



Children with heart disease at school

Information brochure for parents and children

Updated
Edition
2021



www.bvhk.de

**Bundesverband
Herzranke
Kinder e.V.**

**Federal association
for children with
heart disease**

Imprint

Publisher

🏠 Bundesverband Herzkrankte Kinder e.V. (BVHK)
Vaalser Str. 108
52074 Aachen

📞 0241-91 23 32
✉ info@bvhk.de
🌐 www.bvhk.de
🌐 www.herzclick.de
📘 facebook.com/herzkrankte.kinder
📺 youtube.com/bvhkde
📷 instagram.com/bvhk.de

Editorial team

1st edition: Lawyer Anja Bollmann, Bergisch Gladbach as well as Anke Niewiera and Hermine Nock, BVHK, Aachen
4. Edition: Hermine Nock

Translation

Ethno-medizinisches Zentrum Hannover

Design & typesetting

Andreas Basler / www.andreasbasler.de

Cover photo

FilippoBacci - iStock

Print

Heider Druck GmbH, Köln

Editions

Editions in German:
1st Edition 2012, 5000 copies,
Funded by DAK
2nd Edition 2014, 5000 copies,
Funded by BMG
3rd Edition 2017, 5000 copies,
Funded by Techniker Krankenkasse
4th Edition 2021, 5000 copies

Editions in English:
1st Edition 2022, 5000 copies,
Funded by AOK

Reprints, including excerpts, only with the express permission of the publisher. All rights reserved © BVHK 2021

Note

Names of persons

In the case of persons such as doctors or nurses, we always use the masculine form for ease of reading. Of course, this refers equally to women and men.

Copyright

Picture credits for externally purchased pictures are listed in the respective articles directly on the pages. We pay careful attention to compliance with image credits. Should you nevertheless find an insufficiently labelled image, please inform us. We will then correct the proof as soon as possible.

Donation account

Bank: Sparkasse Aachen
IBAN: DE93 3905 0000 0046 0106 66
BIC: AACSD33



Our association is recognised as a non-profit organization (register of associations, district court Aachen VR 2986) and was awarded the DZI donation seal for its verifiable, economical and statutory use of funds.

Funding

The BVHK would like to thank AOK-Bundesverband GbR for its financial support!



Inhaltsverzeichnis

I. FOR PARENTS

1.	Our child with heart disease in everyday school life: accepting limits	4
2.	Basic requirements for successfully accomplishing everyday school life	4
3.	Which school suits my child?	5
4.	Inclusion - one school for all	7
4.1	What is the difference between integration and inclusion?	7
4.2	The long road to joint teaching	8
4.2.1	Special schools	8
4.2.2	Teaching in the context of inclusion	9
4.3	Concrete support for inclusion in the class group	9
5.	Social law basics	10
5.1	Special educational needs	10
5.2	Lessons with common learning target versus lessons with different learning target	11
5.3	Compensation for disadvantages	11
6.	Sport makes you strong	12
6.1	Assessment of resilience	12
6.2	Balance between extremes	13
7.	Excursions and class trips	14
8.	How can you prevent something from happening or from getting stuck in the emergency chain?	15
9.	Conclusion	15

II. FOR YOUNG PEOPLE - On the way to a career

1.	How do I find „my“ profession?	16
2.	Career guidance	17
3.	Training or study?	17

III. EXPERIENCE REPORTS

Daniel: Many detours in the search for the „right“ school	18
Nico: The model of cooperative teaching - An alternative to inclusion?	20

Checklist for teachers/educators	24
Addresses - Your local contact	26



I. FOR PARENTS

1. Our child with heart disease in everyday school life: accepting limits



You have a child with a congenital heart defect. You may have to say goodbye to certain life plans and this is associated with a kind of grieving process. Depending on the impact of the condition, this situation can be very challenging for the whole family. You want the best for your child, but sometimes you struggle to make that happen. Perhaps you have not yet found the right balance between granting autonomy and consistent parenting.

