# The Early-Aid-System in Germany

Armin Sohns [1]
Annette Hartung [2]
Olaf Kraus de Camargo[3]

*Abstract*

*The authors give an overview of the history of Early Aid centers in Germany. The legislative basis for the services provided as well as the professional standards required to provide these services are explained. Changes in society and different needs of children today in comparison to the beginning of early intervention services are described with a case example illustrating the benefits of a family centred approach and interdepartmental cooperation.*

*Key words: Early intervention, policy, practice, Germany, complex aid*

## Families in need for support

*Mrs. W., a social pedagogue of an Early Intervention Center receives a phone call from Mrs. H. who works at the social service of the city. Mrs. H. wants to refer a four year old boy, L.K. for early intervention. She met the child and the mother the same day in her office on the occasion when Mrs. K applied for social assistance. Mrs. H. observed that the boy demonstrated behavioral problems, not being able to follow rules and seemed quite delayed in his language skills. On the phone, Mrs. H. has the impression that this child needs urgent intervention. Mrs. W. clarifies that such a referral needs to be initiated by the parents. As the mother is still in the office of Mrs. H., it is possible for her to talk directly with Mrs. W and initiate the referral process. Both agree with a home visit for the intake meeting during the following week.*

[1] Ph.D., Fachhochschule Nordhausen, Germany, (E-mail: sohns@fh-nordhausen.de)
[2] Ph.D., Fachhochschule für Gesundheit, Gera, Germany, (E-mail: annette.hartung@gesundheitshochschule-gera.de)
[3] Ph.D., McMaster University, Hamilton, Canada, (E-mail: krausdc@mcmaster.ca)

*Mrs. W lives with her two sons M. (12 years) and L. (4 years) in a condo located in the outskirts of town. The condo is doomed and will be torn down soon. Only two of the 16 apartments are still occupied. Many windows are broken, the area has an abandoned, ghostly aspect. When Mrs. W. arrives she is being expected by Mrs. K at the door. Although Mrs. K.'s name is not familiar to her, she recognizes the woman as one of a group of people, some of them homeless, that usually gather on the marketplace downtown. She seems to spend the major part of her days there. The apartment is in a neglected condition. Some of the cushions of the sofa are torn out, the broadloom carpet is full of dust that fills the air with each step. Mrs. K. points at L., who is hiding behind an armchair. Mrs. W. tries to approach him but he runs away and produces some unintelligible vocalizations. She tries to entice him with a toy that she brought with her and puts it on one of the chairs (she doesn't feel comfortable in putting them on the carpet). L. approaches her running, grabs the toy and throws it across the living room. Mrs. W. decides that in these conditions it will be difficult to create a stimulating play atmosphere. She spends the rest of the visit explaining to Mrs. K. all the forms necessary to initiate the early intervention and asks if L. is attending a kindergarten. Mrs. K. answers that this is not the case and Mrs. W. has the impression that Mrs. K. herself has own learning difficulties or even a mental retardation. Mrs. W. offers to look at the possibility of registering L. into a kindergarten, as he is due to enter school in the following year. Mrs. K. is in agreement with this. Mrs. W. asks, if any other „services" are involved at the moment with the family and as this is not the case she also offers to initiate an application for educational support at home. Mrs. K. is also in agreement with this suggestion and has no objection in involving the local children's aid society for those services.*

*In the following days Mrs. W. tries to find an adequate kindergarten for L.. She meets the staff of a nearby institution and they indicate to know L.: „he is frequently roaming through the neighborhood or the nearby industrial area and we saw him several times taking a nap lying in the ditch. He goes there probably when he gets tired." Nonetheless, this institution is not willing to offer a spot for L.. Eventually Mrs. W. is able to approach a kindergarten of the church and „talk them into" accepting L. in their institution at least for the next three months. Mrs. W. reconnects with Mrs. H. informing her about the solution and requesting an additional support for integration of L. in the kindergarten, a so called „integration placement". Mrs. H. denies that request based on the argumentation that in first place it will not be feasible to organize an additional support in such a short time frame and in second place, once the integration support is being granted, the early intervention will have to cease. As the early intervention is also home based and necessary for that family this would not be an desirable outcome. She suggests that Mrs. W. tries to arrange a continued „regular placement." Mrs. W. also calls the children's aid society and is informed that they are already aware of the case and that a social worker had been assigned to support Mrs. K. They agree on a case conference and decide that the social worker will focus in trying to find an adequate living space for Mrs. K. and her two sons to improve the hygienic conditions. Mrs. W.*

