

Sexuality and Disability

Sexuality Education for Individuals with Impairments.

The activities of the Bundeszentrale für gesundheitliche Aufklärung (BZgA) in this area

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Susanne Bell

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Sabine Wienholz

This is now the third time we have addressed sexuality and disability as a topic in the FORUM series. We want to know about the current state of affairs: has the sex-positive future (Ralf Specht) that we hoped for in FORUM in 2010 already begun? What about women with a disability? Can they now practise their sexual self-determination unhindered (Martina Puschke)? Has empowerment become an educational goal for all parties and institutions involved, as Lothar Sandfort demanded?

Much has happened since the Convention on the Rights of Persons with Disabilities and the German government's National Action Plan. The BZgA has increased its efforts to implement the new guidelines and is revising existing services (Mirjam Tomse, Stefanie Paschke). It initiates and funds projects such as ReWiKs, which will be introduced by Barbara Ortland.

'In summary, we are very pleased that much has changed for the better in all the working areas described,' say Annica Petri and Bärbel Ribbert as they take stock in their contribution about being qualified in the field. 'Over the past 20 years many things have been set in motion for parents with disabilities,' notes Annette Vlasak in her essay. Susanne Bell notes that there is 'a somewhat more open-minded attitude on the part of the public and the media'.

So they do exist: the small and at times larger areas of progress in achieving self-determined sexuality for individuals with a disability in Germany. The authors of this publication are largely agreed on this. However, they are also clear about what remains to be done in their fields of work in order to achieve complete self-determination and real inclusion. Petra Schyma for example points to the necessary sustainability of funding for inclusion projects beyond their pilot phase. Sabine Wienholz's research has led her still to see controlling and limiting structures at work that stand in the way of self-determined sexuality and use of contraception by young people with a disability. Ralf Specht reminds us that this work should follow an integral approach in which a bespoke overall concept and interlocking action plans replace well-meaning but hasty action for action's sake.

The editors

Sexuality Education for Individuals with Impairments

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Stefanie Paschke, Mirjam Tomse

It is an important aspect of the BZgA's work to design services and materials in such a way that individuals with and without impairments can be reached equally with health promotion messages in the areas of sexuality education and family planning. The authors of this contribution will outline the basis on which this happens.

Legal Foundations

The UN Convention on the Rights of Persons with Disabilities (UN CRPD) strengthens individuals with impairments in their right to self-determination in all matters regarding marriage, relationships, family and parenthood.¹ In September 2011 the Federal German Government published the National Action Plan to implement the UN Convention. Part of this implementation involves the removal of barriers in all areas of life. In many organizations measures that support individuals with impairments in their self-determined sexuality have not yet been taken comprehensively into account. Since Germany ratified the UN CRPD, the BZgA has also gradually boosted its implementation of the regulations and provisions. In May 2012 it initiated the project 'Sexuality Education and Disability'. The most important principle of this project is the promotion of empowerment, participation and competence of people with impairments.

Furthermore, the Pregnancy Conflict Law (Schwangerschaftskonfliktgesetz, SchKG)² requires that the BZgA develops and disseminates sexuality-education measures that are uniform throughout the country, with the involvement of the federal states and in collaboration with representatives from the family advice institutions run by all organizations working in this field.

This legal remit is implemented, among other things, by creating framework concepts on sexuality education and by carrying out scientific studies and research projects. These are used as a basis for developing highly practical target-group-specific materials that are widely accepted and readily used in sexuality-education efforts.

Studies and Concepts as the Basis

On the basis of the framework concept on sexuality education agreed with the federal states, the Concept on Sexuality Education for Individuals with Impairments was created. 'It is the goal ... to support people with impairments in living (or being able to live) with an informed, self-determined approach to sexuality that treats both them and others responsibly' (BZgA 2015, p. 19). Reference is also made to the framework conditions and definitions, to the subject of disability as an experience of life and to its impacts on sexuality, relationships and parenthood. Furthermore the core assumptions and goals of sexuality education are set out. In this way sexuality education is seen in holistic terms while taking target-group-specific aspects into account. The concept is rounded off with further subject areas and concrete measures to implement this task.³

In order to do justice to the scientific foundation, quality-assured procedures and scientific surveys and evaluations are indispensable. The procedures have to take different target groups, their types of impairments (e.g. when choosing means of communication) and the different living environments (e.g. living in institutions) of the people into account. Both in research and evaluation viewing individuals with impairments as 'experts about their own reality' is essential.

¹ UN CRPD, article 23: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-23-respect-for-home-and-the-family.html> (accessed on 18 Jan 2018)

² Schwangerschaftskonfliktgesetz: www.gesetze-im-internet.de/beratungsg/BjNR113980992.html (accessed on 6 July 2017)

³ Both framework concepts can be ordered free of charge from the BZgA. A version in simple language will also be available soon.

The BZgA supported three surveys by the University of Leipzig that were designed to be both participative and barrier-free:

- ‘Youth Sexuality and Disability’
- ‘Family Planning for Young Adults with a Disability’
- ‘Opportunities for Young People with Cognitive Impairments to Participate in Sexuality Education’

While the first two surveys focused in particular on adolescents (aged 12–18) and young adults (aged 18–25) with sensory and/or physical disabilities as a target group, the latter study focused on the target-group of young adults (aged 18–25) with cognitive impairments. The surveys were conducted by one of two methods: one was the use of a questionnaire developed with accessibility as its standard and tested in advance; alternatively, oral face-to-face interviews were conducted in order to obviate any hurdles young adults with cognitive impairments might have with reading and understanding written questions. At times parents/legal guardians and teachers were also asked questions for these multi-perspective surveys in order to obtain a comprehensive view of this young target group and its social environment. The studies provided valuable insights into the subjects of sexuality education in schools and at home, first sexual experiences and contraception, physical development, choosing partners, desire for children, attitudes toward the sexuality of people with cognitive impairments, and experience of violence.⁴

Services for Young People – An Example for Implementation

It is the goal of the BZgA to help young people with impairments to live (or be able to live) with an informed, self-determined approach to sexuality that treats both them and others responsibly. Sexuality education has to aim at conveying information and encouraging motivation and communication (BZGA 2015). When developing and revising media and services delivering sexuality education, needs and barriers must be tested and taken into account. Barriers in the delivery of information can exist at different levels. The media on offer have to meet the needs of people with impairments in their technical, visual and linguistic design in order for them to be usable and to succeed in conveying information. The media and services delivering sexuality education are being revised in line with legal requirements⁵ and scientific results; the different needs of individuals with impairments are taken into account in line with the underlying principle of inclusion.

One example of the different levels of implementation is the revision of the youth platform for sexuality education, www.loveline.de. The website is continuously updated, both technically and with regard to its content. In addition to pictorial and video descriptions, the website’s usability and layout have been changed. As a result, the website is now recognized by supporting computer programs with text-to-speech functionality and can be used by individuals in that way. The language of the texts on the website was simplified while the texts were expanded to include a category ‘in brief’. This category summarizes the central information of a subject area right away. That means important messages can be picked up and understood easily and quickly, which makes it easier for individuals less familiar with reading to access information. Furthermore, the website’s pictures have

changed. More images of young people with impairments were incorporated in order to represent them clearly as part of the target group. The intention is for the subject of impairments to be picked up both in the text and the pictures. Work is currently under way to add information for young people with impairments in the texts and links. Young people with and without impairments are helping to develop the way in which this information is prepared and integrated on the platform. This online service gives us the opportunity to test changes immediately with regard to their usability and acceptance among the target groups.

In order to address a bigger target group, the BZgA also reduced barriers in its campaign to advertise the website. Postcards with flirtatious messages were developed that a) refer to the www.loveline.de service and b) address the topics of feelings, flirting and intimacy in an appealing manner. The messages are written in simple language and are supported by a picture. One of the pictures was designed with raised contours so that it can be felt. All of the messages on the postcards are also there in Braille. The postcards represent an inclusive medium in that they point individuals both with and without impairments to information about different areas of sexuality education. The feedback we have received is that the postcards are widely distributed and used.⁶

Services for Multipliers

In order to support the sexual self-determination of individuals with cognitive impairments in assisted-living situations, staff and multipliers need to get appropriate qualifications. This was also shown in a survey of employees in assisted-living facilities that provide integration support (ORTLAND 2016; cf. also the contribution by B. ORTLAND in this publication). For this reason the BZgA supports the participative project ‘ReWiKs’, which is designed to run for a number of years. The Catholic University of Applied Sciences of North Rhine-Westphalia, the Protestant University of Applied Sciences Rhineland-Westphalia-Lippe and the Humboldt University in Berlin are involved in this. The project aims to provide further training for employees working primarily with residents with cognitive impairments. A reflection manual, a practical reference guide and a two-part skill enhancement manual with materials for staff and multipliers will be produced. Once the materials have been developed, they will undergo participative practical testing. Individuals with cognitive impairments will be involved and consulted in all phases of the project as experts about themselves to test the materials’ applicability, manageability and sustainability. The reflection manual and the practical reference guide will also be made available in a simple-language version.⁷

4 Further information about the studies has been compiled on the BZgA’s research platform: www.forschung.sexualaufklaerung.de.

5 Behindertengleichstellungsgesetz, (Disabled People Equality Law 2016, BGG)

6 The flirtatious postcards can be ordered from www.bzga.de.

7 Further information about the project has been compiled on the BZgA’s research platform: www.forschung.sexualaufklaerung.de.

The goal: allowing independent information-gathering and self-determined decision-making

It is an important function of the BZgA to adapt existing services and materials in the future in such a way that individuals with and without impairments can be reached equally. Being able to find information independently is the basis for being able to make self-determined decisions. As a result, individuals with impairments must find technical conditions that are such that they can inform themselves independently and easily. Their concerns have to be considered and be part of the input into the information provided. Access to information about health, and particularly the content relating to sexuality education and family planning, is to be continuously checked and improved in the spirit of an inclusive society.



Mirjam Tomse is a social worker with a degree in social pedagogics. She works for the Bundeszentrale für gesundheitliche Aufklärung as an academic consultant in the area of sexuality education, with a focus on inclusion.

Contact:
mirjam.tomse@bzga.de



Stefanie Paschke has a degree in remedial pedagogics and works for the Bundeszentrale für gesundheitliche Aufklärung as an academic consultant in the area of national and international collaboration, research and further training. The focus of her work is on the topics of sexuality and disability as well as the prevention of sexualized violence.

Contact:
stefanie.paschke@bzga.de

Literature

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Has the sex-positive future already started?

Ralf Specht

Ralf Specht presents an overview of what has already been achieved as well as of the deficits that still exist when it comes to making the sexual rights of people with a disability a reality. He demands an integrated approach to sexual education, prevention and intervention.

Things are happening

It is the third time I have been given the opportunity here to give my assessment on the 'sexuality-education situation' in Germany with regard to sexuality and disability. This pleases me a great deal since I have spent more than 20 years working freelance as a lecturer at the Institut für Sexualpädagogik (isp) and being employed on various projects dealing with this subject area. As an employee of PETZE in Kiel I am currently helping institutions working in integration support to optimize their child-protection structures as part of the BeSt pilot project.

In my article I want to take stock, in broad strokes, of what has already been achieved and where I think there is still need for change. Three limitations up front: this is a subjective evaluation that will doubtless ignore many existing positive approaches that I do not know about. In addition, the shortness of my article means I cannot represent the full diversity and the living conditions of people with a disability in our society, which are (fortunately) very varied. This, along with the different characteristics and effects of different disabilities, means that some kind of limitation is necessary. For that reason I will limit myself in my analysis to the situation of individuals with a mental disability who are being looked after either in residential care or otherwise.

And with that, back to the opening question: has the 'sex-positive future' already begun? Yes, in the past fifteen years a lot has happened, much of it important, which will also become clear from the contributions and project descriptions in this publication.

A brief overview

The Convention on the Rights of Persons with Disabilities has long since been ratified by Germany. That makes the right to self-determination, to equal treatment and participation binding. Action plans to achieve implementation have to be created on an ongoing basis and progress must be checked.

Sexual rights are now established for individuals with a disability too. Thanks to the reform of the criminal code relating to sexual offences in 2016, the much criticized unequal treatment with regard to sexual assault has been abolished. The sexual abuse of individuals who are unable to offer resistance will finally incur the same severity of punishment as that of individuals who can defend themselves.

There are many positive approaches in the institutional field too. Many institutions and services are now confronting the task of implementing sexuality-education elements. Some institutions are now working successfully on the basis of well-founded research into sexuality-education concepts. In recent years in particular, individuals with a disability have had access to an increased amount of media and materials addressing different sexuality-education topics in Simple Language. In addition to this the sexuality-education in-service-training scene is diverse and colourful in many regions, at least for those acting in a professional capacity.

The literature on offer, including that on specific questions and topics, is growing and the subject combination of disability and sexuality has now arrived in teaching and research too. Different regional and nationwide projects are looking for solutions that go beyond the individual, and have generated valuable insights.

And not least, account is finally being taken of the fact that individuals with a disability are proven to have two to three times the risk of suffering from sexual assault over the course of their lives. Consequently their situation is finally being reflected in the debates about sexualized violence. Appropriate prevention and intervention concepts have been demanded and also increasingly implemented by various parties for a few years now.

Back to the future – isolated, not well thought-out, poorly co-ordinated

The reality of the lives of individuals with a disability, be they adults, children or teenagers, is not automatically changed through the establishment of rights, the presence of literature and media, or debates about sexualized violence.

The shadows of the past are long because up until fairly recently the sexuality of individuals with a disability was widely treated as taboo. Far too often they were refused opportunities for self-determination, particularly in the area of sexuality, in part because of prevailing myths such as ‘excessive libido’, or, conversely, ‘eternally child-like’. For decades, actions in these institutions were shaped by such notions; the educational culture and the working reality of the institutions and the professional parties involved are shaped by them. It is commonly demonstrated by the buildings themselves: they are one thing first and foremost, namely practical and low-maintenance. Considerations of aesthetics and individuality were completely neglected, particularly in older establishments, as if people with a disability did not have an awareness of such things and did not need them.

One example: an institution for children and young people with a mental disability develops a sexuality-education concept with the help of outside support; a working group consisting of full-time employees is set up. The institution’s current handling of sexuality, prevention and self-determination is analysed. One concrete finding is that the girls and boys in their care do not currently have the option of perceiving their body as a whole, since there are only small mirrors above the sinks. It comes to be realized that hanging up larger mirrors that allow people to view themselves head-to-toe is a concrete and quite straightforward way of improving their awareness of their own bodies.

At the next meeting of the working group one employee comes along completely frustrated. He reports that the plan drawn up by the team had been viewed in very different ways and that numerous concerns were blocking the implementation of the idea. Some colleagues were worried, for example, that full-body mirrors could trigger an increase in ‘acting out sexual impulses’, while others said that the mirrors could lead to ‘uninhibited sexual behaviour’.

Many institutions fail to get beyond some initial sexuality-education ideas once they realize that by dealing with the topic of sexuality and self-determination they get more questions than answers, at least in the beginning. The different attitudes of the staff will clash, particularly with such a personal and value-charged subject; in the educational field there is then rarely time to delve into an issue appropriately. Consequently it can happen that the subject is completely abandoned again.

Another example from an institutional environment: a residential institution has three training days for the topic of sexuality, abuse-prevention and self-determination – two

days for a group of male residents, and one day for those acting in an educational capacity. Up until now these topics were taboo at this institution, and this was to change with the new leadership. The training days went well and were well-received all round. As a result the residents expressed their needs for sexuality more clearly and more directly. The staff placed a greater emphasis on enabling sexual self-determination. However, there were also situations that were assessed differently by different employees. For example, two residents were observed sitting next to each other on a sofa, touching each other’s genitals. The residents were both adults, but had different levels of impairment. In addition the employees suspected that one man involved had previous experience of abuse. What should be done about this scenario was viewed very differently. Some saw this encounter as an opportunity, while others emphasized the need for protection. Yet others also feared that this would open the floodgates to sexual inclinations if nobody were to put a stop to it.

These examples highlight a fundamental problem: many now know in theory that sexuality is a fundamental topic and that the prevention of, and intervention in, sexualized violence are important tasks. However, the practical implementation is rudimentary and timid. It is becoming increasingly clear that individual measures have a limited effect and that some measures can even contradict each other. It can happen that one institution finally has the urgently needed discussion about sexualized violence against children, teenagers and adults and then subsequently, fearing sexual violence in the institution, completely loses sight of the residents’ right to sexual self-determination. Such actions are contrary to sexuality-education approaches looking at prevention, where self-determination is a core element. In addition there are sceptical relatives, financial pressures and the unclear division of responsibilities among the various authorities.

One major remaining deficit is that in their training, professionals are still not necessarily fully prepared, if they are prepared at all, for the topics of sexuality and sexualized violence.

Consequently, committed employees and individuals in leadership positions work themselves into the ground in many places because of the complexity of the subject matter. There are two patterns we can observe here: sometimes those in charge of an institution recognize that there is a need for action, and so they just give their staff additional tasks. Such a hierarchical top-down delegation of responsibilities without including the employees in the process does not do justice to the subject matter or to the individuals living in the institution. The results are equally unsatisfactory, generally speaking, when staff attempt to establish sexual education without a conceptual umbrella and without support from above – i.e. using a bottom-up approach. Neither approach promises to be successful. On the contrary: such approaches can quickly mean that after the first frustrating experiences the introduction of an appropriate sexuality-education programme is abandoned.

Fit for the future – an integral approach instead of hasty ad hoc measures

So what do institutions and services need so that individuals with a disability can express their sexuality with as much self-determination as possible and so that staff are able to

make this a natural reality in the everyday lives of these individuals?

A sex-positive future requires an integral approach for sexual education, prevention and intervention. This approach is characterized by three central building blocks: firstly it has to be integral in the sense that the empowerment and participation of the people in question are both the starting point and the core concern. That means nothing less than making empowerment and participation the guiding principles of the entire educational approach and of the services – not just regarding sexuality and prevention (also see the contribution by SANDFORT in this publication).

