, definitions, recommended reading, information about competitions, etc. on the topic of accessibility and new media.

Contact:

Projektbüro mekonet c/o ecmc
Europäisches Zentrum für
Medienkompetenz GmbH
Bergstraße 8
45770 Marl
Telephone +49 (0)2365 94 04 48
Fax +49 (0)2365 94 04 29
info@mekonet.de www.mekonet.de

Sex ‘n’ tips [Sex ‘n’ tips]

The BZgA has published four pocket-sized brochures entitled “Sex ‘n’ tips”. “Sex ‘n’ tips Verhütung” [Contraception] provides information on the most commonly used contraceptive methods. As most young people use condoms or the pill, these methods are explained in detail. A brief summary of the other means and methods is provided.

“Sex ‘n’ tips Körper und Gesundheit” [Body and health] addresses the physical and emotional changes that occur during puberty, personal hygiene, genital self-examination, the risks posed by the use of drugs and medication, piercings, tattoos and cosmetic surgery as well as sexually contracted infections. “Sex ‘n’ tips Mädchenfragen” [Girls’

questions] and “Sex ‘n’ tips Jungenfragen” [Boys’ questions] deal with physical development during puberty, key development questions from boys and girls, methods of contraception and much more.

Ordering address:

BZgA
51101 Köln
Fax +49 (0)221 89 92 257
order@bzga.de
Sex ‘n’ tips Verhütung
Order No. 13066000
Sex ‘n’ tips Körper und Gesundheit
Order No. 13066003
Sex ‘n’ tips Mädchenfragen
Order No. 13066002
Sex ‘n’ tips Jungenfragen
Order No. 13066001
Sex ‘n’ tips Erste Liebe
Order No. 13066004

Willkommen – Wenn es anders kommt [Welcome – When things are not what you expected]

Willkommen – Das andere Wunschkind [Welcome – The different planned child]

Two new brochures, produced by the BZgA in collaboration with Elternselbsthilfe [parents self-help] associations, support families with disabled or chronically ill children. The brochure “Willkommen – Das andere Wunschkind” is geared towards doctors and offers suggestions for their initial discussions with parents following a diagnosis of “disability”.

The brochure “Willkommen – Wenn es anders kommt” contains advice for families with a disabled or chronically ill child and provides information on a range of issues including support, counselling and therapeutic services, legal issues, financial assistance, self-help groups and funding institutions. This new material, which is supplemented by information on the website

www.kindergesundheit-info.de (see below), is intended to provide affected parents with important information and to support doctors in their discussions with parents.

Both brochures are now available from maternity clinics, community paediatric services and disability associations and can also be ordered free of charge from the BZgA.

Ordering address:

BZgA
51101 Köln
Fax +49 (0)221 89 92 257
order@bzga.de
• Willkommen – Wenn es anders kommt
Order No. 11140000
• Willkommen – Das andere Wunschkind
Order No. 11140001

Informationsmaterial für Schwangere [Informative material for pregnant women]

The new version of the Pregnancy and Family Assistance Act [Schwangerschaftskonfliktgesetz, SchKG] came into effect in Germany on 1 January 2010. In accordance with this Act, doctors must inform women whose pre-natal screening has detected abnormalities about living with an intellectually or physically disabled child and the life of people with disabilities. To assist with this legal requirement, the BZgA has produced a handout for doctors to give their pregnant patients.

The 20-page informative brochure is intended to help parents deal with the diagnosis and advise them where they can get practical help during this difficult time. It also refers to the fact that every man and woman has a right to psychosocial counselling. The informational materials also contain contact details for self-help groups, advisory centres, disability associations and associations of parents with disabled children.

On 1 January 2010, the BZgA sent

three copies of the new handout "Informationsmaterial für Schwangere nach einem auffälligen Befund in der Pränataldiagnostik" [Informative material for pregnant women whose pre-natal screening has detected abnormalities] to all gynaecology specialists.

Details on the Pregnancy and Family Assistance Act are available on the website of the Bundesministerium für Familie, Senioren, Frauen und Jugend [Federal Ministry of Family Affairs, Senior Citizens, Women and Youth] at www.bmfsfj.de.

