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# Pregnancy Advice

The right of every woman and every man to receive advice regarding sexuality education, contraception, family planning and pregnancy, as guaranteed by Germany's Pregnancy Conflict Law [Schwangerschaftskonfliktgesetz], puts great demands on pregnancy advice services. Developments such as prenatal and pre-implantation diagnostics as well as changes to the law, such as the Federal Child Protection Law [Bundeskinderschutzgesetz] or the Law on Confidential Births [Gesetz zur Vertraulichen Geburt] require an ongoing openness to learning and the acquisition of up-to-date knowledge in very different areas of expertise.

Jutta Prolingheuer and Ursula Kunz, two pregnancy conflict counsellors at the Diakonisches Werk Karlsruhe, provide an overview of the competencies that advisors must have or acquire and introduce the broad spectrum of services offered by advice centres.

Federal Minister of Family Affairs, Kristina Schröder, explains the law governing confidential births, which came into effect on 1 May 2014. After that date, pregnancy advice centres took on a key role in implementing "confidential births" by participating in the organization.

The Bundeskinderschutzgesetz, which came into effect on 1 January 2012, caused three main developments for pregnancy advice centres, which Lydia Schönecker will report on. The key concepts here are the strengthening of the protection of confidence in pregnancy advice (right to anonymous advice), the obligation to participate in the "Frühe Hilfen" networks and the "authority to pass on information in the event that a child's wellbeing is at risk".

Claudia Heinkel discusses the demands placed on counselling services with regard to the professionally and ethically tricky area of prenatal and pre-implantation diagnostics; she outlines the situation of the couples in the various phases before, during and after the diagnostic procedure, before deriving the various tasks to be performed by the advice service.

The national foundation "Mutter und Kind – Schutz des ungeborenen Lebens" ["mother and child – protection of unborn life"] has been offering financial help since 1984 to improve the living conditions of mothers-to-be in problem situations. We report on the results of a flanking evaluation.

Further contributions in this issue address the subjects of pregnancy advice and migration, pregnancy advice on the internet, and the inclusion project "I want to get married too!" by *donum vitae*.

In FORUM 1–2014 the focus will be on the subject of adoption.

We wish you a stimulating read.

*The editorial team*

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# The Art of Counselling

*Jutta Prolyingheuer, Ursula Kunz*

**This article provides information about the broad spectrum of services provided by pregnancy advice centres, including with regard to situations of conflicts in pregnancies, and about the many and diverse challenges counsellors face.**

Women and couples respond with different emotions to the news that they are expecting a baby: joy, fear, insecurity, despair... many ask themselves questions to which there are no quick, easy answers.

The services provided by pregnancy advice and conflict centres help with finding these answers. They are offered all over Germany close to any address and they fulfil a state remit. Women and couples can get in touch with pregnancy advice centres in person, by phone, by email or online.

The goals of the advice centres are clearly defined by law in the Pregnant Women and Family Assistance (Amendment) Law [Schwangeren- und Familienhilfeänderungsgesetz (SFHÄndG)] and the Pregnancy Conflict Law [Schwangerschaftskonfliktgesetz (SchKG)]. Section 2 of SchKG deals with the contents of pregnancy advice sessions. Sections 5–7 of the SchKG, in conjunction with sections 218 and 219 of the German penal code (StGB), provide the working foundation for all the pregnancy advice and conflict centres.

## **Pregnancy advice – advice in line with section 2 SchKG**

Boys, girls, men, women and couples turn to advice centres when they want information about contraception and family planning, when they have questions about sexuality, when there are conflict situations in pregnancy, and when they have questions with regard to pregnancy and birth. Pregnancy advice centres help their clients get used to the idea of the new circumstances during the pregnancy and after the birth of a child.

Every woman and every man has a legal right to advice regarding “questions of sexuality education, contraception

and family planning as well as questions directly and indirectly relating to all aspects of pregnancy” (section 2 SchKG). This legal right is very comprehensive with regard to timeframe and content. It includes the right to information, to general social advice, to being put in touch with assistance, to psychosocial counselling sessions, and to crisis intervention; it covers the period before, during and after a pregnancy.

These advice services pose a challenge for the employees of pregnancy advice centres. They must have extensive expert knowledge in very different areas of expertise: maternity leave, parenting benefit, child benefit, maintenance law, basic existence minimums, law regarding foreign nationals, the German Social Legislation Code (SGB) parts II, V, VIII, and XII, child care options, knowledge of the local social infrastructure, and much more besides.

The art of counselling consists, among other things, in the counsellor’s ability to gain the trust of the client, in order to make possible a longer-term relationship if necessary. A friendly, respectful manner as well as empathy for the current needs and limits of those seeking advice allow counsellors to build a relationship of trust. The ability to deal with conflicts and stress, having life skills, life experience and the ability to reflect, the ability to create boundaries and an awareness of one’s own biography are all important requirements to ensure good quality counselling sessions. Questions about legal rights, financial assistance and other services that support families, questions about family law and the law regarding foreigners, and support in implementing legal claims are everyday issues in pregnancy advice sessions. It is often the case that parents-to-be have incorrect information or none at all about their rights, they need support in dealing with the authorities and with filing appli-

cations. To do this, the counsellor gets an understanding of the social environment of the clients and makes a sensitive assessment as to what assistance would be suitable, accepted and feasible.

Many people have considerable inhibitions when it comes to applying as “suplicants” to the authorities; they fear there will be difficulties. In individual cases it can be a good idea to accompany clients to the authorities and support them in their application (this can include organizing papers as well as finding the “right” tone for the man or woman behind the desk). Many pregnant women come from other cultures and need additional orientation when it comes to German customs about having children and parenting. Language barriers can be overcome by making use of interpreters. Questions about welfare entitlements in relation to their residence status make pregnant women insecure and hence represent one of the subjects of counselling sessions.

It is not uncommon for the news of a pregnancy to trigger existential fears. “I can’t possibly afford it!” is a sentiment often heard in counselling sessions.

It is still largely the case that for women especially, a pregnancy is a dent in her career. The fear of being dismissed, of not having a temporary contract renewed and the fear of not being able to perform, because of their physical limitations, their mini-job (a job with a maximum wage of € 400 and informal flat-rate insurance and tax arrangements) that is vital for their livelihood all fuel their fears for their occupational and financial future. They are usually relieved when the pregnancy advice centre provides information regarding the rights and duties of the employer in the event of a pregnancy, in respect of subjects such as employment protection, maternity leave and information about parental leave and parenting benefit. This is an important aspect for women and families with low incomes.

Women in job training or at university face completely different questions in the event of a pregnancy: can I interrupt my training and finish it later? How can I continue studying with a child? Am I entitled to a semester’s leave and how can I pay for one? The support of the foundation “Mutter und Kind” as well as one-off grants for basic baby equipment in line with SGB II provide tangible relief. These applications are often a good occasion to address the women’s individual circumstances and to discuss further areas of need if present.<sup>1</sup>

Starting a family fundamentally changes the life of a woman, the life of a couple. It is one of the main tasks in pregnancy counselling to support and accompany women and couples in coping with this life-changing event. The counselling sessions help them develop competencies to reshape their circumstances with regard to themselves, their relationship, their family and their work.

The advice sessions address how a pregnancy changes individuals’ role as they become parents and how it also requires the partnership to be reoriented. If the counsellor managed to establish a relationship early on, he or she, as a neutral person, has the opportunity openly to discuss subjects such as taking responsibility for the child, the importance of expressing wishes to one’s partner, to come to agreements about the division of labour, concerns about isolation, and options about getting help from family members. Questions about childcare often trigger discussions about personal ideas of how to be a “good” parent. The goal here is to strengthen parental competencies and to investigate fears. Sometimes fears stem from the fact that

parental role models are being questioned or that one partner does not trust the other to be a “good” mother or a “good” father. The sessions can also be used to examine quite generally what it means to be a good mother or a good father.

The pregnancy advice service makes an important contribution to men and women examining their own attitudes and norms about parenthood with regard to their own current circumstances.

### After the delivery

The duties of the pregnancy advice centres do not end once the child is born. Women like accepting the option of being visited in the clinic and at home. Subjects that previously were not on the radar at all are now the main focus of the advice. For many, the experienced day-to-day with the baby feels different than the idea of it did: questions about feeding and nursing, taking it easy during the post-partum period, and not least exhaustion are all on the mother’s mind after the delivery. Everyday life with the baby and experiencing a different reality from the partner (paid work and “being a housewife”) as well as a lack of mental stimulation in the life with a newborn can lead to conflicts between partners.

Single parents in particular experience the absence of a partner as a great stress factor. A lack of time, a lack of support and not being able to escape the sole responsibility for the child occupy single parents immediately after the birth.

The pregnancy counsellors will take sufficient time for the psychological consultation and for determining what assistance, if any, is necessary. Their sensitivity and their knowledge about the starting difficulties when having a family are fundamental factors allowing those seeking advice to enter into a relationship of trust with them. It forms the foundation for allowing them to openly discuss problematic developments and to accept help, and it includes the worry about ensuring the wellbeing of the child.

The earlier the counsellors can get in touch with the parents, the easier it is for the latter to go to the advice centre when they have questions and problems. In this way, long-standing relationships develop between the counsellors and the parents, and these parents are likely to get in touch again if another pregnancy occurs.

The counsellors must have a feeler for subjects that could be charged with shame or embarrassment. These topics could lurk unspoken in the background of a counselling session, hampering it. This could be the case in pregnancies that are the result of rape, as well as for women who are the victims of domestic violence and/or sexual assault.

### Pregnancy conflict counselling according to sections 5 and 6 SchKG

Another duty of state-accredited pregnancy advice centres is conflict guidance in line with sections 5 and 6 of the Pregnancy Conflict Law (SchKG). These sections regulate the duty that exists in Germany to provide advice. Once

<sup>1</sup> See the contribution by C. THIELEBEIN et al. in this publication

received, a termination can be legally obtained up until the twelfth week. The advice session always includes the issue of an advice certificate. A “reconsideration” period of 72 hours must pass between receiving the guidance and the medical procedure. The counselling session is subject to professional confidentiality and can, on request, take place anonymously.

Conflict guidance is a particular challenge for advice centres. Their aim focuses equally on the protection of the unborn life as it does on shaping the pregnant woman’s life. The tightrope act between remaining neutral about the outcome and providing protection, between the participation and silence of the woman, requires a huge amount of professional competence. The counsellors need to have diverse methodological skills in order to transform the mandatory advice session into a “guidance opportunity”. This is successful if the woman can be made to believe that the counselling session, despite its mandatory nature, can be a helpful opportunity to discuss, with a neutral person, worries and fears with all their contradictions.

Tips, moral instruction and judgement have no place in these conversations. The personal assessments of the woman are respected; potential choices for action and decisions are developed with her. It is only when a woman is given this space that she can make a decision that she can be comfortable with long-term and integrate into her future life.

In some cases a one-off consultation is not enough. It is possible that women opt to keep the child despite social and/or psychological difficulties. In that event, if the women wish it, they can access longer-term, comprehensive support until long after the child is born.

Part of the conflict guidance session is to provide information about the opportunities for medical care, to address who would pay in the event of a termination, and to discuss the option of further counselling sessions.<sup>2</sup>

### Advice before, during and after prenatal diagnostics

The rapid development of prenatal diagnostic examinations has made many women insecure. Pregnancy advice centres offer them the opportunity to address questions about prenatal diagnostics before, during and after these exams. Every woman has to decide for herself whether she wants any of these diagnostic procedures, and if so, which; she must also decide what impact a potential finding would have for her and the unborn child with regard to continuing the pregnancy or terminating it at a late stage.

Conversations in the pregnancy advice centre support parents in finding out how they would feel about dealing with a sick or disabled child, and they inform parents about the help available for a life with a disabled child. Fears about being confronted with their own suffering and the suspected suffering of the child, about the strain on the relationship and on siblings, about isolation and questions of the parents’ career development are taken seriously and addressed with regard to the decision about the pregnancy. The confronta-

tion regarding questions about prenatal diagnostics often touches on the parents’ idea of a family, on ethical norms and values, and takes them to their own limits.

This advice session is a particular challenge for the counsellor with regard to dealing with the dynamic of the couple and with the overwhelming experiences resulting from the impossibility of having to decide for or against a child; they also have to support the grieving parents.

To do this, counsellors need heightened abilities to bear and pick up on conflicts, they need the creativity to find individual solutions, and they have to be willing to confront their own ethical position.<sup>3</sup>

Shifting family planning to a later, “more suitable” time touches on the work of the pregnancy advice centres. This may result in renewed need for advice, for example when there is an unfulfilled desire for children or when there are questions about reproductive treatments. Among the questions discussed will be to assess the options, risks and funding choices for an artificial insemination. Sometimes, if the reproductive treatment was successful, there is at a later date further need for advice regarding psychosocial questions relating to reducing the number of fetuses in case of a potential multiple birth. The pregnancy advice centres also offer help in the event that the reproductive treatment was unsuccessful, in which case they help couples cope with saying goodbye to their desire for children and with developing new prospects.

### Information about adoption and foster care

In rare cases women do not believe they are able to raise the child they are carrying, but they are also not able to opt for a termination. In those cases the questions about how a child could still be born and have a good start in life are dominated by advice on foster care and adoption.

In order to inform women of these options, the counsellors must have knowledge of the legal aspects of adoptions and of the impacts of an adoption on the child, the biological mother and the potential adoptive parents. Insofar as a mother needs time to think to make her decision and the child could temporarily be placed in a foster family, the pregnancy advice centre can accompany the woman to the foster care service and help her with her decision making.

Depending on when during the pregnancy the desire for an adoption is voiced, there can be long-term accompaniment or advice about the steps that need to be taken. It can also be a good idea that the pregnancy advice centre accompanies the woman during the period after the birth and the handover of the child, because the decision to give a child up for adoption could “feel” different to the biological mother from what she initially expected.

### Prophylaxis

Prophylactic services in the field of sexuality education and family planning supplement the work done by the pregnancy advice services. They target all age groups and take place in co-operation with schools, communities and educational institutions.