Sexual self-determination can only be successful if people learn and are encouraged to participate. With the topic of sexuality in particular, which is a highly personal matter, it is hard to justify when people with a disability are excluded from decision-making and planning processes and others are deciding for them. It is therefore to be welcomed that participation panels such as advisory boards in residential facilities and in workshops and increasingly, women's representatives too, are emerging in many places and that the concept of peer counselling is gradually being recognized. These important stimuli must not gloss over the fact that we as a society and many disability-specific services and institutions still have a lot to learn when it comes to the inclusion and participation of individuals with a disability. Doubts about whether the Federal Participation Law (Bundesteilhabegesetz) will create lasting change here are certainly justified.

Secondly this approach has to be integrated in the sense that it includes a balance of structures that are protective on the one hand while encouraging of independence on the other. The widespread practice in institutions and services to work either with a preventive approach or a sexuality-educational approach, or to deal with both areas, but separately, falls short of what is required. It is much more sustainable to see both areas as connected and to shape them in tandem, i.e. preventively and sex-positively.

An outlook that is integrated in this sense and therefore open creates a different perspective on many of the situations staff are confronted with. A 'classic example' is when individuals with a disability either remove their clothes or masturbate in public. This behaviour is often not based on an intention to provoke or transgress boundaries; instead it is the result of habit and/or lack of a learning process. Of course this behaviour must be stopped in situations where it is not desired or allowed – there needs to be a justified boundary. But from an educational perspective this does not suffice. If it did, it would mean that the 'wrong' behaviour was forbidden but also that the desire itself was forbidden. It is important, after setting the boundaries, to explore the needs that underlie the behaviour and to think about where the individual can express that need. Metaphorically speaking, it means making space available. Every space has a boundary and every boundary a certain space. The one is not possible without the other, and this complexity should always be taken into consideration when acting in an educational capacity.

For professionals working with individuals with a disability, the future issue with granting sexual self-determination will be creating spaces for this, while defining boundaries and guaranteeing that they are adhered to. This development cannot be an optional extra; it has to be rooted in institutions and services at all levels.

And with that we reach the third component of an integral approach. Ideally and typically, institutions working in

integration support should be supported by external experts when optimizing their sexuality-education and preventive structures.¹ The integral element here is that participants at every level receive further training and assistance at the same time so that they can shape a process of change together.

The starting point of this process of change should always be an analysis of the existing structures and the needs of a particular institution. The resulting services must be specific to the institution. It should be ensured that measures are taken at the level of

- the institution (e.g. by developing concepts and guidelines)
- the professionals involved (e.g. through training sessions, regular case conferences)
- the individuals with a disability (e.g. through educational services, participation concepts)

For many institutions such an integral approach would mean nothing less than a paradigm shift and a change in attitude. Instead of waiting until sexually problematic behaviour or the suspicion of sexual assaults demands action, as is unfortunately much too often the case still in many institutions, the right approach is to proactively provide lifelong support for individuals with a disability in their development of their life plans, including their sexuality, to make corresponding services available and to set up support networks. External advice centres and services are a necessary support here. The potential of social networks and the co-ordination and linking up of existing services are currently only taken advantage of in isolated cases.

Summary

'Of course I cannot say whether things will get better when they change; but I can say this much: things must change if they are to become good.' (Georg Christoph Lichtenberg)

Much has happened. The framework conditions have been set and there are many positive approaches with regard to a sex-positive future. But hasty and ad hoc measures still prevail in many places. What is needed instead is a new, integrated approach, the broad strokes of which I have outlined. This is the only way we can develop and implement tailored and interlinked action plans and concepts for the overall organization, the professionals in the field and for the people with a disability.

This complex task cannot be delivered by the institutions and services alone. The state is called on here to provide sufficient financial resources and to set the appropriate political framework conditions. This does not just affect the development of concepts, training and advice, it also affects the area of research and teaching at universities. It is not enough to fund pilot projects; what happens afterwards is crucial. The insights obtained have to be made available systematically and therefore need to be adopted more quickly and comprehensively into the relevant working practices.

As we all know, it takes a lot of work and resources to get processes of change rolling in institutions, and to make sure

¹ Very positive experiences are currently being made with this method in the 'BeSt' pilot project (see the project outline in this publication). Evaluated results will be available in 2018.

a new course is pursued. However, I do think that this new path is worthwhile for everyone involved. With that in mind I would like to end with a quote from the Indian scholar Sri Aurobindo: 'If your goal is big and your means small, act anyway. Your means too will grow through your actions alone.'



Ralf Specht lives in Hamburg and has run training sessions for individuals with a disability and the people who support them. He is a lecturer at the Institut für Sexualpädagogik (isp) and works for PETZE in Kiel, where he is involved in the projects 'Beraten und Stärken (BeSt)' and 'Echt mein Recht! Entwicklung einer interaktiven Ausstellung für Erwachsene mit Behinderung'.

Contact:

*Ralf Specht
Training Consultant
ralf.specht@web.de
www.isp-dortmund.de
www.petze-kiel.de*

Has the UN Convention on the Rights of Persons with Disabilities meant that sexual self-determination can be experienced in practice?

An approach from the point of view of women with a disability

Martina Puschke

Since the UN Convention on the Rights of Persons with Disabilities has come into effect, a lot has changed, particularly for individuals with learning difficulties. Nevertheless there are still a number of unsolved problems in the area of sexual self-determination, which are addressed in this contribution.

The UN Convention on the Rights of Persons with Disabilities (UN CRPD) has been in effect in Germany for the past eight years. Even beforehand, sexuality was a basic right under the constitution. Now the sexual and reproductive rights have been captured in article 23 of the UN CRPD. Further articles allow us to draw conclusions about sexuality-related issues, e.g. equality and non-discrimination (article 5), awareness-raising (article 8), freedom from exploitation, violence and abuse (article 16), and respect for privacy (article 22).

Has the human rights perspective now 'arrived' in the topic of sexuality, apart from being quoted in almost all the current publications on the subject? What tangible changes, from the perspective of women with disabilities, have taken place in the years since the UN convention came into effect? Have the framework conditions improved so that women with disabilities can express their sexuality in a self-determined way?

Without making a claim to completeness this article will highlight the developments of the past eight years from the perspective of women with disabilities.

First things first: even before the UN CRPD came into effect ...

- sexual self-determination was a basic right
- there were (film) initiatives by disabled individuals on various aspects of sexuality
- there was peer advice on self-determined sexuality
- there were debates about sexual assistance or support for people with disabilities
- there were advice centres that provided advice on the topics of sexuality and disability
- there were special dating agencies for people with disabilities

- there were sexuality-education concepts that also took individuals with disabilities into account
- there were pilot projects on sexuality in disability-support institutions and much more

An initial overview

According to the political special-interest group for women with disabilities, Weibernetz e.V., a particularly large amount has been done for the group of people with learning difficulties.¹ The project 'Ich will auch heiraten!' ('I want to get married too!') by donum vitae has, for example, developed services for pregnancy advice centres so that people with learning difficulties can be advised better.² Pro familia in Hesse had a similar project ('Projekt Inklusion' ['Project Inclusion']) in order to remove barriers from advice centres.³ Other pro familia advice centres run various projects addressing the topics of sexuality and disability, in order to give people with learning difficulties, in particular, better advice.⁴ And AWO has had the programme 'In Sachen Liebe

1 I use the expression 'people with learning difficulties' ('Menschen mit Lernschwierigkeiten') instead of 'people with mental disabilities' ('Menschen mit geistiger Behinderung') based on the view put forward by the self-representation organization 'Mensch zuerst e.V.' that 'mental disability' is stigmatizing; see too: <http://www.menschzuerst.de/pages/startseite/wer-sind-wir/grundsatzprogramm.php#menschzuerst> (most recently accessed: 23 June 2017).

2 http://www.donumvitae.org/projekt_inklusion

3 <https://neu.profamilia.de/angebote-vor-ort/hessen/landesverband-hessen/projektinklusion.html> (most recently accessed: 23 June 2017)

4 For example at pro familia Ingolstadt: <http://www.eva-sindram.de/index.php/sexualitaet-behinderung> (most recently accessed: 23 June 2017)

unterwegs!' ('Out and about in the name of love') for many years now.⁵

In addition to the advice services in Simple Language in pregnancy advice centres, as well as in advice centres addressing sexuality and relationships, there are now various brochures on sexuality, contraception and pregnancy in Simple Language. That was an important step to enable individuals with learning difficulties to inform themselves and, building on that, to address specific questions with a close friend or in an advice centre. We know from many women with learning difficulties that they are familiar with several brochures and that their questions concerning contraception, living as a lesbian, and pregnancy are becoming more concrete.

A different exemplary project that aims on the one hand to increase the knowledge of residents in residential facilities, and on the other to remove structures in institutions offering disability support that are discriminatory or lead to violence goes by the name of ReWiKs.⁶

Improved framework conditions?

If projects like those cited above mean that the framework conditions and services in and outside of institutions will in the future orient themselves – depending on self-determined choice – to the needs, requirements and wishes of individuals, then much will have been achieved. In addition to personal decision-making about sexuality, relationships, contraception and parenthood, this approach also includes providing support with individuals' expression of their sexuality, with choosing or correctly using a contraceptive, providing adequate spaces for couples and offering services for parents (cf. JENNESSEN/ORTLAND/RÖMISCH 2015).

One crucial requirement for sexual self-determination is general self-determination in everyday life. As a result of paternalism (from the well-meaning concern to negate the desire for children), power structures and threats (having to move out in the event of a pregnancy, without providing alternatives) and even manipulation (knowingly withholding information), there can be no self-determined sexuality (cf. ZINSMEISTER 2010). Nor, in such structures, do individuals

learn to defend themselves against unwanted sexual acts. It is correspondingly common for women with disabilities to experience sexualized violence (two to three times more frequently than women generally) – in and outside of institutions (cf. FEDERAL MINISTRY FOR FAMILY AFFAIRS, SENIOR CITIZENS, WOMEN AND YOUTH 2012).

We still seem to have a long way ahead of us before individuals with disabilities have true self-determination in their everyday lives. To achieve this end everyone involved must make every effort.

Women's representatives for more self-determination

One building block to strengthen the co- and self-determination of women with disabilities is women's representatives in factories and residential institutions for individuals with disabilities. These are women that female staff and female residents can talk to at eye level regarding all matters that affect them in the institution. In training sessions following the long-standing and time-tested curriculum by Weibernetz e.V.⁷ they are comprehensively prepared for their role, for which they can choose an additional female support representative. Addressing questions about sexuality, contraception and parenthood is just as much part of this role as providing protection from (sexualized) violence and addressing this violence. Building an advice network outside of the institution is an important component, because the women's representatives cannot answer all of the questions themselves. A more in-depth consultation in an expert advice centre could also be necessary if the woman in question would like such a thing.

Legislative framework conditions in the context of sexual self-determination and protection against sexualized violence

The most recent legislative reforms contain provisions to strengthen sexual self-determination and to have protection against sexualized violence in two places⁸ where such provisions would not initially be suspected: in the criminal code relating to sexual offences and in the 'Sheltered Workshops Co-determination Regulations' (Werkstättenmitwirkungs-Verordnung, WMVO).

The new WMVO provides for mandatory women's representatives

The WMVO has been revised as part of the creation of the Federal Participation Law for individuals with disabilities. New provisions include the requirement that starting in 2017 sheltered workshops (working environments for individuals with disabilities) must have women's representatives from the ranks of those with a disability employed there. They are chosen by the female employees.⁹ Rhineland Palatinate led the way among the states and amended its state law on types of residential options and participation to include a provision that residential institutions for individuals with disabilities also had to have women's reps from the ranks of their female residents. Other states are currently working on corresponding standards.

However, women's reps cannot fix everything

The fact that sheltered workshops and residential institutions in various states now have to have women's reps is a major success in the drive towards shaping policies aimed at equality for disabled individuals. It is quite a novelty, because up until now gender equality has not been a significant aspect

5 <https://www.forum.sexualaufklaerung.de/index.php?docid=1281> (most recently accessed: 23 June 2017)

6 Reflexion, Wissen, Können – Qualifizierung von Mitarbeitenden und Bewohner_innen zur Erweiterung der sexuellen Selbstbestimmung für erwachsene Menschen mit Behinderung in Wohnrichtungen, see also <https://www.evh-bochum.de/laufende-projekte/articles/rewiks.html> (most recently accessed: 26 June 2017) and the contribution by B. Ortlund in this publication.

7 Curriculum for training sessions for women's representatives in institutions (2016) based on the Weibernetz project 'Frauenbeauftragte in Einrichtungen' ('Women's Representatives in Institutions'), supported by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, under <http://www.weibernetz.de/frauenbeauftragte/infohefte.html> (most recently accessed: 26 June 2017)

8 Violence and the exercise of power are the primary factors in sexualized violence. Sexualized violence is a topic in its own right independent of the topic of sexuality. Nevertheless this area is addressed in passing in this contribution because the topic in the reform of the criminal code relating to sexual matters is sexual self-determination and protection against sexualized violence and because women's representatives in institutions act on both matters.

9 The first elections are generally taking place in parallel with the election for the workshop councils in autumn 2017.

when addressing disability. We cannot expect that, without further involvement, disability care institutions will actually demonstrate the appropriate commitment just because there are women's representatives. What we need in addition to the desire of the management is additional measures on the part of the institutions.

In particular, the creation of women's representatives does not guarantee protection from sexualized violence. Women's representatives can be good initial contacts for female staff and residents; they can offer services that strengthen the women and they can be the voice of the women when communicating with management. However, on their own they cannot provide sufficient protection from violence, they cannot give expert advice and they definitely cannot take on the task of an independent monitoring body as demanded by the UN expert committee. In its concluding remarks on the state of the UN CRPD's implementation in Germany in 2015, the committee demanded that there should be one or more independent bodies for complaints in the context of violence and for the monitoring of institutions (cf. UNITED NATIONS 2015). This body/these bodies have to be based outside of institutions and run by an expert panel.

Far-reaching reform of the criminal code relating to sexual offences

The second legislative achievement in the context of sexual self-determination and increased protection from sexualized violence is the 2016 reform of the criminal code relating to sexual offences. We owe this to a Council of Europe measure – the Istanbul Convention. The criminal code relating to sexual offences now contains a consent clause specifically for people who are impaired in their decision-making (e.g. as a result of a disability). Consent must occur prior to every sexual act. If it does not, then the sexual act is deemed to have taken place involuntarily and can be punished accordingly. If the reason for the inability to make decisions is based on a disability or disease, the penalty is increased (cf. FABER 2016). This gave increased protection against sexualized violence directed towards women with disabilities or diseases and strengthened their right to sexual self-determination.

Conclusion

Since the UN Convention on the Rights of Persons with Disabilities has come into effect, quite a few things have changed regarding increased sexual self-determination for disabled people. However, the majority of these changes have been for individuals with learning difficulties, as the examples above demonstrate. The federal government¹⁰ as well as state governments and other bodies have funded projects whose advice and support structures that emerged from the project experiences will hopefully be made available long-term to people with disabilities. The legislative reforms provide good foundations that now have to be put into practice.

The framework conditions outlined above remain problematic in institutions that make a self-determined life more difficult.

From the perspective of women with disabilities there are, however, many additional hurdles in the context of sexual self-determination, of which only a few can be mentioned in brief here.

1. Women with disabilities are still evidently denied their sexuality

In the year 2015 the young blogger Katja still felt that people with disabilities were being denied their sexuality and therefore she decided to write about her sex life in her straight-talking blog in order to get rid of prejudices and to encourage other women with disabilities. She writes: 'I also noticed that, for example, disability is equated with asexuality. What is shocking to my mind is that many people with a disability are ashamed of their sexuality and do not like talking about it, because the subject of sex and disability is taboo. Even if people admit that individuals with a disability have a sex life or would like one, they still tend to say nothing more than that they want closeness, cuddling and love. Of course we all want that. BUT when I was still single I can well remember that sometimes I also just wanted to shag. Believe me, many others with a disability feel the same way!'¹¹

2. Lesbians with a disability are still frequently invisible

Where are lesbians with disabilities in the LGBTI scene? In the 1990s there were proactive groups of 'disabled dykes' ('Krüppellesben') and a corresponding nationwide network, but things have become quiet both in politics and in the lesbian movement. Although the annual lesbian spring gathering is almost barrier-free, the other meeting places of the LGBTI scene often are not.¹²

3. Women with disabilities often do not yet choose their contraception in a self-determined way

Women with learning disabilities who live in an institution are particularly likely to report in focus groups that they get the three-month contraceptive injection even though they do not currently have any sexual encounters with men. Almost every second woman living in an institution 'uses' contraception in this way (cf. RUNGE 2013, p. 40). This firstly suggests that they do not choose their method of contraception themselves; it also suggests that there is a substantial external desire (on the part of staff or parents) to avoid a potential pregnancy.

4. Sterilization remains a topic for women with disabilities

Women living in disability care institutions are particularly likely to be confronted with the subject. 75 % of women with physical or mental disabilities living in institutions have had sexual experiences. Of them, one in ten women have been sterilized. The percentage is higher among women with learning disabilities. Of them only 37 % have had sexual experiences but 17 % have been sterilized. Even among women with learning difficulties who have not had any sexual experiences, 14 % have been sterilized (cf. ZINSMEISTER 2012, p. 231).

Only half of the women opted for sterilization of their own accord. The other half let themselves be convinced by medical staff, experts or parents, had little knowledge about contraception, or did not see any prospects for themselves to live with a child (ibid.).

¹⁰ Predominantly the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth as well as the BZgA

¹¹ <http://einfach-katja.de/2015/02/>

¹² http://www.weibernetz.de/download/Positionspapier_Lesben_2017.pdf

5. Women with disabilities are not sufficiently protected from sexualized violence

As already described above, women with disabilities experience sexualized violence very frequently. There are different options for confronting this (empowerment of women with disabilities, training sessions, concepts in institutions of disability care, legal regulations etc.; cf. PUSCHKE 2013). However, these do not work as a comprehensive, effective and appropriately funded overall strategy to protect women and girls with disabilities from violence as the UN committee demands (see above UNITED NATIONS 2015).