Your child with heart disease must learn to accept his or her possibly lower performance and to deal with it in a self-confident way. Help ensure that classmates understand his behaviour, accept his „special role“ in certain situations and support him if necessary. Your child should be able to give and accept help. With mutual acceptance and tolerance as well as the willingness to learn from each other, „real“ integration can be achieved.

2. Basic requirements for successfully accomplishing every day school life

The entire social environment is decisive for successfully dealing with the congenital heart defect, i.e. not only you as parents, but also the school and peers. The following has a particularly relieving effect:

- » Constructive approach, e.g. viewing the disease as an element of everyday life that can be managed with support.
- » Support from the social network, from relatives (e.g. grandparents), acquaintances (e.g. neighbours) and professionals (e.g. teachers)
- » Realistic assessment of the prognosis
- » Sensitive, but also consistent parenting behaviour that enables the sick child to grow up „normally“ to a large extent.

3. Which school suits my child?

There is a wide range of school types that offer different school programmes and support options depending on the federal state.

The implementation of the UN “Convention on the Rights of Persons with Disabilities” (CRPD) falls far short of the requirements. Therefore, some parents still want to make use of their right to choose and consciously decide in favour of a special school (Förderschule) with a high number of qualified special educators or specialized teachers and the corresponding equipment. These special schools, which are usually located far away, often offer disabled children very individual support in small classes by specially trained teachers. This is not always and everywhere sufficiently guaranteed in inclusive regular schools close to home, even since the CRPD came into force.

When considering this, bear in mind that the previous circle of friends from the neighbourhood usually goes to the regular school „around the corner“ and that social contacts can otherwise only be maintained in distant special schools with great effort. With the help of integration aides and / or disadvantage compensations, the desired equality of opportunity for impaired and non-impaired children in the inclusive regular school can be supported. Under certain conditions, disabled children do not have to be taught at the same level as non-disabled children, but are prepared for a different school-leaving qualification with the help of special support plans (target-differentiated teaching).

Be open about your child’s heart condition when registering. Do not conceal or play down your child’s limitations or needs so that the teachers can deal with them appropriately. For your child, the illness is another facet of his or her biography, a possible stress factor to be dealt with in addition to the general, age-specific developmental tasks. At school, your child should experience as much consideration as necessary, but also as much normality as possible. With the help of this brochure and the brochure „Sport macht Stark“ (sport makes strong) you can inform the different subject teachers of your child yourself.





Background information

Inclusion (at school) is a political decision according to which the Common Education (Gemeinsamer Unterricht, GU) is seen as an overarching value. Therefore, everything else, including the proof of its effectiveness, has to take a back seat. Positive results usually only come from particularly well-equipped model schools. The rehabilitation scientist Bernd Ahrbeck (2011/12; p.33), who is critical of inclusion, quotes Huber (2009, p. 243f.) in this regard: „overall, no evidence can be found for a positive effect of the heterogeneous learning group on social integration in inclusive education practice“. Furthermore, he states: „the additional performance gain [especially of children with learning disabilities in regular schools] is bought by higher psycho-social burdens“.

Parents should be guided in their decision for the „right“ school by the idea of where their child can be individually supported best. This may not be politically correct and some associations may not like it since it can delay the implementation of inclusion, but it may well be in the best interest of the individual child to choose a special school even today. Furthermore, possible regular schools should not only be judged on the basis of the school concept („paper is patient“), but you as parents should get a direct insight into the work on site, e.g. through an individual observation beyond the „open day“.

Source: Ahrbeck, B. (2011/12, 2nd issue). Der Umgang mit Behinderung. Stuttgart: Kohlhammer.