The goal of these sex-education services is to avoid unintended pregnancies through education, the provision of information about contraceptives and their application, and

<sup>2</sup> See the contribution by K. SCHRÖDER on confidential births in this publication

<sup>3</sup> See the contribution by C. HEINKEL in this publication  
(These notes added by the editors)

about dealing with sexuality. In addition, depending on the participants' wishes, other subjects may include love, friendship, sexuality, understanding each other's roles, sexual orientation and attitudes. Special subjects like pornography, sexual violence and prostitution are discussed, depending on age and interest.

### Networking

Knowing about the limitations of one's work, and knowing about the network of different institutions and services that the advice centre can make use of, allow counsellors to make concrete, targeted referrals. For this reason it is vital that the advice centre has good connections to translators, lawyers with different specialisms, to colleagues working in infant welfare, health visitors and jobcentres.

Regular participation in various working groups and bodies takes place in regard to all subjects related to pregnancy. This facilitates the networking of the pregnancy advice centres among themselves and allows the participants to engage in a content-related confrontation with the quality of existing municipal services and their possible extension. As a result of the breadth of the subjects, individual employees in many pregnancy advice centres have specialized in certain matters, such as subjects like migration, prenatal diagnostics, social law, same-sex families, sexuality education... The "specialists" expand their knowledge in expert working circles and incorporate it into their work at the advice centre.

In order to guarantee the work of pregnancy advice in every regard, the staff regularly participate in in-service training and conferences and reflect on their own actions in case reviews and supervision.



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# Confidential birth – A chance for mother and child

*Kristina Schröder*

It is not easy to understand the motivations of women who give birth to their child on their own and then want to give away the newborn as quickly as possible. Feeling overwhelmed, helpless and desperate and having profound material fears are all part of it. These women have gone through a pregnancy characterized by loneliness and fear, and they face a future in which they cannot under any circumstances imagine a child. Being alone with these feelings, with the pain and with the need of the new life during the birth is a situation that nobody would wish on any woman – not least because this situation is life-threatening for her and for the child that she wanted to or had to keep secret at all costs. Pregnant women in precarious situations need help urgently because their life and that of the baby is at stake.

The committed counsellors at pregnancy advice centres display a lot of empathy and sensitivity when offering help to pregnant women; they do fantastic work. Unfortunately they do not yet manage to reach all women who want to keep their pregnancy secret. Some women do not know about their right to anonymous advice; others do not take advantage of the service. Some of them abandon their child after birth or kill it.

Services such as baby drop boxes, anonymous births and anonymous handovers of the child can help women in their acute need and can sometimes save lives. However, they also have serious weaknesses. Baby drop boxes have the dis-

advantage that the mother and child have no medical care during the birth – the consequence here is that complications during the delivery can be life-threatening. Anonymous births are medically safe, but they disregard the child's basic right to know its own identity. They force doctors and clinic staff to work in a legal grey area.

A real solution for the desperate women and their children has to offer legal certainty, be medically safe and sensitively weigh up the rights and needs of all the participants.<sup>1</sup>

## **The law ensures confidentiality**

Doing these demands justice in a piece of legislation has taken such a long time because some of the interests of the mother and child are contradictory. The desire of the mother to remain anonymous contradicts the basic right of the child to learn about its origin. The law also had to do justice to the rights of the biological father, the right to legal certainty for the doctors and clinic staff involved, and to the needs of the new parents in a future adoption. In light of the importance of the lawmakers' decision, it was right that we took the time to carefully weigh up the difficult ethical, legal and medical aspects. I am pleased that the law to extend the help available to pregnant women and to regulate confidential births, which came into effect on 1 May 2014, offers a model that takes into account the rights and needs of all parties affected. We are thereby also implementing what the Deutscher Ethikrat [German Ethics Council] recommended to the Federal Government in 2009.

How can we imagine a confidential birth from the perspective of a pregnant woman? The first goal is better access

<sup>1</sup> The 2011 study "Anonyme Geburt und Babyklappen in Deutschland – Fallzahlen, Angebote, Kontexte" ["Anonymous births and baby drop boxes in Germany – case numbers, services, contexts"], commissioned by the Federal Ministry of Family Affairs, confirmed this clearly. The 2009 report of the German Ethics Council regarding the anonymous handover of children also reaches this conclusion.

and hence better provision of services to pregnant women in precarious situations. For that reason, extending the help available to pregnant women in precarious situations is a fundamental component of the law. One thing that is envisaged is that the government will increasingly publicize the help available to pregnant women and mothers – particularly their right to anonymous advice – in order to reach all women in such precarious situations if possible. To do that, we also have to include and sensitize the environment of the women affected. We also want to promote an understanding for parents who give up their child for adoption. The Federal Ministry of Family Affairs is already preparing a relevant campaign.

Since women in precarious situations only accept low-threshold help, the government is also setting up a special, nationwide crisis line for pregnant women in psychosocial conflict situations. This crisis line will be available around the clock and will also be supplemented by an online service so that women have the opportunity to seek help via a chat, without initially talking to anyone in person. Through this crisis line, women seeking help can find out about the option of getting professional and anonymous advice in a pregnancy advice centre near them.

A second major component of the law is the new service of confidential births. The advice centres will only offer it when women do not want to reveal their identity despite good services being available. Confidential births are primarily about getting women to accept obstetric care while protecting their confidentiality. But they are also about honouring the rights of the child and the father. The principle of confidential births is to give mothers anonymity for 16 years, after which the child is given the right to view its file. State institutions will only get involved in the process as far as absolutely necessary. The mother can trust that her file will remain confidential for 16 years. The assurance of confidentiality in conjunction with early and ongoing advice is the linchpin of confidential births.

Now that we have confidential births, we have for the first time a choice that replaces anonymous births with a legally secure option that takes into account the needs of the mother and child. In the long term, we want confidential births to make services such as baby drop boxes redundant. The aim here is not to reduce the number of services that have in recent years and with a lot of effort and personal commitment established well functioning networks for women to give up their children anonymously. It is a service of great value for those affected, and it was the best solution that rights and the law permitted to date, albeit in a grey area. Now I want to use the experiences from these networks to implement the new regulations as well and as quickly as possible.

### Pregnancy advice centres create trust

Sections 3 and 8 of the Pregnancy Conflict Law [Schwangerschaftskonfliktgesetz], stipulate that advice centres shall play a leading role when it comes to confidential births. They control and organize the entire process. They are particularly suited to this task thanks to their high level of expertise and of acceptance among those seeking help.

The main goal of the counselling sessions is that pregnant women accept help, particularly obstetric help. The women are also to get an overview of their situation and be shown

solutions to their desperate situations, as is the case with any counselling session. These sessions are the key to ensuring that no woman, if possible, is left alone with her problems.

The pregnancy advice centres see their clients as the focus of the process, and the advice sessions are thus immediate, confidential, free, extensive, ongoing and are not set on a specific outcome. Their function as bridge builders to further psychosocial advice areas and services can turn out to be particularly helpful.

The only feature that is new is the confidential birth, when a woman rejects the conventional help put forward in the Pregnancy Conflict Law. In this event, the advice centres are to answer the following questions for the women affected:

- What is the process of a “confidential birth”?
- What rights do the mother, child and father then have?
- When and how is the child adopted?
- What options are there to get the child back?
- What personal issues can the mother put forward against the child’s right to see the file about his/her origin?

The federal government supported providers of pregnancy advice and the states responsible for the advice centres in preparing the expert staff for this new task in a timely fashion before this new law came into effect. Those responsible received tested guidelines for the advice process, standardized throughout Germany; there is a uniform set of standards available for the counselling, and for the implementation of a confidential birth.

To improve the quality of the counselling and to provide the women with long-term support, the law also stipulates that the work of the pregnancy advice centres should take place in regular co-operation with adoption agencies. This then does justice to the best interests of the child. If a woman opts against this collaboration, her wish is naturally to be respected. The paramount consideration is the women’s trust in the confidentiality of the counselling.

### The process creates trust

A confidential birth can only do its name justice when the women can be offered a reliable process in confidential counselling. The pregnancy advice centres guarantee the confidential advice, while the law extending the help available for pregnant women and regulating confidential births ensures the reliable process.

The process mainly focuses on the needs of the mother and child. First the woman chooses a pseudonym and a first name for the child. The advice centre then records her personal information in the “statement of origin” and seals it in an envelope. The pseudonym, the birth dates and the address of the advice centre are all recorded on the envelope. In this way the envelope can be assigned to the right child if he/she wants to find out about his/her origin after 16 years. The advice centre then registers the pregnant woman under her pseudonym at the maternity clinic or with a midwife/obstetrician. The aim here is to take away her fear of the admission formalities and of the need to explain herself. The advice centre informs the local youth welfare service about the upcoming birth so that it can take on the child in good time.

If a pregnant woman who wants a confidential birth is admitted without her having received any advice beforehand, the clinic or the midwife has to inform a local advice centre



of this immediately. In this case the advice centre makes sure that the woman is immediately given expert advice, even after the delivery. If the woman rejects this advice, the principle of ongoing help to solve the conflict situation still holds, meaning that the women are still not left alone; instead, they continue to receive the offer of help and advice.

After the birth, the clinic (or the midwife at the home birth) immediately informs the advice centre about the location and date of the birth. The advice centre records this information on the envelope, which is then sent to the a federal agency [Bundesamt für Familie und zivilgesellschaftlichen Aufgaben] for safekeeping. The clinic or the midwife must also register the birth at a registry office within a week. To ensure that the assurance of anonymity is maintained, the registry office is to be informed only of the mother's pseudonym along with the first name chosen by the mother, the place of birth, the day, hour and minute of the birth and the child's sex.

If a woman has opted for a confidential birth, there are two options. The mother can still choose a life with her child. As would be the case in an adoption process that goes through the court, she would have around one year after the birth to choose this. During this time she can take back her child if it is compatible with the latter's wellbeing. If the mother sticks with the decision to remain unknown to her child for the time being, the child will grow up in an adoptive family and the envelope with the data will remain locked in the safe of the Bundesamt für Familie und zivilgesellschaftliche Aufgaben for 16 years. After 16 years the child can view the file at the Bundesamt. If the mother does not want this, she can invoke "paramount interests" of confidentiality. In the event of a dispute the family court will decide whether the interests of the mother are to be prioritized over the right of the child to know his/her origin.

### Confidentiality saves lives

Pregnant women who wish to remain anonymous need a service that will help them and the child effectively and long-term both early on during the pregnancy as well as during and after the delivery. Despite their worries and precarious situation, women must be able to give birth with the best medical care instead of delivering the child secretly and in highly risky circumstances – something which the existence of baby drop boxes could entice them into. These are not banned by the new law, but they are being evaluated and there are now clear and articulated standards to protect the child.<sup>2</sup>

Confidential births on the other hand create a service that protects the lives and the health of the mother and child. They do justice to the reality lived by the affected women and they make sure that we can reach women in precarious situations with sufficient services.

That is not the only reason why confidentiality is the better alternative. It also creates more fairness because it respects the rights and needs of all the parties affected: those

of the mother, those of the child, those of the biological father and also those of the new parents in the event of a future adoption. It also creates legal certainty for doctors and clinic staff, who until now have been in a legal grey area when supporting pregnant women in precarious situations.

In order to test whether the new rules stand up in practice, the law is being evaluated in its interaction with existing services that allow women to hand over their child anonymously.

Even at this early stage I wish to thank the pregnancy advice centres and the adoption agencies, who will play a key role in confidential births, for their good and important work. They uphold the process, create trust and can save lives with this law. The federal institutions, and the individual states, professional associations and clinics all have to be engaged in participating in this important task to make it a success story. I therefore ask for your support so that more affected women in precarious situations can have services available to them that they can accept.

I am confident that we are already on the right path, and I am certain that the pregnancy advice centres will also be able to use their skill as professional openers of doors when it comes to confidential births. Their competent, respectful, trustworthy and empathetic support allows pregnant women in difficult situations to find self-determined, individual solutions.

<sup>2</sup> Supporting the law governing confidential births, a voluntary organization working in this field, the Deutscher Verein für öffentliche und private Fürsorge e.V., on the initiative of the Federal Ministry of Family Affairs, agreed recommendations for minimum standards for baby drop boxes in June 2013.



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<sup>3</sup> This contribution was written and edited while the minister was in office (editor's note).

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# Pregnancy advice, early help, child welfare – legal foundations<sup>1</sup>

*Lydia Schönecker*

The Federal Child Protection Law (Bundeskinderschutzgesetz (BKISchG)), which came into effect on 1 January 2012, has brought about three main new developments for pregnancy advice centres<sup>2</sup>:

- The protection of confidence has been strengthened further in pregnancy advice, since the right to anonymous advice, which previously was only mentioned expressly in law for pregnancy conflict counselling (section 6 sub-section 2 of the Pregnancy Conflict Law (Schwangerschaftskonfliktgesetz, SchKG), now holds for pregnancy counselling in general (section 2 sub-section 1 SchKG).
- Furthermore, the law made pregnancy advice centres particularly important co-operative partners with regard to early help. They are not just listed as one of the (many) partners in section 3 sub-section 2 of the Law on Co-operation and Information in Child Protection (Gesetz zur Kooperation

und Information in Kinderschutz, KKG) that the youth welfare services are required to incorporate into the locally present networks or into any new networks; according to section 4 sub-section 2 of the SchKG they are now expressly required, conversely, to participate in these networks.

- In addition to these inter-case rules of co-operation, the newly introduced standardized authority to pass on information in the event that the wellbeing of a child is at risk (section 4 KKG) also strengthens collaboration in individual cases. It also holds for the “members or representatives of recognized advice centres according to sections 3 and 8 of the SchKG” (section 4 sub-section 1 clause 5 of the KKG).

The goal of Early Help is to strengthen parents’ competencies in order to secure the wellbeing of children. Because of its connexions to child welfare, it is often associated in people’s minds with children’s welfare being at risk. These associations are quite often charged with fear, and cause parents to want to distance themselves from the (new) tasks and responsibilities associated with Early Help. The following section answers relevant questions from the practical field, with the goal of contributing more legal certainty. The main focus is on explaining what each of the described new regulations in the BKISchG mean specifically for pregnancy advice centres.