As a result, the opening questions of whether women with disabilities can now experience their sexuality in a more self-determined way, eight years after the UN Convention on the Rights of Persons with Disabilities came into effect in Germany, cannot be answered with a clear yes. There are still too many gaps that have to be filled on the basis of a human rights perspective.



Martina Puschke has a diploma in pedagogical studies and lives in Kassel. She is the project head at the nationwide political special interest group for disabled women, Weibernetz e.V. The focuses of her work lie at the interface between disability policy and women's policy, and particularly the subjects of equality, sexualized violence and anti-discrimination.

Contact:

Martina Puschke
Weibernetz e.V.
Samuel-Beckett-Anlage 6
34119 Kassel
Germany
Phone: 0561 72885-313
martina.puschke@weibernetz.de
www.weibernetz.de

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Empowerment in the Institute for the Self-determination of Disabled Persons

Lothar Sandfort

Since 1997 the Institute for the Self-determination of Disabled Persons (Institut zur Selbst-Bestimmung Behinderter, ISBB) in Wendland, Lower Saxony, has offered sexual support services. Since then more than 300 disabled men and women have worked there on their sexual identity.

The Institute for the Self-determination of Disabled Persons in Trebel is rooted in the German civil rights movement for disabled individuals of the 1970s and 1980s. In those days there was a strong link to the American 'Independent Living' movement, which started ten years before its German counterpart and was originally launched by a small group of disabled students at the University of California in Berkeley. It was because of this contact, which shaped the communication on this topic, that the term 'empowerment' was adopted into the German movement for disabled individuals.

At first this term referred to the empowerment that the physically disabled in Germany, inspired by the German student rebellion in the late sixties, had achieved for themselves. In an emancipatory process of demonstrative ingratitude ('cripple movement') they discarded the image of the 'Musterkrüppelchen', the 'dear little model cripple' (grateful, well-behaved, easy to manage).

Self-help and advice centres became established in Germany over the following decades. They were often called 'centres for self-determined living'. The ISBB in Trebel is a result of this process. One of the last taboos, an individual sexual biography, became the motivation for setting up this specialized advice centre. Following demand, the focal points became the sexual life circumstances of mentally disabled individuals and the educational staff's need for advice.

These personal empowerment experiences resulted in an instructional concept for social work: 'empoweragogics' (in German: Empoweragogik, from 'empower' and 'pedagogics'). This neologism contains the mutual tension within itself. The power of the educator over the pupil seems to contradict the pupil's process of empowerment. But individuals can only empower themselves. In the ISBB we have adopted an

'agogic' (in German: Agogik)¹ basic attitude that we consider a support to empowerment.

Empowerment can and must be an educational goal – for all

Within the educational debate to date there has been the notion that empowerment could only flourish if the protagonists possessed the necessary cognitive abilities and reflective skills. This excludes many suffering from mental disabilities from having empowerment successes.

In a sympathetic teaching ('agogic') attitude the process of empowerment needs zero reflective skill on the part of the disabled person. It suffices that they live because then they act. Even when the logic within the perceptual process rejects consensus, they act. When they breathe, they act. They cannot do nothing. Every action has a before and an after and therefore a story. And every story has a purpose: it is the effort to preserve oneself in wellbeing as far as possible. Every person who is perceived has helped create a relationship through his/her mere existence. The perceiving person can recognize the purpose of the perceived person's life story and help them unfold it within this logic. The mere act of conscious perception contains empowerment. The person who was perceived has been given the power to build a relationship.

¹ 'Agogics' (Agogik) as used in this paper is a collective term used in the social sciences to mean the field of professional teaching and accompaniment of individuals of any age. It has the goal of supporting individuals in their social and self-sustaining skills and their professional competencies.

Fortunately, in the majority of social encounters teachers ('Agogen' ['agogues']) come across people whose remit they do not have to discover. People who can actively build differentiated relationships, who create a bond via a large number of creations. The most recent educational guiding principle, inclusion, is currently experiencing its limits. It is becoming clear that every time the subject of disability enters a life, it triggers rejection by the individual and in the social environment – it is defined as a crisis. Inclusion as self-evident togetherness right from the start is psychologically impossible. The maximum that is possible in such a crisis is integration. If the individuals affected possess their own strength and power, that is incredibly helpful.

The cultural exclusion of disabled individuals is not due to the ill will of a hostile society; instead it is each person's helpless mental protection mechanism. The notion that a life plan might be vulnerable is scary and this fear generates the actual taboo: the vulnerability of our own life. We cannot bear the thought that suffering and death, hardship and severe insecurity could render all of our efforts entirely pointless from one second to the next. Those who have become a symbol of suffering must not get too close to us: the sick, the bereaved, strangers, the infected, the disabled ... Christian culture has turned suffering through death on the Cross into a major theme. Suffering had to be given a purpose. That has not really helped. As long as suffering cannot emancipate itself as a self-evident part of life, those affected will always be under pressure to be excluded.

In order to stand up to that, people need a powerful sense of self-worth. However, they also need an awareness of their own cultural impact. When disabled people lead their lives in the belief that their disability does not just mean suffering but also joy and happiness, then others will indeed let them live in a more integrated manner. If they can interpret experiences of crisis as a gain, that even contributes to their attractiveness. Suffering requires recognition, not hostility.

A new guiding principle

It tends to be specific institutions that take on the brief to manage suffering: hospitals, hospices, undertakers, teams in disability care. The latter group, unlike institution staff in the previous century, are now able to take the people in their care to destinations outside of the residential facilities. The public feel reassured when the disabled excursionists are accompanied by professionals. Overly close, personal contact is to be avoided. When the disabled individual exhibits non-standard behaviour, the carers are held personally responsible.

The disabled individuals must not be, and are not, caused any personal harm. They are already perceived as people who are suffering. The institutions have the societal remit to reassure the public that the disabled people are well. To this end, the disabled individuals have to make a well-fed, clean and cheerful impression. Organizations collecting money, such as Aktion Mensch or the TV lottery, generate exactly this impression in their media clips, thereby securing their funding. Those in charge of institutions are constantly at

pains to prevent internal problems from leaking to the outside. Risk factors such as sexuality are not desired. Most disabled people in the institutions are doing well, they feel happy and not all institutions are the same. Depending on the history of any given institution, there are relatively frank or else close-lipped employees in leadership roles and in the care teams.

Violations of individuals' basic rights are tolerated less and less by all staff and a constant proportion of around 20% have, in my experience,² a problem with sanctioning those in their care through punishments. For others, privileges and punishments remain the only educational tools.

For culturally progressive (ped-)agogues empowerment is no longer an alien concept. Being culturally progressive means believing that the people in their care also have basic rights, such as the right to the unhindered development of their personality. Being culturally progressive means believing that the same cultural rules and values that hold true outside also hold true in the institution – for example nobody is allowed to run naked across the hall and doors should be closed when going to the toilet. When internal and public rules diverge too much, new walls are put up around the institution.

In 1992 the current law governing care came into force in its first version. At the time the legislators placed a very high value on the right to self-determination. The will of the person in care has had precedence since then. Section 1901 sub-sections 2 and 3 of Germany's civil code (BGB) state:

(2) The carer shall look after the affairs of the person in care in a way that is in line with the latter's wellbeing. The wellbeing of the person in care also includes the opportunity to shape his/her life in line with his/her abilities according to his/her own wishes and ideas.

(3) The carer shall meet the wishes of the person being cared for insofar as this is not contrary to his/her wellbeing and places no undue burden on the carer. This also applies to wishes that the person in care has stated prior to the appointment of the carer, unless it is obvious he/she does not want to stick to these wishes. Before the carer performs important matters, he/she shall discuss them with the person in care, insofar as this does not conflict with the latter's wellbeing.

A ruling issued by the Federal Court of Justice in 2009 confirms this precedence of the will of the person being cared for in regard to wishes that are an expression of his/her right to self-determination.

In everyday life the legal guardians, particularly when they are the parents, often make decisions without even discussing matters with the person they are caring for. They believe they already know what is and what is not in the 'best interest of the person in their care'. The family courts responsible are not generally interested in this. They are supposed to check from time to time whether those providing the care are respecting this legal requirement in their approach to care: 'The wellbeing of the person in care also includes the opportunity to shape his/her life in line with his/her abilities according to his/her own wishes and ideas.'

The institutions in disability care, even individual employees, have the opportunity – indeed the duty – to turn to the family court if they see any breaches here.

² This is based on insights from many encounters in the ISBB. Even just the accompanying careers often confide in detail and describe their working day. Added to that are the insights from my supervisory activity for teams and my work in institutions.

Empowerment includes information for disabled individuals about their rights and in particular about their basic rights. The opening up of care rights to parents as carers had not yet been envisaged prior to the passage of the law, in other words while it was being prepared. There were some opinion formers, such as Dr Klaus Dörner from Gütersloh, who assumed that enough volunteers would be found who would be willing to work in care. As a member of the de-hospitalization movement that was taking place at the time, Dörner was very popular, not least among Bundestag advisers. However, even the initial proposals they put forward were met with a barrage of protests, particularly from the ranks of the Lebenshilfe, an influential organization of parents of disabled people.

If the ideas of de-hospitalization could have been implemented, then many who were being cared for could have led much freer lives. Parents naturally often have ideas regarding their children's wellbeing that differ from those held by the children themselves. Things are no different among those who do not have a disability. That is often helpful, other times unfortunately not.

A person's basic right to the free development of his/her personality includes sexual development

The ISBB also expresses empowerment in its preferred methods. The methods of communication are modelled on experiential educational understanding in Germany.

The main questions the ISBB looks at are those surrounding sexuality, or more precisely the sexual history of the system seeking advice (individual with/without a carer)³. What has been said in this essay so far could also be applied to other problems disabled individuals experience, such as aggression. However, the ISBB became a sexuality advice centre for good reason.

We already knew that non-verbal methods of giving advice would take precedence when we started our work. Verbal methods place too much weight on comprehension. We wanted to provide an opportunity to communicate and learn through actions and behaviours. Learning via actions has major advantages for all people, and for individuals with cognitive impairments non-verbal expression is a necessity.

How, then, can we communicate about sexual behaviour, particularly as therapists working within the rules of our professional associations? To find solutions here we sought to work with prostitutes and set up interdisciplinary collaborations. We discovered quite quickly that women and men in traditional prostitution tend to have problems with feelings. Often they can only practise their job by locking out their feelings. However, we also needed other attitudes, feelings and the ability to communicate unpleasant statements too – to disabled individuals, who should not be exposed to harm, after all. The ISBB cannot work without honest feedback. So we started training our own sex surrogates. Including sex surrogates has become an important method within our sexuality advice work.

The sex surrogates occupy the emotionally charged field in which – or, rather, with which – the person seeking advice gets to interact in a way comparable to a high ropes course or a sailing boat on the IJsselmeer. Experts may already be familiar with both from other experiential educational settings. Our sex surrogates do not attempt to lead, they

allow the other person to act. They are prepared, and we as a team follow up together with the system seeking advice. In the ISBB experiences are made that point the way ahead.

Those seeking advice tend to understand our metaphor of a training camp very well. 'You can practise here. The truth is on the pitch.' They often spontaneously understand this saying from the history of German professional football.

The surrogates at our erotic workshops are among the culturally open experts. In order to come to us they generally have had to assert themselves over sceptics in their local institution and they will, as a rule, have had supportive superiors. The individuals seeking advice were fortunate and had good legal care providers.

A mentally disabled woman seeking advice had the habit of hugging care staff and therapists tightly for extended periods of time. Most permitted this. To do so, they had to de-eroticize the woman in question and see her as a disabled person, an innocent child. The learning goal for the trainees was to be aware of the woman's breasts during the embrace and to experience her body as erotic during the long and intense hug. When they did this, they themselves rejected the embrace. After that, they were asked to comment on this rejection. That was unfamiliar at first for the disabled woman, but from these rejections she learned to recognize when she came across as erotic to others, and that the others then generally rejected this contact. That is empowerment.

She has a boyfriend who was also present. The 'rejecters' were able to refer to him. He liked that.

A look to the future

Sex surrogacy has existed in the ISBB since 1997. It was conceived in a phone conversation between our long-standing employee Nina de Vries and myself. Since then this method has proved its worth many times. More than 300 disabled men and a few disabled women have worked on their identity as men and women. In Trebel they usually used sex surrogates in the context of sexuality advice provided by the ISBB. Even after many years of successful work the ISBB is still part of the avantgarde – but no more than that either. And there is a reason for this: as already mentioned, we are working against a powerful opponent, the fundamental fear of the fragility of life.

It all becomes clear when looking at the complete system involved in working with disabled individuals. The public remit to keep disability at arm's length is still well fulfilled by the disability care system. Every institution for disabled individuals that wanted to build close to residential areas had to labour against protests from the neighbourhood. That is the reason why so many institutions are situated in out of the way locations.

Nevertheless everyone is satisfied. The only ones that suffer are the disabled residents who wish for a different life, for example one with the same sexual opportunities as non-disabled people. They have just one way to defend themselves: they have to cause problems, and are then bullied with a withholding of affection, punishment, medication, scorn and sometimes with forensics. Only if they are lucky will they

³ Translator's note: while the word 'system' in this context may seem strange, it is taken over directly from the German where the connotations are the same.

come across sympathetic ‘agogues’ who then often come under pressure themselves. However, some of them manage to get help, at the ISBB for example.

A paradigm shift in education is urgently needed: empowerment. Individuals in care who are frustrated sexually and in other regards need a different understanding and more of it, as well as different ways to express themselves other than to cause vague problems.

The huge system of disability care is, however, satisfied with the status quo: politicians, supporting agencies, universities and other educators, educational science, the managements of residential facilities and sheltered workshops, disability societies, parent groups and the majority of educational staff in the teams. Sexuality is apparently consigned to the allegedly ‘sleeping dogs’.

To this day the educational community manages to fulfil the remit issued by the general public, albeit with difficulty. Well-fed, clean, happy impression at a distance. That’s enough.

Only the administrative authorities of the supralocal social-work bodies are interested in what happens in the institutions. The system of disability care, especially in Germany, is much too expensive. Decentralization and self-determination are more cost-effective in the long run. Both currently exist side-by-side and have to be paid for. Authorities demand that the educational proceedings in the teams are steered by means of individual support plans. Management and their teams know, of course, that every success in self-determination would lead to a reduction in staffing numbers. The IHPs⁴ (‘individual support plans’) are filled in correspondingly. The authority staff know this by now and just assume the educational work is successful. They make cuts. But that leads precisely to the staffing shortage that restricts the necessary ‘agogic’ work so badly. It is a vicious circle.

The political parties could bring about change, as could the media. When politicians voiced the idea of tackling the sexual problems of disabled and old people using state funds in January 2017, the vast majority of the media reported the proposal decidedly objectively. So there is hope.



Psychologist Lothar Sandfort, b. 1951, paraplegic since an accident in 1971, wheelchair user, married, three children. He is a systemic psychotherapist with a focus on non-verbal communication, a trainer in sexual advice, sex surrogacy, peer counselling and the director of the Institute for the Self-determination of Disabled Persons in Trebel/Lower Saxony (ISBB).

Contact:

*Institut zur Selbst-Bestimmung
Behinderter
Nemitzer Straße 16
29494 Trebel
sandfort@isbbtrebel.de
www.isbbtrebel.de*

⁴ IHP (Individuelle Hilfeplanung – individual support plan) involves data being passed on from the institution to the authority, usually in the form of a computer database in which the staff have to enter their teaching measures and their successes.

Sexuality and contraception for individuals with impairments: what qualifications are needed? What qualifications exist?

Annica Petri, Bärbel Ribbert

What do expert staff and institutions working in advice, support and care need in regard to assistance and qualifications in order to implement the right to sexual desire, sexuality, contraception and parenthood? The authors present their experiences from the family planning centre Familienplanungszentrum Hamburg e.V.

Over the past ten years quite a few things have shifted for people with impairments with regard to the implementation of their right to sexual desire, sexuality, contraception and parenthood. The coming into effect of the Convention on the Rights of Persons with Disabilities in 2009 certainly contributed to that. We now have more relevant expert literature, working tools were and are being developed and many informative websites have been translated into Simple Language. It has become increasingly commonplace in training sessions to allow that individuals with different impairments have a need for sexuality. At the same time we hear in advice sessions that parents and others providing support are uncertain when it comes to the practical accompaniment of the individual implementation of the right.

We are taking a look from the point of view of the Familienplanungszentrum, a pregnancy advice centre in Hamburg, that was already making efforts to check and improve the access to the advice centre for individuals with impairments prior to the UN Convention. It was important to us that we would not just be 'open to everyone' on paper: we knew that we would not reach individuals with impairments automatically; instead, we had to work for this goal. In addition to personal qualifications, redesigning rooms, adapting processes and creating working tools, our two-year project 'Eigenwillig' also included further training for support workers in disability care and in schools from the outset. The project was singled out as a good-practice project¹ for its innovative capacity and sustainability.

Since the project was first initiated in 2006 the services offered by the Family Planning Centre are now quite naturally taken up by individuals with different impairments too: adults come for relationship counselling, girls see a gynaecologist. Boys and girls come to have sexuality educators

explain physical processes or how to use contraceptives, using Simple Language and clear methods. Others come to receive advice and counselling about their pregnancy prior to a potential termination or they come because they want a child. Inclusive school groups, special schools and integrated schools as well as vocational schools attend our sexuality education events. Parents of children, young people and adults with disabilities often take advantage of our advice sessions too.

What needs for qualifications do we see?

Before we address the concrete needs for qualification and the tested measures in Hamburg, we want to take a brief look at the regional effects of the UN Convention on the Rights of Persons with Disabilities that came into effect in Germany on 26 March 2009. In 2011 the federal government published its National Action Plan for the implementation of the convention. Action plans were subsequently put in place in the states too. In the area of health, Hamburg's state action plan adopted evaluated experiences from the Family Planning Centre with the goal of making all pregnancy advice centres in Hamburg fully accessible for individuals with impairments: 'In the context of promoting health, there are ways in which access to competent advice regarding sexuality education and family planning can be improved for individuals with disabilities. This relates both

¹ Distinction by the Kooperationsverbund Gesundheitliche Chancengleichheit in 2011; www.gesundheitliche-chancengleichheit.de

to the area of gynaecological care for women and to the entire area of sexuality education for all age groups' (FREIE UND HANSESTADT HAMBURG 2013). The pregnancy advice centres in Hamburg were thereby given a good foundation for further activities to improve the care of people in need of support.