*will continue with developmental support and find a definite kindergarten placement for L.*

*In the following days L. starts attending kindergarten and is being seen there on a regular basis by Mrs. W. In the first days he struggles with the rules and hygiene (initially he has such bad body odor that he needs to be bathed at the kindergarten) but during the subsequent days the situation stabilizes. L. adapts to the daily routine of the kindergarten and mostly respects the house rules. He also increases his vocabulary and his speech becomes clearer. During the home visits Mrs. W. observes that L'.s 12 year old brother functions as the main caregiver. He frequently spends time with L., reading books to him (mostly about dinosaurs and sea creatures) and tells him stories („scary stories") he invents. L. is very attached to his older brother who is attending middle school successfully.*

*Mrs. W. is able to convince the kindergarten to maintain L.'s placement also after the summer vacation, as he will be going to school in the following year. The social worker is able to find a new apartment for the family and Mrs. K. moves into it with her two children. With the support of the social worker it is possible for Mrs. K. to maintain the new apartment clean. Nonetheless, she spends the most part of her days on the market place with her friends downtown, the care for the children occurs irregularly and she does not maintain a routine. Despite those conditions L. shows a nice progress in his development over the year and so Mrs. W. suggests that he should be placed in school as a regular pupil. She contacts the school authority but is informed that L. did not „pass" the admission exam and will have to attend a special school for children with developmental delays and other special needs. Mrs. W. explains the trajectory and the substantial gains that had occurred during the last year and convinces the school board to allow L. to attend a regular school with additional support, in a so called „diagnostic and support class" for children with less pronounced delays. She informs Mrs. K. of the „successful" discussion with the school board but Mrs. K. is not satisfied at all and insists that her son attends the special school for developmentally delayed children. The advantages she sees are the easy transportation (pupils are picked up and brought home by bus) and that school has a whole day schedule, providing care for L. also during the afternoons. Mrs. W. accepts the mother's decision and early intervention ends, as usual, with school entry.*

**The development of the legislative and institutional structure**

Today Germany is covered by a so called system of Early Childhood Intervention centres (=ECI of German "Frühfördereinrichtungen"). These centres offer family-centred help for children with developmental risks and their social environment. The law distinguishes two separate types of institutions within this system: the Interdisciplinary ECI centres and the social-paediatric centres (SPZ).

It was in the early seventies of the last century when the systematic development of institutions for Early Childhood Intervention was started. The creation of the social-paediatric centres (SPZ) is very often linked to the name *Hellbrügge*. Under his

leadership the first social-paediatric centre in Munich was founded in 1968 (Hellbrügge, 1981). The social-paediatric centres were planned to be supra-regional interdisciplinary ambulatory institutions of the health care system. In these centres teams of physicians, psychologists, pedagogues and therapists work in a hierarchical structure with a medical leadership. The recognition of this kind of health care service by German legislation took more time and occurred at the end of the eighties in the Fifth Book of Social Laws (SGB V). The care delivered at the social-paediatric centres is therefore a service paid for by the public and private health insurance companies.

The first ECI Centres were also founded in the early seventies (Sohns, 2000). The legislative establishment of these centres occurred after the „Recommendations of the German Council on Education" (Speck, 1973) that influenced the third law modification of the Federal Law for Social Services (BSHG) in 1974. This law launched the foundation of numerous regional ECI centres in Germany. They showed multiple professional concepts and approaches but tried to reflect and satisfy the recommendations of the Council in the interpretation of Speck: The Intention of these recommendations was to create more possibilities for joint learning of children with and without disabilities to achieve integration inside and outside of schools and beyond this to deliver aid in the early stages of development during which disabilities are first manifested trying to prevent a later segregation at school. Early Childhood Intervention was therefore understood as a service for social integration. (Speck, 1996)

In the following decades over 1000 ECI centres were founded in Germany and literally covered the country with a system of Early Childhood Intervention. The professionals were in the majority pedagogues that delivered help to the children with disabilities and their families giving advice about activities of daily living and special pre-school education of the children (psycho pedagogic approach). Following the recommendations of the Council on Education the help was delivered mostly home-based within the living environment of the children and their families.