Ordering address:

BZgA
51101 Köln
Fax +49 (0)221 89 92 257
order@bzga.de

- Brochure
Order No. 13450002
- Set of three with letter for gynaecology specialists
Order No. 13450001

Early Childhood Intervention. Pilot Projects in the German Federal States

The first pilot projects, which built upon the constructive approaches to early intervention already being used in many locations, were launched in 2006 under the auspices of a programme of action entitled "Frühe Hilfen für Eltern und Kinder und soziale Frühwarnsysteme" [Early intervention for parents and children and community early warning systems]. The Nationales Zentrum Frühe Hilfen [National Centre for Prevention of Neglect and Maltreatment in Early Childhood] is sponsoring a total of ten projects in all 16 German federal states. All of the projects got off to an extremely promising start and the research data that they generate will help to close any gaps in knowledge. A summary of the projects, which were selected jointly with the federal states, is contained in a brochure entitled "Frühe Hilfen – Modellprojekte in den Ländern" [Early Childhood Intervention. Pilot Projects in the German Federal States].

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Order No. 16000170

Das Netz vergisst nichts! [The Internet never forgets!]

Nearly every young person in Germany has a profile on *schuelerVZ*, *werkentw*, *Facebook*, etc. These profiles often contain general personal details, photographs, videos, information about hobbies, family circumstances and school. Photographs, videos and data relating to friends and other pupils are also often published on these sites. Even when a person leaves the social network, his or her links and comments often remain in other profiles. Photographs and videos can easily be copied and distributed further afield, taken out of context or modified, even after they have been deleted. Very few people are aware of the implications of such activities. The new cartoon flyer "Das Netz vergisst nichts!" [The Internet never forgets!] deals with the often reckless way in which young people and children use their photographs and videos, especially "party pics".

The flyer, which is also an aid for teachers discussing data protection, defamation and a person's right to have control over their own image [Recht am eigenen Bild], is available free of charge and can be downloaded from the Internet. Class sets are also available.

The project that produced the flyer, www.handysektor.de, is a partnership between the Landesanstalt für Medien Nordrhein-Westfalen, LfM [the media broadcasting authority in North Rhine-Westphalia] and the Medienpädagogischer Forschungsverbund Südwest, mpfs [media education research group in the southwest], provides information in various brochures about the risks of mobile communication and media usage, explains technical terms and provides tips on using mobile phones safely.

Contact:

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Dr. Peter Widlok
Zollhof 2
40221 Düsseldorf
Telephone +49 (0)211 77 00 71 41
pwidlok@lfm-nrw.de
www.lfm-nrw.de

Medienpädagogischer
Forschungsverbund Südwest (mpfs)
Thomas Rathgeb
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www.mpfs.de

Jahrbuch 2008/2009 der Deutschen AIDS-Hilfe e.V. [Deutsche AIDS-Hilfe e.V. Yearbook 2008/2009]

The yearbook provides an insight into the work of the DAH association and its federal office. Among the issues covered in the yearbook are medical and research topics, antiretroviral therapy and prevention, immigration and health, exchanging ideas and experiences with Eastern Europe, HIV and morality, dealing with AIDS in the workplace as well as self-stigmatisation and stigmatisation by others.

The 108-page brochure is directed at outreach workers, experts, policy makers and the government. The yearbook is available free of charge.

Ordering address:

www.aidshilfe.de/materialien

SPECIALIST BOOKLET SERIES

E-Learning und Sexualpädagogik [E-learning and sexuality education]

This expert report, produced by Jürgen Fritz and Uwe Sielert on behalf of the BZgA, examines the usefulness and suitability of computer-aided learning and digital media for conveying information relating to sexuality education and practical competence.

This publication, volume 33 in the series, is entitled "Forschung und Praxis der Sexualaufklärung und Familienplanung" [Research and practice in sexuality education and family planning]. It defines aspects of e-learning, evaluates them from a pedagogical perspective and examines the usefulness of different strategies in terms of teaching sexuality education.

The authors illustrate the various aspects that need to be considered when designing and implementing an e-learning project and how it can be integrated into youth work.

Volume 33 is available at a nominal charge of 11 euros.