The qualification needs regarding the sexual education of individuals with disabilities have expanded in recent years. At first the focus of training sessions and qualification measures lay exclusively on experts working in disability care in assisted-living groups and sheltered workshops as well as special schools; the current challenge, however, is in providing additional qualifications for experts in further fields of work that have now adopted an inclusive approach, such as advice centres, gynaecological practices, schools and daycare centres.

The goal of these qualification measures is to open up the right to self-determined sexuality and informed participation to individuals with impairments in all areas of work (CLAUSEN/HERRATH 2012). To achieve this, the qualification must take into account the diverse needs of people with disabilities, the needs of the experts and the framework conditions of the institutions and support agencies.

It is helpful to keep in mind the guiding principle of the UN Convention – inclusion: 'Inclusion is not about individuals having to adapt in order to participate or 'keep up'. It is about our society opening up. Our guideline, which we should take for granted, should be diversity and our fundamental attitude should be that every single individual is valuable with his/her own abilities and conditions' (BENTELE 2014).

Components in qualification measures

In what follows we will introduce time-tested modules from our own qualification measures. We will avoid adapting the modules systematically to individual areas of work or assessing certain target groups. Instead we will use examples from different areas of learning to make our illustrations.

Self-reflection

Connected to the inclusion guideline quoted above, the most important core aspect of all kinds of training and further training is that those providing the support confront their own attitude: where are they insecure? What are their fears and inhibitions? How, for example, is a woman's unplanned pregnancy dealt with in an assisted-living facility or a pregnancy advice centre? Is she merely told how difficult or even impossible it would be to carry the pregnancy to term or is she also told that it is her decision, and that she will get support regardless of the choice she makes? Individuals with disabilities who want children or become parents are still 'hot potatoes' for many experts and parents. It is not just the internal confrontation of the support workers that is important here in order to make the right to self-determined family planning a reality. There are often not enough support systems for parents with impairments and their children, such as supported or assisted parenthood services.

This kind of work-related self-reflection also helps determine the areas in which the rights of individuals with disabilities are being limited by institutions and experts themselves, rather than being more difficult to implement

because of the disabilities of those being supported. Many of those providing support are not aware, for example, that even in assisted-living arrangements, the adult residents can decide for themselves who is allowed to spend the night in their room. Information about the legal framework conditions can often help here (ZINSMEISTER 2012).

A further aspect of self-reflection is to give experts space to reflect on their own boundaries and to incorporate them in the process. It could be, for example, that one care worker, worried about unplanned pregnancies, only recommends hormonal injections as a contraceptive option to all the female residents. Parents of a female resident might also exert pressure in this regard, thereby reinforcing the staff member's attitude. But when we look at the resources and lifestyles of the individual women, different forms of contraception that are more compatible should be considered. All that is required in order to use them is that the necessary education and support be provided.

Knowledge of psychosexual phases of development

Another important module for experts is obtaining fundamental knowledge about people's psychosexual development. In what ways is sexuality expressed in childhood? What developmental steps happen in teenagers? What happens then in young adults? Building on this foundation, which ought to serve as an orientation, not a standardization, the next question addresses the unique features caused by disability. What if there are (severe) physical limitations? What if people do not communicate through language? What special forms of socialization do people with disabilities experience? How can that influence their development?

This knowledge of psychosexual development is to be used as a general guideline, but it is not universally applicable. The real skill when interacting with individuals with disabilities is always to see the person with his/her individual resources: what desires, abilities and preconditions does a person come with? A visually impaired child will definitely need to be addressed differently from an adult with a learning disability; a heterosexual girl with impaired mobility has a different need for support from those of a homosexual man who cannot hear: the types and degrees of the impairments are very individual and require different support measures; as a result the contents of qualification measures must be differentiated. Diversity as an inclusive starting attitude means seeing disability as a category alongside sex, cultural background, sexual orientation, age, gender identity and educational background.

Subject area: violence

A third module addresses the topic of violence and the experience of violence. Studies confirm that women with disabilities are hugely affected by violated boundaries, violence and sexualized violence (BMFSFJ 2013). This has powerful and often lasting effects on the sexual self-determination of girls and women. This is also reflected in our advisory work. In addition to experiences of violence, people with disabilities make the everyday experience that their boundaries are violated as a matter of course, both in care contexts and in social interaction. In the context of sexuality, by contrast, they are then supposed to exercise and express their own boundaries. In our view the concept of prevention should be incorporated in all qualification measures. Furthermore we believe it is necessary to create and install

protective concepts to prevent sexualized violence in care institutions. This happens relatively rarely at present.

Subject: sex-positive design

On the other hand a fourth module provides an opportunity for confrontation with ideas of how to create a sex-positive institution. What spaces does an institution offer to make room for intimacy, the development of, and occupation with the subject of sexuality?

How to act in a sexual context is something we learn from social interactions. We learn when we are on our own and with others what we like and what we do not like. Allowing such age-appropriate contact supports people with and without disabilities in learning how to have a relationship. They learn to be aware of their own desires, to voice them, to set boundaries when something is unpleasant – all of these things are important experiences and learning moments: what happens during the interaction if we inadvertently step too close to someone else? The best-case scenario is that people learn from such situations, often as children, to respect the boundaries of others.

Individuals with disabilities need space for these learning processes, which should be made available to them as early as possible, and they need experts who can support them without being present all the time.

Working with parents

Another obligatory qualification module is working with parents on sexuality-related topics. Institutions in disability care are encouraged to root parental work firmly in what they do. If parental work takes place on a regular basis, communicating about the sexual behaviour of the individuals receiving support becomes easier – outside of difficult situations in which conflicts with parents can occur. In parental conversations mothers and fathers could be informed about the subject of psychosexual development, and they could be invited to discuss it. Many parents who are initially sceptical are then very interested in the subject and have many questions. At parents' evenings mothers and fathers often express their relief when they find out that it is not just their child exhibiting certain behaviours, and that these are not an expression of their disability but an expression of age-appropriate development. Fears and worries about the child can be discussed better.

Using working tools

We consider the use of suitable clear materials and specific working tools as a further indispensable component in this field (ARBEITERWOHLFAHRT BUNDESVERBAND 2006). The goal is to ensure that individuals with disabilities understand information well and can make informed decisions about their lives.

Valuable working tools such as the Paomi models have now been developed that help not just individuals with disabilities, but other groups too, to learn about bodily processes and sexuality. The sexuality-education classic, the basket of contraceptives, has proven itself as a sexuality education tool for people with disabilities: it contains a broad spectrum of contraceptives. They can be presented and explained but also touched and tested on models. This includes a demonstration of how to use condoms.

For those providing support, institution-specific, sexuality-related concepts give them certainty in their actions as well as transparency. Qualification measures encourage

them to develop appropriate concepts. It is a good idea to include people with disabilities and parents in their development.

Stemming from the qualification measures the participants often form the desire to stay linked beyond the training event. In Hamburg the need for ongoing exchange and qualification resulted in a regular networking meeting by the 'Sexuality and Disability Round Table'. Twice a year it also hosts an expert exchange that includes professionals from a whole spectrum of agencies and areas of activity.

Inclusive sexuality education right from the start

Now we would like to highlight an area that so far has received little attention when it comes to the self-determination of individuals with impairments – sexuality education in nursery schools.

There are many nurseries in Hamburg that are now inclusive in their approach. Many look after disabled and non-disabled children together. Inclusion as the guiding principle means that some everyday situations are being evaluated anew. It is not enough for children with disabilities to 'just be there for everything' and for teachers to assume that the children feel like they are participating as a result. The need for qualifications with regard to sexuality education is considerable.

For the seventh time a certified training course to accompany nursery teachers in Hamburg educators is taking place; it is called 'Sexuality Education Competence in Nurseries'. This qualification, currently unique, takes place in the context of a co-operative project between pro familia Hamburg, the Family Planning Centre and unaffiliated sexuality educators with the support of the Paritätischer Wohlfahrtsverband Hamburg and the Sozialpädagogisches Fortbildungszentrum Hamburg. One special feature of this one-year training course is the inclusion of a training module that deals closely with the sexuality education of children with disabilities. This separate module has really stood the test of time. Participants report back that they develop a greater awareness of this group and that they feel sensitized to its general concerns as well as its specific ones in the context of sexuality. They are opened up to seeing and interpreting an everyday situation in different ways. When they know how childhood sexuality is expressed, they no longer interpret it as an expression of 'uninhibited sexuality' when a four-year-old boy with Down's syndrome masturbates; instead they can categorize it as an age-appropriate development.

Sometimes the goal is to make offers to a child with disabilities so that he/she can relate the topics to him/herself. Particularly when it comes to children with cognitive impairments, it can be more difficult for them to access a confrontation with the subjects of the body, feelings and boundaries. Simple language, working with pictures or symbols of feelings, repeating terms so that the messages are taken in and remembered are all important approaches.

When children with disabilities are dependent on help and assistance, it can also be important to examine the exact ways in which the actions are executed. In nurseries, changing nappies and washing children who have wet or soiled themselves are everyday occurrences. Many nurseries address attentiveness in changing situations. Many nursery teachers are not familiar with the specific situation of children of different ages who have disabilities: should a six-year-old child be changed with the same movements as a

three-year-old? What accompanying words should be chosen? Is enough space for autonomous action and control provided? Depending on the child and the situation, this can vary and should always be determined in detail. Of course this will not be possible in all everyday events for which there is not much time, but experts often have a changed attitude. A routine of 'I'll help you because you can't do it' is transformed into 'I'll support you as little as possible so you've got the space to develop'.

The significance of such an everyday situation that at first glance seems banal is very significant when we look at the flourishing of self-determination.

In the field of schools specialized in training individuals in social work, the topic of children with disabilities is not currently very high on the agenda. Measures to provide sexuality education are often absent. We think there is a great need for further training here too.

Conclusion

In summary we are pleased that much has changed for the better in all the areas described. We too, the team at the Family Planning Centre, are part of an ongoing process, constantly learning more together with the individuals with disabilities and the many support workers we work with.

At the same time much still needs to be done in order to move participation forward:

- Sexuality-related concepts should be rooted in institutions of all areas (whether or not an institution takes a sexuality-education approach or implements qualification measures often depends on the commitment of individual members of staff or the management).
- Training and further training measures, for example for nursery teachers and for gynaecologists
- Development of support opportunities for parents with disabilities through supported and assisted parenthood (SPECHT 2003; PIXA-KETTNER/ROHMANN 2012).

Annica Petri is a social pedagogue, a sexual pedagogue and a counsellor.

Bärbel Ribbert is a pedagogue, a counsellor and a director.

Both work in the Familienplanungszentrum Hamburg e.V.

The Familienplanungszentrum was lauded by the Senate co-ordinator for the equal treatment of disabled persons as a pioneer of inclusion in healthcare.

Contact:

Familienplanungszentrum HH e.V.

Bei der Johanniskirche 20

22767 Hamburg

www.familienplanungszentrum.de

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Participative organization development in the area of sexual self-determination

The materials from the ReWiKs research project

Barbara Ortland

Since November 2014 the BZgA-supported research project 'Reflection, Knowledge, Ability – Qualifications for staff and residents to increase the sexual self-determination of adults with disabilities in assisted living institutions' (known by the German acronym ReWiKs) has developed specific materials for the various target groups, led discussions with those working in the field and tested them. The 'ReWiKs materials' can be used as a foundation for participative organisation development in the area of sexual self-determination. The reasons behind the research project, along with its design and current state will be presented below.

The reason behind the project: a high incidence of sexualized violence against adults with disabilities

Results from studies about sexualized violence committed against people with disabilities (SCHRÖTTLE et al. 2012; ZEMP/PIRCHER 1996; ZEMP et al. 1997) have made clear the increased need and urgency for efforts in the area of prevention and intervention regarding sexualized violence. Successful and comprehensive measures in the areas of sexuality pedagogics and sexuality andragogics¹ are controversial components of preventive work (cf. MATTKE 2015; LIMITA 2011). The presentations by ENDERS (2012, 149 ff.) on the requirement for structures in institutions to be more hostile to perpetrators also highlight the need for organization development.

Basis: results of current surveys

We see concept approaches and individual ideas to create sex-positive structures that support the sexual self-determination of all residents in integration-support institutions time and again in the relevant specialist literature (cf. WALTER 2005; FEGERT et al. 2006; CLAUSEN/HERRATH 2013). The frequent demand is for staff (cf. CLAUSEN/HERRATH 2013) to get more training so they can respond adequately to the needs of the residents. It has become clear from the analyses of the qualitative interviews with staff working in integration support (cf. JESCHKE et al. 2006) that because of the complex, not least internal-psychological processes among the staff, (traditional) further training courses are not enough; instead they need to be constructed in a diverse manner, both with

regard to content and structure. Further suggestions – differentiated in their content – regarding these needs for support and development prospects came out in a survey (conducted by the author in 2013 [n=640]) of staff working in integration-support institutions (cf. ORTLAND 2016).

Design of the ReWiKs research project

These results were the reason why the research project presented here was set up. It is being implemented by the present author (Katholische Hochschule NRW) together with her colleagues Kathrin Römisch (Evangelische Hochschule Bochum), Sven Jennessen from Humboldt Universität Berlin (until August 2017 University of Koblenz-Landau) along with their respective collaborators. The project focuses on three issues and is based on close co-operation with residents and staff in integration-support institutions.

An overview of the project focuses

Project area reflection (Koblenz-Landau/Berlin)

Reflection manuals are being developed for both residents and staff based on the 'guidelines for successful sexual self-determination', which exist both in technical language for staff as well as Simple Language for residents. The purpose of these manuals is to reflect in detail on the current working and living situation and to find starting points for necessary changes.

¹ Andragogics (German: Andragogik) = The science of adult education

Project area knowledge (Münster)

Building on newly developed training modules that have been discussed with professionals in the field, some example training modules and a wide variety of materials will be developed for various settings (alone, in a team, in larger groups), which can then be tested, evaluated and developed further by those involved in this area. In addition, training courses will be developed for multipliers who want to drive forward sexual self-determination in the institutions at the organizational level.

Project area skills (Bochum)

Based on a comprehensive assessment of successful projects aimed at implementing (sexual) self-determination, two manuals will be developed – one in technical language, one in Simple Language – in which recommended actions for change will be worked out, tested, evaluated and developed.

Project area: reflection*Reflection manual in technical language*

The 'guidelines for successful sexual self-determination in integration support institutions' form the basis of the reflection manual. These guidelines were formulated on the basis of the studies cited above and discussed with professionals in the field. After the inclusion of some additional factors as well as some changes to the language, the final version of the ten guidelines was published (Example guideline 1: 'Adults with disabilities live their sexuality in a self-determined manner and will be supported in line with their needs, their age and their development. They are experts regarding all aspects of their sexuality.')

In a next step, reflective questions were formulated for every guideline covering the areas 'attitudes', 'structures' and 'practices'. In order to align them with the needs and topics of this working area they too were revised with regard to their content and their language, on the basis of feedback from staff working in residential integration-support institutions.

A working version of the reflection manual (ReMaxS) was tested in seven residential institutions. The reflection questions about the individual guidelines were discussed in groups of between three and ten staff and where the groups were usually heterogeneous with regard to profession and hierarchy (n=62). The evaluation of the discussions focused on the following central questions: does the tool encourage confrontations within a team? What factors favour and inhibit confrontation?

Minutes of the group discussions were kept and audio recordings were also made, so that the central discussion can be transcribed and analysed. Furthermore there was a written evaluation by means of a questionnaire about working with the tool. Helpful insights into the appropriate and constructive use of the tool were deduced from the results of the various data; these insights were then adopted as recommended actions in the manual's introductory information section. In addition to a lot of qualitative feedback, which pointed out both critical aspects and the potential of the reflection manual, the evaluations of the tools were generally positive.

Reflection manual in Simple Language

The first step was to create the guidelines in Simple Language and these were then used as the basis for the manual in Simple Language. These guidelines were discussed with eighteen residents from five residential integration-support institutions and relevant subject areas for the development of the reflection questions were determined. After more content was added and some changes were made to the language, pictograms to accompany the topics were developed. In a next step reflection questions are formulated about the nine guidelines in Simple Language that allow individuals with intellectual impairments to confront the central issues of sexual self-determination in a residential institution. The counterpart for residents to the reflection question for staff cited above could be the following statements, supplemented by pictograms: 'I am expert in my sexuality. The staff know this.' The contents and visual aids for a working version of the manual in Simple Language are currently being developed. This working version will then be evaluated – and if necessary modified and completed – with the help of resident groups in five integration-support institutions.

Project area: knowledge

Based on empirical studies and experiences from working in the field, five comprehensive training modules were developed and targets and exemplary training curriculums were put forward. They are seen as fundamental for the staff to have in order to be qualified to help residents achieve sexual self-determination in institutions. Fifteen institutions were willing to co-operate in discussing the modules and then later the training blocks. During an initial exchange both the residents and staff incorporated their expert knowledge. The modules were revised and differentiated using the results from these discussions, after which a comprehensive and differentiated inspection and compilation of all the existing published materials on the training topics took place for the residents. Where topics were not present, they were developed so that they would be taken into account in the work in the future.

As the project progressed it became clear that the very considerable differences in knowledge among the staff in the residential institutions required a two-tier approach, so that:

- a training manual is created for the personal and team-related development of the staff in the residential groups using low-threshold materials
- and that – building on this – multiplier training courses are developed for staff who want to conceptually advance the issue of sexual self-determination in the institutions.

During the second year of the project the focus was on testing and revising the training materials further and on the personal and team-related learning by the staff in the residential groups. By September 2016 a trial version of the comprehensive training manual was produced (around 500 pages), which contains materials that focus on the following subject areas: talking about sexuality, reflecting on values and norms, viewpoints/perception of disability, professional brief, relationships, sexuality, development of a gender identity/sexual diversity.