© maxinkabb - iStock

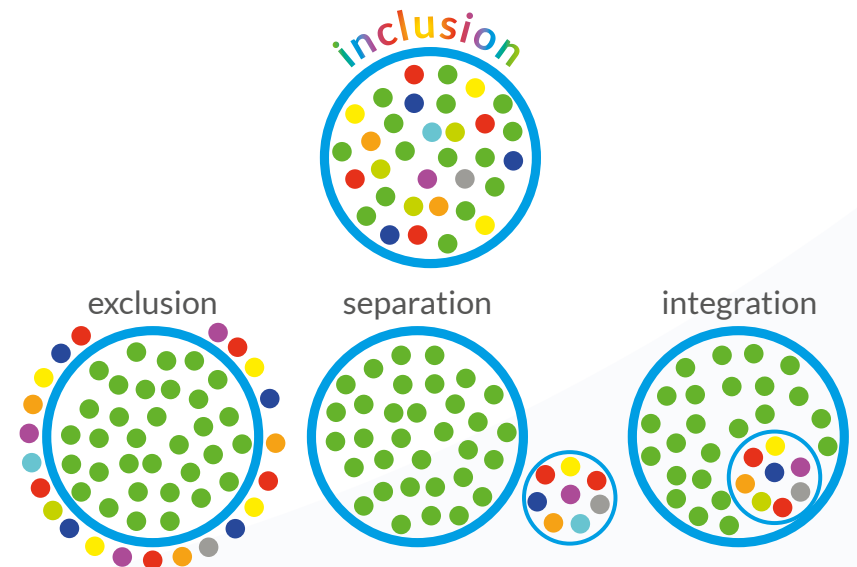
4. Inclusion - one school for all

4.1 What is the difference between integration and inclusion?

The Convention on the Rights of Persons with Disabilities (CRPD) regulates the rights of disabled people to self-determination and equal participation in the society. This includes the right to education without discrimination and with the certainty of equal opportunities..

The original English text of the CRPD consistently uses the term „inclusion“, while the German translation is „Integration“. This is often criticised as confusing because the concept of integration is outdated compared to that of inclusion:

- Integration provides for the incorporation of the disabled person into an existing system.
- Inclusion sees him or her from the outset as an equal part of the society to which the institutions must adapt and not vice versa



„Inclusion means: all are equal and all are different, none is excluded.“

(Ines Boban/Andreas Hinz)

Source: <http://www.down-syndrom-rheingau-taunus.de/index.php?id=7>



4.2 The long road to joint teaching

4.2.1 Special schools

With the introduction of inclusion, there should no longer be a school form that is exclusively available to disabled children with special educational needs and thus results in the targeted segregation of these children. The existing special schools should also be actively involved in the further development of inclusion and no longer exclusively teach children with disabilities. Many special schools have already developed concepts with which they do not have to give up previous support standards and yet open up their type of school for inclusion. For example, adapted to the possibilities of their handicapped children, they have established cooperation with neighbouring regular schools. Through joint working groups (AGs), mixed homework supervision and more extensive support for individual special children at the regular school, the „extent of inclusion“ is aligned with the needs of handicapped children.

The previous concepts of being able to teach 9-16 children in small classes can be retained and thus continue to accommodate children with special needs who often require much more attention.

In most federal states, parents of children with disabilities are entitled to a free choice of the type of school for their child. So

far, within the framework of inclusion, special schools with a focus on „physical disabilities“ and „mental disabilities“ have been maintained in large parts of Germany. Special schools with focus on „learning“, „language“, „emotional and social development“, „hearing and communication“ and „vision“ have already been greatly reduced or completely closed in some regions. The complete abolition of special schools is being sought by some state governments.

Children who have an intelligence impairment in addition to a congenital heart defect are often particularly sensitive and quickly overwhelmed. The slow introduction to learning in small classes of a special school can be a great relief for them at the beginning of their schooling. The aim of special schools is to transfer children to general schools during their school career.