Ordering address:

BZgA
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Fax +49 (0)221 89 92 257
order@bzga.de
Order No. 13300033

EDUCATION TOOLS

**Liebe(r) selbstbestimmt
[Love and self-determination,
by and for ourselves]**

In a two-year project, a multidisciplinary team consisting of practitioners and researchers produced this practical guide for those providing psychosocial counselling and sexuality education to people with intellectual disabilities. The target groups include specialists in (crisis) pregnancy counselling, family planning and sexuality education, special needs teachers and individuals involved in continuing professional development (CPD) and adult education.

The project folder contains expert articles on sexuality, pregnancy and parenting skills, information on dealing with people with intellectual disabilities (body perception, body awareness, getting to know people, love and relationships, the desire to have a family and parenthood) and legal principles regarding sexuality, relationships and parenthood for people with intellectual disabilities. Also included are methods, projects and workshop ideas for sexuality education services. The appendix contains a game (about wishing to have a family) for use in group work. There are also references and media, some with comments, and contact details for relevant federal bodies. Working together with Netzwerk People First Deutschland e.V., all of the expert articles are written in plain language and can be photocopied. A CD containing a summary of the content is provided with the A4 folder. It costs 15.95 euros including postage and can also be downloaded at www.awo-schwanger.de/lieb_selbst.html.

Ordering address:
AWO-Bundesverband e.V.
Verlag & Vertrieb
Postfach 41 01 63
53023 Bonn
verlag@awo.org www.awo-schwanger.de

**Hauptsache gesund?
[The main thing is to be healthy?]**

This is the name of the kit developed by the Caritasverband der Diözese Rottenburg-Stuttgart [an association of Catholic welfare organisations in the diocese of Rottenburg-Stuttgart] containing materials for preventive work

on the topic of pre-natal screening. It gives young people and young adults in schools and youth groups a chance to find out about the opportunities and risks of pre-natal screening and to examine their own values regarding living with disability.

Central to the whole package is the touring exhibition "Hauptsache gesund?", which features images and texts about the feelings and thoughts of the persons concerned. "Zeitreise durch die Schwangerschaft" [Time travel through pregnancy] provides interactive access to "Schwangerschaft und PND" [Pregnancy and pre-natal screening]. A manual containing additional information, materials and questions designed to stimulate debate can also be used independently of the exhibition. The kit provides comprehensive information and materials to encourage users to reflect on the issues surrounding pre-natal screening, crisis pregnancy and living with disability. Target groups include specialists, voluntary organisations and young people.

The accompanying DVD includes a 17-minute film on the subject of "Leben mit Behinderung" [Living with disability], which makes it clear that disabled people can live a self-determined and shows where advice and help can be obtained. The manual, including the DVD "selbst.bestimmt.leben" [self-determined living] costs 13 euros.

The exhibition, which consists of ten easy-to-assemble partition walls can be borrowed free of charge. Transport and assembly costs are not included.

Ordering address:
Caritasverband der Diözese Rottenburg-Stuttgart e.V.
Birgit Baumgärtner
Strombergstraße 11
70188 Stuttgart
Telephone +49 (0)711 26 33 11 40
baumgaertner@caritas-dicvrs.de
www.dicv-rottenburg-stuttgart.caritas.de

DOCUMENTATION

**LIEBe HABEN
[LIKING AND LOVING]**

The 60-page reader "LIEBe HABEN – Sexualität und geistige Behinderung" [LIKING AND LOVING – Sexuality and intellectual disability] documents the symposium of the same name that took place on 22 November 2009 in Singen. Expert articles address issues such as

parents' fears, sexual assistance, sexuality education services, information, methods and finding a partner. The first issue to be tackled is the barriers to sexuality in this society.

Another two articles cover contraception and legal issues. The reader costs 10 euros plus postage.

Ordering address:
pro familia Singen
Fax +49 (0)7731 12 58 5
singen@profamilia.de

MAGAZINES

**Behindertenpädagogik
[Special needs education]**

The quarterly magazine "Behindertenpädagogik" deals with issues relating to special needs education in terms of education and teaching in pre-schools, general education schools, vocational schools, universities, technical colleges and adult education institutes. It is published by Landesverband Hessen e.V. im Verband Deutscher Sonderschulen, Fachverband für Behindertenpädagogik [Hesse state association in the association of German special schools, professional organisation for special needs education].