The co-operating institutions were given various methodological, didactic materials in the form of textbooks in Simple Language, caricatures, (autobiographical) texts with reflection suggestions, working tools and suggested training curriculums. These were, for example, supplemented with

a selection of Metacom symbols² so that individuals who have no written language competence and/or are reliant on supported communication could also take advantage of the services. The materials were targeted at the residents and staff. At the same time as the training folder was created, selected materials were successively discussed in various settings with professionals in the field and tested in training services with men and women with disabilities.

In September 2016 the following options for testing the materials were offered to the fifteen co-operating institutions:

- a) Issuing and explaining a training folder, including a feedback form for the evaluation, combined with a reflection conversation about the user experiences in early 2017. Ten institutions chose this option.
- b) The project team implements training sessions for training groups that are more homogeneous (staff or residents) or for training groups that are more heterogeneous (staff and residents together). Eight training sessions were held.

The initial insights from the training sessions that were implemented (option B) reveal a generally positive evaluation with regard to their content and their methodological approach/working materials, as well as with regard to the joint event involving both staff and residents. The reflection conversations and the evaluation of the feedback forms about the training folder (option A) are currently taking place.

Three-day training courses for multipliers who want to develop the concept of sexual self-determination further in their residential institutions are currently being developed. They are to be tested in three different groups in autumn 2017.

Project area: skills

The goal of the two manuals (for staff and residents) developed in this project area is to create recommendations for action on the basis of the 'guidelines for successful sexual self-determination'. To this end, the intention is for examples of good practice and already extant knowledge from working in the field to be collected and combined with insights from theory and research.

To research the knowledge already extant in the field, the first step was a comprehensive nationwide internet search for concrete projects and institutions that deal or have dealt with supporting self-determined sexuality for individuals with disabilities in the broadest sense. A three-step analysis process was developed in advance to manage the selection and evaluation of the research results:

1. documenting all of the websites put up by project providers and institutions that were researched, coupled with notes on whether they contain research results relevant to the issues at hand;
2. arranging all of the projects and institutions that were found in a rough analysis grid that contains both the subject areas of the guidelines and related/superordinate topics (e.g. empowerment quite generally);
3. a detailed analysis of the research results in respect of how they address the guidelines or aspects of the guidelines.

Next, projects were chosen and support in the form of an interview was requested. The central criterion for choosing the projects and institutions was that as many topical aspects of the guidelines as possible be covered. In addition institutions and projects that displayed some unique feature

because of where they put their focus were also contacted. This approach led to a very heterogeneous group for the interviews: staff of residential institutions, individuals involved in implementing ongoing or already completed projects, residents, and project participants.

Among the topics covered by the qualitative interviews were, for example, opportunities for expressing sexuality, confrontation with subjects such as contraception, relationships and parenthood, and the prevention of sexualized violence. The focus was on implementation opportunities, concrete approaches and stumbling blocks. 28 interviews with 34 interviewees were conducted; 19 of them were staff of institutions or project workers, and 15 were residents and project participants.

The content of the interviews was evaluated. A working version of the practical manual for employees is currently in its initial test phase.

Conclusion

The experiences with the professionals working in the field in the discussion and test phases in all three locations demonstrated time and again that the ReWiKs materials addressed many relevant individuals in an appropriate manner. This will make possible a long-term participative development of the organizations at every level of the hierarchy with the goal of achieving successful sexual self-determination for residents.

2 Metacom is a collection of symbols from 'supported communication'.



Professor Barbara Ortland has been a professor at the Katholische Hochschule NRW, Münster campus, since 2009. After studying special-needs education and working as a teacher she spent ten years at the Technical University in Dortmund, teaching 'physical and motor development'. The current focuses of her work lie in the area of supportive communication, the sexual development of people with different disabilities, sexuality education in schools, and the sexual self-determination of individuals with disabilities in adulthood.

Contact:

*Prof. Dr. Barbara Ortland
Katholische Hochschule NRW
Abteilung Münster
Piusallee 89
48147 Münster
b.ortland @katho-nrw.de*

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Sexual self-determination – then what?

More than 20 years of ‘supported parenthood’¹ in the Federal Republic of Germany

Annette Vlasak

Emerging from the educational social work sector, a few special support services were established for parents with disabilities in the mid-1990s that went on to receive nationwide enquiries. Ever since then, the term used in Germany when talking about supporting mentally disabled individuals with children in their social function as parents has been ‘Begleitete Elternschaft’ (‘supported parenthood’). The trend has been increasingly to stop separating such parents from their children (VLASAK et al. 2015).

A start in Schleswig-Holstein and Brandenburg

At first it was isolated providers of social services for people with disabilities, largely in northern Germany, who coined this term. More than 20 years ago disabled parents and their children moved from all over Germany to Kiel, to the Marie Christian Homes. The family project in Friesack/Mark in Brandenburg was one of the first providers of a residential project designed for families in supported parenthood that managed to do justice to both needs of the family by having youth welfare services and integration support services work together. These days almost every state – although not everywhere and not enough in every place – offers supported parenthood services.

‘Landesarbeitsgemeinschaft Begleitete Elternschaft’ (state ‘supported parenthood’ working group) Brandenburg-Berlin

A special situation developed in the state of Brandenburg. Supported parenthood was already backed by the state youth welfare office (now the Ministry for Education, Youth and Sports) in the 1990s. In October 2000 the first specialist conference was organized at which a working group was established for the six providers in Brandenburg at the time. Providers from Berlin joined this state working group at a later date.² It has now set up an association that looks at developing supported parenthood in Brandenburg further; it is supported by the State Ministry for Education, Youth and Sports. Under its oversight a ‘supported parenthood’ qualification curriculum was developed that currently contains five modules.³ The society also supports research projects that address supported parenthood. A course for parents with mental disabilities is offered annually.⁴ In addition to the two-day annual meeting in June the society

now organizes a specialist conference for professionals in the field, which takes place every year in autumn. 2018 will also see the first specialist and family conference for and with affected families.

‘Bundesarbeitsgemeinschaft (BAG) Begleitete Elternschaft’

In 2002 three ‘supported parenthood’ providers met in Bremen in order to found a working group at federal level (‘BundesArbeitsGemeinschaft’ or BAG).⁵ The providers felt they had to battle with a lot of difficulties and problems in the institutions; the hope was that regular meetings would allow them to work on them together, to develop the support services further and to improve the situation for disabled parents locally. The support for individuals with disabilities who were or wanted to become parents was to be improved at the ground level by being evidence-based. Ever since then the BAG has met for two days annually in different regions of Germany. It now has more than 30 firm members. In addition every meeting is also attended by guests who are new to this field and who hope to get advice and support from the long-standing members.

1 Translator’s note: the German term ‘begleitete Elternschaft’ means, literally, ‘accompanied parenthood’, but the term we have chosen here is ‘supported parenthood’.

2 <http://begleitete-elternschaft-bb.org/>

3 <http://begleitete-elternschaft-bb.org/index.php?inhalt=weiterb@seite=fach>

4 http://begleitete-elternschaft-bb.org/pdf/Berufsbegleitende_Qualifizierungen_Fach_und_Leitungskraefte.pdf

5 <http://www.begleiteteelternschaft.de/>

Legal foundations

Under the terms of the legal provisions of the German Social Code (Sozialgesetzbuch, SGB) parents with disabilities can claim parenting help (for the family) and integration assistance and participation support (for the disabled parent). Children of parents with disabilities can assert rights to an upbringing, care, protection and participation. After the UN Convention on the Rights of Persons with Disabilities (UN CRPD), which was formally ratified by the EU in 2010, the German government followed with the National Action Plan for the implementation of the convention in 2011; some states also have their own action plans.

Youth welfare and integration support

Although there is no list of services for 'supported parenthood' in the German Social Code catalogue, families can refer to three legal rights:

1. Parents have the right as a rule to help with raising children according to sections 27 ff. SGB VIII.
2. Parents have the right as a rule to integration assistance/participation support according to sections 53 and 54 SGB XII.
3. A child has the right to an upbringing, care, protection and participation (SGB VIII/Convention on the Rights of a Child).

The various services offered by youth welfare and integration support are based on these legal norms. Most parents would like help within their own home, in a non-residential setting. However, that is sometimes not enough to rule out the potential endangerment of a child's wellbeing. For that reason a more intensive support service is often necessary, at least during the first years of a child's life. There are now various funding options that combine the services performed by integration support and by youth welfare in such a way that needs-based support can be ensured. Up until a few years ago there was a legally paradoxical situation in Germany regarding the funding of parents with disabilities in institutions under the terms of section 19 SGB VIII. In March 2009 the Federal Social Court ruled that youth welfare had the ultimate funding responsibility for this service, while the Federal Administrative Court took the opposite view and stated in October 2009 that integration support was ultimately responsible for paying for services for young disabled parents. Fortunately the Federal Social Court decided in 2012 to revise its original ruling. As a result social welfare providers are now responsible for paying for services used by disabled people in institutions too, under section 19 SGB VIII.⁶

6 Bundesarbeitsgemeinschaft der überörtlichen Träger der Sozialhilfe, *Mitgliederinfo* 21/2012; http://www.lwl.org/spur-download/bag/21_12.pdf

7 <https://www.behindertenrechtskonvention.info/>

8 <https://www.behindertenrechtskonvention.info/schutz-von-ehe-und-familie-3900/>

9 Translator's note: this organization (Deutscher Verein für öffentliche und soziale Fürsorge) translates its own name thus. However, 'Private' as a translation for 'soziale' could be misleading; what is meant is 'voluntary sector' as opposed to 'public sector'.

10 MICHEL, M. (2015): Unterstützte Elternschaft. Angebote für behinderte und chronisch kranke Eltern. Eine Analyse zur Umsetzung des Artikels 23 der UN-BRK; http://begleitete-elternschaft-bb.org/pdf/fachtagung2015/Unterst_Elternschaft_Analyse_Umsetzung_UN_BRK.pdf

11 <https://www.awo-potsdam.de/files/data/pdf/Elternschaften%20von%20Menschen%20mit%20geistiger%20Behinderung.pdf>

12 https://mbjs.brandenburg.de/media_fast/6288/expertise_zusammenleben_geistig_behinderter_eltern_mit_kinder.pdf

UN Convention on the Rights of Persons with Disabilities

By signing the UN Convention on the Rights of Persons with Disabilities (UN CRPD)⁷ the Federal Republic of Germany mandated itself to take 'effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships' (UN CRPD art. 23 section 1).

'States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities' (UN CRPD art. 23 section 2). 'In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents' (UN CRPD art. 23 section 4).⁸

Therefore there is a legal foundation for the work with disabled parents. A few years ago there was still the option of excluding parents with disabilities from certain youth welfare services on principle; this is simply not possible anymore.

Stumbling blocks in implementing the UN CRPD

Much has been put in place for disabled parents in the past twenty years, but not enough and not everywhere. Disabled parents who want to live with their children may still have to move to other federal states because there is no suitable support service locally. Parenthood as an aspect of life is not specifically named in section 54 SGB XII (integration support), which has resulted in experts in social welfare offices not feeling responsible for this area of participation in the life of the community. This is the situation despite individuals' contact to their own children being the most important one conceivable and also the most far-reaching social contact in the life of any person. When high levels of support are needed, children are still being separated from their own parents right after birth. It is also the case that in many regions the support services on offer for disabled parents are not known about. There is little information material out there for parents in Simple Language. Parenting courses are not barrier-free. Finally, there is still a great deal of prejudice in society at large towards parents with disabilities.

The German Association for Public and Private Welfare⁹ published a recommendation in 2014 in which it outlined how parents with impairments and their children could be given practical support (MICHEL 2015¹⁰). This recommendation was even translated into Simple Language. The association states that shaping the social sphere in such a way as to be inclusive is a central task and it demands that 'parents with impairments [...] be given the same access to services that parents without impairments enjoy'.

A lot of work and many changes are necessary to fulfil this undertaking. Parents with disabilities do not have an easy time of it in society. It is the frequent experience of workers in supported parenthood that social services often do not take the needs of disabled parents into account. There is also a shortage of concrete studies here.

Research and evaluation

In the German-speaking world there are now a few studies that were conducted within the framework of supported parenthood. After initial investigations by the University of Bremen (PIXA-KETTNER 1996; 2005¹¹) there were some evaluative projects in Brandenburg, conducted by the state youth welfare office and the University of Potsdam¹² and most recently a research project by the Université de Fribourg in

Switzerland¹³. There are doctoral dissertations and increasingly Master's theses on the subject coming out of social pedagogy departments at universities (cf. e.g. SCHIEMENZ 2014¹⁴).

University of Bremen

The late Professor Ursula Pixa-Kettner from the University of Bremen, who sadly left us far too young, made a significant and early contribution to shaping supported parenthood in social pedagogy circles and beyond. It was she who, early on, with her students conducted the first nationwide study on the living circumstances of parents with a mental disability in Bremen, thereby raising awareness for this issue among experts in the field (PIXAKETTNER et al. 1996).

Much has changed since then. The number of people who became a mother or father despite having a mental disability has grown significantly. A big leap in numbers can be seen in around 2000, as a further study from 2005 found (PIXAKETTNER 2005).

The reasons for this are diverse: disabled individuals have now become self-confident enough to make their desire for children a reality even if they are advised against this. People with a mental disability are also less likely to live in residential homes; instead they live in shared housing or in their own flat. Since 1992 it has been illegal in all of Germany's federal states to sterilize minors with a disability, and sterilizing women and men with disabilities has also become legally more difficult (section 1631c BGB, section 1905 BGB).

German-speaking world

There are now some studies in the wider German-speaking world that have been conducted in the context of supported parenthood. A few smaller research projects followed in the wake of the aforementioned studies conducted by the University of Bremen. In 2004 the state youth welfare office of Brandenburg and the University of Potsdam studied the living circumstances of parents with mental disabilities and their children in Brandenburg. Findings included developmental delays in the children, particularly in their language development. Even more specifically the Université de Fribourg in Switzerland conducted a study overseen by Professor Orthmann, in which it researched the development of 157 children from Germany who were living with their parents in a supported parenthood context; the competences of the disabled parents were tested at the same time.¹⁵ This study notes that the children were on average much more competent than their parents, particularly with regard to their cognitive development, but that they were less well developed than other children of their age. In addition it became clear that parents with mental disabilities were much more competent in dealing with the tasks of everyday life than their cognitive abilities would suggest. Compared to other mentally disabled people they do well. However, their children do not have such high levels of practical skills as other children do. These children need good social educational support outside the home to help them with their development at school and their life skills in order to give them the same developmental opportunities as other children their age.



Annette Vlasak was a deaconess in the GDR specializing in remedial education. After the fall of the Berlin Wall she developed a concept for supported parenthood, which led to the founding of the family project at the AWO Friesack in 1997/98. As someone who was persecuted by the East German dictatorship it was only after reunification that she was able to study alongside her work. She runs the non-residential department of the Albatros-Lebensnetz gGmbH, where the various youth and integration support services are combined in such a way that the support offered matches the needs of the individuals.

Contact:

Albatros-Lebensnetz gGmbH
Wartenberger Straße 24
13053 Berlin
info@albatros-lebensnetz.de
www.albatros-lebensnetz.de

¹³ <http://fns.unifr.ch/sepia/de/sepia-d/>

¹⁴ https://monami.hs-mittweida.de/files/6575/Masterarbeit_Tilli+Schiemenz.pdf

¹⁵ <http://fns.unifr.ch/sepia/de/sepia-d/>

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VLASAK, A., et al. (2015) in: PIXAKETTNER, U. (ed.): Tabu oder Normalität? Eltern mit geistiger Behinderung und ihre Kinder. Heidelberg: Universitätsverlag Winter, 3rd edition

Inclusive advice¹: results from the project ‘I want to get married too!’

Petra Schyma

‘I want to get married too!’ is the title of the inclusion projects that donum vitae ran from March 2013 to April 2016, supported by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth. This statement is an expression of the desire for equal participation in society, for love, happiness, a relationship and parenthood. The project goal was to implement suitable services in pregnancy (conflict) advice for individuals with learning difficulties.

The UN Convention on the Rights of Persons with Disabilities (UN CRPD art. 23) and the subsequent National Action Plan put forward by the federal government guarantee the right of persons with disabilities to sexuality, a relationship and marriage. Associated with this right is also the right of access to age-appropriate and barrier-free information about sexuality, reproduction and family planning. When the German Social Code (Sozialgesetzbuch, SGB) chapter IX ‘Rehabilitation and Participation’ came into effect in 2001 there was a paradigm shift: from simply caring for people with disabilities to resource-oriented support, from outside decision-making by a system of helpers to self-determination and equal participation.

Requirements of advice given to individuals with learning difficulties

Section 2 clause 10f of the pregnancy conflict law (Schwangerschaftskonfliktgesetz, SchKG) says: ‘(1) Every woman and every man have the right to obtain information and advice anonymously from an appropriate advice centre regarding the purposes cited in section 1 sub-section 1 about matters of sexuality education, contraception and family planning as well as all issues directly and indirectly relating to pregnancy.’

¹ Translator’s note: the German term ‘Beratung’ can be translated as ‘advice’, ‘counselling’ or ‘guidance’, each of which has connotations not necessarily present in the German term. Here, the words ‘advice’ and ‘adviser’ have been used as being the most general, though the ideas of ‘counselling’ and (in particular) ‘guidance’ are not ruled out. The term ‘advice’ here should not, however, be taken to include the idea of ‘recommendation’ which the English word might sometimes include.

The desire to give practical effect to this right was the motivation behind the donum vitae project ‘I want to get married too!’. Existing advice services were adapted to the needs and desires of individuals with learning difficulties/mental disabilities and the competence of the advisers was expanded with specific expert knowledge.

In what follows, significant results from the project work and the academic consultation will be presented. The article will describe what demands were made, when advising this target group, of the advisers themselves, of the advice situation, the advice conversation and in the running of group events. One component of the pilot project was expanding the existing online advice service for this target group.