© m-gucci - iStock

4.2.2 Teaching in the context of inclusion

Inclusion is based on living and learning of all children in a general school. This means that even a child with learning difficulties who has not been assessed in the „AO-SF“ procedure will receive an individual support plan. This means that children with mild learning difficulties and partial performance disorders such as dyscalculia, reading and writing disabilities or dyslexia are also supported without a procedure to determine special educational needs (AO-SF) having been initiated. This appears to be relevant for a relatively large proportion of children with heart conditions. This is because they sometimes do not perform well enough for normal regular schools, but „learn too good“ for special schools and are therefore caught between the two school systems. The AO-SF procedure continues to be used in order to better support children with special needs without giving them a special position in the class.



© dolgachov - iStock

4.3 Concrete support for inclusion in the class group

With simple help, you and the teachers can make it easier for your child with heart disease to find and keep „his/her place“ in the class. If necessary, clarify the following possibilities with the school for relief:

- » The timetable should ideally be arranged in such a way that your child has short distances and as few steps to cope with as possible.
- » With a second set of books, your physically restricted child does not need to lug a heavy school bag back and forth between school and home.
- » You or your child with heart disease may ask some of the classmates e.g. to take over the transfer of the school bag when changing classrooms.
- » Perhaps your child can use a lift if he or she finds it difficult to climb stairs?
- » Special examination conditions can be agreed upon for children with poor concentration or slower learning, e.g. more time for class work or other tasks in sports (see p. 25 point 5.3 Compensation for disadvantages).
- » If your child has been absent for a longer period of time due to illness, classmates as well as teachers can pass on the most important information about the subject matter or homework.
- » In the case of long inpatient stays, school children can be taught in a „School for the sick“ inside the clinic and the home school transmits the learning material during the stay in hospital. It is also helpful for sick children to have video links, letters or phone calls from their classmates so that contact does not break off.



5. Social law basics

5.1 Special educational needs

Children with a particularly high need for individual school education are also entitled to special educational needs in inclusive education. This special educational support supplements the general school support for children with and without disabilities. According to the recommendations of the Standing Conference of the Ministers of Education and Cultural Affairs of the federal States (KMK), special educational needs are to be assumed „for children and young people whose educational, developmental and learning opportunities are so impaired that they cannot be adequately supported in lessons at general schools without special educational support“.



© kallig - iStock

Special educational needs are determined by the preparation of a report. In many federal states, the so-called AO-SF procedure can only be applied by the parents. The teacher often gives the indication of the child's special support needs. Within the AO-SF procedure, the focus of support, the learning goal and the attainable school-leaving qualification are determined. The form of special educational support depends on the possibilities of the local school and the support needs determined in the report. Children with special educational needs can choose between admission to a special school or participation in inclusive education. The content and form of the special needs assessment and the report should be agreed upon by the parents in close cooperation with the school. The report makes it possible to closely follow learning goals and special needs, and is intended as an aid for teachers, parents and the child. It is updated at the end of each school year / school semester and can also include a change in the focus of the support or learning goal. Upon request, parents will receive a copy of the updated report at any time during the school career. They are informed regularly, at the latest with the report, about the focus of the support, the intended school-leaving qualification and whether a change of the school form from inclusive to special school or even the removal of the need for support is recommended.

In some federal states, a distinction is made between individual need for support, special educational as well as special need for support. In the case of so-called partial performance weaknesses, such as difficulties in learning to read or spell, there is usually no special educational need.

The individual / special support of children with partial performance weaknesses is determined and implemented by the regular schools, e.g. through promotional lessons.

5.2 Lessons with common learning target versus lessons with different learning target

Children with special educational needs can be taught at special schools or in inclusive classes with the methods of common or different learning targets. If children with disabilities are taught according to the same curricula and learning objectives as children without disabilities, there is equality of learning targets. This is especially true in the case of physical disabilities without cognitive limitations. For teaching children with learning or mental disabilities, other learning goals are agreed upon within an AO-SF procedure in order to strive for realistic school-leaving qualifications and to avoid excessive demands. Children who receive "different learning target" lessons do not always receive a report with grades, but a text report or a text supplement to the report. Their educational goal can be, for example, a lower secondary school leaving certificate (Hauptschulabschluss) after grade 9, a LB certificate (learning disability) or also no school leaving certificate.