Issue 4/2009 covers historical topics such as special needs education during the Nazi period, the introduction of compulsory schooling for the "educable feeble-minded" in Sweden in 1944/45 and "Propaganda für die Sonderschule" [Propaganda for the special needs school]. The main focus is on "Konzepte zum Umgang mit Heterogenität" [Strategies for dealing with heterogeneity].

Among the other issues covered are the conversion of the Römerstadtschule in Frankfurt to an "inclusive school" and a report on alternative learning processes at a school for the visually impaired

The magazine costs 10.50 euros plus postage.

Ordering address:
Psychosozial-Verlag
Goethestraße 29
35390 Gießen
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info@Psychosozial-Verlag.de

Weltweit! Mädchen, Mädchenrechte, Mädchenarbeit international
[Worldwide! Girls, girls' rights, international girls' empowerment]

Issue 1/2010 of "Betrifft Mädchen" [Regarding girls] focuses on the international girls' empowerment movement. According to the press release for the magazine, positive discrimination and solidarity with girls – especially in a globalised world – should not end at the national borders of Europe. Gender justice in general and the education of girls in particular are important prerequisites for genuine progress in development cooperation. One aspect of this global perspective is the empowerment of girls, the aim of which is to achieve girls' rights to self-determination and participation, an important element of positive social change. Topics and content: gender as a key category for sustainable development, genital mutilation, a report on practice-based projects and networks in Ghana, the USA, Sweden and Europe and an extensive list of links.

"Betrifft Mädchen" costs 6.50 euros plus postage.

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BOOKS

Vielfalt wagen
[Taking a chance on diversity]

"Vielfalt wagen" is the name of the Festschrift published in 2009 for the renowned Kiel-based social education expert Uwe Sielert, who has contributed on several occasions to the FORUM series. The editors explain the significance of the title of this 280-page publication in the first article in which they set out a historical review of social and sexuality education since the 1970s. "Sexuality education would [...] not have reached the stage that it has today if Uwe Sielert had not made it such a matter of personal importance and played a major role in shaping it over the last 25 years," writes Frank Herrath in his article (p. 31).

A total of 19 other essays represent the broad spectrum of an approach to

sexuality education that embraces diversity. The topics covered include youth work, youth social work, family and quality assurance.

The Festschrift is published by Logos Verlag and costs 34 euros.

Available to buy:

in bookshops

STUDIES

Väter-Studie [A study of fathers]

In November 2009, the Familienministerium [Ministry of Labour, Social Welfare, Health, Family and Women] in Rhineland-Palatinate published a study investigating the conditions that must prevail for young men to be able to play an active role as fathers. The Institut für Sozialarbeit und Sozialpädagogik e.V. in Frankfurt am Main conducted the study. It surveyed HR managers and fathers and their partners in Rhineland-Palatinate about the opportunities for and obstacles to a better work life balance and the need for support from employers and policy makers.

In the study, 301 16- to 35-year-old women and men and 308 HR managers from companies with more than 20 employees were asked about their views and wishes when it comes to reconciling a career with family responsibilities. Ten fathers who had taken parental leave also took part in qualitative interviews.

The official title of this study of fathers is "Motive und Rahmenbedingungen für die Vereinbarkeit von Erwerbstätigkeit und Familie für Väter" [Motives and conditions for the reconciliation of paid employment and family for fathers].

Ordering address:

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 Rheinland-Pfalz
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 Bauhofstraße 9
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 www.masgff.rlp.de
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FILMS

Liebe und so Sachen
[Love and such things]

In June 2009, the pro familia association in Hesse launched a professionally produced sexuality education film entitled "Liebe und so Sachen...", an educational tool for working with people with intellectual disabilities. The project was developed over several years with the support of Aktion Mensch [a national lottery organisation in Germany working in the field of disability], the BZgA, a pro familia "friends association" and private donors.

Director Cornelia Thau has made a feature film that addresses the everyday world of the target group and offers a wide range of starting points for discussion. Juliana Götze and Mario Gaulke play Tina and Kai in the film – both actors have Down Syndrome. "Liebe und so Sachen ..." looks at a number of scenarios – getting to know someone, the first kiss and the need for physical intimacy.