<sup>1</sup> This article was written to assist the pregnancy advice service of the Nationales Zentrum Frühe Hilfen (NZFH) and the Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege (BAGFW), which will soon appear in the series “Materialien zu Frühen Hilfen”.

<sup>2</sup> Incidentally, the “law to extend the assistance available for pregnant women and to regulate confidential births” came into effect in May 2014. It gives pregnant women in conflict situations the opportunity to give birth with medical assistance while maintaining their anonymity. At the same time the interest of the child to know its origin is maintained because the personal data of the mother are recorded. The experts at the pregnancy advice centres are given a central role. However, this contribution will not go into any further detail about the (legal) questions that arise in this context.

## Collaboration in individual cases

### What conditions must be met to have the authority to pass on information under section 4 KKG?<sup>3</sup>

In the style of the time-tested approach in child and youth welfare, based on section 8a of book VIII of the German social legislation code (SGB VIII), section 4 of the KKG also seeks to give the individuals explicitly listed there, who because of their professional context come into contact with situations where children's wellbeing is put at risk, an action guideline.<sup>4</sup> In principle, a two-step process is envisaged:

*1st stage: they must fulfil their own remit to help (section 4 sub-sections 1 and 2 KKG)*

During this first stage, if weighty factors indicating that a child's wellbeing is at risk become known, the individuals must first fulfil their own remit to help (section 4 sub-section 1 KKG), and if necessary, this will be supported by getting on board an "expert experienced in this respect" (section 4 sub-section 2 KKG). In detail, the following steps are to be followed for the correct approach:

- The level of risk must be assessed: if an expert as listed in section 4 sub-section 1 KKG becomes aware of weighty factors indicating that a child's wellbeing is at risk, the caseworker must first discuss the situation with the individuals who have legal custody of the child ["Personensorgeberechtigte": normally one or both parents] and maybe also the child itself.
- Working towards taking advantage of further help: if the caseworker believes that in order to avert the risk to the child further help must be drawn on, then he/she is to work towards a relevant joint approach with the individuals who have custody of the child, as long as this does not endanger the effective protection of the child.
- getting an expert experienced in this respect ("experienced expert") on board: since the assessment processes pertaining to the child's at-risk situation and to the feasibility of the concrete procurement of help are often particularly complex and demanding, the caseworker can get support by requesting that the public youth welfare provider honour his/her right to anonymous case advice and provide an "experienced expert".

*2nd stage: informing the youth welfare service (section 4 sub-section 3 KKG)*

If, in a specific case, an approach following the steps as outlined in the first stage is not feasible (e.g. because of an urgent need to act) or remains unsuccessful, then there is a second stage granting the expert the authority, if necessary against the will of the individuals with custody, of providing the youth welfare service with the information necessary to avert the risk. However, before this happens, the caseworker is required to inform the individual(s) with custody about this intended step (on the principle "maybe against their will but not without their knowledge"). An exception exists when this transparency would jeopardize the effective protection of the child.<sup>5</sup>

### How exactly is the concept "child's wellbeing is at risk" defined? Is there a standardized catalogue of criteria that can be used to assess whether the wellbeing of a child is at risk?

The concept "a child's wellbeing is at risk" is not legally defined. However, the German Supreme Court [Bundesgerichtshof (BGH)] provided a definition in 1956 that is still valid today. According to this definition, a child's wellbeing is at risk when there is "a current danger that exists to such an extent that it can be said with considerable certainty that if left to develop, there will be considerable harm" (BGH FamRZ 1956, p. 350).

This judicial definition was left deliberately open with its undefined legal concepts ("current danger", "considerable harm") in order to take account of the diversity and complexity of potential situations. From a legal perspective, the assessment and decision of the appraisal based on the specific individual case is left up to the responsible caseworker (MEYSEN/SCHÖNECKER/KINDLER 2009, p. 73).

### Is there an obligation to call on the help of an "experienced expert"?

No, it is entirely up to the caseworker whether or not to get an "experienced expert" involved. The "experienced expert" is intended to provide advice and support and should not be seen as a box that has to be ticked. If, for example, the individuals who have custody quickly signal their willingness to search for help together with the youth welfare service, there is no need to continue the process put forward in section 4 of the KKG and involve an "experienced expert".

It is already standard practice for pregnancy advice centres to give expert advice, and include external experts if necessary (section 2 sub-section 2 clause 3; section 6 sub-section 3 nos. 1, 2 SchKG). In addition, perceptions that a child's wellbeing is (potentially) at risk, and dealing with that, can be taken into consideration, but only on the condition that the pregnant woman consents. Taking advantage of the (new) advice service by way of an "experienced expert" seems most appropriate when the pregnant woman is not willing to give this consent and when anonymous advice, which would make the consent of the pregnant woman unnecessary, is not possible. It is a good idea when it appears necessary to call on additional expertise beyond the general specialist advice.

3 It is legally contested to what extent the specific terms of the individual states' child protection laws are still applicable. The understanding here is that because the constitution (Art. 31) gives federal laws precedence over state laws, it is to be assumed that the state laws are superseded by the federal standard laid down in section 4 KKG – at least with regard to issues they both relate to. (MEYSEN/ESCHELBACH 2012, pp. 108 ff. are of the same opinion.)

4 For a detailed account of the understanding of this authority, see MEYER/ESCHELBACH 2012, pp. 108 ff.; DIJuF/NZFH/IZKK 2013; the explanations written before the new legal regulation are also helpful (MEYSEN/SCHÖNECKER/KINDLER 2009; SCHÖNECKER 2009; SCHÖNECKER/MEYSEN 2010).

5 To facilitate checking the circumstances under which data are passed on without consent, cf. also the process outlined in DIJuF/NZFH/IZKK 2013, pp. 42 ff.

### Is the appraisal of the “experienced expert” binding for the further decisions and courses of action taken by the counsellors?

No, the responsibility for the case remains with the caseworker in the pregnancy advice centre, even after taking advantage of the support of an “experienced expert”. The caseworker alone decides on how to proceed further; therefore he/she is solely responsible for deciding, if necessary, whether there is (already) a situation where it is necessary to pass on information to the youth welfare service, potentially against the will of those with custody of the child, because he/she (the caseworker) lacks the ability to help (section 4 sub-section 3 KKG).

However, in order to be able to present clearly, if necessary, the specific reasons why the assessments and suggestions of the “experienced expert” (who will generally have particular expertise) were not followed, this divergent course of action should be documented with good justifications by the caseworker in the pregnancy advice centre.

### To whom can counsellors turn if they want to make use of an “experienced expert”?

Such a claim should always be made to the youth welfare service (section 4 sub-section 2 KKG, section 8b sub-section 1 SGB VIII), which is responsible for maintaining an adequate service.

The youth welfare service is not, however, allowed to fulfil this claim itself through its “general social service” [Allgemeiner Sozialer Dienst (ASD)]; it must fulfil it through outside experts. This is to avoid the situation where the representative of the ASD and the “experienced expert” are the same person, because this would be bound to lead to a conflict of interests, thereby defeating the object of section 4 sub-section 2 KKG. The purpose is to allow the caseworker to take advantage of anonymous professional advice before making a decision about whether the youth welfare service (and therefore the ASD) ought to be informed or not.<sup>6</sup>

Of course there is also the option that the operators of pregnancy advice centres also maintain their own “experienced expert”. This is particularly likely from time to time with integrated advice centres whose operators are also recognized as providers of voluntary youth aid. However, it must be kept in mind that because of very different risk situations (e.g. mental illness or addiction on the part of the parents, domestic violence, neglect, being underage), which all trigger the need for different reactions and help, not every “experienced expert” will be sufficiently competent for every counselling requirement, so that it could become necessary to bring in an external expert.

The duty of ensuring that the caseworkers in the pregnancy advice centre have an “experienced expert” available lies with the youth welfare service, so that the provision of such a person by a pregnancy advice centre can be a good idea, but is not strictly necessary; the two are at most compatible.

### What exactly does “handing over the required information” mean?

If the caseworker reaches the decision, in line with section 4 sub-section 3 KKG, that he/she has exhausted all the help he/she could give, and, looking at the child’s risk situation, considers it necessary to get the youth welfare service involved, then the caseworker has the authority to pass on the necessary information. The goal of this step is to inform the service responsible for averting this risk, which is thereby equipped with more scope and competencies for action. The content and extent of the information passed on should be determined keeping this purpose in mind: the information that is “required” is the information the caseworker in the advice centre believes the youth welfare service will need in order to avert the risk.

### What measures to protect children are in principle conceivable?

If the youth welfare service has been informed that a child’s wellbeing is at risk, it is required, as a first step, to approach the individuals with custody as well as the children or young people themselves in order to discuss the risk with them and to work towards the help it believes is necessary in order to avert the risk (section 8a sub-section 1 SGB VIII). The SGB VIII itself lists a broad range of help (for more detail, see ch. 4.2.3 of this publication). However, help from other sources (health visitors, addiction advice, women’s shelters, psychiatric clinics etc.) is also conceivable.

Therefore the youth welfare service must first attempt to develop an approach supported by the individuals with custody. It is only when these efforts remain unsuccessful or there is an urgent need for action because of an acute risk, i.e. it would be irresponsible to (continue to) struggle with the individuals with custody, that the youth welfare service has the authority to initiate further measures to avert the risk even against their will.

Two situations in particular are conceivable:

- The youth welfare service applies to the family court (section 8a sub-section 3 SGB VIII) to intervene in order to initiate the help believed to be necessary. The family court will itself check whether the child’s wellbeing is at risk, on the one hand, and to what extent the individuals with custody are willing and able to avert the risk on the other (section 1666 of the German Civil Code [Bürgerliches Gesetzbuch, BGB]). If the family court reaches the decision that further measures are required to avert the risk, it can order them. According to the explicit list in section 1666 sub-section 3 of the BGB these measures, which could be relevant for the current context, include:
  - instructions to take advantage of local help such as the services provided by child and youth welfare and healthcare (no. 1)
  - banning an individual temporarily or for an indefinite period from using the family home or some other home, or spending time within a specified distance thereof (no. 3)
  - replacing declarations by individual(s) with custody (no. 5)
  - partial or complete withdrawal of custody (no. 6).

Except as laid out below, only the family court may order measures to avert risk that go against the will of the individuals with custody.

- Exclusively in the event that there is no time to await the decision of the family court because of the urgent need for

<sup>6</sup> MEYSEN/ESCHELBACH 2012, pp. 123 f. are very clear on this.

action, the youth welfare service has the (emergency) authority to take the child into care against the will of the individuals with custody and temporarily initiate help for the child (section 42 SGB VIII). However, in the event that the individuals with custody object, the youth welfare service must immediately apply to the family court if this has not yet happened. The family court will then check the suitability and necessary measures to avert the risk under procedures laid down in section 1666 BGB.

### **What intervention options are there for unborn children?**

If the pregnancy advice centres accept the child protection remit, they are very often in a situation where they have to uphold it in relation to unborn children. This does not just force them to face the special challenge of recognizing and determining whether a child's welfare is at risk. Options to intervene against the will of the pregnant woman and put protective measure in place for the child are naturally limited prior to the birth.

Since the law did not explicitly include the unborn life in the protective remit of section 8a SGB VIII, youth welfare services are not bound to observe this protection. Nevertheless, they too have a responsibility to consider how such risk situations for unborn children can be dealt with appropriately, for example by child and youth welfare offices (DIJuF-Rechtsgutachten 2007, p. 300; DIJuF-Rechtsgutachten 2008). It is a good idea if the youth welfare service takes its bearings from the parameters outlined in section 8a SGB VIII. The remit to help has now explicitly expanded to the period of pregnancy under the new Federal Child Protection Law (BKisSchG) (incorporated into section 16 sub-section 3 SGB VIII).

The options to intervene with pregnant women who are putting their unborn child at risk are however quite limited, including for the youth welfare service. One conceivable option, which is often chosen by youth welfare services, consists in informing the maternity clinics in the surrounding area as a precaution. From a data protection perspective, there is a requirement here that the youth welfare service has reached the expert, well-founded appraisal that the child's welfare will very likely be at risk after the delivery and that this risk can only be countered by passing on the relevant information to the maternity clinics, given the lack of other options to secure the protection of the child. Furthermore, details about the pregnant woman and her personal circumstances are not allowed to be passed on unless the youth welfare service believes this information is necessary in order to allow the clinic to fulfil its duty (cf. DIJuF-Rechtsgutachten 2011). However, whether the youth welfare service is in turn informed after the birth of the child depends entirely on the assessment and decision reached by the doctors (or the midwives and nurses if necessary) in the maternity clinic in line with the parameters outlined in section 4 KKG.

In addition it is always an idea to consider suggestions for interventions from the family court. In this case there is the hurdle that the court will also only see itself as responsible from the birth onwards. It is controversial among legal experts whether family courts can issue orders prior to a birth in situations where a child's wellbeing is at risk. Such an application of section 1666 BGB can be answered in the affirmative when looking at the decisions reached by the Federal Constitutional Court [Bundesverfassungsgericht], which has

ruled that unborn life is worthy of protection (BVerfGE 39, 1; BVerfGE 88, 203). However, the family court, too, is of course limited with respect to the interventions and orders it can impose on the pregnant woman. Court orders to refrain from a certain harmful behaviour often have limited efficacy because of the lack of control and sanctions that can be imposed. More intense interventions in the pregnant woman's life to protect the unborn child (e.g. forced admission to hospital) are generally considered disproportionate because of the associated massive infringement of the pregnant woman's basic rights; as a result, these options are not available to the family court. One conceivable approach, however, could be to conduct a discussion in court together with the parents-to-be and the youth welfare service (section 157 of the Family Proceedings Law, FamFG). This could potentially induce the pregnant woman to accept help to protect her unborn child, maybe in response to being shown the possible consequences (e.g. the risk of losing custody) (DIJuF-Rechtsgutachten 2008).

### **Are there special features with regard to the protection of trust for integrated advice centres whose operators are also recognized as "voluntary providers of youth assistance"?**

No. Although the services of voluntary providers of youth assistance generally fall under the scope of section 8a SGB VIII, which, in contrast to the specifications in section 4 KKG, does not just allow the responsible caseworker to inform the youth welfare service after going through the individual steps, but rather demands it. As an advice service outside the service catalogue of the SGB VIII, pregnancy advice in integrated advice centres does not fall under the scope of section 8a SGB VIII (DIJuF-Rechtsgutachten 2007); instead the counsellors providing these advice services are bound to the regulations in section 4 KKG.