© xavierarnau - iStock

5.3 Compensation for disadvantages

People with disability-related disadvantages, e.g. at school, university or work, according to § 126 SGB IX (Social Code), are entitled to so-called disadvantage compensation. This does not represent a reduction in professional requirements and thus no preferential treatment.

If you would like to claim disadvantage compensation for your child, please contact the class teacher and, if necessary, the school administration. In the case of final examinations, the school must apply on time to the district government for disadvantage compensation - the deadline may even be November of the previous year. Specific examples of the measures to compensate for disadvantages in terms of lesson organisation, examination procedure and methodological support can be found in Part I for teachers in chapter 4.2. from p. 9 et. seqq. and in detail at www.bvhk.de. It is best to go through this list to see which measures could be helpful for your child; this can be an important basis for an appropriate discussion with the teacher. For children who are slow learners as well as those with poor concentration, special examination conditions can be agreed, e.g. other tasks in sports or more time and/or breaks during class work.

Compensations for disadvantages are not linked to a special educational need for support. All support instruments can be combined with each other in all forms of teaching. This also applies, for example, to the involvement of an integration assistant.



6. Sport makes you strong

6.1 Assessment of resilience

Children with minor residual findings (mostly mild heart defects such as small defects of the atrial or ventricular septum or mild valve defects) can participate in school sports essentially without restriction.

On the other hand, in children with severe heart defects

- » who still have residual findings after surgical correction
- » with cyanosis
- » problematic long-term therapy (e.g. anticoagulants) or pacemaker

special considerations for cardiac stress during sport lessons are necessary.

Just very few children with heart disease tend to exceed their physical limits and thereby put themselves in danger. Children with congenital heart defects should be especially trained in the conscious perception of the body's stress reactions so that they can competently, independently and confidently take over their own pressure control. They should be explicitly asked to decide for themselves when to take breaks during physical activity. If your child succeeds in an appropriate self-assessment and takes responsibility, this means a great relief for their teachers. This also reduces the risk of misjudgement in both directions: overloading by ignoring symptoms of pressure as well as undercharging by overprotection.

Performance and competitive sports are taboo for many children with heart disease. In such lesson units, dedicated teachers assign other important roles to children with complex heart conditions (e.g. referee, timekeeper) and allow them to take breaks when necessary.

Especially in the case of cardiac arrhythmia or severe oxygen deficiency (cyanosis), teachers should be informed exactly what to do if the heart is racing, for example (allow the child to retreat or normalize the heartbeat through forced breathing) or stumbling.

You can optimize the flow of information by releasing the paediatric cardiologist from the obligation of confidentiality so that direct contact with the teachers is possible.



© Ben Gingell - iStock

6.2 Balance between extremes

Children with heart disease are sometimes kept away from sports to spare them. As a result, they are often unsteady, clumsy and develop motoric deficits. In our brochure „Sport macht stark“ (Sport makes strong), you will find important information about what to bear in mind with regard to sport for children with a congenital heart defect (www.bvhk.de).

The behavioural spectrum of (sports-) teachers towards children with heart disease is diverse. It ranges from insecurity and fear with the endeavour to exempt the child from physical education or to keep the child away from all offers of school sports as far as possible, to completely ignoring existing restrictions. With good will, creativity and using the available educational discretion, an appropriate middle ground can be found between the two extremes. In this way, children with heart disease can be successfully supported in their motoric abilities and well integrated into sports lessons.



© etrenkova - iStock



7. Excursions and class trips

Already when choosing the destination, you should inform the teachers exactly what your child with heart disease is able and what he is unable to do. Exciting activities (roller coaster) mean too much risk for some children with heart disease. Long walks or physically demanding activities are unsuitable for children who are limited in their abilities due to heart defects. With a little imagination and consideration, joint activities are quite possible; often small individual adjustments are enough.

The teachers should know whether and which medication your child has to take regularly.