The 57-minute film, which is available on DVD, uses simplicity to convey its message. Animated drawings, which illustrate physical and sexual situations with sensitivity, are incorporated into the film. The accompanying booklet contains several suggestions for using the film.

The DVD and accompanying booklet cost 39 euros for private individuals and 69 euros for institutions and organisations; postage is not included.

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Behinderte Liebe 2 und 3
[Handicapped love 2 and 3]

Medienprojekt Wuppertal has been offering new films by and about young disabled people on the subject of love and sexuality since September 2009. In the film series "Behinderte Liebe", young people with various disabilities openly describe their positive and negative experiences, their hopes and fears on love and sexuality. The 10- to 45-minute stories are used as

educational media to sensitise young people with and without disabilities. The topics covered include the first time, finding a partner, dating sites, the relationship between love and sexuality, lust and masturbation, sexual assistance, homosexuality, prejudice and discrimination, wishing to have a family, disabled parents.

“Behinderte Liebe 2” is 235 minutes long; “Behinderte Liebe 3” has a duration of 202 minutes. Both productions are available as DVD and video, are recommended for young people aged 12 and over and cost 40 euros each (or 15 euros to rent); postage is not included.

Ordering address:

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www.medienprojekt-wuppertal.de

Sex, we can?!

“Sex, we can?!“ is the name of a new Austrian sexuality education film for young people. The film was commissioned by the ICE [Internet Centre for Education] of the Wiener Bildungserver [Vienna education server] together with the Wiener Programm für Frauengesundheit [body providing counselling and support for women’s health issues]. The aim of the film is to increase young people’s self-confidence when it comes to matters of love and sexuality. According to the presentation, this is “a crucial requirement in helping them to protect themselves against unwanted pregnancy and sexually contracted diseases”.

The sexuality education film, which has been available to download since the end of 2009, is a “fake docu-soap” for the main target group of 14- to 16-year-olds and is an impressive production featuring act breaks and surprises. The information is portrayed from both a male and female perspective. The young viewers accompany a young couple as they experience love and sex for the first time. Over the course of the film, the protagonists’ comments allow viewers to share their feelings, thoughts and questions and to get answers to typical questions through information sequences.

The website accompanying the film contains educational information such as details of contraceptive methods,

sexual maturity, conception, pregnancy and birth, plus a glossary of relevant terms.

Contact:
www.sexwecan.at

TRAINING

**Vom Säugling zum Kleinkind
[From infant to toddler]**

The latest infant research and empirical clinical evidence confirms the importance of early prevention and intervention. Counselling and therapy for parents and their infants and toddlers can prevent early disorders from deteriorating over the years.

One important requirement for the years ahead is the development of facilities and contact points that can support parents and children during the potentially crisis-ridden transition to parenthood and the mutual adjustment processes in early childhood.

“Vom Säugling zum Kleinkind – Elternberatung, Bildung & Prävention” [From infant to toddler – parent counselling, education & prevention] is a project sponsored by the Institut für Fortbildung, Forschung und Entwicklung (IFFE) e.V. [Institute for Further Education, Research and Development]. The objective of the project is to ensure the continuing professional development of specialists including practice-based research and development in various professional fields.

This project is linked to the family centre at the Fachhochschule [University of Applied Sciences] in Potsdam, which also provides case supervision and team-based continuing professional development on a range of topics.

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INSTITUTIONS

NaSowas

In addition to providing individual counselling support to young people and their family members, the “NaSowas” advisory centre also offers specialist counselling for young people who are coming out, continuing professional development for teams and colleagues, support for lesson preparation and project days, media and materials for young people, parents and specialists.

Teachers and educationalists can borrow a resource kit from “NaSowas”, which contains information on love and sexuality, sexual orientation, gender roles, homosexuality and coming out. The target group for this kit is teenagers aged between 12 and 18. It includes games, worksheets, films, articles and other materials. The advisory centre also provides support for planning projects and lessons. The kit can be borrowed for up to four weeks. A fee of 20 euros to cover costs is charged.