For this reason it can happen quite often in integrated advice centres that some caseworkers are subject to section 8a SGB VIII, while others are subject to section 4 KKG. However, there should be virtually no practical difference since the steps are the same. It has to be assumed that counsellors who have to recognize that all of the steps demanded by section 4 KKG have remained unsuccessful and that further help should come from elsewhere (the youth welfare service), i.e. they will generally take advantage of their authority to do so.

### **What can happen if it is not recognized that a child's wellbeing is at risk or if this is incorrectly judged? When do counsellors become culpable?**

Judgements as to whether a child's wellbeing is at risk in any particular case and with what methods this can be successfully combated are necessarily of a prognostic nature. If it turns out during the further development of the case that an incorrect appraisal was made in this regard and if the caseworker responsible comes under pressure to justify herself as a result, this circumstance should hold a crucial place in a potential legal investigation. The legal judgement as to whether the appraisal and the decisions that were subsequently made were appropriate and permissible should not be made from the (better) perspective that comes with hindsight, but should be made taking the facts into account as they were at the time the decision was made (MEYSEN/SCHÖNECKER/KINDLER, *Frühe Hilfen im Kinderschutz*, 2009, p. 73).



However, the notion of making caseworkers criminally liable in cases where a child is harmed is not something that would normally even be considered. For one thing, it can hardly be assumed that the caseworker can have the necessary guarantor position with regard to the (unborn) child (a detailed account on the guarantor position in SCHINDLER 2012). Should the law enforcement agencies be of a different opinion in a particular case, the prosecution would have to prove “beyond reasonable doubt” that the caseworker was criminally negligent in not performing an action (e.g. informing the youth welfare service) that would have prevented the harm to the child. This seems improbable in two regards. Firstly, there are many protagonists and possible actions involved in child protection cases, so it would be generally impossible to prove “beyond reasonable doubt” that the action the caseworker failed to implement was the one that would have prevented the harm to the child. Secondly, a caseworker who implements the steps required in section 4 KKG with the means available to the best of her knowledge and conscience can hardly be accused of objectively or subjectively violating her duty of care (i.e. engaging in culpable behaviour).

In short: caseworkers’ fears that they will be legally more culpable if they become involved in observing the child protection remit, in the event that their appraisal turned out to be “wrong” in a particular case, is unfounded, and only a perceived rather than an actual threat.

## Networking activity

In addition to the regulation governing co-operation in individual cases, the promotion of co-operation in the sphere of child protection, as intended by the BKiSchG, is based on a second important foundation: the work in local networks that goes beyond individual cases (section 3 KKG).

The goals of these local networks – particularly in the area of Early Help – are defined as follows by the law:

- Reciprocal information about everyone’s scope of services and tasks
- Clearing up structural questions pertaining to the design and development of the service
- Co-ordination in child protection cases (section 3 sub-section 1 KKG)

In addition to these clear goals, one requirement for the success of such networks will be that the necessary trust is developed among the participants. A central aspect here is the willingness to correct hackneyed images and (negative) experiences and to engage in a serious dialogue about the possible options and limitations of the different professional groups as well as to communicate about the specific conditions needed for success.

One very fundamental aspect for networking activity that goes across cases is that those involved have to take into account that this must be strictly distinguished from the collaboration (which for pregnancy advice experts is now based on section 4 KKG) that takes place in individual cases: this networking activity is not about exchanging specific personal data or data relating to the families obtained from working on individual cases; instead it is about exchanging information of significance for interdisciplinary co-operation in general. To ensure this clear separation, parliament was moved to allow the possibility of anonymous advice as part of general pregnancy advice (section 2 sub-section 1 SchKG).<sup>7</sup>

### Who says how the networking activity is to be conducted? Are there co-determination options?

The BKiSchG has put the organization of the network structures into the hands of the operators of the public youth assistance (which generally means the youth welfare services) (section 3 sub-section 3 KKG).<sup>8</sup> Therefore they are responsible for inviting all the participants and taking over all further planning and organizational tasks.

Section 3 sub-section 3 clause 2 KKG expressly states that the participants should agree on the fundamentals for binding co-operation. This means that the network partners – and therefore also the participating pregnancy advice centres – have explicitly been given the option of co-determination, at least in the negotiation process as part of these agreements. This could even mean that the participants of a local network choose a different person from the youth welfare service for the co-ordination and management.

### Can a claim for funding be made for this networking activity?

Probably not, although, interestingly, the legal requirement that obliges the pregnancy advice centres to participate is found in the regulation governing the financial duty of the states to support the advice centres (cf. section 4 sub-sections 1, 3 SchKG); however, deriving from this that the federal government has obliged the states to provide financial support for this additional task of the pregnancy advice centres would go too far.

Instead, the pregnancy advice centres do their work in the networks – just like many other network participants listed in section 4 sub-section 2 KKG – as part of their regular work (according to section 4 sub-sections 1, 3 SchKG). The states are responsible for determining the human resources required as part of this legal remit.

<sup>7</sup> In the preamble (BT-Drucks. 17/6256, p. 30) it says: “The promise of anonymity is also required to counteract the potential worries on the part of those seeking advice that could be triggered by the future involvement of the pregnancy advice centres in the Early Help Network that this co-operation would extend to individual cases and not just structural matters.”

<sup>8</sup> However, the states have an express right to regulate matters differently.



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# Advice regarding prenatal diagnostics and pre-implantation diagnostics – a service offered by the pregnancy advice centres

*Claudia Heinkel*

**In her essay, Claudia Heinkel discusses prenatal diagnostics (PND) as conflict-rich normality in general prenatal care. She also looks at psychosocial advice for pre-implantation diagnostics and the special challenges faced by the counsellors, and she outlines the current debate on specialized advice centres and comprehensive provision of PND advice services.**

Every couple that has a child in Germany today has to confront the subject of PND<sup>1</sup> right from the start of the pregnancy and make a large number of decisions. Originally a service for a small group of families with a high probability of having a severely disabled child, PND has developed into a search for deformities and genetic abnormalities and has become a firm component of general prenatal care. It is now offered to all pregnant women and, if they are 35 or older, it is urgently recommended; furthermore, women enquire about it as almost a matter of course (cf. here BUNDESZENTRALE FÜR GESUNDHEITLICHE AUFKLÄRUNG 2006).

The transitions from check-ups on the health of the mother and the child to targeted searches for clues of chromosomal changes are fluid.

This norm of a prenatal search for disabilities and deformities is ethically highly explosive: PND is providing more and more and more exact knowledge about the embryo, but the therapeutic options continue to be limited. The vast majority of diseases and deformities can only be diagnosed, but not treated. In addition, mutations such as Down's syndrome are not diseases that could ever be treated. If the results come back "abnormal", the only alternative to birthing a disabled child is to terminate the pregnancy. The potential consequence of an abnormal result – killing an intended,

but sick or disabled child – therefore "hangs like the sword of Damocles over all pregnancies" (SCHUMANN 2007, p. 41).

PND isn't just an individual problem, it is also a topic of social significance because it is contributing to a change in central social categories. Parental responsibility these days also now includes responsibility for the genetic configuration and health of their children. Pregnant women increasingly feel they are responsible for not having a child with a disability.

Furthermore, parents with a disabled child in the age of PND constantly have to explain why they have had a child with a disability despite all the diagnostics on offer; or else they are stylized into heroes because they "voluntarily" opted for a child with a disability and therefore for an allegedly arduous life.

PND supply and demand have triggered a dynamic that turns the hope for a healthy child into a duty to have one. At the same time this gives rise to the expectation, by expectant parents, that medical technology could and should guarantee such a healthy child, an expectation no diagnostic programme can fulfil.

## The legal basis for PND advice

Various legal rulings focus on making available to expectant parents an optional, comprehensive, multi-professional advice service that deals with this conflict-rich service of prenatal examination. This includes the legal right to psychosocial advice, as outlined in section 2 of the Pregnancy Conflict Law (Schwangerschaftskonfliktgesetz, SchKG), which also encompasses the information and advice on PND.<sup>2</sup>

<sup>1</sup> Prenatal diagnostics includes non-invasive examination methods such as ultrasound, first trimester screenings and the new genetic blood tests as well as invasive procedures such as amniocentesis and chorionic villus sampling, which carry a risk of miscarriage, cf. BUNDESZENTRALE FÜR GESUNDHEITLICHE AUFKLÄRUNG (2011)

<sup>2</sup> See the article by J. PROLINGHEUER and U. KUNZ in this publication

In 2010 parliament expanded the SchKG, by adding the new section 2a: if there is an abnormal result of a PND exam, before doctors discuss a medical indication in favour of a termination, they must advise the expectant parents and they must also inform them of their legal right to advice in accordance with section 2 of the law; if the expectant parents give their consent, the doctors will also refer them to psychosocial advice centres, self-help groups, or to disability associations.

Almost at the same time in 2010, the Genetic Diagnostics Law (GenDG) came into effect. Section 15 of this legislation requires doctors to inform their patients about their legal right to advice in a pregnancy advice centre not just after a finding, but before a genetic exam. However, there is no requirement for doctors to refer their patients accordingly.

### Psychosocial advice before, during and after PND

Psychosocial advice in the context of PND is an independent service provided by the pregnancy advice centres in accordance with section 3 SchKG; it is legally regulated and takes place in line with professional standards. This advice orients itself on the situations of the expectant parents and their needs in this area.

#### Counselling before prenatal diagnostics<sup>3</sup>

##### *The couples' situation*

At this point in time the couples are feeling positive. They have accepted the pregnancy or they wanted it and they are embarking on the exciting journey of becoming parents. They are looking forward to seeing their child on the ultrasound and want a confirmation "that everything is alright". In most cases they are not aware that they are taking advantage of an exam that could destroy this positive feeling early on (or choose not to think about it). An abnormality on the ultrasound, such as abnormal nuchal translucency, normally triggers a chain of further prenatal exams, which in extreme situations causes serious conflict situations. Expectant parents often also do not know that they have a right not to know.

##### *Tasks for the advice centres*

It is quite rare that women come to advice centres at the start of their pregnancy with a need for advice on PND only. It is more common that the experiences with prenatal exams and the associated fears and insecurities get discussed as part of general pregnancy counselling. The requirement here is that the counsellor is sensitized to the subject of PND and can hear the unspoken messages. Pregnancy counsellors are generally familiar with situations where technical questions (e.g. about financial assistance) can often mask their clients' other problems. They are proficient at being alert to this and at providing a proactive counselling service in an empathetic manner.

One way a woman could make a specific request for advice about PND could be that she has already lost a child because of a PND result and/or when she is torn between her unease about an invasive exam and her doctor's urgent recommendation to have it done (e.g. because of her age).

Advice before PND is mainly there to strengthen the expectant parents in their decision-making ability so that

they can settle for themselves what they want to know. What exams would they like? What consequences would an abnormal result have for us? What further information do we still need? What other ways exist for us to give us peace of mind?

#### Counselling while parents-to-be are awaiting their results

##### *The couples' situation*

Couples experience the period when they are waiting for the results of a non-invasive exam and, even more so, of an invasive exam, with great anxiety. The wait can be several weeks from a first suspicion during an ultrasound exam to the assured findings. The fear of having a disabled child is constant during this period. Often, the women subconsciously try to make this waiting period more bearable by emotionally distancing themselves from the child. They do not talk about their pregnancy and they put off preparing for the child.

##### *Tasks for the advice centres*

The reason why women would come to an advice centre in this instance can be very similar to why they would come in before any PND: the pregnant women come for general pregnancy advice, the counsellor is alert to the subject of PND and offers to talk about it. The fear of a problematic finding can also be a direct reason why women seek out advice. Earlier involvement with the advice centre or the recommendation by a midwife or doctor make it easier for women in this situation to access advice. Sometimes the woman is informed about unsettling findings between advice sessions about social assistance, whereupon her worry becomes a reason for counselling on the subject.

At the heart of the advice sessions during PND is the task of emotionally stabilizing the clients and supporting their relationship to the child. Empathetic listening, structured follow-up questions, and organizing thoughts and feelings can all help with this. This also includes taking the great fear of a disabled child seriously and giving it space during the counselling session, while differentiating the often threatening ideas about disability and making the fears concrete.

At this point the counselling sessions also give the parents the opportunity to think about the central question: what will we do if we get abnormal results? What do we think we are capable of? Where are our limits? If required, information about disabilities, the help that is out there and contact details can be passed on. However, counsellors must respect it when clients, in their situation of inner anxiety, withdraw and are not able to talk about it.

#### Counselling after an abnormal result

##### *The couples' situation*

Most couples receive good news after PND: their child is developing normally and the suspicion of deformity could be ruled out. However, for some their worst fears come true: their child has a disability or illness – of varying degrees of severity – and in rare cases it is not compatible with life.

3 Cf. LAMMERT/NEUMANN (2002); WASSERMANN/ROHDE (2009); EVANGELISCHES ZENTRALINSTITUT FÜR FAMILIENBERATUNG (2006)

Immediately after being given the diagnosis, the couples are often in an extreme emotional situation. They are in shock and cannot take in information anymore, e.g. what doctors are telling them. The diagnosis destroys the life dreams and plans they had with their child. They fluctuate between apathy and despair, anger and incredulity. They feel guilty, or they refuse to believe the diagnosis. The pregnant women often end the relationship to their child. They often urge for a quick termination so they are able to escape from this unbearable situation.

To complicate matters, nobody can tell them exactly how their child will develop with this disability and what its life will be like. Nobody can tell them how far their strength would go, nobody can take the burden of responsibility from them.

#### *Tasks for the advice centres*

The counsellors' first task is to catch the couples emotionally and to stabilize them. They need time to come out of their state of shock. The counselling can open up a window of opportunity during which the pressure to make necessary decisions can be removed. In order for the parents-to-be to process their experience emotionally, it is important that they do not make a hasty decision based on panic, which they could later regret (cf. ROHDE/WOOPEN 2007).