If he/she can do this independently and reliably at home, he/she does not need the teacher's help. If the teacher has to remind or support your child, inform him or her in good time before the trip. Give the medicine in individual doses and label them so that your child always knows whether he/she has already taken the daily ration or not.

If your child needs blood-thinning medication: you as parents allow your child much more freedom and leeway

if you practise INR self-monitoring (measurement of the blood clotting value) with him or her early enough using a so-called "coaguchek" device. The device is paid for by the health insurance in case your doctor has applied for it and you have received a referral. Your child can then measure his or her value on his or her own and assess whether and how much Marcumar® (or comparable blood-thinning medication) is necessary.

Children suffering from oxygen deficiency should not travel to mountains (higher than 1,700 metres above sea level). For planned air travel, please consult your paediatric cardiologist.

Approach anxious, overprotective teachers, talk to insensitive teachers. If this has no effect, involve your paediatrician / paediatric cardiologist and, if necessary, the school administration. To do this, you must release them from their medical confidentiality obligation. Open and intensive cooperation as well as specific clarification will help the school, your child and you to create a successful school time without tension.



© Liderima - iStock

As much consideration as necessary, as much normality as possible

8. How can you prevent something from happening or from getting stuck in the emergency chain?

Provide the school with a detailed, easy-to-understand doctor's note, your mobile number and emergency instructions. These documents should be deposited in a place known to the entire teaching staff. This also applies to care in primary schools (OGS), after-school care attached to the school and comparable institutions that do not have access to the teachers' room. In addition, your child should have the instructions with him/her in his/her school bag. This way, every involved person is prepared for emergencies and can act prudently and correctly. It is also important that the school knows to which hospital your child should be taken in case of an emergency. If the emergency doctor needs to be called, the school will contact you immediately; therefore, please make sure that you are available at all times.

9. Conclusion

Unfortunately, the topic of „chronic illnesses“ is not systematically included in teacher training, so that some teachers need some time to deal with the new situation.

Try to establish a trustful relationship with the school and your child's teachers. Provide the teachers with important information right at the beginning (e.g. brochures and instructions on how to deal with your child's individual situation). If necessary, allow them to contact the treating paediatric cardiologist, whom you must release from the duty of confidentiality for this purpose. Let them know that you are available to answer their questions. And in the first instance, assume that the teachers want the best for all their pupils - even if this is sometimes not entirely successful in implementation.



© Fatcamera - iStock



II. FOR YOUNG PEOPLE

On the way to a career

1. How do I find „my“ profession?

No matter whether it's an internship, training or a job:

At some point you will be faced with the question „what kind of work do I want to do later?“ Your talents and interests already crystallise at school: are you more technically and scientifically fit or are you more interested in geography or religion? Are you endowed with manual skills? Can you express yourself well in language? Do you enjoy subjects like German or English? Do you like dealing with people and would you like to learn a social profession?



© industryview - iStock

It is helpful to do additional voluntary internships in companies and organisations while you are still at school. This allows you to find out early enough whether your career choice suits your ability to cope with pressure and whether it matches your expectations. At the final interview, you can ask for valuable tips for your career choice.

Perhaps you have acquired additional skills through dealing with your heart defect, and you are, for example, particularly conscientious and well organized or can empathise well with other people?

Your condition may have limitations that do not allow for physically demanding jobs, such as firefighter, pilot or roofer. However, you may be able to work in a field related to your dream job that you have not yet considered. For example, you could plan an interesting job at the airport if your dream job of pilot is not an option.

Find out as early as possible from the:

- » Integration Service (IFD)
- » Integration Office, whether you are entitled to compensation for disadvantages.

You can find more helpful contacts at www.bvhk.de and www.rehadat-bildung.de.



2. Career guidance

You don't have to make this decision on your own. Many organizations and institutions provide help and advice.

3. Training or study?

Maybe you don't want to do a training, but would rather study? "Deutsches Studentenwerk" offers a comprehensive range of counselling services especially for people with a chronic illness or disability. It is also possible to combine training and study. You can find more information at www.studentenwerke.de.