Contact:
NaSowas
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23552 Lübeck
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nasowas@lambda-online.de
www.nasowas.org

LAG Mädchen- und Jungenarbeit NRW

[State task force working for empowerment of girls and boys in North Rhine-Westphalia]

The objective of the empowerment of girls and boys is to establish a level playing field when it comes to diversity of choices and to support young people in discovering their own resources and skills, finding their own way and developing a variety of self-determined definitions of femininity and masculinity.

In a four-page joint statement, the Landesarbeitsgemeinschaften Mädchen- und Jungenarbeit in North Rhine-Westphalia have called for a broad-based, gender-sensitive education policy that incorporates the needs of boys and girls.

The key demands in the statement are for no further reduction in staff, gender-related specialised training and

qualifications in child and youth services, better networking, stabilisation and expansion of existing structures and quality development and assurance.

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INTERNET

www.profamilia.de

pro familia has put together a number of brochures for people with disabilities and they can be found at www.profamilia.de/shop/index.php?cmd=artdetail&q=203. The topics covered include sexuality and rights, sexuality and physical disability, sexuality and intellectual disability. Among the services listed is an overview, broken down by federal state, of the numerous pro familia advisory centres, which provide special services for people with disabilities.

The association's website also contains publications by specialists such as an expert report on sexual assistance and a document on quality standards for the outpatient gynaecological care of women with disabilities.

www.barrierefreie-blogs.de

Making contact with like-minded people, creating their own profiles, documenting their own experiences, hobbies and dreams – Web 2.0 offers young people with and without disabilities many opportunities to become actively involved on the Internet and to network with others. Yet Web 2.0 is still not completely accessible to everyone, making it difficult for young people with disabilities to have equal access to the Internet.

To change this, LAG Lokale Medienarbeit NRW e.V. [State task force for local media relations in North Rhine-Westphalia] initiated the "barrierefreie blogs" [accessible blogs] project in collaboration with Technische Jugendfreizeit- und Bildungsgesellschaft (tjfbg) gGmbH [organisation that promotes technology and education for young people]. The aim of this project is to develop an extremely simple and accessible blogging system that enables young people with and without disabilities to create and maintain their own blogs.

This free service was sponsored by the Ministerium für Generationen, Familie, Frauen und Integration [Ministry of Inter-Generational and Family Affairs, Women and Integration] in North Rhine-Westphalia.

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www.kindergesundheit-info.de

For many parents, the news that their child is disabled or chronically ill creates uncertainty and worry. But it is also often difficult for the doctors treating the child to deliver this diagnosis to parents. To support families and the medical profession in such situations, the BZgA has come together with branches of Elternselbsthilfe [parents' self-help association] to compile information about living with a disabled or chronically ill child. These brochures are now available at the Internet portal www.kindergesundheit-info.de.

www.intakt.info

INTAKT is an Internet platform for parents of children with disabilities. It was launched to provide support for families living with a child with disabilities to help them in everyday situations and also to help them to help themselves. The website also addresses people working in the disability sector either on a professional or voluntary basis.

Parents can access legal information and contact details of advisory centres and communicate with other parents in forums and chat rooms. Self-help

groups, experts and organisations can use the website for publicity purposes and also as a knowledge exchange network.

This body responsible for this service is the Familienbund der Katholiken, FDK [Catholic Family Association] in the diocese of Würzburg.

www.mixyourlife.ch

In a survey of 340 15- and 16-year-olds conducted by the Basel-based Kinder- und Jugendgesundheitsdienst [Child and youth health service], one third of the young people did not know that there was no vaccination for HIV/Aids. According to the survey, 86% of pupils would like more expert information on the subject of sexuality. They are very interested in finding out about such issues on the Internet. For this reason, a new Swiss website provides young people with comprehensive and useful information relating to the subject of health. The focus is on information and advisory services available to young people directly in the canton of Basel-Stadt.

The health promotion and prevention of illness division in the Basel-Stadt Gesundheitsdepartement [Department of Health] developed the information platform www.mixyourlife.ch with the help of young people.

The website contains information on a variety of health-related issues including exercise, nutrition, mental health, sexuality, addiction and general health. All of the issues are related to specific services such as the cervical cancer vaccination or counselling for addiction problems. A "topic of the month" is published regularly – the first topic covered was sexuality.

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