The counsellors' main task is to help the parents make an independent decision for or against a termination – one they can stand behind, taking their ethical and religious convictions as well as their life story into account. The idea is to look at both courses of action – deciding to keep a child with a disability or deciding to terminate the pregnancy – and mentally to go through both of those. The idea is to figure out with them what their resources and the limits of their capabilities are; the parents need to be given the information they need to make a decision, be it information about terminations, information about life with a disability, or contacts with other affected parents.

#### **Counselling after a decision to terminate based on a medical indication**

The couples have opted for a termination and received the necessary medical indication under article 218a of the penal code to obtain one. In this case the purpose of the counselling session is to support couples as they endure their decision. The couples should be emotionally stabilized and they need to be prepared for the upcoming delivery. They are not always aware that a termination at an advanced stage of pregnancy involves an induced delivery where the pregnant woman must give birth to a stillborn child. The counsellor will encourage the couples to take leave of their child and discuss with them how they would like to do that. Should there be a farewell ritual? Would they like a minister present? How should the siblings be included? What about the social circle? Should there be a funeral? How can the memory of the child have a place in the family? If necessary, the counsellor will also refer the parents to a hospital chaplain.

#### **Aftercare following a termination based on a medical indication**

A late-term abortion is a dramatic event for all the women involved and their partners. Often, the couples do not properly allow themselves to mourn their lost child because they actively chose to end its life. They often feel guilty, they are ashamed of their decision and they may well doubt the

rightness of their decision from time to time. Their environment does not always react appropriately to their grief.

A need for counselling can arise when the woman or the couple want support in their grieving process and in coming to terms with the event after a termination. It is also possible that the experience only crops up again at a later date, e.g. during a subsequent pregnancy, and the woman wants advice again.

The counsellor accompanies the couples in the situation immediately after the termination and, if need be, for an extended period as they go through the process of grieving for their lost child. If necessary, the counsellor can also set up contacts with bereavement groups for affected parents or to psychological counselling/couples' counselling facilities for further psychological advice or therapy.

#### **Advice after a decision to have a child that will probably be disabled and after the birth of the child**

A pregnancy that is carried to term with the knowledge that the child is disabled is a particular challenge: the parents do not know what to expect and they still face months during which they have to endure this uncertainty.

The counsellors therefore face the task of strengthening the parents with regard to their decision and to promote their relationship with the child. That also includes them being given time and space to acknowledge and voice their grief over their "lost" dream child and their fears about the future. The counsellor supports them in their preparation for the birth and also includes family members and the couple's social circle. He/she will give the couple information about life with a disabled child and put them in touch with other affected parents if appropriate. The counsellor will also help the parents before and after the birth of their child to build up a network of help, by putting them in touch with early-support centres or in-home paediatric nurses. If need be, he or she will also give concrete assistance, such as finding a suitable family assistance organization. It is important for the parents to know that they are not abandoned after the birth of their child and that they have a place where they can go for further advice and support.

#### **Special challenges faced by counsellors**

Counselling in the case of PND is advice that focuses on a controversial ethical area, and this can be a professional and personal challenge for the expert counsellors. The experts in PND counselling have to bear almost intolerable situations with the couples, they have to find words for things for which there are no words and they have to support people who are making decisions about the life or death of their child, which will take them to the limits of what they can bear.

The necessary foundation for this counselling is solid skills as an counsellor and counselling experience in the area of pregnancy and pregnancy-conflict counselling. One additional need for in-service training can result because PND counselling, more so than pregnancy counselling, involves couples. In addition couples could require support during their grieving process for a longer period of time after a termination. It is helpful when counsellors acquire additional competencies or when they have expert reference people to whom they can refer couples for more intensive support if the need arises.



It is vital for PND counselling that counsellors have their own, thought-through ethical stance about the subjects associated with PND and clarify their personal attitude, abilities and limitations in a constant confrontation: how do I feel about disability? How do I deal with suffering and misfortune in my life and in other people's lives? How do I deal with loss, grief and death? What helps me cope with crises and conflicts? What do I mean by a happy life? Only then can they respect couples' decisions and accompany them in an empathetic manner even when the couples' decision goes against their own attitude.

The counsellors are dependent on providers and management observing and honouring this advice service by taking the required measures needed to ensure the quality of the counselling available, such as regulated supervision, in-service training, team case discussions, sufficient time resources for the preparatory and follow-up work of the counselling sessions, time to build and nurture the network, for counselling and guidance outside of the advice centre too (e.g. hospital).

#### How much medical knowledge is necessary?

At the heart of psychosocial counselling is the person seeking the advice and her experience, i.e. her emotional state, not the diagnostic findings. Counsellors do not have to be medical experts in order to work in PND counselling. They do, however, need up-to-date knowledge about the prenatal exams that are being offered to their clients, and they need to know about the prenatal care system. They also need basic information about the most common disabilities and illnesses that could be diagnosed and they need to have an idea of how people with these disabilities live. Here too it is the case that they do not personally have to be experts in assistance for the disabled; instead they just need to know about the help that is out there and they have to have contacts to self-help groups and institutions for the disabled.

For that reason PND advice requires a regional network of different professions, institutions and services that counsellors can readily draw on, at short notice if necessary. This network does not just encompass doctors, midwives, early-support centres, self-help groups and in-home paediatric nurses; it also involves services that support families, healthcare chaplaincy, funeral institutes, bereavement groups and psychological (couples') counselling facilities.

### Current debates

#### How do the advice centres reach the parents-to-be?

The Federal Ministry of Family Affairs has commissioned an evaluation for the implementation of section 2a SchKG (see BUNDESMINISTERIUM FÜR FAMILIE, SENIOREN, FRAUEN UND JUGEND 2013). The results of this evaluation confirm the feedback from the advice centres on the ground: the number of referrals of parents-to-be to advice centres by doctors has only increased slightly since 2010. The efforts for co-operation between advice centres and doctors are particularly successful when the initiative comes from the doctors themselves. A significant percentage of the gynaecologists surveyed see their role largely as passing on informative flyers and as suggesting to patients to visit an advice centre. They are far less likely to provide an active and motivating referral, e.g. by personally getting in touch with the advice centre, as expressly demanded by the law. In addition, the

referral tends to take place after a definite finding, not when there are irregularities, e.g. during the first trimester screening, which can already cause incredible uncertainty among the expectant parents. For doctors, psychosocial advice is primarily a decision-making aid before a termination. The majority of doctors do not consider the issue of providing emotional support during the nail-biting wait for the results, let alone help in making a decision at the start of the pregnancy for or against prenatal screening.

Implementing the duty doctors have to provide information and referrals in practice requires well-regulated co-operation and networking between different professions, especially between doctors, psychosocial advice, self-help and assistance centres for the disabled. This presupposes mutual knowledge of all the tasks, standards and procedural methods as well as respect for the various professional fields.

The results of the evaluation show that there is still quite some work to be done in order to reach the goal of the law, namely to offer all expectant parents a low-threshold, multi-professional counselling service.

#### Specialized advice centres or comprehensive coverage?

Since the law was changed in 2010, there has been a lively debate among experts about whether every advice centre should offer counselling in respect of PND or whether, analogous to medical services, a system of a few specialized advice centres should establish itself, which could potentially be given additional financial means.

Advice centres with a speciality in PND counselling near clinics where prenatal screening takes place have the advantage that women who might have to travel long distances to the specialized clinics to clear up a suspicion can be referred at short notice to an advice centre near or even in the clinic if there is a finding.

At the same time there are also significant concerns about such a centralization: a system of only a few specialized advice centres would merely serve to increase the attention on the situation after a finding and reinforce the notion of counselling as nothing more than a decision-making aid for or against a termination. The right to counselling before PND to strengthen expectant parents' decision-making competencies as well as during PND to provide emotional support would be marginalized even further.

In addition the new range of genetic blood tests performed early in a pregnancy go against such a specialization: these tests can be offered by gynaecologists and the companies are now advertising their products to women at a low "risk" of having a disabled child. All advice centres, not just the specialized ones, will be confronted with this service and its consequences<sup>4</sup>.

Pregnancy advice is characterized by looking at its clients and their whole situation. Every pregnant woman in Germany, and therefore every client of general pregnancy advice centres, is confronted by PND and has a right to professional advice. The aftercare after a termination and

4 Cf. HENN/SCHMITZ (2012); Netzwerk gegen Selektion durch PND (2012) regarding the potential for conflict associated with the new blood tests.



after the birth of a disabled child are both part of the core tasks of every pregnancy advice centre in an area local to the woman. It is therefore vital that every advice centre maintains PND counselling as part of its service.

### **Psychosocial advice regarding pre-implantation diagnostics – a task for pregnancy advice centres**

#### **The legal basis of pre-implantation diagnostics (PID) in Germany**

PID is the targeted examination of artificially produced embryos for specific genetic traits before they are implanted into a woman's womb. The requirement for this PID is artificial insemination.

PID is in principle not allowed in Germany; however, according to the Preimplantation Diagnostics (Regulation) Law (PräimpG), it will be allowed in two circumstances in the future:

1. when one or both of the parents have a high risk of passing on a "serious hereditary disease"
2. when the embryo has been "severely damaged", making a stillbirth or miscarriage very likely.<sup>5</sup>

PID is only possible in centres specifically approved for this purpose. It is necessary for an ethics commission to agree to the woman's application to have PID and that she has been informed and advised about the genetic situation. It has not been defined in law what a "serious hereditary disease" is or when the risk is "high"; instead, this should be answered on a case-by-case basis by the ethics commission.

The approval of PID in these two cases was preceded by a long debate, where one side demanded PID to be banned because, it was claimed, it had the purely selective purpose of preventing children with disabilities and malformations, and that this could open the door to potential abuse, such as producing children with certain traits. Proponents on the other hand said that this would only affect a small group of tragic cases for whom this exception should be made on grounds of humanity.

<sup>5</sup> The regulation governing pre-implantation diagnostics (PIDV) regulates the implementation of the law, such as the approval of the centres or the work of the ethics commissions. PIDV came into effect on 1 February 2014. Only from that time on was PID legally possible in Germany (given these two circumstances)

<sup>6</sup> The preamble of PIDV (DRS 717/12), says of section 3 sub-section 2 clause 3: "pregnancy advice centres and advice centres for couples with an unfulfilled desire for children can be useful co-operative partners when it comes to the psychological and social consequences of pre-implantation diagnostics. There is a legal right to psychosocial advice as outlined in section 2 of the SchKG".

<sup>7</sup> Cf. the position paper of the NATIONAL ETHICS COUNCIL (2003), p. 30ff, for the risks and stress factors of artificial insemination and PID for the woman and the children created in this manner.

<sup>8</sup> PND takes place during pregnancy, PID as part of fertility treatment. PID searches for specific genetic markers, whereas in PND the findings are generally unexpected. The results generally only take a few days for PID, whereas the wait can be several weeks for PND. Cf. WOOPEN (2013).

### **Compulsory counselling by a doctor before PID regarding medical, psychological and social consequences**

The law requires doctors to provide "information and advice regarding the medical, psychological and social consequences" of PID (section 3a sub-section 3 clause 1 of the Embryo Protection Law (EschG)); they have to do so before PID is approved and therefore before the start of any reproductive treatment. In the preamble to this regulation, the law expressly recommends that the PID centres co-operate with the pregnancy advice centres, citing the legal right outlined in section 2 of the Pregnancy Conflict Law (SchKG).<sup>6</sup> Unfortunately, in the PID regulation the co-operation with an advice centre is not defined as a duty to be performed by doctors as it is, analogously, in section 2a of the SchKG. This would have given the recommendation significantly more weight, helping it to be implemented in practice.

#### **The legal right to psychosocial advice with regard to PID**

The legal right to advice under section 2 of the SchKG also encompasses Counselling before, during and after PID. It should therefore also part of the regular services provided by pregnancy advice centres.

#### **The situation of the women and couples**

The couples are often in a stressful situation: these are couples who already have a child with a hereditary genetic disorder and who desire a further – healthy – child. They are couples where one parent or a family member is personally affected, or who have already lost a disabled or severely ill child. They are couples who would like a child but who, possibly because of a genetic problem, have suffered several miscarriages or stillbirths and who are hoping to have a healthy and viable child thanks to PID. In order to receive PID, they have to have artificial insemination, coupled with the associated physical and psychological stresses for the couple, particularly for the woman and the children created in this manner.<sup>7</sup>

#### **Tasks for the counsellors**

Even though the starting position and the setting of PND and PID differ from each other<sup>8</sup>, the psychosocial advice in the event of PID has a similar set of tasks as it does for PND: it is to strengthen couples in their decision-making ability for or against PID, it is to give them the opportunity for emotional relief, especially during the treatment, and it is to support them after – potentially unsuccessful – treatment, helping them to process what they experienced.

To reach a workable decision for or against PID it is necessary that the conflict-laden factors associated with PID are addressed: the success rates for artificial insemination are limited, depending on the age of the woman. PID is not able to guarantee a healthy child. An extreme case would be that parents, despite undergoing PID, could suffer a PND finding about a different disease or disability during the pregnancy, whereupon which they would be confronted with having to decide for or against their child.

#### **PID counselling presupposes multi-professional co-operation**

As is the case for PND, the co-operative structures between doctors and advice centres are necessary in order that the

couples affected hear about their right to advice. It would be desirable for them if the centres approved for PID took up the law's recommendation and initiated a well-regulated collaboration with the local pregnancy advice centres in their town.

In addition, couples must be able to access psychosocial advice where they live, so that they can determine whether they even want to go down that road or to get emotional relief after an unsuccessful treatment. This requires the joint efforts of doctors and advice centres.

The operators of advice centres are called upon to observe their responsibility to ensure the quality of the advice for PID as well and to allow the expert advisors to access further training, supervision and case discussions if necessary; they are to inform the public of these services and they need to provide the time needed to allow the centres to co-operate.