We at the "Bundesverband Herzkrankte Kinder e.V." (Federal Association for Children with Heart Diseases) are also there to answer your questions about school, training and work, and our peers are there to help you with any other problems:

www.bvhk.de/peerberatung.

Contact the BVHK:

By phone: 0241 – 91 23 32 or

by e-mail: info@bvhk.de

By the way, you can also find a lot of information on this topic on our websites www.bvhk.de and www.herzklick.de. Just click in.



© industryview - iStock



IV. EXPERIENCE REPORTS

Daniel: Many detours in the search for the „right“ school

Our son Daniel, who has a heart condition, started school when he was just under seven years old. It was very difficult for us to find a suitable school type for him. Daniel attended an integrative day-care centre run by Lebenshilfe and had a place there for curative education. His twin brother Kai attended the same day-care centre but was a regular child in another integrative group.

Our son Daniel, who has a heart condition, started school when he was just under seven years old. It was very difficult for us to find a suitable school type for him. Daniel attended an integrative day-care centre run by Lebenshilfe and had a place there for curative education. His twin brother Kai attended the same day-care centre but was a regular child in another integrative group.

Daniel was tested several times regarding the right type of school: by the kindergarten and also by the Social Paediatric Centre (SPC). The tests showed normal values, e.g. for IQ or the perception of correlations, but, among other things, significant restrictions in visuomotor skills. The SPC advised to attend a special school for the physically disabled. The day care centre was not officially allowed to give a recommendation, but the discussions went in the same direction.

But, we couldn't imagine Daniel at the special school. We saw his limitations, but we still wanted to give him the chance to try a regular school. Enrolment at a GU school in the neighbouring town was out of the question.

The headmistress of the local primary school encouraged us to give it a try, since the school entry phase is three years anyway. Her words „you have certainly experienced worse than a possible repeated school year“ convinced me to give Daniel this chance. As support, we applied for an integration assistant through the district's social welfare office. Unfortunately, our application was not approved. As a result, we were very unsure whether the chosen way was the right one for Daniel.

The decision turned out to be unfortunate. Daniel was overwhelmed and we were forced to do a lot of extra work in the afternoons.



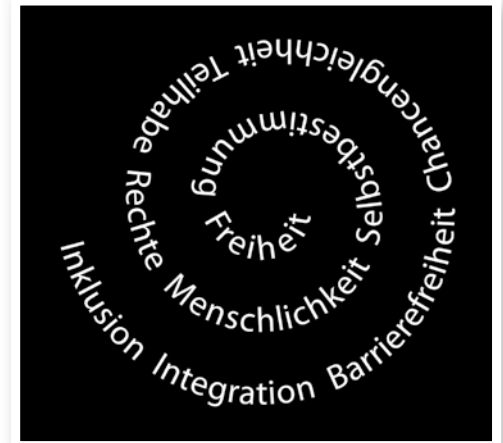
We tried to compensate for the gaps that Daniel had built up in the subject matter over time compared to his peers with a lot of dedication and effort in the time off school. This must have felt like punitive work to Daniel: while his brother Kai had long since finished his homework, he crammed during precious free time, only to realize the next day that others (especially Kai) had learned the material easier, faster and better. After the first school year, Daniel was put back into the first class again, but the problems did not improve. Another application for an integration assistant was rejected.

Finally, we decided to change to a school with extremely small classes. This meant drastic changes for the whole family, including long travel times. But even this „dwarf school“ was not prepared for the needs of special children and Daniel increasingly lost touch with the subject matter. Reaching the class target was a long way off. In the meantime, Kai had already moved up a grade, which was very distressing for Daniel. School and homework always involved tears, arguments and shouting. The afternoon escalation was pre-programmed.

