

Working together for siblings



FamilyTies quality circle

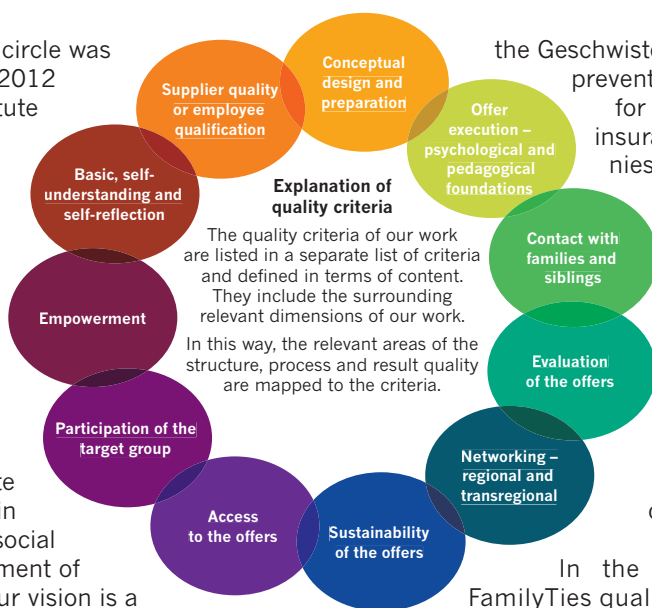
Guiding principle base for recommendations „from practice to practice“

Passing on the existing knowledge to others - this is what the FamilyTies wants the quality circle to be in future with recommendations „from practice to practice“. The committee is composed of institutions with many years of experience in the psychosocial accompanying of healthy siblings of chronically ill or handicapped children. Thus, the quality circle has developed to an interdisciplinary specialist body. Base for future activities is a common vision which has now been adopted.

The quality circle was initiated in 2012 by the Institute

for Social Medicine in Pediatrics Augsburg (ISPA) and the foundation FamilyTies. The 10 –15 members want to improve and promote the quality in the psychosocial accompaniment of siblings. „Our vision is a comprehensive coverage of siblings with needs-oriented, diverse and sustainable offers“, the mission statement says.

The members of the quality circle consciously position themselves as a psychosocial specialist committee – and thus delineate themselves from purely leisure activities. Important is the measurability of the effect of offers because transferable standards are indispensable for the sustainable financing of sibling services. This is proved by the certification of the two groups Supporting Siblings (SuSi) and



the GeschwisterTREFF as a preventive measure, for which health insurance companies can assume the costs (www.ispa-bunter-kreis.de). Both groups were able to build on the criteria developed by the quality circle.

In the future, the FamilyTies quality circle will contribute to an ever wider public awareness and a social presence of the special life situation of siblings, e.g. with his recommendations „from practice to practice“.

Through the work of the quality circle, all interested parties have access to a bundled expertise, which makes the quality of sibling faisable, verifiable and usable.

The concept of the Familienbande Qualitätszirkel as well as a list of the members can be viewed and downloaded at: www.stiftung-familienbande.de -> Über uns -> Qualitätszirkel.

Editorial

Dear friends of FamilyTies,

Who defines the quality of sibling offerings? Experts? Affected? Health insurance funds? Is an offer that works according to the prescribed quality criteria automatically higher quality than others? Is the psychosocial approach better than a pedagogical one?

There is no general answer to any of these questions. Offers must help especially the affected siblings and families. Whether an educational or other approach is the right one, a leisure offer or one that works contentually – decide who is concerned, where they feel more reserved to find a sheltered space. Transmittable offers with a verifiable effect on transparent quality criteria, however, have two important advantages compared to others: Firstly, standardized knowledge will be passed on, which will facilitate the development of new offers. Secondly, the offers have the potential to establish themselves in the long term and sustainably because they find a place in the health system.

FamilienBande wants the quality question to be discussed again and again from new perspectives. We are on.

At this point, we would like to take this opportunity to thank all those who have worked for the siblings' children and their families in 2016. We look forward to working with you in the new year.

Together for siblings!



Adib Jacob
Chairman of the
Novartis Foundation
FamilyTies



Irene von Drigalski
Managing Director
Novartis foundation
FamilyTies



Book of siblings

„Maybe rather differently“: what siblings think about experts

In the book „Maybe rather differently“ siblings from the age of 11 to 16 years are commenting quotes from the expert literature. The book is a collaboration of students of Social Work and Sonja Richter from the Langau Educational and Recreation Center.