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# Help for pregnant women in emergency situations. Main results of the evaluation “Bundesstiftung Mutter und Kind – Schutz des ungeborenen Lebens” [“Federal Foundation Mother and Child – Protecting the Unborn Life”]

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**Women in emergency situations who want financial aid from the Bundesstiftung Mutter und Kind, generally have to apply for it through pregnancy advice centres. An evaluation by the Federal Ministry of Family Affairs found that in addition to the direct effects of the financial support, there are clear positive effects as a result of going through the advice centres: the low-threshold access to pregnancy advice centres that is thereby generated, as well as the access to the diverse system of early help, is experienced as useful and helpful by the applicants and the experts.**

Important choices are made for the development of a child during its first months of life. If the burden of financial worries is lessened for the expectant mother during the time of her pregnancy and delivery, and she is shown how to access the diverse support network of early help, this will benefit the mother and child in the long term.

The Bundesstiftung “Mutter und Kind – Schutz des ungeborenen Lebens”<sup>1</sup> was established in 1984; its goal is to provide financial assistance in order to improve the circumstances of expectant mothers in a serious emergency situation and to make it easier for them to opt in favour of the child. The foundation uses the nationwide network of the pregnancy advice centres to distribute its materials, which provides low-threshold and local access for the pregnant women. For this reason the women must apply for the foundation’s funding support from a pregnancy advice centre. Across the country, more than 1200 advice centres are involved in filing applications and providing individual advice with regard to support available from the foundation.

By having to file for financial assistance with the Bundesstiftung Mutter und Kind before the child is born, it is possible to establish the contact between the pregnant woman and the advice centre early on. Therefore there is enough time before the birth to determine options for further support and assistance services to suit every individual case.

In June 2011 the evaluation Bundesstiftung Mutter und Kind – Schutz des ungeborenen Lebens started out as a door opener to the network of early help for pregnant women in emergency situations with which the Federal Ministry of Family Affairs, Women and Young People had commissioned

the Institute of Social Research and Social Policy and the Büro für Evaluation und wissenschaftlichen Service. During this scientific survey the investigation looked at how the services provided from the funds of the Bundesstiftung impact the situation of the applicants. An additional area of interest was the question whether the financial service of the Bundesstiftung, by being linked to the pregnancy advice centres as “door openers”, affects confidential, competent advice on the one hand and other support systems and services on the other.

## **Methodological concept of the evaluation of the Bundesstiftung Mutter und Kind**

The evaluation’s concept was designed in such a way that the effects of the Bundesstiftung could be presented and assessed from several angles and in varying depths of focus. This multi-perspective design was reflected in the fact that the most important protagonists responsible for awarding assistance from the Bundesstiftung were included in the evaluation:

On a structural level, the evaluation included experts in senior positions in the various operators of the pregnancy advice centres alongside the representatives of the central institutions in the federal states. Because of the direct collaboration between the pregnancy advice experts and the pregnant women in precarious situations, the experience of these experts was also an important component of the evaluation. For this reason there was not just a written survey of the pregnancy advice centres; there were also further, more in-depth qualitative interviews with the advice experts, which were necessary to address more complex questions.

<sup>1</sup> [www.bundesstiftung-mutter-und-kind.de](http://www.bundesstiftung-mutter-und-kind.de)

The applicants' perspective was also given special significance. Their circumstances, their need for advice and their perception of the support provided by the means of the Bundesstiftung Mutter und Kind were focused on in two separate survey methods: a quantitative documentation of the cases as well as qualitative interviews with the applicants.

### **Financial assistance for pregnant women in precarious situations**

Every year, some 92 million euros is made available to the Bundesstiftung Mutter und Kind by the federal government for the fulfilment of the foundation's remit. The funds are allocated to the central institutions in each of the 16 states, using an allocation system based on the population figures. These central institutions, based on the Foundation Establishment Law, are solely responsible for allocating the funds to pregnant women in particularly precarious situations and for approving applications in their federal states.

Under the terms of the above law, expectant mothers can be granted assistance if they turn to a pregnancy advice centre because of a precarious situation. With regard to the term "precarious situation", the guidelines governing the allocation and use of the Bundesstiftung's funds stipulate an income limit that must be taken into account when a precarious situation has been found, so that it is mainly the financial situation that is decisive.

In 2012, almost 130,500 women throughout the country were supported by the funds of the Bundesstiftung, meaning that around one in five pregnant women received support. One large target group consists of women whose only income is their social security benefit and other women at risk of poverty. As a result, women who are foreign nationals and other women with a migrant background are therefore also often applicants for support from the Bundesstiftung.

The funds of the Bundesstiftung Mutter und Kind can be approved for various purposes. The law permits approval for uses to do with the pregnancy, the birth, and the care and the raising of the young child. In particular, this allows recipients to acquire the initial equipment/supplies for the child, to continue running the household, to help with housing and furnishings, as well as with the care of the young child. The guidelines for awarding and using Bundesstiftung funds also stipulate that financial assistance can also be granted for ongoing services to support the livelihood and secure the training and the temporary housing of the expectant mother. In actual fact, the majority of approved funding goes towards maternity clothes, the initial supplies needed for the child, and for housing and furniture. Ongoing services, on the other hand, are only approved in rare cases.

### **Network activities of the pregnancy advice centres**

In order to point the applicants to further appropriate support, it is important that the pregnancy advice centres network with other relevant institutions. In most pilot regions the networking activities with the local institutions offering further support for pregnant women and young mothers is very good. There are often working circles and networks for different subject areas, into which the pregnancy advice centres insert themselves. The most common

structural networks exist between them and other pregnancy advice centres, protagonists in the system of Early Help, with children's and youth welfare services, and with family and educational guidance.

Networking with the health services varies greatly by region, even though the pregnancy advice centres make great efforts to increase co-operation. Many of the advice experts consulted would like improved collaboration with medical professionals. There is agreement that a successful implementation of early help for the mother and child is only possible if it starts as early as possible and if the medical system – gynaecologists in particular – participates.

Furthermore there are networks with the basic security offices of the social benefits providers. However, as many of the advice experts surveyed in writing mentioned, and as became clear in other parts of the investigation, collaboration between advice centres and job centres is often very problematic, and an improvement in this co-operation is urgently necessary.

### **Pregnant women's problem situations**

According to the assessment of the advice experts as well as of others participating in the evaluation, the precarious situations of pregnant women have dramatically increased in recent years. There is both a growing crisis in individual problem areas as well as an increase in the complexity of the pregnant women's overall problem situation.

As part of the evaluation it became clear that the pregnant women's problem situations often encompass several areas. In most cases there is a poor financial situation because of unemployment or insecure employment. According to the appraisal of the pregnancy advice experts, the percentage of expectant mothers (but also of expectant fathers) affected by financial problems is increasing, including among those in work and even those in middle-income brackets. Low wages, insecure employment conditions and temporary work contracts that are not renewed because of pregnancies are seen as the causes. Many families have an income that is both insufficient and insecure. Another aspect frequently addressed was that general financial stressors had greatly increased in recent years, which is particularly true for the costs of housing and mobility.

However, there are also clearly recognizable increases in the area of socio-emotional stressors. According to the opinion of many pregnancy advice experts, psychological problem situations have also greatly increased in recent years – increasingly among the pregnant women themselves and also among family members, such as the children's fathers.

Both the worsening of pregnant women's individual situations as well as the increase in the complexity of existing problems pose new challenges for the advice experts. The complexity of the problem situations has meant that the advice spectrum relating to the relevant legal foundations, which keep changing at ever-shorter intervals, has expanded massively. As a result, the demands placed on the pregnancy advice centres with regard to in-service training and ongoing knowledge updating keep growing.

## Effects of the financial support provided by the Bundesstiftung Mutter und Kind

The evaluation differentiated between the direct and indirect effects of the support provided by the Bundesstiftung. The effect of the financial support, which the Bundesstiftung Mutter und Kind calls a “door opener”, is access to the advice centre on the one hand, because this is the only place where the application can be made and the individuals seeking advice receive further advice and information in this context. An indirect effect could also be that the comprehensive and individual advice opens the door or guides the way to further support services.

The results of the evaluation show that the majority of applicants primarily seek out pregnancy advice centres in order to receive help in a financially difficult situation. Several applicants made it clear that they would not have sought out the pregnancy advice centres had there not been a prospect of obtaining such financial help from the Bundesstiftung. These results indicate that the service of providing financial support has a door-opening function, allowing women to access advice.

It became clear during the one-on-one conversations that there are often other problems, but that the applicants cited the financial service as the primary reason, since they found it easier to start a conversation via their difficult financial situation. The pregnancy advice experts use this way into the advice service in order to inform the pregnant women of further support in other areas of life and to offer them this support.

The various protagonists surveyed made it clear in the interviews and group discussions that because of the prospects of financial support, it is largely an educationally disadvantaged group, often with multiple problems, that can be motivated to seek out an advice centre. It was also emphasized that this group generally speaking will not have taken advantage of an advice centre before. The means of the Bundesstiftung were therefore seen as a highly appropriate, low-threshold access to the available system of support.

### Crucial financial support

Financial support very early on is very important to the applicants, since they can use the money to cover their initial needs. In many cases it is this financial assistance that makes it possible to close the crucial funding gap so that the women can prepare for the pregnancy and the first few months of the baby's life, which they would otherwise only be able to do under great financial pressure and usually by getting into debt. The means of the Bundesstiftung are particularly good at fulfilling this function because unlike other services, they are generally made available to the women at short notice and at the crucial early point in time. It is this short-notice nature that allows a targeted application of the means, which is then in many cases able to prevent further crises.

One effect on the pregnant woman that results directly from the financial support is great relief and relaxation of tension. The promise of financial assistance is a huge weight off the pregnant women's shoulders and this relief means that the expectant mothers can turn their thoughts to other upcoming tasks, while being open and trusting towards further advice and support services.

## Support through the counselling session

As a result of the concrete financial assistance and the associated individual advice, the applicant can start to trust the pregnancy advice service as a supportive entity and develop a relationship of trust with the counsellor. According to the statements of the majority of the applicants interviewed, they would visit a pregnancy advice centre again should there be further problems.

The counsellors help pregnant women gain an overview over the further support systems at their disposal and they help them take advantage of these other services. This also includes possible social resources, particularly getting support from friends and family. In addition the women seeking advice are informed of the state services available to them and they are supported in their application; furthermore the counsellors help to check notices issued by other authorities.

An additional indirect effect is the information about other possible support services that the women only receive through their counselling session. One effect that is considered to be particularly lasting is the referral to other advice and support systems, particularly in the area of Early Help. The expert advisors and the representatives of the operators confirm that this indirect effect is of great relevance. This targeted early contact to the pregnant applicants makes it possible to offer them individual support during their pregnancy as a preventive measure.

The financial support of the Bundesstiftung, coupled with comprehensive pregnancy advice, bolsters the self-confidence of the applicant and possibly of her partner. The “nesting” made possible thanks to the financial support is hugely relevant with regard to the applicants' feeling of self worth and their future role as parents. Furthermore, the applicants are greatly encouraged during a period in their lives usually characterized by uncertainty. This uncertainty, which can often arise because of the situation of the pregnancy, is lessened through the application session and the individual conversation with the counsellor.

### The means of the Bundesstiftung and pregnancy advice as mutual catalysts

The effects of the financial support provided by the Bundesstiftung Mutter und Kind are developed and enhanced by the direct interplay between the financial support and the psychosocial advice service. The offer of financial support by the Bundesstiftung opens the door to the advice centre. Here, the pregnant women learn not just about the concrete and early financial help available, but also about further support; during this process they are able to develop trust in the advice process. The relief the pregnant women experience when they receive financial support can effect them opening up to other problems and accepting further advice.

Pregnancy advice enhances the material effect of the Bundesstiftung's means by providing comprehensive further advice and support during a time when the expectant mothers are at a crossroads in their lives. In addition this service can refer the women on to other complementary advice and support systems, which usually means particularly lasting support for the women and their families. The pregnancy advice centres, as the service through with the application for financial support is filed, are a particularly

beneficial framework for the implementation of the goal and purpose of the Bundesstiftung Mutter und Kind.

In summary it has been confirmed that the financial support, paid for by means of the Bundesstiftung Mutter und Kind, has a “door-opening function” for the advice service. It has also proven to be the case that applying for support from the Bundesstiftung is a service ideally located with the pregnancy advice centres. This is because it results in mutually reinforcing effects – between the financial effects of the support provided by the Bundesstiftung on the one hand and the acceptance of the advice service by the pregnant women on the other. Another factor that was highlighted was the great significance of a good network between the local pregnancy advice centres and other support services such as specialist doctors and midwives, who play an important multiplier role because of their early contact with the pregnant women.





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# Migration and culture-sensitive pregnancy advice – a task for institutional counselling

Alexandra Ommert

**The diverse cultural significances of pregnancy and starting a family should be known to pregnancy counsellors, and this should be reflected in their work. The development and spread of further training measures based on a dynamic notion of culture is therefore an important requirement for institutional counselling that is sensitive to cultural and migrant backgrounds.**

The professional remit of pregnancy advice is to be accessible in every way and to make possible the right to access to services and information. That also means identifying and removing hurdles that stand in the way of this access. The Federal Republic of Germany is a migration society; movement between states is increasingly being taken for granted and is becoming easier, at least for European citizens. According to the Statistisches Bundesamt (Federal Statistics Office), around 16 million people in Germany, or 19 % of the population (2011 figures), have a migrant background.<sup>1</sup> Migration is therefore normal and part of life in our society.

pro familia addresses the professional remit of making possible the right to information and access to services for all those seeking advice as advice that is sensitive to culture and migrant backgrounds. When it comes to people with a migrant background, it is important to consider what concrete conditions, such as residency status, level of education and socio-economic status, might create special hurdles to access to advice services and information.

With regard to the different ways to access these advice services, it is necessary to enquire about personal experiences with medical services, relevant reservations and resulting barriers, as well as the different relevance of starting a family (not least because of the migration experience) and to identify an increased risk of poverty that is particularly likely for single mothers with a migrant background. Provided that there is sufficient reflection on access to services, people without a migrant background who are disadvantaged from a socioeconomic or educational perspective will also benefit.

In order to illustrate this, I will discuss the terms “migrants” and “culture”, before going on to address the tasks and challenges of institutional counselling.