Demands made of the advisers

Helpful factors for obtaining qualifications were in-service training sessions particularly in Simple Language and in provision of legal advice for individuals with mental disabilities. Calling on the help of such individuals as ‘comprehension barometers’ proved fruitful. They were advisers rather than advice-seekers in this context and gave the advice workers significant insights into how to understand this target group.

Individuals with learning difficulties are often supervised and looked after in institutions. This tends to be accompanied by limited mobility in the public realm. In addition there is a lack of knowledge about advice services on offer outside of the institutions. For this reason the advice services for individuals with learning difficulties need to be advertised in institutions. They in turn need to spread this information to family members, legal guardians and staff and thereby break down initial thresholds and reservations. Good links

with institutions working in disability care helps workers in the field reach individuals with learning difficulties.

One problem these individuals are confronted with is that of getting to the advice centre. It is often not possible for them to come on their own. That could be because of the nature and severity of the impairment, but also because the staff lack the confidence to allow clients² to go to advice centres on their own, or else they have legal concerns in this regard. Background knowledge of the different characteristics of learning difficulties or specific syndrome-related features and of the individuals' living environments is beneficial for advice sessions. People who do not (or cannot) live independently and who instead live in the care of their parents or in a residential facility are often restricted in their self-determination regarding relationships and sexuality. For this reason it is important to ask clients concrete questions about their living circumstances, personal experiences, the reason for their visit and the desired outcome. They are the experts in their own living circumstances.

Requirements of the advice situation

Generally speaking providing advice to individuals with learning difficulties comes with the same requirements as any other advisory situation. Any advice session should be conducted in a protected context and in a respectful and resource-oriented manner. Clients must be supported in making their own decisions.

Throughout the pilot project a few special features became clear: it is crucial to get to know one another and to remove insecurities on both sides in advance. During the advice session, the topic at hand is to be communicated without producing a defensive reaction. That means all parties involved and the social environment have to be included, which means in turn that an advice session in this context does differ from the regular *modus operandi*. The first step is to listen to everyone involved; then the setting can be adapted appropriately.

Over the course of the pilot project the following questions were developed to help with assessing a situation:

- Who has to be included in the decision-making process?
- Are there support networks?
- What would help increase the decision-making freedom of the woman, the man or the couple?
- How can advisers maintain boundaries?
- Who steers the procedure?
- Who decides what?
- What do parents as legal guardians need?
- How can parents (with their fears) be supported?
- How can information, e.g. about legal questions, be communicated and, if necessary, separated from the process of overcoming fears?
- When should advice sessions be conducted with the parents/legal guardians alone, when together with the clients?

The intention is for people with learning difficulties to be empowered to make their own decisions (e.g. in choosing a contraceptive or when they want children). The use of suitable, simplified materials and methods is helpful in achieving this. It is necessary in advice sessions to pay attention to the relationship between impaired individuals and their legal guardians, especially with regard to decisions made by those seeking advice. Is it really their decision or is it being made because carers are pressuring them?

Parents of people with learning difficulties, especially when they fulfil the role of legal guardians, develop many fears and also need someone they can talk to. It is a special challenge in an advice session if women are sent to such a session when they didn't want to come. In that case it is important to reflect on these configurations and to step away if necessary. When advising couples, it is helpful to involve male advisers to make the advice gender-sensitive.

Requirements of the advice session

The main thing that differentiates advice sessions for people with learning difficulties from the rest is the time factor. Advice sessions last longer; too much information within one meeting overwhelms clients.

Special requirements of the advice session:

- Get briefed about clients – determine their prior knowledge of the subject to be discussed
- Use of suitable information materials
- Ensure there is time for clients to ask questions
- Ensure there is time for advisers to take questions to ensure the communicated information has been understood
- Support in applying for assistance
- Help with making contact with other parties (gynaecologists/administrative bodies) if necessary.

It makes sense for advisers to find out how much those seeking advice know about sexuality and what their perception of it is; it is then possible to build on that information. For that reason it is fundamental to reflect on the starting position in order to develop effective solution strategies.

Providing advice in Simple Language is a crucial requirement for a successful exchange. In other words, facts and circumstances are expressed in a different manner that is easier to understand. Pictures and drawings can be used to support the spoken word; visualizing what a typical day would look like with a child can help work through the issue of a desire for children, for example. The brochures in Simple Language, such as from *donum vitae*, can be used as a supporting resource.

Requirements for designing group events

Information evenings or film nights can be held on the subject for family members and carers in advance of the event. An initial meeting between the participants and the advisers within the institution can trigger their interest in such services. In this way group events can be publicized, concerns can be dealt with and open questions can be resolved. Information sheets sent out to the legal guardians together with the invitations can help resolve reservations and increase the number of people in the target group who take up the planned sexuality-education services.

The offer of externally run group events in the institutions must first be publicized through preliminary talks. One advantage here is that the participants are very easy to reach. Sexuality-education services in institutions are important in order to bring in new stimuli from the outside. External services are also needed because many of the topics addressed by the advisers are not addressed by the institutions,

² Translator's note: the term used in German is 'Klient/Klientin' (m./f.). This has the same connotation as the English word and no attempt has been made to place any further interpretation on it.

or only inadequately. It needs to be settled in advance whether staff in the institutions should participate in the group event. The use of Simple Language and simplified materials and methods is important throughout the sexuality-education services too.

Requirements of online advice

The design of an online advice service differs from personal sessions and is tied to certain technical requirements. It can be used anonymously and therefore allows people who cannot access sexuality-related information in other ways the opportunity to acquire information independently. Protecting the privacy of those seeking advice is important when it comes to online advice. This criterion is met by the provider-side. This type of access could only be a problem for users if they need support to access the internet, or if they are not allowed to access it on their own.

Supporting and inhibiting factors for the feasibility of this pilot project

Structural requirements

For the long-term establishment of the services and their transference to other advice centres, the concept must be thought through with the consideration in mind that individuals with learning disabilities need more time for advice and sexuality education.

Getting rid of barriers in the sense intended by the UN CRPD is an important requirement for ensuring self-determined participation in the life of the community. Individuals with learning difficulties may have multiple disabilities and therefore may also be dependent on an absence of barriers generally, so that mobility, sight and hearing impairments do not get in the way. Communication and information are as barrier-free as possible in the project; if there is a need, sign language interpreters and Simple Language can be used. It must be possible in all advice centres to make an appointment by phone, fax or email. That is very important because people with auditory impairments cannot use the phone or only have a limited ability to do so.

Access to the clientele

Access to the clientele takes place via networking and publicity in order to inform, to break down fears and prejudices, and to sensitize people to the fact that individuals with learning disabilities also have a right to sexual self-determination. In order to access the clientele directly the project uses 'come to us' structures as well as services that seek the target group out. Both options display advantages and disadvantages (see below).

For the services to be established long-term in advice centres, a combination of both access routes is sensible. The group events in the institutions often led to individual sessions in the advice centres – they essentially acted as a way of opening the door for individual follow-up conversations.

Borderline situations

There are barriers when advising clients with learning difficulties that prove to be particular challenges for advisers: for example, there is a lack of recognition by the public that individuals with learning difficulties have the right to sexuality, relationships and parenthood; likewise the public fails to see this group as adult. With regard to sensitizing the clients' families and the like, problems regarding this topic occur primarily among older parents of disabled adults; they also struggle to recognize their children's right to a self-determined life, particularly when the parents are also the legal guardians of their adult children and are present at advice sessions. If clients with learning difficulties want to have children or are already pregnant, they are emotionally and legally dependent on their parents, which can limit their decision-making freedom with regard to a pregnancy.

Further difficulties come about when the cause for seeking out an advice session and the desired goal are hard to ascertain, or when it is hard to determine how much the clients have understood or what help is necessary and possible.

Sexual assault/abuse

All advice centres were confronted with the subject of 'sexual assault/abuse'. Affected women were encouraged by the group events to talk about their experiences. In some cases

Walk-in ('come to us') model: group offers and advice in the advice centre

Advantages

- is closer to the idea of inclusiveness
- accompanied advice sessions are often helpful
- confidentiality and anonymity are guaranteed
- promotes self-determination in the field of contacts and advice

Drawbacks

- difficult if advice-seekers cannot come alone
- staff numbers inadequate – cannot bring clients
- institution chooses who else comes along, endangering self-determination

Outreach services: Advisors go to the institutions

Advantages

- carers/supporters are within reach
- services are known through flyers
- insight into the world of the clientele
- advice-seekers are reached who cannot come to the advice centre alone

Drawbacks

- very time-consuming
- services largely confined to evenings
- institutions decide whether the services are wanted
- confidence in the 'microcosm of the institution' is endangered

the social environment reacted thoughtfully and appropriately when the experiences of violence were addressed; in other cases individuals were completely overwhelmed by the situation. A further problem: girls and women are recognized as a target of physical, psychological and sexual violence, whereas boys and young men are not yet really viewed in this way. Professional experience has shown that there need to be services for them. However there are often no male advisers to run group events or individual sessions.

Parenthood

Even though the pilot project was aimed largely at group and individual services to develop sexuality education and self-determination, all advice centres, as expected, also addressed the desire for children and parenthood. The following problems came to light:

- Reservations (by others in the individuals' surroundings) if they wanted children or were already pregnant. Solutions that were put forward ranged from terminating the pregnancy at the request of the client's mother as the legal guardian to repeating the advice session at the request of the client's gynaecologist and to continuing the pregnancy and moving the young family into a suitable support system.
- If there is a shortage of suitable services for young parents with learning difficulties or if these services are not known about, then the reservations and fears felt by the young parents' parents regarding the sexuality advice and education given to their children – e.g. the fear of having to take on a full parental role for a grandchild – are increased.

If there is a desire for children, or a woman is in the early stages of pregnancy, then advisers are well placed to provide advice to the pregnant woman or the young parents and to refer them to suitable support services. If there are no suitable services or the responsible service providers have a negative attitude, then it becomes hard to put the right support in place in time.

The concept of supported parenthood gives parents with learning difficulties access to a very good service of outpatient or resident support in line with Germany's Social Code (Sozialgesetzbuch, SGB) chapters VIII, IX and XII, tailored to an individual's need for support (LENZ et al. 2010; DEUTSCHER VEREIN 2014; also see the contribution by A. VLASAK in this publication). In many regions in Germany there are as yet no suitable services to support parents with disabilities. In addition service providers working in integration support and youth welfare still have many questions about responsibilities when it comes to paying for supported parenthood.

Sustainability

Pilot projects generally face the problem of ensuring the sustainability of the results after the initial support period ends. The inclusion project 'I want to get married too!' revealed that preparation for the project and implementing the services require a longer time frame because:

- as laid out above, access to the clientele was difficult
- prejudices and fears had to be broken down with good public relations work
- advising the clients required a lot more time
- the advisers had to acquire the necessary qualifications in training sessions
- the technical requirements had to be created for the online service

Regular training courses and sharing experiences internally by a provider, between providers and even between different disciplines contribute to stabilizing the services of the pilot advice centres as does making available the materials for the work with individuals with learning difficulties that were developed or collected during the project.

However, long-term implementation is ultimately not possible without the provision of both funds and staffing. Advising individuals with learning difficulties is time-consuming and requires a lot of commitment, expert knowledge and empathy.



Petra Schyma (social worker and sexual pedagogue) is a consultant with the donum vitae Bundesverband e.V. in Bonn. In addition to managing the pilot project 'Schwangerschaft und Flucht' ('Pregnancy and Escape'), she also managed the inclusion project 'I want to get married too!' – implementing bespoke services in pregnancy conflict advice and general pregnancy counselling for individuals with mental disabilities. Before that she worked in pregnancy (conflict) advice and in an institution for individuals with learning difficulties.

Contact:

*Petra Schyma
donum vitae Bundesverband e.V.
Thomas-Mann-Straße 4
53111 Bonn
schyma@donumvitae.org*

Antenatal classes for women and couples with disabilities

Co-operative project between pro familia and CeBeeF Frankfurt am Main

Susanne Bell

Since 2010 CeBeeF¹ (Club Behinderter und ihrer Freunde [‘Club of the Disabled and their Friends’]) and pro familia have offered antenatal classes for women and couples with disabilities in Frankfurt am Main. This article will give an overview of the concept, the content and experiences made.

Just like other women and couples who are expecting a child, people with disabilities also have many questions during this time about the pregnancy, the birth and life with a newborn baby. At the same time there are important special aspects. These could be switching medications during the pregnancy and the delivery, or movement, breathing and relaxation exercises that have to be modified because of a physical disability. Some participants require more time to prepare for the birth since a sign language interpreter might need to translate the contents of the course along with any questions. They might need the course to move at a slower speed, and the use of visual materials and models to make the topics comprehensible to participants with learning difficulties. In addition it is important for parents with a disability to be able to think about what needs to be taken into account from an equipment perspective, and for what activities they might need help, and how this could be arranged.

Concept

The course offered by CeBeeF and pro familia is aimed at women and couples with a range of disabilities. Parents-to-be with physical disabilities, sensory disabilities (blind/visually impaired/deaf/hard of hearing), learning difficulties, chronic illnesses and mental impairments in a variety of relationship situations have taken part in the course to date.

The concept is intended for a small number of participants – maximally four women or couples. The course is structured to take place on eight evenings and also includes a prior consultation and a follow-up meeting where the child is brought along. It generally starts from the 25th week of

pregnancy and will also take place if just a single woman or couple signs up. In this case, or if long travel is involved, the course can be structured in a more compact manner, after agreeing this with the participants. The instructors running the course will discuss any special needs with the participants in advance and make individual options possible.

Throughout the course the participants, their questions, wishes and resources take centre stage. On the one hand knowledge about pregnancy, birth and infant care is passed on; on the other the course instructors see themselves as mediators, helping the participants to develop their own solutions that work for them.

The team of course instructors consists of Hannelore Sonnleitner-Doll, a doctor at pro familia, and Susanne Bell, a mother in a wheelchair and a long-time activist in political disability work. Hannelore Sonnleitner-Doll has run a gynaecological advice surgery for many years, specifically also for women with disabilities in the barrier-free pro familia advice centre in Frankfurt. Susanne Bell is an adviser in the spirit of peer counselling²; she runs the breathing, movement and relaxation sequences.

Contents

The first aspect of the course addresses where the woman or the couple is in the pregnancy. The development of the child throughout pregnancy, nutrition, medications, self-care, mobility and exercise are talked about, as are support opportunities such as a midwife during pregnancy and in post-natal care. Questions about the ‘Mutterpass’ – the expectant mother’s record of prenatal and natal care – and gynaecological exams are discussed. Using visual materials and models the individual phases of the birth are demonstrated and explained. Any instruments that might be used, as well as caesarean sections, are presented in order to assuage the participants’ fear of them, should they be necessary during the delivery process.

¹ Pronounced Tsay-Bay-Eff, from the German letters CBF.

² Peer Counselling in the ‘self-determined living’ movement refers to advice given by disabled individuals to other disabled individuals and is used there as an emancipatory counselling method. Disabled advisers can develop an empathetic understanding for the situation of those seeking advice or they can be role models; those seeking advice can build trust.

Breathing exercises, body awareness and movement sequences and relaxation periods are part of every session and are adapted to the abilities of the participants. As a result of their heterogeneity there is a broad spectrum of variants here.

At further sessions the participants learn about breast and bottle-feeding as well as about how to care for an infant. The parents-to-be will change and dress life-sized baby dolls with real clothes. Women with physical impairments were able to experience whether they could manage better standing up or sitting down, or whether a specially prepared spot on the floor could provide the safest option – for a woman who is paralysed on one side for example. They try out how they can best nurse their child – sitting or lying down – and how they can use cushions or other padding to help them with this.

The parents-to-be talk with the course instructors about resources and can develop their own ideas. A father built a cot that a wheelchair could roll under for example. Other parents purchased cots whose height they could adjust electrically; later, when they did not need it any more, they were able to sell it on to other parents-to-be that the course instructors could introduce them to. Deaf parents need visual and tactile signals (such as a vibrating mattress) to replace a baby monitor. Parents who are severely visually impaired had to develop methods to measure and prepare baby food correctly.

Another topic of discussion during the classes is what everyday life can be like for the family after the birth. The subjects of mobility and support in daily life fall into this category. With regards to creating networks, the participants create a sketch of their ‘team of helpers’. They could be reliable friends, neighbours or family members, professional helpers, the midwife and maybe the health visitor and all the other people who form the network in all aspects concerned with caring for the baby.

In the case of couples, the fathers and mothers-to-be will spend one evening by themselves with a male adviser from pro familia and the female course instructors respectively. Topics discussed could be the relationship between the parents themselves or the distribution of labour, which – like in all families – is geared to the abilities and opportunities of the mother and the father. Parents with a disability might have to make sure that one partner who is not impaired or less impaired in certain areas does not take on too many tasks, such as looking after the baby while also supporting the other partner. Single parents might also need more help. To pre-empt the risk of becoming overwhelmed, a paid assistant could be an option now, even if that had not been necessary prior to starting a family.

Experiences

The special antenatal course can help parents to be who have a disability to find their way around topics that go beyond standard preparation for birth, such as a need for assistance, tools and a division of labour within a relationship. Not everything can be simulated in advance; some needs only show up in practice, once the parents have arrived home with their newborn. Nevertheless women and couples with a disability can get a good idea of where they might need support after participating in these intensive antenatal classes.

Thanks to the protected context and the small number of participants, the women and couples have the opportunity

to bring up personal and intimate matters relating to them specifically.

It is also a goal of the course to strengthen the self-confidence of the parents-to-be. It has often been reported in the course that this has happened. One participant reported that prior to the course she had felt very insecure when talking to staff in youth and social welfare offices where they had made certain applications; but as the course went on – in her case thanks to practising with dolls – she gained the confidence to know she would be able to look after her baby well despite her physical disability.