The further development of the ECI Centres was accompanied by conflicts on the professional and political level. The Federal Law for Social Services established in §40 that the professional resources for ECI should be measures of "remedial pedagogy". In the consequence the financial resources for these measures had to be provided by the counties. Because of these circumstances the ECI Centres were urged by many counties to employ pedagogical professionals. Especially in the medical community this development was criticized. Even the "Deutsche Ärztetag" as the highest professional organisation of physicians in Germany formulated a resolution in 1976 against the establishment of the Early Childhood Intervention Centres: "Contrary to the recommendation of the ‚German Council of Education' to establish new centres with pedagogical focus the ‚Deutsche Ärztetag' recommends the expansion of existing medical institutions. This way the tendency to unilateral orientation of Early Childhood Intervention measures can be avoided. Concomitantly higher effects could be obtained with less costs" (Berufsverband der Ärzte für Kinderheilkunde und Jungendmedizin Deutschlands, 1976, 846). On the other hand the (pedagogical) Early Childhood

Intervention Centres opposed medical hierarchical structures (obligatory medical direction) as established in the social-paediatric centres.

It seems obvious that these discussions, characterized by professional distrust and mutual rejection, were not favourable in developing interdisciplinary co-operations. In regions where these co-operations did occur they were based on personal relations and mutual respect between persons of different professional groups, especially with community physicians.

After the legal recognition of the pedagogical ECI Centres in 1974 it took until 1988 for the legislation to recognize the social paediatric centres (Gesundheitsreformgesetz, 1988). After that long period of non-coordinated parallel the relation of these both systems was structured in 1992: The treatment in social-paediatric centres “should be focussed on these children that cannot be cared for by adequate physicians or adequate Early Childhood Intervention centres because of the severity or the chronicity of their illness or impending illness. The social-paediatric centres shall co-operate closely with the involved physicians and Early Childhood Intervention centres” (GStruktG Art.1, § 119 SGB V and § 4 FrühV).

For the first time an interdisciplinary approach in Early Childhood Intervention was required by the “Law of Rehabilitation” (Rehabilitationsgesetz, 9th book of Social Laws, SGB IX) of 2001 and the “Ordinance of Early Childhood Intervention” (Frühförderungsverordnung FrühV) of 2003. By these laws Early Childhood Intervention Centres and SPZ are the only institutions who can offer Early Childhood Intervention measures. On an organisational level the SPZ are seen as supra-regional institutions (tertiary care) and the ECI Centres as local/regional institutions. Both must employ an interdisciplinary team.

Today the (home and centre based) system of ECI is composed by about 130 SPZ and about 1.000 Early Childhood Intervention Centres. In the SPZ the interdisciplinary teams have mainly a diagnostic focus, but are also able to offer long-term centre-based care. Some of them also offer in-patient care (social-paediatric hospitals). On the other hand these centres are not able to offer home-based care. That means that the parents are obliged to take their children to the centres and sometimes endure long trips to receive adequate help. In second place the professionals at these centres have no possibility to evaluate the impact of environmental factors upon the functional health of their patients. The financing for these services is provided by the public health insurance.

In opposition to the SPZ the regional system of ECI centres is working as well centre-based as home-based. In most cases home-based means the actual home of the child, but in many centres (especially in East Germany) it also means working with the child in kindergarten. Traditionally in East Germany before 1990 the kindergartens were considered the main social environment for children. While the share of home-based care reached about 80% in 2000 the ongoing financial cuts reduced it to about 50% in 2008 (Engels et al., 2008). This means in the consequence that parents are increasingly

obliged to take their children to the centres. In opposition to the social needs and scientific evidence an environmental-based approach is being continuously sacrificed by the financing institutions. These are in the case of ECI the counties. They are traditionally responsible for the pedagogical professionals. Accordingly the ECI Centres had hired mainly pedagogues. But due to differences between the states in the federal system of Germany one can also find ECI with interdisciplinary teams. In those the medical therapeutic professionals are mostly financed by the health insurances. In two of the 16 states ECI is integrated in SPZ and therefore does not offer home-based care. In one state the ECI Centres are mostly associated with remedial schools. Despite of the federal character of the law of rehabilitation (2001) it has not been possible to harmonize the regional differences.

**The development of professional standards in ECI**

Accompanying the legislative development and the establishment of a financial basis for ECI institutions the last decades were marked by an intensive development of professional standards leading to important paradigmatic changes in the approach of children with disabilities and their families.