## Who are the migrants?

The figures of the Statistisches Bundesamt are based on a definition of migrants, which refers to people with a migrant background more narrowly defined: “In the sample census, this population group includes all those who have migrated to Germany since 1950 and all those born in Germany with a foreign nationality as well as Germans born in Germany who have at least one parent living in the same household who immigrated or was born as a foreign national in Germany (www.destatis.de)”. This definition alone indicates that this migrant group will be heterogeneous, since their personal experiences will differ greatly because of the migration and the way this affects their circumstances.

Migrants are distinguished by being members of different migrant generations, coming from different countries, or having different religions; they differ by residency status, educational background, skin colour, gender, sexual orientation, health etc. Therefore the subject of pregnancy gives rise to equally diverse concerns and hurdles. The differentiation into more precise and concrete categories is also discussed in the current social scientific debates on intersectionality and diversity.<sup>2</sup>

1 [https://www.destatis.de/DE/PresseService/Presse/Pressemitteilungen/2012/09/PD12\\_326\\_122.html](https://www.destatis.de/DE/PresseService/Presse/Pressemitteilungen/2012/09/PD12_326_122.html) [last consulted 21 Nov. 2013]

2 The two terms differentiate between important categories for the examination of social inequality. While intersectionality (cf. e.g. LUTZ/WENNING 2001; LUTZ et al. 2010) focuses on the overlaps of these categories and emphasizes membership of several groups, diversity management (cf. e.g. KRELL et al. 2007) focuses on the entrepreneurial approach to the different potentials of people with a migrant experience. Both approaches seek to differentiate between the categories considered relevant and analyse unequal access in society.

Despite the heterogeneous nature described, the group of people categorized as having a migrant background differ in some respects – at least statistically – from the rest of the population: their level of education and income is comparatively lower and their job insecurity and unemployment is higher. “Compared with the average of the native population, they are more exposed to uncertain life and residency prospects and to an increased risk of poverty and poor health. For that reason we must assume that there is a greater need for advice and support.” (WEISER 2007, p. 4) There is also a much younger age structure, for example in the group of people with a Turkish or Russian background (cf. BZgA 2010). That means a large number of them are of reproductive age or are still to enter reproductive age. For that reason pregnancy advice is particularly pertinent for them.

Central instruments to determine obstacles to access are obtaining data and documenting advice sessions. When dealing with these instruments, the primary focus should be not just on anonymity and data protection but also on the individuals’ specific counselling needs and therefore on the relationship of trust and on the advice setting. It is right to be sceptical of simplistic enquiries about country of origin or nationality, as this provides little information about the concrete circumstances of those seeking advice, while at the same time unnecessarily creating and reinforcing difference (cf. PRO FAMILIA BUNDESVERBAND 2011, p. 11). It is especially sensitive for people with an insecure or unclear residency status to answer the question of nationality, and it is not always possible to explain to them properly what happens with their answers and that these will not redound to their disadvantage. At the same time this data tells us little about their residency status, the pregnant women’s financial situation and whether they are receiving family support or whether they are alone with their pregnancy. It would therefore be important to develop an appropriate approach to obtaining data. Surveys with a qualitative design could be a good idea; they would make it possible to learn about the concrete circumstances of the individuals seeking advice as well as about their concerns. Without surveys differentiated in this manner, it is almost impossible to make generalizable statements about the special requirements if stereotyping is to be avoided. Therefore there is a need for development here.

### **What is the understanding of culture on which advice sensitive to culture and migrant background is based?**

It is not just being categorized as a migrant that produces differences where common features could be more important; the understanding of culture and how it is dealt with should also be critically reflected on.

Current academic debates assume a dynamic, procedural concept of culture that is largely determined by the actions of people who have been shaped by cultural (historically based) practices, but who are never fully determined by them.

Culture is in motion, changing because of its constant exchange with other cultures, different social circumstances and people’s practices (cf. SARMA 2012). Such a perspective captures culturally complex societies in a more realistic manner: “The idea that people can be distinguished along clear cultural boundaries and put into cultural boxes masks how varied, contradictory and stubborn social practices are.” (HASENJÜRGEN 2013, p. 30)

If this dynamic and procedural concept of culture is accepted, then cultural influences will shape people’s thoughts and actions, but they cannot be reduced to them, nor are they determined or immutable. The significance of pregnancy and starting a family is also based on such a dynamic concept into which old and new ideas, current techniques, practices conveyed by the media and medical standards flow, which expresses itself differently for every individual.

In doing so, this dynamic cultural understanding separates itself from cultural determinism as well as from cultural relativism: “In current debates about migration and Europeanization, cultural determinism that focuses on ethnicity runs into problems because it pins people down to their countries of origin. Cultural relativism focuses on the aspect of the incomparability of cultures and is often cited polemically in the context of the debates about multiculturalism, integration and belonging.” (SARMA 2012, pp. 13 f.) Both concepts are still at play in current political debates, and find their way into the educational measures for counsellors, such as in the form of intercultural training. The problem with these two understandings of culture is that culture is not seen as changeable. This means that people are pinned to “their” cultural affiliation, that there are premature judgements and that stereotypical assumptions are at play. Individual concerns and circumstances are at risk of disappearing behind all of this.

Counselling that is sensitive to migration and culture should be based on a dynamic understanding of culture. This entails a great challenge for the counsellors, both with regard to their expert and theoretical knowledge and with regard to their personal willingness to continuously reflect on and question their own preconceptions. In order to be able to implement this challenging task, they need further training that is based on a dynamic, process-oriented understanding of culture. Most recent investigations have shown that the scientific insights and discussions that have led to a differentiated and more complex understanding of culture are not included in most (in-service) training sessions on intercultural competencies. Instead, they often use out-dated concepts of culture that reinforce images of otherness and alien cultural circles, instead of handling them reflectively.<sup>3</sup> The manifold cultural significances of pregnancy and starting a family should be known and reflected on by pregnancy advisors. It is therefore an important requirement for migration and culture-sensitive institutional counselling that further training measures based on a dynamic understanding of culture are developed and disseminated.

### **Migration and culture-sensitive counselling as a task for institutions**

In 2009, the DEUTSCHE ARBEITSKREIS FÜR JUGEND-, EHE- UND FAMILIENBERATUNG (DAKJEF, German working committee for youth, marriage and family counselling) developed

<sup>3</sup> Cf. SARMA (2012) and the contributions in BAHL (2009), particularly KOCH (2009). On the development of guidelines for intercultural training in the psychosocial field, cf. MÓSKO (2013), though this work does not go into any detail about the underlying understanding of culture.

“expert recommendations for institutional counselling that is sensitive to migration and culture”, defining intercultural opening as a diversified task for the advice institutions; a first, important step is to reflect on the access those seeking advice have to the counselling services and to identify and remove potential hurdles. A rights-based understanding of counselling could serve as a compass for this task. In a nutshell, this means seeing those seeking advice as holders of rights, who have a right to self-determined, well-informed decisions. In order to support these, it is the job of institutional counselling to enable access to information and counselling services.

Institutional counselling sensitive to migration and culture is an attitude to counselling that has two basic premises:

1. Employees should possess differentiated knowledge and intercultural competencies. For that reason, in-service training sessions that are sensitive to migration and culture should be based on dynamic concepts of migration and culture.
2. The process of counselling that is sensitive to migration and culture is shaped by the entire institution. That means among other things that personnel development is conducted with this as a focus, that external depictions and publications are critically assessed, but also that resources are made available for relevant projects and in-service training events.<sup>4</sup> In-service training programmes are an interface insofar as they develop competencies sensitive to migration and culture and are a resource for steering the contents in the institutions.

The in-service training of individual employees is not enough, however, since counselling sensitive to migration and culture is not a special category; instead it is an issue that applies across the board, one that is important in all the working areas of an institution or advice centre (WEISER 2007, p. 4). Therefore, access to pregnancy advice that is sensitive to migration and culture is not just crucial for the counsellor, but also for the employee who is the first to make contact with the client. However, the advice centre as an holistic entity is just as much in the spotlight: how intercultural is the team? In what part of town is the advice centre? Are there flyers and posters in several languages? Does the advice centre make itself known in different communities, such as through information evenings or events? When answering these questions it is also advisable not to work with premature stereotypes. Instead, the self-reflective question should stand in the foreground: for what segment of society does the team/advice centre stand? How does the advice centre want to change its services?

Institutional advice sensitive to migration and culture is therefore a process that should be supported by the entire advice-centre team and management and that should be reflected in the overall concept. For this reason the DAKJEF has developed a model concept for team-oriented in-service and further training for institutional advice sensitive to migration and culture that has as its goal the further training of the entire team, and that supports and accompanies the advice centre’s process of change.<sup>5</sup>

## Conclusion

One sign of quality in institutional pregnancy advice is advice that is sensitive to migration and culture and whose goal it is to provide access to information and counselling services to all those seeking advice. Processes of change in the entire institution and in-service training events that are sensitive to migration and culture should orient themselves on the current status of academic research. To investigate hurdles to access to information and advice services experienced by certain segments of the population, it is a good idea to develop appropriate qualitative methods of gathering data that refrain from seeing migrants as a homogeneous group, and instead focus on the concrete factors of their circumstances, such as level of education, language skills, socio-economic status, poverty and unemployment, residency status etc. This would support those seeking advice while taking their circumstances into account, and it would also make improvements to access to information and advice services achievable.

<sup>4</sup> This also corresponds to the guidelines on intercultural opening by the PARITÄTISCHER GESAMTVERBAND (2012).

<sup>5</sup> This further training is currently offered by the BUNDESKONFERENZ FÜR ERZIEHUNG (bke). A report on the first implementation can be found in bke 2012.



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# Online advice via chat and email. Pregnancy advice on the internet

Christine Lampert

**Quick, competent, low-threshold and free – the Caritas online pregnancy advice service has many advantages and is used intensively. The author explains the concept and shares her experience with this service, spanning several years.**

## History and context

The idea of creating an “online pregnancy advice service”, the way it exists today at [www.caritas.de/schwangerschaftsberatung](http://www.caritas.de/schwangerschaftsberatung), was developed in the year 2000 by the group of advisors at the Catholic pregnancy advice centres of the Speyer diocese.

In connection with the reform of the Catholic pregnancy advice service, there was a discussion in the diocese about how and through what media women and couples could be reached in the future if they had questions and problems in connexion with a pregnancy, particularly during an existential pregnancy conflict.

The development of psychosocial advice services online, e.g. crisis lines, encouraged us to implement such a service for pregnancy advice too. The German branch of Caritas took up this initiative and the project was implemented in co-operation with the Caritas association for the diocese of Speyer. The psychosocial face-to-face advice service offered by the Caritas was therefore expanded by a further low-threshold, contemporary access route.

This online pregnancy advice service is also seen as a door-opener into (Catholic) pregnancy advice. While certain requests for information and/or decision-making questions can often be answered sufficiently by chat or email, if, for example, the counsellors are to help them with financial assistance, the individuals seeking advice have to seek out a pregnancy advice centre. In 2006 the virtual pregnancy-advice site was integrated into the online advice site of the German branch of Caritas and expanded by a regionally tailored email advice service that uses a postcode filter.

It is qualified counsellors at Caritas and the Sozialdienst katholischer Frauen [Social Service of Catholic Women (SKF)]

who work for the online pregnancy advice service at set business hours, following a shared concept and agreed quality standards, offering information and advice.

The online advice service has two levels for individuals seeking advice: the information and orientation layer: here users will find subject-oriented texts, FAQs and an advice centre search in the section “Ratgeber”.

Then there is the level of psychosocial advice: this is offered in the form of email advice (one-on-one advice in the form of time-delayed written communication) and chat advice (instant written communication).

This online advice uses SSL encryption in a closed, server-based system. The individuals using the online advice service are informed about the security standards and confidentiality aspects.

## Concept

### The virtual advice centre

The online pregnancy advice service is constructed as a “virtual advice centre” with a chat and email advice function. This virtual advice centre is centrally organized and operates nationwide. It has fixed hours of operation. The chat service is currently available for a total of 28 hours between 10 am and 9 pm, Mon–Fri.

The chat advice service is based on the idea of an “open surgery” and is always open for (at least) two hours. There are always two pregnancy counsellors responsible for a chat session. As part of this service, the counsellors offer a private advice session in person. This one-on-one advice service is preceded by a lobby, a “waiting room”.

The counsellor responsible for the lobby co-ordinates the



access to the advice room, answers “simple” questions, e.g. about local advice centres, makes sure all the users present treat each other respectfully, makes sure time slots are adhered to, and is in contact with the colleagues in the advice room. If several users have the same question, the lobby counsellor will moderate the exchange. The counsellor responsible for the advice session conducts the private consultation in a systemic solution-oriented manner. The two counsellors on duty can communicate quietly with each other.

There are currently approximately 150 online counsellors from Caritas and SkF participating in the virtual advice centre. The teams change from chat session to chat session; “further advice”, a scheduled meeting with a user is not intended. The counsellors cannot be identified by name. The virtual advice centre also answers email questions without requiring a postcode, or from regions that do not have online advice centres.

In this email advice, for which the users create a password-protected account, the user and counsellor establish an advice contract. This ensures that there is a continuity of advice. First emails are answered within 24 hours; after that the counsellors and users agree on a response frequency.

### **The online advice centres**

In addition to nationwide virtual advice centres already described, there are also 154 online advice centres run by Caritas and SkF (as of 12/2012). These are physical pregnancy-advice centres that participate in the online advice offered by the Caritas and that answer incoming questions, filtered by postcode, that fall into their area of expertise.

For these online advice centres, the “door opening” function to the physical advice centre is very concrete. Users and counsellors meet in the flesh when it comes to issues such as filing applications. A further advantage of this form of online advice is that a face-to-face service can be combined with an email service. This way individuals seeking advice and users can stay in touch when it is difficult to schedule or keep an appointment.

### **The institutional framework of online advice**

It is exclusively pregnancy advisors from the Catholic pregnancy advice service that work for the online pregnancy advice service. They have completed degrees in social work, education or psychology and they have further training in psychosocial advice and practical experience in pregnancy advice.

The online counsellors have a positive attitude to web-based advice; they are competent at using the internet and are confident in using the relevant forms of communication. They should also possess a differentiated “reading and writing competence”, have the ability to “understand” texts and be able to express themselves in writing.