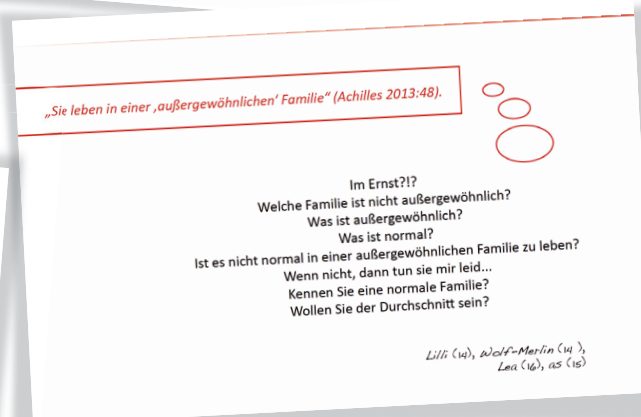


Sonja Richter

Research on sibling children is important. However, the opinion of experts does not always meet the understanding of those affected. The book „Maybe rather differently“ allows those who know how it is to spend the day with a handicapped sibling to speak up: the healthy brothers and sisters. Because it

is them who know how it feels when the talk is about a „special situation“ and for them everything is not as strange as the experts are describing their situation. In „Maybe rather differently“, the siblings comment, interpret and correct scientific statements on siblings and describe their live from their point of view.

„The idea for the commentaries is due to the fact that siblings are experts on their own behalf“, Sonja Richter says. During a week-long siblings' meeting, the young people were busy with the quotations and independently prepared their own opinions – in any case an interesting reading.



Quote:

„The children themselves experience the relationship to their disabled sibling as normal; Nevertheless, there are great differences to a sibling relationship between healthy children.“ (Haberthür 2005:21).

Reply:

That depends in my opinion mostly on the strength of the disability, since one with someone who is sitting in a wheelchair as a child can not do so much alone. In addition, the age difference plays an important role and the handicapped family member is nevertheless loved by all as much as the others. Bob (13)

For me it is natural that siblings hold together and help themselves in difficult situations in life. However, you will not find this, you cannot set on families with a disabled person! Let the pictures look like... Lilli (14)

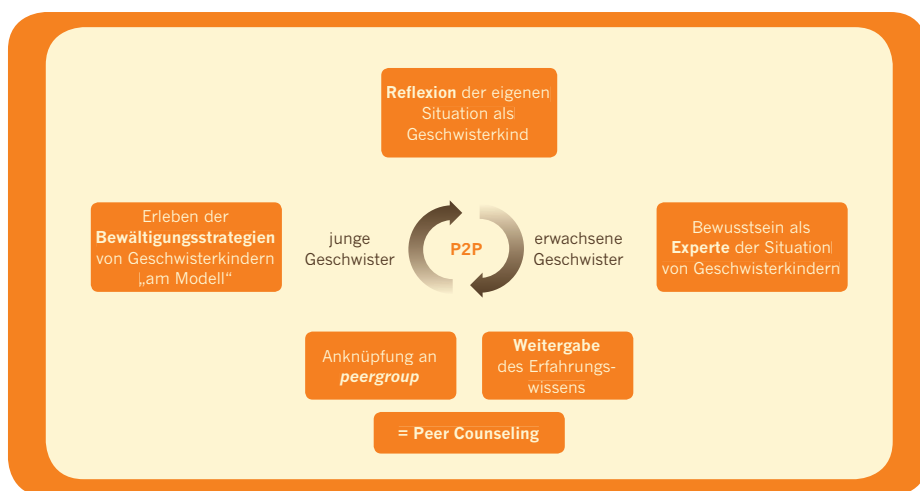
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Siblings for siblings

Peer2Peers- consulting

Enable young people and adolescent siblings to pass on their experiences to younger siblings - this is the goal of the project „Siblings for Siblings - Peer2Peers Consulting“. For this purpose, the University of Leipzig, together with the Association for Siblings, is developing a workshop program which, for the first time, systematically views the experiences of young and adolescent siblings in the long-term perspective. This work is supported by the Novartis Foundation FamilyTies.



The central guiding principle is the self-helpbased exchange of siblings „at eye level“ (peer-counseling approach). Siblings who need support are advised by siblings who have had similar experiences. These „peer-counselors“ can help to cope with psychosocial challenges based on their experiences and find solutions for upcoming problems.