While in the early sixties and seventies of the last century this approach was based on the belief that disabilities may be compensated by intensive therapeutic interventions with the intention to „cure“ or „heal“ the disability (bio-medical concept), this view underwent major changes during the eighties (Rauh, 1985; Schlack, 1989). And while the former view was characterized by "technocratic and function-oriented therapeutic approaches" (Weiß et. al., 2004), professionals as well as parents felt uncomfortable with the strict separation of experts on one side and lay parents on the other side implied with that approach. This distribution of roles implied that parents had to follow the expert advices and were reduced to mere "co-therapists“ for their children (Holthaus, 1989). The technocratic approach was further challenged by the results of scientific research about the effects of therapeutic interventions in developmental disorders. These results can be summarized as showing very little effects of strict one-dimensional functional approaches but more promising results of approaches that were environment-based and individualized (Weiß et al., 2004). Following this philosophy the professional standards of former "Early Childhood Intervention" were developed to approaches that can better be described as "Early Aid" (in the following partly replacing the term ECI). They are characterized by a strong interdisciplinary and transdisciplinary work allowing an ecologic-systemic approach. Following the original aims of the legislation ("social integration“, German Council of Education) (Speck, 1973) an social-environment-centred system of Early Aid could be established (family-centred and kindergarten-centred).

The core principle of that approach is the recognition of the advantage of holistic procedures over uni- or multi-disciplinary therapeutic "interventions“ that do not take into account the family system and the environment of the child. Especially in the first phase of confrontation with the disability of their child parents are insecure, often shocked, experiencing feelings of being offended, blamed and ashamed. Associated with

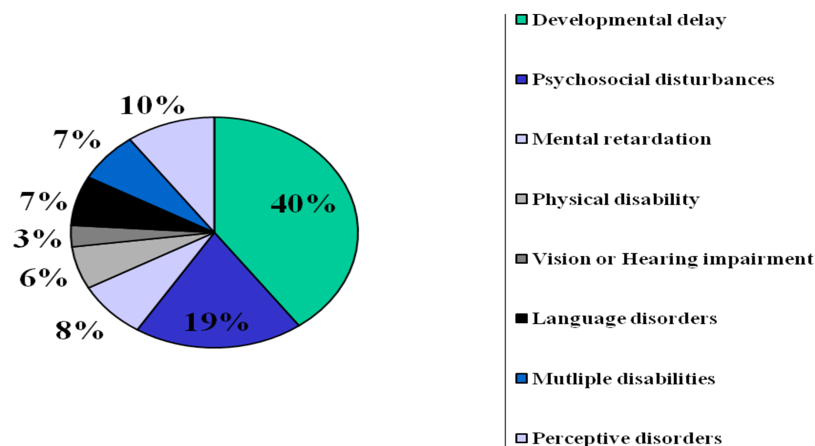
that emotional stress is the burden of the intensive daily routine of special care for the child, additional administrative issues and the many appointments filled with therapies or diagnostic procedures. The social context in many cases also suffers transformations. Less family members and friends tend to be available for help and support (Sohns, 2000). On the other hand the traumatized parents often hesitate to request professional help to deal with the many problems they are facing (Sohns, 2000). In such a situation it is in the interest of the child that the whole family – and in certain cases even other professionals involved with the child – receives support of professionals that can deal with the many emotional aspects of the special situation the family is living and offer appropriate information and advice.

On the contrary to the historic approach based on the role of parents being co-therapists receiving 2 orders“ from experts and having to “comply“, this new approach respects the autonomy of the child and the family. The responsibility for the actions to be taken remains within the family. Thus the family members and the child continue to be the “initiators“ based on the knowledge that self-initiated actions tend to be more productive and show longer lasting effects than externally imposed actions. In Early Aid the professional measures are therefore always aimed to support the initiative of the child and the family. This principle has been coined with the expression “Aiding for Self-Aid“

**New demands resulting of social transformations**

The necessity for such a transformation of professional standards derives also from the modifications of the kind of disabilities or indications for granting Early Aid. In the beginning the majority of children receiving “ECI” had “classic disabilities“ in the sense of structural or functional defects or disturbances (Sohns, 2000). The percentage of children attended with these disabilities has been shrinking continuously over the last decades. The last epidemiological survey regarding Early Aid in Germany in 2001 analysed all institutions offering Early Aid in one state (Mecklenburg-Vorpommern) and can be considered representative for the German federation:

*Graph 1.* Epidemiological Survey on Early Aid in Germany 2001



Graph 1 shows that children with physical, mental and multiple disabilities comprise only 20% of all children. The majority are children without clear-cut diagnoses. Nonetheless these children and their families are without doubt in need of support and care. In many of these cases it is still difficult (also due to the young age of the children) to decide if the cause of the disability is organic, if the child shows initial symptoms of a mental retardation or if the difficulties are due to environmental factors delaying or inhibiting the development of that child. Therefore it is important to concentrate on the resources available in each child and each family and try to establish situations and attitudes that foster a healthy development.