In preparation, they are given technical training on the management of the advice module, the online advice service and their own data and on the use of the chat and email module; they are given content-related training regarding the concepts of virtual counselling.

An orientation framework was developed for the online pregnancy advice service that regulates responsibilities, quality requirements, data protection, discretion, evaluation and worst-case scenarios. In addition, the online advice site

has a “counsellor area”, where papers on fundamental issues and manuals can be found and where specific questions are given binding answers.

The operators of the advice centres provide the staff and the time as well as the financial and technical resources. They come to a framework agreement with the German branch of Caritas, recognize the orientation framework for the online pregnancy advice and are responsible for the regional publicity work. They allow the online counsellors to participate in further training events, in supervision, diocesan meetings and online pregnancy counselling events on a nationwide level that aim at nationwide co-ordination, quality assurance as well as the further development of the service.

At the start of 2013 counsellors from 23 (out of 27) dioceses were working in online pregnancy advice (virtual advice centres and online advice centres).

### **Online advice – advantages for users**

The users decide whether and to what extent they want to share their identity. The anonymity allows them to be freer and less inhibited in what they say, increasing their willingness to reveal themselves while at the same time enjoying a lot of protection. They can determine their own level of openness. Sometimes it is easier to write than to talk. And those who write watch themselves think...

The users choose the time, the place and also the structure of the advice. Web-based communication is familiar and normal. Users organize their own help online, which allows them to experience themselves as capable of acting. Use of the online service is free.

### **Online advice – the special feature from the counsellors’ perspective**

The virtual framework of the advice, the absence of anyone else in the same room, the written communication, the autonomy of the user, the lack of clarity about the identity of the communication partner, the non-binding nature of the medium and not least the problem-prone technology and data transfer are all challenges for the online counsellors. Online counselling also leaves behind archivable traces in the form of paper printouts.

The communication between the user and the online counsellor takes place with a time delay by email or almost synchronously by chat, in writing. The textual perception is brought into focus, reading between the lines, noticing breaks, omissions and pauses is important.

The online counsellors keep making themselves aware of what they (do not) know about the user and her situation. Being solution and resource-orientated in the advice session is helpful. Counsellors do not have to know how the problem allegedly arose. They trust in the competencies of the users. Starting with the user’s written expression, the counsellors therefore often turn hypotheses, impulses and interpretations into questions. Systemic questions bring possible approaches to the fore; for example, questions oriented at the future can be asked. Appreciation is expressed through “compliments”. The communication tends to be colloquial and is also adapted to the language of the user.

## Pregnancy advice online – figures from the 2012 evaluation

In 2012, 1732 chat consultations and 1909 email consultations took place as part of the online pregnancy advice service. These figures have been stable for three years. On the one hand the service provided by the online Catholic pregnancy advice service has reached its maximum, on the other hand the number of online users within the German population is hardly rising. (Internet use in Germany is currently 76.5%<sup>1</sup>, among students 77.6%. In the group of 14–19-year-olds it is 97.5%<sup>2</sup>). This online advice service is no longer a unique feature of the Catholic pregnancy advice service.

Incoming communications can be divided into

- requests for concrete information
- descriptions of problems and asking questions
- descriptions of complex problems
- crisis advice

Pregnant women make up the largest percentage among the users. Partners, family members, friends, acquaintances and people from the social environment of someone they are worried about, as well as sometimes teachers, seek information and advice as well.

Most communication pertains to the issue of pregnancy. The following related subjects were cited the most often in 2012:

- financial situation (65%)
- questions about legal entitlements (54%)
- work and training situation (24%)
- physical and psychological stress (19%)
- fear of responsibility (15%)
- child currently not wanted (12%)
- existential pregnancy conflict (6%)

Compared to those seeking advice in the conventional (face-to-face) pregnancy advice centres, users turn to online advice very early on in their pregnancy, in the 4th to 8th week (13%), often not long after they find out about the pregnancy. The online service is also more likely to be used by men with their own needs for advice. 6% of users say they are male. Young people often ask questions online about sexuality and family planning.

Overall the users are more heterogeneous and the spectrum of subjects broader than in conventional pregnancy advice. The online service is used by educated individuals as well as by educationally disadvantaged users and by those for whom German is a foreign or second language.

## What about the future of the online advice service?

Current trends regarding the use of mobile devices and newly developing services can be discerned. They should not just be taken in by way of an adaptation or a re-launch; they could open new communication avenues, such as a combination of different advice settings. At the same time it is necessary to conduct research into the efficacy, including long-term, of online advice as well as into methodological aspects.

1 Press release: (N)onliner Atlas 2013: number of internet users is only rising slightly again – Data-protection and security concerns are frequent reasons for non-use. Posted by Sabrina Ortmann On 22. April 2013 @ noon In 2013 [here translated]

2 (N)onliner Atlas 2013 der Initiative D21, p. 22



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Links

[www.e-beratungsjournal.net](http://www.e-beratungsjournal.net)  
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# “I want to marry too!” – an inclusion project by donum vitae

*Petra Schyma*

**On 1 March 2013 donum vitae launched a project to implement the tailor-made services in pregnancy conflict advice and general pregnancy advice for people with mental disabilities. It is funded by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) and will run for three years.**

donum vitae Bundesverband e.V. is a state-approved provider (and funder) of pregnancy conflict advice centres, represented in more than 200 locations in Germany. donum vitae offers psychosocial advice and finds concrete assistance in all situations relating to pregnancy and in the event of a pregnancy conflict situation. Based on the Christian understanding of the human being, the association gives advice without aiming for specific outcomes. It sees itself as the advocate for mothers, fathers and unborn children. In addition, donum vitae provides general pregnancy advice, sexuality education and prophylaxis, online advice and psychosocial advice in the context of prenatal diagnostics throughout Germany.

## **The human right to sexuality, relationships and parenthood**

One of the foundations of the project “I want to marry too!” is section 2 of the Pregnancy Conflict Law, which states that every woman and every man has the right to get advice on matters regarding pregnancy, sexuality education, contraception and family planning. At their heart, the UN Convention on the Rights of Persons with Disabilities and the Federal Government’s National Action Plan (NAP; Bundesministerium für Arbeit und Soziales 2011) on the implementation of this convention demand the implementation of the universal human rights for the special requirements and circumstances of people with disabilities. In Article 23 of the UN Convention, the ratifying states commit themselves to take appropriate measures to give people with disabilities effective participation in all questions relating to marriage and relationships, and to give them access to the relevant

information and to sexuality education. Article 3 of the German Constitution says that “all people are equal before the law”. The right to self-determination is therefore guaranteed directly by the constitution, i.e. as a basic right. It includes the right of all people to have their privacy protected and to have the freedom to shape their lives in accordance with their own beliefs – and this relates to relationships, ways of life and having a family. In its “Visions of a Civil Society” the NAP states: “People with a disability enjoy their rights and capacity to act on equal terms with others. They can choose for themselves and make their own decisions about the help they need” (op. cit., p. 89)

## **Self-determination and participation cannot yet be taken for granted**

Since the 1980s we have become more and more aware that people with mental disabilities also have needs, desires and longings for closeness, relationships and sexuality. According to WALTER (2005), the general normalization of circumstances has led to disabled people being granted the same right to develop their personality and to accept their sexual communication as an integral part of their participation in society.

ORTLAND (2008) talks about a “relational understanding” of disability. From a systemic-constructivist perspective disability is understood as a relation between the person labelled as disabled and his or her environment. Societal conditions have negative influences on the individual development of people with disabilities. According to ORTLAND, it is necessary to have sexuality education tailored to disabled people because many people with disabilities still experience

a negation of their sexuality. Making sexual subjects taboo, a lack of sex education, segregationist social tendencies as well as stigmatization in everyday life make it particularly hard for people with mental disabilities to participate in society, with regard to relationships, marriage and sexuality, in a way others take for granted. Their concrete circumstances reveal that the ability to experience sexuality and relationships in our society cannot yet be taken for granted.

### Advice in the context of prenatal diagnostics

In the donum vitae national association's project "Psychosoziale Beratung im Kontext von Pränataldiagnostik" ["psychosocial advice in the context of prenatal diagnostics"] and in the co-operative project, conducted together with the state association in Bavaria, "Unter anderen Umständen schwanger" ["pregnant in different circumstances"] donum vitae has developed measures and services to accompany families and couples who are expecting or have already given birth to a disabled child. donum vitae offers nationwide psychosocial advice in the context of prenatal diagnostics, to advise and accompany pregnant women and their partners so that they can make their own decisions and live with them.

The experience from advice centres shows that the prenatal exams, now often performed in a routine manner, and their results can often push the affected women and couples into significant conflicts if they learn that the finding is "abnormal".

In addition to the personal dismay, the potential of prenatal diagnostics also has a social dimension.<sup>1</sup> It has been found that social acceptance declines for women and couples who deliberately opt to continue with a child with an illness/disability or who did not take advantage of prenatal diagnostics and have a sick/disabled child as a result. The individuals affected often experience negative reactions such as being confronted with the statement: "That's not necessary these days anymore!" This demonstrates that there is a widespread illusion that the disabilities and diseases in question were preventable. Often, every disability is also equated with suffering. But do people with Down's syndrome, for example, suffer?

In the current social reality it is a special task to bring into people's consciousness the dignity and right to life of children threatened by illness or disability and to point out alternatives to abortion. During the decision-making phase of the conflict affected parents also ask themselves: "What will become of my child when it is grown up?"

It is against this background that the project "I want to marry too!" was developed. It has the goal of adapting the advice and sex-education services of donum vitae for people with mental disabilities in order to participate in the inclusion process.

### "I want to marry too!" – project description

The project title "I want to marry too!" emerged from the counselling sector. The statement is an expression of the desire for equal participation in social life, for love, happiness, a relationship and parenthood.

The first sexual experiences, to feel like a man or a woman, are harder for young people with a disability, since they are often prevented from engaging in that by parents or carers in institutions who put in place (over-)protective restrictions. Nevertheless they develop desires for relationships, marriage and sexuality. They therefore need services and advice regarding sexuality education that takes into account this circumstance and reacts to it in a methodologically and didactically appropriate manner. Acquiring knowledge leads to the ability to make decision. This includes: sex education, knowing about different forms of sexuality, consciously experiencing your own role as a man or woman, and developing a sexual identity. Advice services must take account of this. For this reason it is necessary to develop a network with local advice centres, sex education services and information materials.

It is here that the donum vitae project on the implementation of the right services in pregnancy conflict advice and general pregnancy advice for people with mental impairments starts out; it is overseen by the donum vitae national association. It includes the opening event that took place in Bonn on 18 November 2013, conferences, further training events, newsletters and expert information.

The project is being developed with seven pilot advice centres and online advice. The focal issues are developed and implemented in the pilot advice centres. For networking purposes, there will be an annual workshop on the association level, which is tasked with evaluating the results and enabling expert exchange. Further training sessions on relevant issues will be conducted during the course of the project to strengthen the counsellors' competencies.

There is external academic accompaniment for the project. An advisory board has the task of helping to shape the inclusion process, deliberating the results obtained for the individual developmental steps and incorporating the interests and perspectives of people with a mental impairment into the work. The advisory board consists of experts in their own field, experts in assistance for disabled people, representatives of the specialist division of the BMFSFJ (Federal Ministry for Family Affairs), board members of the association, and representatives from the academic accompaniment.

### Implementing the project into counselling and sexuality education

In order to implement the right services in counselling and sexuality education, disability-friendly materials are needed. The association developed brochures about counselling and sexuality education in Easy Language with the help of funds provided by the Bundeszentrale für gesundheitliche Aufklärung (BZgA) to.

Existing counselling and sexuality-education services are adapted and developed to suit the needs of people with a mental disability. The advisory skills are expanded with expert knowledge specific to the target group. Communication is a big challenge since many options are possible, from non-verbal to nuanced communication. Experts in the advice centres give advice in Easy Language, especially on the topics of pregnancy, pregnancy conflicts, sexuality education, marriage and starting a family as well as financial assistance. They provide information about sexual assistance, sexual services and supported parenthood.

<sup>1</sup> See the article by C. HEINKEL in this publication

The ability to give advice in Easy Language requires methodological diversity and process-orientation. It has to be taken into account, in the counselling setting, that women and men with a disability are often under legal supervision. Living-environment counselling and network advice place specific demands on the counsellors. It might be necessary to include parents and/or staff of institutions in the counselling process.

Questions about contraception and a desire for children should be dealt with particularly sensitively. Adults with a mental disability are in relationships of dependence with their legal supervisors or with the staff of institutions, which can lead to conflicts of interest.

There is a perceptible gradual shift in attitude among experts with regard to the question of parenthood for people with a mental disability. As a result, more recent studies have focused more on the necessary, supporting effect of the family networks and therefore on the question of their professional and family support. According to PIXA-KETTNER (2009), women and couples with mental disabilities have almost no opportunity to express their desire for children and parenthood. Here too advice is needed.

Further subjects for counselling are sexual assistance and sexual services. “A distinction is made between active and passive sexual assistance. Passive assistance includes all measures that create concrete requirements for sexuality.” (SPECHT 2013) Active sexual assistance, sexual services, entail that “an external person is actively involved in a sexual situation”. SANDFORT (2010) makes a fundamental distinction between sexual assistance and sexual services.<sup>2</sup>

The study on the circumstances of, and stressors on, women with impairments and disabilities in Germany, which was presented in November 2011, shows that compared with the rest of the female population, they experience sexual violence more often. A network between institutions, advice centres and different professions is necessary to develop joint strategies against violence.

The right to self-determination, including for people with a mental disability, is also guaranteed by basic rights. With the project “I want to marry too!” donum vitae seeks to implement the central idea of “lived” inclusion together with the disabled people, and make possible access to advice as well as age-appropriate and disability-friendly information about sexuality, reproduction and family planning.



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<sup>2</sup> See Forum Sexualaufklärung und Familienplanung 1–2010 and 2/3–2001 on the subject of disability, sexuality and sexual assistance etc. [www.forum.sexualaufklaerung.de](http://www.forum.sexualaufklaerung.de) (ed.)



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