The contact with those affected is a stimulus for all participants. Adolescent siblings are experts, their experience is honored in this way and harnessed for other interested parties. They are contact persons for young siblings, are their reflections, and provide strategies. The project is a win-win situation for all parties involved.

The target group of juvenile and adolescent siblings in the long-term perspective

In order to optimally prepare young and adolescent siblings, the first step is to gain scientific insights for this tar-

get group,^{2,3} there are few studies on the requirements for siblings of chronically ill or disabled children in the long-term perspective.^{4,5,6}

With detailed narrative interviews, the life situation of adolescent and adolescent siblings is examined years after diagnosis, treatment or death of a brother or sister in order to examine the requirements in the course of time and to show individual approaches to integrate the challenges as a sibling into a narrative of life.

This information forms the basis for the workshops in which young and adolescent siblings are to be prepared for their role as peer-counselor.

The workshop program should be available by mid-2017 and will be made available to the public.

You can find the bibliography to this article at:

www.stiftung-familienbande.de

-> FamilienBande AKTUELL 2/2016.

„Big“ FamilyTies Sponsorship Award 2016/2017

Soon the invitation for the FamilyTies Sponsorship award 2016/2017 will be launched. A novelty in the history of the „FamilyTies“ Foundation: We will merge the 2016 and 2017 awards to a „large“ prize endowed with € 15,000 and to be awarded on the occasion of the Fifth Anniversary of the FamilyTies expert meeting in June 2017 (see below).



Save the Date: FamilyTies Expert Meeting 2017

On **23./24. June 2017**, the 5th FamilyTies expert meeting will take place in Nuremberg. Please save this date already today. Further information can be found at www.stiftung-familienbande.de/fachtagung



Literatur-Tipp

Book tip from Marlies Winkelheide:

Do not get too close

From Erna Sassen



The novel portrays a special sibling relationship between two adult sisters – one with a mental illness and an eating disorder. It is about the degree of responsibility in a sibling relationship, self-determination and self-destruction, and a common

family history, which is handled differently. The key message is, that all is only about being seen and heard. No more and no less. The book portrays very sincerely a siblings relationship with very different life drafts. It is about letting live and letting go, but also about the joint, obliging connection.

FamilyTies website

Division and offer search: Thank you for your feedback!

With the FamilyTies search engine FamilyTies is offering support to specialists as well as to affected persons Following a survey, we have further optimized the expert area as well as the search engine in order to offer even more service for you as being an expert and make the offers for affected families even easier to find.

With now almost 300 offers for siblings and their families, the search engine is THE central element of the FamilyTies homepage. Here, offers and assistance for siblings, their relatives and specialist circles can be easily found. The offers can be assorted according to the type of the offer, the postal code or sorted by the place. To make offers appear in the search engine, the organizers of the offer must be registered in the expert area. So far 175 facilities have followed our call to register with their offer in the expert area.

In spring, we received overwhelming feedback from our members in the survey. There were many suggestions for improvement, which we implemented if possible. For example, we added two more categories to the original 9 categories that describe the type of the offer: „adult sib-ling“ and „family help“. This shows that the supply for siblings is becoming more diverse and individual. A further change concerns the preview of the offers: here, besides the title and venue of the offer we have added the disease focus and the age of the desired target group. This helps you to find the right offer even faster.

Always up-to-date: specialist area for experts

Institutions that wish to present their siblings offer in the offer search engine must first register in the expert area – a closed area for specialists. After successful registration, you will receive your login data from us, with which you can then enter your offer by yourself. In addition, we will keep you up-to-date with current expert news and



Die Angebots-Suche der Stiftung FamilienBande

important technical appointments. You can also use our documentation scheme. With this sibling offers can be documented quickly and effectively. You can then print and save your results. The aim is to use a „common language“ to standardize topics of the respective offers, and make their content and methods visible.

If you would like to register for the department and thus the offer search, you can do this at:

www.stiftung-familienbande.de/top-navigation/fachbereich

You can find help and offers in your area at:

www.stiftung-familienbande.de/angebots-suche



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We value your opinion!

Please let us know what aspects of FamilyTies NEWSLETTER you have enjoyed or what could have been done better. If you would prefer not to receive the newsletter, please send a brief e-mail to:
info@stiftung-familienbande.de

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