To achieve this it is not sufficient to work only with the knowledge and the techniques of remedial pedagogy. Other qualifications become necessary and the knowledge of many disciplines is needed. In response to these requirements many Early Aid centres in Germany developed an interdisciplinary system of professionals working in teams, assuring this way a continuous cooperation between professionals of different disciplines (medical, pedagogic, psychological and therapeutic). In the actual legislation regarding rehabilitation (law of rehabilitation) all of the following and above discussed aspects can be found and are required for institutions of Early Aid: interdisciplinary, a holistic approach, social integration as a major goal and a preferred focus on preventive approaches (Sohns, 2002).

Many children that are identified during medical, psychological or educational assessments as “developmentally delayed“ do not present initially with all the possible contributing factors to that delay, especially when the environmental conditions are not known. Educational diagnostics is therefore always oriented towards the underlying conditions that may influence the development of resources for these children. To have this information it is always necessary to observe the development of the children in the follow-up: *Only after being admitted to the kindergarten and receiving early intervention, L. was able to show his potential and develop further. It also revealed the limitations of the different systems of their abilities to support him. On one side, his home and living conditions explain why, although probably having an average intelligence, L. was so behind in his language development. On the other side, this case example cannot explain why his older brother developed so differently; did he grew up in different, still more favorable conditions or is he more resilient or has he been assessed by different specialists at school entry that provided him with more adequate support?*

The above mentioned story is an example demonstrating which professionals can be involved in the support of a family with a vulnerable child and also which systems issues might arise in the collaboration of the involved professionals.

It also illustrates how developmental trajectories can be determined by system rules and conditions. If it were the case that in Germany not only schools for children with special needs offer full-day schooling but also the regular schools, the probability that L. could have attended a regular school would certainly have been greater. On the other hand, in

the case example many parties are quite satisfied with the schooling decision: The regular school is relieved in not having to care for another “difficult“ child, the special school is able to demonstrate demand and therefore the reason to continue existing and being funded and the mother is satisfied as the solution is more convenient for her own limitations and lifestyle.

This example also illustrates how early intervention and social work are closely related with each other. We observe a growing number of children growing up in social disadvantaged conditions, parents having to cope with higher demands on education, care and fostering of their children in an environment that at the same time has become much more restricted in developmental possibilities for children. Parents, and especially those with lower education, find themselves increasingly isolated in trying to tackle the modern demands on parenting skills while living without the relationship of a multi-generational family or the support a traditional village or ward structure would naturally offer. Many of them feel overwhelmed. It is necessary that early intervention measures take such constellations into account and offer support to address especially those social issues. Possible ways of support could be in empowering parents in their competence to request additional services as social work, daycare or kindergarten placements. In some case, as shown in the above example with L., certain tasks have to be assumed temporarily by a professional. Early Intervention encompasses therefore are broad field of activities and tasks.

**The different tasks of Early Aid and the difficulties in realising them**

According to the holistic approach several different tasks have to be achieved by the interdisciplinary team. It starts with the important aspect of *Early Identification* of children in need of Early Aid, according with specific developmental risks. Different approaches are used to identify these children. The majority is seen during the regular developmental screenings performed by family doctors and paediatricians. If they suspect of the need of further diagnostic interventions they can refer the children to the SPZ or Early Aid-centres. Unfortunately the access to the SPZ is hindered by long waiting lists (up to one year) and in many regions there are great distances to be covered by families without much financial possibilities. The access to the Earl Aid-centres is dependent on the clearance of the request by social administration, and to the physicians of the public health service. Especially families from social disadvantaged segments of society are quite reluctant in complying with these formal requirements as they feel stigmatised by them. Therefore it has been proposed and formulated in the law of rehabilitation that the access to first visits in Early Aid centres should have a low threshold and allow worried parents to get help without bureaucratic barriers. The financing of such an “easy-entry“ still awaits a solution.