‘It takes a village to raise a child.’ This much-quoted African saying implies that children need many reliable people who are there for them and that parents cannot do everything themselves – nor should they. For parents with disabilities the subject of having a network is often particularly important when their limitation means they cannot cover certain areas. However, it is here of all places where they often encounter barriers. This could be in the area of communication, if a sign language interpreter is not paid for. Infrastructure important to families is often difficult to access purely because of its physical construction. Families also worry they will be less accepted when it comes to things like taking turns with childcare or accompanying children to activities. During this course the participants can brainstorm together where and how they can create networks in their neighbourhood and they can talk about what challenges might be associated with that for them.

Some participants had decided to take part in a further antenatal course in their midwife’s clinic or maternity clinic in order to meet other parents-to-be from the surrounding area or get to know the clinic in advance. This can be a sensible combination, depending on the limitation in question.

Right from the start the course instructors urgently recommend that the women and couples get in touch with a midwife who can be there with them throughout the pregnancy and in after-care. It would be ideal for many women and couples with a disability to have a midwife with a hospital affiliation for the birth who could get to know the woman’s abilities in advance. This model is, however, at least in large cities, rarely possible because of the current shortages in midwifery care.

The course also provides information about services in Early Help, including health visitors, about what options family centres and other local institutions offer and about the concepts of supported or assisted parenthood with the associated advice centres and organizations.

Since 2010 the antenatal course has been part of the co-operation project ‘Being a woman with a disability’ run by CeBeeF Frankfurt am Main e.V. and the local branch in Frankfurt of pro familia. The collaboration of these two organizations in Frankfurt with their broad spectrum of networks in their respective areas has proven very productive for the antenatal course. The course has very good networks with different players both on the institutional and on the personal level: via the social and gynaecological advice service run by pro familia it is linked to clinics, gynaecologists and the midwifery association. CeBeeF has its own advice centre and further services connected to disability as well as very good contacts to relevant authorities and support agencies. In the area around Frankfurt in particular, the course project can refer the women and couples to many suitable services to do with parents and children and give them relevant contacts.

Even beyond the duration of the course CeBeeF and pro familia in Frankfurt offer advice all about the topic of parenthood. Women and couples with disabilities can turn to pro familia's gynaecological advice centre or the general advice service run by CeBeeF if they have a desire for children, for example. Workshops on women-specific subjects are offered via the co-operation project. The team of course instructors regularly invites all parents who have participated in the course to come for a follow-up meeting along with their children. These meetings are popular and offer a further opportunity to network and share experiences.

The reaction to parents with disabilities continues to be characterized by ambivalence and reservations. Gisela Hermes summarizes relevant research results like this: 'It can be assumed that disabled mothers and fathers are generally confronted with negative attitudes and are discriminated against' (HERMES 2004, p. 45).³ Nevertheless, in our view, carefully put, parents with physical or sensory disabilities have been experiencing somewhat more open-minded attitudes on the part of the public and in the media. Parents with disabilities talk about their life in their blogs and in online forums and they exchange experiences. Advertising for wheelchairs and other tools important to this target group has also discovered this topic, and is increasingly depicting families with one disabled parent. Participants in the courses with physical and sensory disabilities were generally self-confident, even when there were uncertainties with regard to many aspects. One participant said: 'We have learned to live with our disability and to shape our everyday lives competently and we have the awareness and strategies needed to continue doing so in future with a child.' The question at hand was 'how?' – how certain situations can be shaped in the best-possible way for the child and the family.

People with learning difficulties on the other hand were more powerfully confronted with the fact that they are essentially not trusted to take on a parental role in a responsible way. This situation, often described in the expert literature, was confirmed in our courses in our participants' experiences. Nevertheless Hannelore Sonnleitner-Doll observed: 'People with learning difficulties who look after their child often grow with their duties and develop competencies that others previously thought them incapable of.'

One option for some people with learning difficulties is 'supported parenthood' in the context of having home visits while living independently. Some women or couples initially desire a more protected framework, such as a parent-child facility. It should be stated here that the vast majority of institutions do not currently work in an inclusive manner, and parents with disabilities can end up getting a place that is far away from where they live. This situation can be particularly

difficult for couples: 'Mothers and fathers with learning difficulties (...) have particular problems when it comes to receiving non-residential care; the mothers (-to-be) are largely referred to specialized mother-and-child institutions. However, there are only a small number of these nationwide and they cannot meet the demand. The women are given the choice of leaving their social network behind, and potentially the father of the child too, in order to move into an unknown institution in an unfamiliar environment, maybe even in a different state – or they can give their child to a foster family.' (ZINSMEISTER 2010, p. 15). Other young parents with learning difficulties decided to get support from their family of origin and moved into the home of their own parents or their parents-in-law, along with their child, even though this causes stress and the problem that parental responsibilities are often taken over by the grandparents.⁴

To allow the parents-to-be to prepare for the birth in a relaxed manner and to adjust to the physical changes and the bond to the child, and to 'build a nest' like other parents, a confirmation of a place to live should take place early and not just before the child is born, let alone afterwards. A supportive network, with a follow-up midwife and a health visitor along with other individuals can only be established when it is clear where and how the young family will live. Bureaucracy must not be allowed to become an obstacle here, for example when responsibilities in different municipalities or districts are affected.

In the debate about the development towards an inclusive society, the subject of family is largely addressed in terms of families with disabled children. An expansion of this approach is necessary: parents with disabilities also have to be considered in all areas. Barriers, whether physical, institutional or communicative have to be removed bit by bit and parents have to find acceptance as well as the necessary assistance and accompaniment, insofar as they need it in order for them to be able to shape their family life in a self-determined manner and raise their children lovingly in the midst of society.



Susanne Bell M.A. is a coach for movement and body awareness (*Bodybliss*) and a co-instructor for antenatal classes for women and couples with disabilities. Since an accident she has been in a wheelchair and has been active for many years in political disability work (*Frankfurter Behindertenarbeitsgemeinschaft FBAG; ISL e.V.*).

³ Hermes describes four categories of incorrect assumptions that women with disabilities are confronted with: 'Disabled mothers can't take on responsibility', 'children suffer under their parents' disability', 'disabled mothers create additional costs for the state', 'a disabled woman will also give birth to a disabled child' (pp. 33–34). Lothar Sandfort addresses one particular prejudice, namely that children of disabled parents needed to help the latter more often, and describes the reaction of parents with disabilities in a humorous way: 'If I look closely, I never send my daughter to fetch me a beer (...) If I look closely, I overdo it. In my head I'm already living against the prejudice that my children are being misused as carers. They don't have to do anything for me anymore' (SANDFORT 1998, p. 155).

⁴ The question that later arose for these families was whether and when the young family would move out and could live in their own home with the right support.

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Many disability-specific organizations have created their own brochures or online information on the subject of pregnancy and birth.

Sexual education from the perspective of adolescents and young adults with cognitive impairments and of their main reference people

Sabine Wienholz

An interview study provides insights into the sexual knowledge of young people with mental impairments and into their interests and questions relating to sexuality. For comparison's sake parents and other reference people were also asked about sexuality education.

Starting position

Since it was the standard view for a long time that people with impairments did not have any sexuality in their lives, the sexual behaviour of individuals with disabilities, in the public perception, either did not or should not exist. There were around 400,000 officially recognized severely disabled individuals living in Saxony on 31 December 2015 (according to the STATE STATISTICS OFFICE). Mental disabilities have seen the greatest increase in recent years; now almost one in four severely disabled individuals in Saxony is affected by a cognitive impairment and/or mental illness. Among the under-25s, those with a cognitive impairment form the largest group. Of all the people with impairments they are the most confronted with reservations and fears. In the past a cognitive impairment was associated with the attributes 'asexual' and 'infantile' and those affected were downgraded to sexless objects (HERRATH 2013). The specific nature of the sexuality of people with cognitive impairments lies in the discrepancy between their physical and their emotional/intellectual development, which makes it harder for them to express sexual desires in an age-appropriate way (WALTER 2005). The view that they lack sexual needs favoured a gender-neutral upbringing in many cases, accompanied by the absence of 'fledging' processes as reflected in over-protectiveness and infantilization by the parents. Alongside this asexuality, there were widespread (and negative) public views about inappropriate behaviour in the form of increased libido based on a lack of learning and experiential environments, which in turn favoured a lack of bodily awareness and gaps in their knowledge about their own and other people's needs (SPECHT 2013). Individuals with cognitive impairments experienced a structurally highly closed-off world from an early age –

largely separate schools (MÜHL 2008), few inclusive extra-curricular options, sheltered places of work, and assisted-living situations with little scope for privacy (STÖPPLER 2014) – in which sexuality was given little or no attention. If sexuality was expressed anyway, it was seen as bothersome and reprehensible. Not only parents in the home environment but also teachers in disability care institutions reacted with hostility; they were overburdened and tended to make restrictive decisions, such as blanket contraception for women (ACHILLES 2010; WALTER 2005; SPECHT 2013).

Educational services and training guidelines are rooted comprehensively and in a highly differentiated manner in the syllabuses of all the different types of school (KULTUS-MINISTERKONFERENZ [State education ministers standing conference], 2010); implementing them depends largely on the professionals involved. Since it was the view in many institutions that any sexuality-education services would 'wake sleeping dogs', sexuality education was reduced to a minimum, usually with a focus on avoiding the unwanted consequences of sexual actions (HERRATH 2013). As a result a strongly 'preventive' character developed over the years, which aimed at avoiding sexual activities in general and pregnancies, and consequently parenthood, in particular. This educational pragmatism is often supported by the parents and legal guardians of young people with cognitive impairments. Fearing abuse and exploitation, parents are particularly interested in sheltering adolescents from negative experiences (WAZAKILI et al. 2009). They deny or ignore the existence of sexuality in general and show little interest in sexuality-education measures to further their children's self-determined, responsible sexuality (MICHEL/HÄUSSLER-SCZEPAN 2005). The result is that when it comes to sexual interests and education we have adolescents with cognitive

impairments who are confronted by a society not very open to their needs, and by overburdened teachers and concerned parents and guardians.

This article deals with the opportunities and limits of the sexual education of adolescents and young adults with cognitive impairments. We will look at both the professionals involved and the topics that are focused on, and compare them with the individual interests of the young people. Communication structures in the family context, courses of action and support options are presented specifically from the parents' point of view.

The data the analysis is based on comes from 42 interviews with adolescents and young adults as well as one main reference person in each case, mostly the mother. The young people were aged between 13 and 26 and attended a special school for mentally disabled students or a workshop for people with disabilities in Saxony. Their impairments varied from mild to moderate; however, there was no specific categorization because of the heterogeneous and at times unstructured diagnoses. The survey consisted of a mix of methods made up of qualitative and quantitative elements. The interviews with the adolescents and young adult were oral and took place face-to-face, with few narrative sequences. The interviews with the main reference people took place either face-to-face or over the phone, depending on the interviewee's preference.

Sexuality education from the perspective of those affected

In order to get an insight into young people's retrievable sexual knowledge, the survey started with two knowledge questions about coitus and conception. The description of the term 'sexual intercourse' was seriously problematic for many adolescents and young adults – less so with regard to knowledge and more so on the emotional level. The young people surveyed associated unpleasant feelings and embarrassment with the question about coitus, which suggests that they have not had the experience of talking about sexuality to people they are not familiar with. Regarding their level of knowledge, their statements were mostly sparse in detail and characterized by diffuse half-knowledge and a concern about the potential consequences: Felix (15): 'So when – so when he – when he, when the man has, like, an orgasm in the woman, then the sperm, like, look for a way to the womb. And then, like, to the egg and then, like, a child is made from that.'

The respondents were less uncomfortable answering the question 'Do you know how babies are made?' The subjective ideas of conception varied greatly depending on the meaning they thought this word had: in addition to the actual principle of fertilization as the basis of pregnancy (Beatrice, 23: 'It's like a little egg, through fertilization. [...] The man has seeds. They then come together.'), there were descriptions of measures and symptoms that occur during pregnancy (Jessica, 21: 'If this is about the amniotic sac ... if it starts to break, the women have to go to hospital. When the labour pains start.')

and patterns of behaviour (Martin, 22: 'Well, from a man and a woman when they sleep together.'). Most of the statements were very brief, reduced to the basics. Alongside this there were diffuse or incorrect statements: 'When you make [babies]. And the man the saliva to the woman. Then it nests, the saliva, nests in the body somehow.

And then the woman feels sick. And then a baby comes.' (Jennifer, 20) The adolescents and young adults primarily obtained their knowledge from a school setting. A typical response was: 'From school. We did all that in class.' (Sascha, 22)

Both the frequency and the extent of sexuality-education classes seemed to be reduced down to a minimum in most cases, with the outcome that most respondents, the older ones in particular, were familiar with very few concrete facts.

According to their portrayals sexuality education generally took place during regular lessons and was imparted by teachers; it was less likely to be taught by external experts or in the form of project days and excursions. Recalling the didactic implementation, the adolescents and young adults mentioned pictures and work sheets as well as materials such as sexuality-education films and dolls. Stefanie, 23: 'I did a project once that was about love, sex, kissing, cuddling and being together.' Despite lacking detailed knowledge and memories, this kind of sexuality education in school can be defined as a formative event within the educational process, particularly when visual materials are used and an 'experience' factor is present.

In addition to what they learned in school, the respondents could have sexuality-education conversations or conversations about sexuality with their parents, or primarily their mother. It was rare for the respondents to feel educated about sexual matters on the basis of their own experiences; alternative sources such as books and films were only mentioned as a side note, and were associated more with stimulation than with education: Jacob, 14: 'I read about that in a book once. And I've watched films on my laptop. Things like porn.'

Despite great difficulties in remembering the topics of the sexuality-education classes offered in school, a clear picture emerged: contraception, pregnancy and childbirth and the structure and development of the sex organs were the most-cited topics by the adolescents and young adults. Information about subjects such as being in love, intimacies, emotional closeness and forming relationships was usually only recalled after prompting. Biological facts and functionalism dominated the memories of the adolescents and young adults regarding the topics they had been taught in school. One topic came in first place: contraception! It generally takes a central role in the sexuality education of individuals with cognitive impairments, often with a clear message:

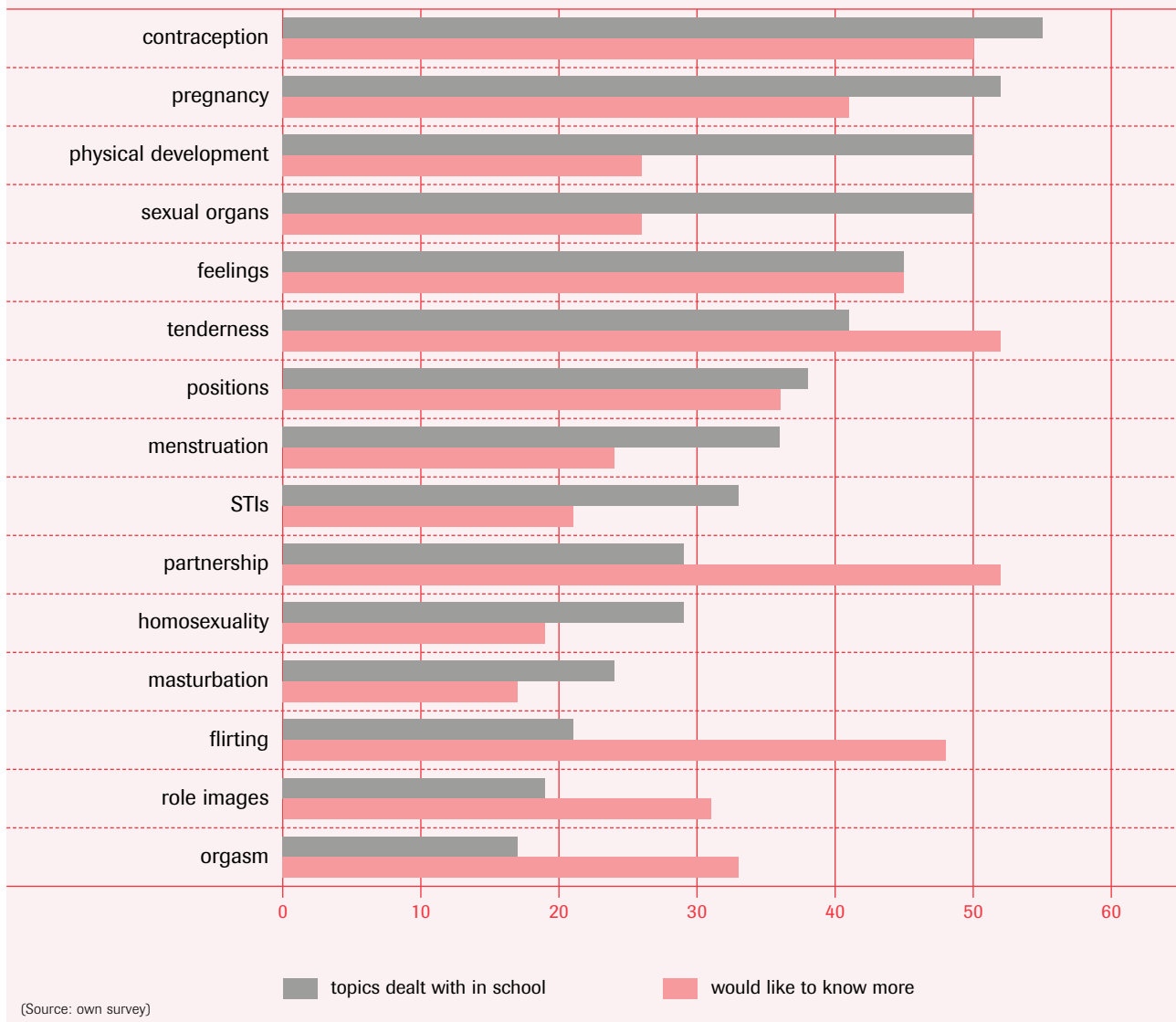
I.: 'Can you remember what exactly she told you?'

Conny, 20: 'Just to be careful when we have sex, be careful. Not start a family right away. Be properly careful. There's something you can pull over. Like rubbers to pull over.' It is secondary in this context that contraceptives can also provide protection against sexually transmitted infections. The core message of sexuality education has been and still is prevention of unwanted pregnancies (unwanted, that is, primarily by third parties).