Another task is the *diagnostic part* in the process of Early Aid. Dependent on the individual circumstances and reported difficulties different professionals assess the child and the family. One of the professionals assumes the position of contact person with the family and gathers the results of home visit, interviews and assessments. After the conclusion of that part the interdisciplinary meeting takes place. In that meeting the

desires and needs as well as the results of the professional assessments are discussed and result in an individualized planning of aids and therapies for child and family. This procedure should be oriented by the International Classification of Disability, Functioning and Health (Kraus-de-Camargo, 2007; World-Health-Organization, 2007). The finished plan has the function of a contract between the family and the Early Aid Centre, establishing goals to be achieved and the methods on which has been agreed on.

As the realization of the plan often requires the contact to other institutions and administrative organs as well as professionals outside the Early Aid centre it is important that the interdisciplinary team coordinates these contacts and cares for them in a network of cooperation. This *regional networking* is also an important task to guarantee an efficient work and should be supported adequately by the financing organs.

Regarding the methods, *intervention and education* of the child have the same status and importance as *advice and support* to the parents or other related persons. It is still very common that financing organs expect that aid should be a specific intervention performed on the child, oriented by the deficits that have been diagnosed and willing to pay only for these procedures that took place in presence of the child. This attitude turns it difficult to offer help to the families in a more flexible manner and according to their necessities. Especially with regard to the increase of children with developmental disorders or so called “behavioural problems“ from social disadvantaged families it might be really more efficient to counsel the parents and other contact persons than to stigmatise the child as “disordered“ offering “therapy“. Another example could be parents in the period immediate after being informed about a significant disability or chronic illness of their child. It might be more efficient in the long term to invest in counselling of the parents in this early phase than to deliver several intensive developmental therapies. So, regarding the task of *taking action*, it is desirable that a high flexibility in offering the most urgent help, as seen by parents and professionals, is possible.

**Development of a "complex aid" - present and future issues**

The law of rehabilitation introduced the legal term of a "complex aid". The intention of this expression is to describe the complex interdisciplinary cooperation between pedagogic and medical-therapeutic measures necessary to support children with disabilities and their families. It offers the chance to develop more effective and more individualized approaches for the growing number of children with developmental risks. As many of these children grow up in social disadvantaged situations it will be necessary to take the findings of neuropsychological research regarding resilience and vulnerability into account. On the other hand the institutions of Early Aid are facing the challenge of restrictive financing and unmotivated feelings of different professionals competing one against another instead of cooperating. It will be necessary that the interdisciplinary teams learn to develop transdisciplinary competencies to face the challenges ahead. At the moment many of them are still working as multidisciplinary teams with many different professionals in contact with one child or one family. With an increased transdisciplinary competence it will be possible to reduce the number of

contact persons per family but it will be necessary that the team cooperates more closely and the different professionals support one another.

The practical experience of how the administration of the districts/counties (responsible for financing pedagogic support) and of the health insurance companies (responsible for financing medical-therapeutic aid) are complying with the law since 2001 is disappointing. It seems that administrative organs face great difficulties in developing a financing model incorporating these classical distinct types of aid. The primary interest seems to be to delegate the maximum of responsibilities to the other administrative organ instead of cooperating one with another. Professionals and experts for Early Aid have not been invited to take part at any of the official meetings that were held at administrative and political level to discuss possible solutions for the financial questions. In 14 of the 16 states could be agreed upon a so called "framework of agreement" for financing this "complex aid". The content of these agreements shows in the majority of cases a great distance to what was the original intention of the law. They propose multiple diagnostic procedures, hinder the interdisciplinary cooperation and do not finance the important aspect of counselling and supporting the parents. But at least these agreements achieve a more formal cooperation between pedagogues in Early Aid centres and the family physicians. In those states (Bavaria and North Rhine-Westphalia) where are already practical experiences with the framework agreements (in terms of formal contracts between Early Aid centres and the social administrations of the counties and health insurances) the Early Aid centres are suffering massive financial cutbacks, reduction of the family centred work (Bavaria) or lack of financing qualified professionals (NRW). Among the professionals the hope persists that with a broader application of the "complex aid" the structural and financial demands will show more clearly that corrections can be made to the framework agreements to allow an adequate financing of the good intentions reflected in the law of rehabilitation. In the near future it might be necessary that the federal government takes responsibility for the law it created specifying more precisely the administrative cooperation between social administration and health insurance.

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