Contrasted to the educational topics on offer in school is the subjective need for information of the adolescents and young adults (cf. fig. 1). Getting to know one another, flirting, being in a relationship, love, intimacy and affection were the favourite sexual topics among adolescents with cognitive impairments. This reflected both their own needs for closeness and relationships and their own experiences: two

Fig. 1

Information needs of the young people compared with what they remembered from topics dealt with in sexuality education at school (percentages)



thirds of the respondents who did not have a steady partner at the time wanted information about flirting and getting to know someone. And 8 out of 42 respondents reported that they had never had a steady boyfriend/girlfriend.

Around half of the adolescents and young adults said they had nobody they could talk to about sexual questions. There were indications here that girls and young women in particular as well as younger respondents did not possess the necessary skills to actively look for someone to talk to. Compared to the other young people with impairments, they were the group with the fewest resources of informational and emotional support when it came to communicating about love and sexuality (and possibly also other topics). The following dialogue with David, 17, is an example of a common response:

- I: 'Do you talk to others about love and sex? With your friends or people like that?'
- D: 'No.'
- I: 'With nobody?'
- D: 'No.'
- I: 'Not with your carers?'

- D: 'No.'
- I: 'Not about girlfriends?'
- D: 'It stays with me.'

Among those who had confidants available, peers held a central place when it came to sexual questions, particularly for the male respondents. Confidants regarding sexual matters were therefore (best) friends and/or flatmates. Among the girls and young women the confidants preferably came from the inner female family circle with a reference to an intrinsic understanding by virtue of the other person having the same sex. Beatrice, 23: 'With my sister and my mum – because it's women's business.'

Sexuality education from the perspective of parents and carers

The main reference people in the lives of the adolescents and young adults, in most cases their mothers, were able to provide much more detailed information about the young people's sexuality education.

In the majority of cases the first sex-education conversation was initiated by the reference person, in other words the sexuality education here was a reactive response by the parents to various events and situations that made it necessary to confront the subject. The most commonly cited events were the first steady boyfriend/girlfriend, when sexuality was addressed in school, and when girls got their period. Bianka's mother: 'Only when she got her period. Yes, only when she got her period. That's the first time we were confronted with that whole subject. Before that it was still taboo for us.'

Further occasions for sex ed conversations within the family were concrete questions and the young people's curiosity, but also the consumption of pornography or the birth of a child in the immediate social environment. The parents/carers were able to observe an increased interest in visual depictions of sexual processes among boys and young men. Max's mother: 'He often reacted to certain images or when he saw something on television, when people were kissing, things like that.'

This reveals that in most cases a certain event triggers a confrontation with the child's sexuality that was previously put out of mind, denied, and seen as a taboo. In contrast to this attitude there were some parents who saw sexuality education as an integrative and precautionary component of their overall child-rearing work. The active and self-organized attitude towards sexuality education can be represented by the following examples: Sascha's mother: 'I think it was just that I wanted to educate him.' A different mother responded to the question about whether there had been a trigger: 'No. It was looking ahead.' (Sophie's mother)

While the adolescents remembered what they had learned in school as their primary source of sexuality education, the main reference people were most likely to cite themselves, followed by the school and teachers. Natalie's mother: 'By me. And by the school too. I mustn't forget them. They did something like that too.'

The discrepancy between the perception of the main reference people and the perception of the children/clients can probably be explained by the different ways in which this information was imparted. The sex education in the home or within supported-living arrangements largely took place in the form of conversations as a latent and ongoing process, geared to the needs and interests of the child. As a result, sex-education conversations that the adolescents and young adults had with their parents and carers stuck less in their minds than the explicit and sometimes exclusive education sessions provided in school.

From the point of view of the main reference people, most of them were available to their children/clients for conversations about sexual matters. The mother (or carer) was equally present as a reference person for both sexes. Fathers, male carers and friends were the preferred reference people for sons and young men, while daughters and young women also cited their sister in addition to their mother.

Here too there was a discrepancy between the perception of the adolescents and young adults on the one hand and the reference people on the other, which is probably based on the parents' reactive attitude throughout the sex-education process, as mentioned above, and on the passive conversational style of some of the adolescents and young adults.

As in the school setting, the sex-education conversations and the communication about sexual matters largely focused on one topic: contraception. The intention very clearly aims

at preventing unplanned pregnancies and only marginally at sexually transmitted infections. The confrontation with birth-control measures is primarily focused and initiated by the main reference people, which is also why it achieves top priority in the area of sexuality education. Contraception and unplanned pregnancies/parenthood are the central subjects that come up time and again throughout the interview, particularly by the mothers and carers of young women. Sexual self-determination, body awareness, physical changes, relationships and other topics are peripheral in the young people's sexuality education, because while they are often the cause for questions by the child/client, they are rarely given the same space or level of detail as the subject of contraception. Maria's mother: 'Yes, we talked about it and that it happens. And we talked about contraception and about her ... life plan in general. Yes, a lot about contraception. She really would like to have children. Which is very difficult in this situation. And it is very difficult for us to bear it. Because of course you look ahead at how things could go.'

The motivation behind the intense confrontation with the subject of contraception was quite commonly the parents' strong need for security with regard to the notion of a sexually deprived milieu in which their child spends time: Conny's mother: 'Now she has contraception for the next three years. And that's important, so that nothing happens for now. Particularly in the sheltered workshop ... you never know.'

In addition to contraception the conversations about sexuality largely took place on the emotional level. Regardless of the young person's gender, the questions that dominated were about relationships, ways of meeting people and emotional closeness. They confirm the importance of the 'soft' topics for adolescents and young adults. Beatrice's mother: 'How can I even build a relationship? How can I go about meeting someone who would be suitable for me? That's an area where she definitely asks questions.'

As was to be expected, conversations about pornography, masturbation and physical hygiene were more common among the teenage boys and young men. With the girls and young women on the other hand, sex-relevant physical processes such as menstruation and physical developmental changes were discussed, usually in connection with the abovementioned prevention of unplanned pregnancies and protection against sexual exploitation. So-called marginal sexual topics rarely found their way into the conversations between the main reference people and the adolescents/young adults.

The sexuality education of individuals with cognitive impairments is seen by most of the main reference people as a challenge. One thing that was tangible was their uncertainty about how much their child/client was able to take on board. Many parents and carers asked themselves which items the adolescents and young adults were able to understand and remember. The lack of feedback from the adolescents/young adults increased this uncertainty further. Differences from people without cognitive impairments were also reflected in the lower interest shown by the young people to initiate a conversation, they said. This was the response by one mother when she was asked what she felt about talking to her daughter about sexual matters: Natalie's mother: 'Yes, I always feel it's difficult because you don't know what you should pass on and what's not necessary. What does she understand? What doesn't she understand? What can't she do? To what extent is this important for her life?'

The specific nature of sexuality education for young people with impairments relates less to content than it does to didactics, as Florian's carer put it:

I: 'Do you see differences?'

FC: 'Yes, in how to put it across. Not with the content, but in how to put it across.'

I: 'What are these differences in your opinion?'

FC: 'For example that you express it in Simple Language. For example. I think there's a greater need to explain something, certainly.'

Printed materials (books, brochures) as well as audio-visual media (films) seemed to be suitable ways of presenting information, according to the respondents; however, digital media and haptic materials were also cited. The attributes of 'simple' and 'clear' were frequently cited, which correlates with the desire for images and visual aids.

The option of allowing the young people to acquire information on their own with the help of digital media was seen as somewhat problematic, as were the networks and peer groups in which the adolescents and young adults with cognitive impairments moved. They were described as being less reliable and less valid in the information they disseminated. Jessica's father: 'Young people without a disability are more likely to have the friends, friendship groups, open dialogue, more literature, a computer, all the media that they can use ... they can quickly check something in secret on the computer. We don't have that. She asks us if she's allowed to use the computer and she can switch it on, but she can't get beyond the first five clicks. She has no idea of the world beyond.'

Conclusions to be drawn for practical work

In youth-sexuality studies it has been found that mothers were central and consistent confidants and sources of information about sexual matters (BZGA 2010; HESSLING/BODE 2015). In our investigation into individuals responsible for providing sexuality education for adolescents and young people with physical and sensory impairments, the school/teachers become the central sources (cf. WIENHOLZ et al. 2013; BZGA 2017). They create the adequate framework for sexual learning opportunities. However, the adolescents' statements hint at a minimized and usually one-sidedly pragmatic confrontation with the subject of sexuality that does not do justice to the needs and interests of the young people. On the part of the main reference people, we see guidance and restrictive structures (long-term contraception, mobility dependence, communication culture) that are intended more for the subjective satisfaction of the parents and to meet their need for control and for room to manoeuvre, than for the sexual and relationship interests and needs of the adolescent children.

According to the UN Convention on the Rights of Persons with Disabilities (UN 2006) all people, regardless of their disability status, have a right to education, including a right to sexual education with the goal of actively managing their own lives with as much independence and self-determination as possible and the implementation of a fulfilling and responsible sexuality. The recommendations therefore aim at consistent and holistic sexuality education, with comprehensive and suitable sexual learning opportunities for individuals

with cognitive impairments (PROCHNOW PENEDO 2014).

The goal should be teaching fundamental sexual knowledge, knowledge of how to act socially and sexually, and behavioural and communication rules that are considered appropriate (cf. LACHE 2015). Because individuals with cognitive impairments have a reduced capacity to remember information and a reduced linguistic understanding, there are special challenges in providing this education on the didactic level. This includes simple, clear explanations with little detail, using haptic and visual materials and taking more time to pass on the information with many repetitions, patience and empathy. Also worth mentioning here are the networking efforts and publicity so that suitable helpful structures, materials and facilities can be accessed if necessary.



Dr Sabine Wienholz has been an academic assistant in school education at the University of Leipzig with a focus on school development research. Before that she spent many years working as an academic assistant at the Institute for Social Medicine, Occupational Medicine and Public Health at the Medical Faculty of the University of Leipzig. Her research focuses are teenage pregnancies as well as (youth) sexuality and disability. Sabine Wienholz is also a member of the board of the Society for Sexual Science (Gesellschaft für Sexualwissenschaft e.V., GWS), a member of pro familia Saxony, the Leipzig sexuality-education working group, and a member of the organization Living with Handicaps (Leben mit Handicaps e.V.).

Contact:

Universität Leipzig
Erziehungswissenschaftliche Fakultät
Dittrichring 5-7
04109 Leipzig
sabine.wienholz@uni-leipzig.de

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ECHT MEIN RECHT! Self-determination, sexuality and protection from sexualized violence

An exhibition for adults
with disabilities

Ralf Specht

Since January 2016 the PETZE-Institut für Gewaltprävention (PETZE Institute for the Prevention of Violence) has been developing an interactive touring exhibition that was presented for the first time at the convention 'Behinderte Liebe 2.0' in October 2017.

This really special task has been made possible by three-year funding from Aktion Mensch. Our long-standing work in training, advice and networking has shown that there are not many accessible materials to address, with adults, the topics of sexual self-determination and protection from sexualized violence. Institutions working in disability care have a particular protective brief here and the many enquiries by workshops and supported-living institutions confirm the high level of interest and the great demand for support.

This exhibition supplements the existing exhibitions for different target groups that have been touring Germany with great success.¹

Target groups

The project is primarily aimed at women and men with mental impairments and/or multiple disabilities. They can explore the exhibition either independently or accompanied. The exhibition is divided into different areas and contains written, visual and audio information along with many interactive elements.

Further target groups include carers, care staff, trainees, institution managers and all the other individuals who have support roles in institutions. Training sessions and additional accompanying materials give them compre-

hensive knowledge and a variety of ideas for their work in disability-care workshops and supported-living facilities. It is their responsibility that the contents of the exhibition be implemented long-term and that prevention of sexualized violence does not remain the theme of a single event like this.

Goals

The central goal of the project is protection against sexualized violence. That includes education and passing on knowledge about the right to self-determination, the body and sexuality, sexual transgressions, protective rights and support options on the one hand. On the other we want to strengthen the participants in their self-confidence and their perception and get them to self-reflect and engage with others through interactive exercises, examples and a variety of other visual, auditory, cognitive and haptic stimuli.

The focal topics are the attentive handling of emotions and boundaries as well as building and shaping different relationships – both privately and at work and in the public realm. The preventive principles are taken up positively and reinforced in a wide variety of ways.

Implementation

An interactive touring exhibition with additional accompanying materials is being developed. The exhibition will be loaned for a period of four to ten weeks to enquiring institutions, first in Schleswig-Holstein, then also in other states.

Before the start of the exhibition, educational supporters in the institution will be trained on the subject and on how to approach the show. There will also be an information evening for family members. This evening will be run by a regionally responsible expert advice centre in co-operation with the participating institution.

If there is the interest, there is the option of putting on workshops to accompany the exhibition that would address related topics or that could address the topics of the exhibition in more detail.

In order to support the target groups in the best way possible, the participating institutions can take advantage of advice and supervision throughout the project's runtime.

Contact:

PETZE-Institut für Gewaltprävention
Dänische Straße 3–5
24103 Kiel
Phone 0431 91185
Fax 0431 92709
petze@petze-kiel.de
www.petze-kiel.de

¹ More information can be found under
<http://petze-kiel.de/ausstellungen/>

BeSt – Beraten & Stärken (Advise & Strengthen)

A nationwide pilot project to protect girls and boys with disabilities from sexualized violence in institutions

Bernd Eberhardt

The pilot project is run in co-operation with the Deutsche Gesellschaft für Prävention und Intervention bei Kindesmisshandlung und -vernachlässigung e.V. (German Society for Prevention of and Intervention in Child Abuse and Neglect, DGfPI) and ten expert organizations nationwide that focus on sexualized violence and disability aid. It is supported by the Federal Ministry for Family, Senior Citizens, Women and Youth.

The goal is to lastingly improve protection against sexualized violence in institutions for girls and boys with disabilities.¹ The experiences and results of the pilot project are to be published, for example, in the form of 'recommended actions to implement child protection concepts as well as an implementation of qualification measures and prevention programmes in disability-care institutions'.

The project is aimed at (part-time) residential disability-care institutions as well as at inclusive/integrative institutions working in child and youth welfare nationwide.

Three central measures have been implemented in 60 (part-time) residential institutions between 2015 and 2018 by way of a pilot project:

1. Advice, support and accompaniment in the (further) development of child protection structures

The basis of the organization-development processes pursued is formed by the guidelines published by the round

1 The language used is based on the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

2 Federal Ministry of Justice (ed.) (2011): concluding round table report 'Sexueller Kindesmissbrauch in Abhängigkeits- und Machtverhältnissen in privaten und öffentlichen Einrichtungen und im familiären Bereich'.

table 'Child sexual abuse in situations of dependency and power imbalances in private and public institutions and in family settings' in 2011.² Depending on the state, and the resources of the institution, this can encompass the following areas:

- sexuality-education concepts
- concepts to implement participation by young people and children
- holistic institution-specific, preventive concepts
- complaints procedures for children and young people
- action guidelines for dealing with cases of sexualized violence and cases where there is suspected sexualized violence

2. Sensitization and training of staff and management

The training measures should be based on the needs of the institutions. In addition to current expert knowledge, these measures include concrete action competencies that can be deployed at work. A confrontation by all staff, including management, with their own and their institution's attitude towards the subjects of sexuality, gender stereotypes, children's rights, participation, how to deal with closeness and distance, and how to deal with power over and violence against children and young people are the foundation of all the development processes pursued.

3. Running and implementing a prevention programme for girls and boys

The programme developed in the project for the prevention of sexual abuse of children and young people with disabilities, 'What to do about sexual abuse? – Ben and Stella have the answers!', is implemented in the institutions. These are the goals:

- informing children and young people about their rights
- supporting them in being aware of their own feelings, needs and boundaries
- providing information about sexualized violence in an age-appropriate manner
- providing information about how to get help and support

The central feature of the prevention programme is that sexual abuse is presented as a stand-alone module and is developed together with the girls and boys. Information about this sensitive topic and strategies of how to act are

presented in an age-appropriate manner. In order to ensure that the prevention programme is implemented long-term it is important that staff in the institution are trained in running the prevention programme independently in the future.

All of the measures listed above take into account the needs of the institutions and are tailored to each institution. In doing so the existing expert competencies and institutional structures to prevent and intervene in sexualized violence are taken into account.

The project is accompanied by a scientific board of advisers. The evaluation is done by the Sozialwissenschaftliche Frauenforschungsinstitut Freiburg (SoFFi F.) in the Forschungsvorbund der Evangelischen Hochschule Freiburg e.V. (FIVE). A central component of the evaluation is the participative development of tools with girls and boys in order to then run group discussions and one-on-one interviews.

Contact:

Deutsche Gesellschaft für Prävention und Intervention bei Kindesmisshandlung und -vernachlässigung e.V. (DGfPI)
Sternstraße 9–11
40479 Düsseldorf
Phone 0211 497680-0
Fax 0211 497680-20
eberhardt@dgfpi.de
www.dgfpi.de

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FORUM *Sexuality Education and Family Planning*

A series of publications from the Federal Centre for Health Education (BZgA)
Leitung: Dr. med. Heidrun Thaïss.
Department Sexuality Education,
Contraception and Family Planning
Maarweg 149–161
50825 Köln

www.forum.sexualaufklaerung.de

The German Library – recorded under CIP as:
Forum Sexualaufklärung; Informationsdienst
der Bundeszentrale für gesundheitliche
Aufklärung/BZgA

BZgA, Department Sexuality Education,
Contraception and Family Planning – Cologne:
BZgA
Published three times a year.
Included after 1996, 1
ISSN 2192-2152

Conception:
Department Sexuality Education, Contraception
and Family Planning
Responsible:
Angelika Heßling
Text and editing:
Heike Lauer, Frankfurt
Translation:
Dr. Michael Scuffil, Leverkusen
Layout and typesetting:
Dietmar Burger, Berlin
Printing: Warlich, Meckenheim
Edition: 1.1.06.18

FORUM Sexuality Education and Family Planning
1–2017 is available free of charge from
BZgA, 50819 Cologne
Order No. 13329280
order@bzga.de
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