So, we decided to change schools again and Daniel has been going to the special school for the physically disabled since this school year. After only a short time, it became clear that this was the right decision. Daniel is a happy child again and learns with great eagerness. He is now one of the good children in the class and very proud of himself. A lot of pressure has been lifted from him and from our whole family. The siblings are also relieved that peace has returned to us. Daniel meets insightful educators who support him and let him learn at his own pace and according to his capabilities.

We can now look forward to Daniel's educational and professional future more relaxed. He will go his way!

Sabine Sch. (names changed)



© Sascha Bergmann - Fotolia.com

© Larsfich - istockphoto.com



Nico: The model of cooperative teaching - An alternative to inclusion?

Our son Nico was born in October 2000 with a severe congenital heart defect, Hypoplastic Left Heart Syndrome. After he had undergone the three Norwood operations at the age of three, the search for a suitable kindergarten began. Not only were the physical characteristics such as low resilience, susceptibility to infections, medication, etc. difficult, but Nico's mental development was at least as stressful for all of us. Due to a long reanimation lasting 45 minutes (cardiovascular failure three days after the Norwood I surgery), a clear developmental delay became apparent, which was accompanied by a lack of speech, stereotypical behaviour, fear of loss and other signs of traumatisation caused by the hospitalisation.



© Familie P.

Nico got a place in an integration kindergarten in the neighbouring village, where he was lovingly cared for and supported for four years together with three other integration children in a group of 18 children. I was very impressed by the way all these children worked together. The fact that all children - whether with or without disabilities - can learn from each other seemed to us to be a good way and the right way for our son.

School enrolment was approaching together with the question: which school is the right one for Nico? He was diagnosed with special educational needs regarding mental development. He was then supposed to go to a special school with a focus on mental development. Since Nico also has a physical disability due to his heart defect, a special school with a focus on physical development would also have been possible. A third alternative was a Waldorf school for curative education, a private school more than 30 km away from our home. Our paediatrician, on the other hand, saw Nico as an integrated child in our regular local primary school.

A year before Nico started school, we had already visited all the schools, at some of which we also stayed at for some time. The difficulty was that Nico „doesn't fit into any drawer“. He has a bit of everything. The kindergarten showed us that he learns a lot from the other children in the group, but that he also needs a place of retreat and very individual care in order to be able to learn and develop at all. So, our regular school was no longer an option, because apart from a few additional hours per week with a special needs educator, he would have been too much on his own. Physically very small and not very resilient, we saw him as an outsider. After all the bad experiences in the hospital we wanted to spare him that.

At that time, we learned about a school model in our district that showed us new possibilities: the so-called cooperation model of the special school with a focus on mental development with a regular school, which has existed in the district of Harburg for more than 10 years. A cooperation class of the special school with a focus on mental development is accommodated at a regular school and works together with a regular class of the same grade. This means, among other things, that both classes have adjacent classrooms - at some schools cleverly connected with a passage door - which are adapted to the needs of the respective children. For example, the classrooms of the special needs children are handicapped accessible and equipped with a kitchenette. The timetable of both classes is coordinated and both classes are taught together in as many subjects as possible. The children with special needs are given tasks by the special needs teachers according to their abilities. At the same time, the separate classrooms make it possible to have separate lessons when, for example, the regular school class is doing classwork, practice time is scheduled or the children with disabilities need their retreat. For Nico, this was exactly the same kind of learning with which we already had positive experience in the kindergarten.

The small number of pupils of 6-8 children in the special school class and usually one regular school teacher, one special school teacher and one educator in the cooperative class, plus the children of the partner class as well as the joint learning, all this benefits him very much.

Since grade 1, Nico has been attending the special school in a cooperative class. In grade 5, he moved to a parallel class at his school, which cooperates with another class of the same grade from the integrative comprehensive school (IGS). I also stayed there and was impressed how naturally and calmly 30 (!) comprehensive school pupils and six special needs children work together at table groups.

This table group model is a special feature at the IGS, since it also includes table group parents' evenings, which serve the special exchange between parents and children.

As an example of cooperative teaching, I outline here an excerpt from the „Project Time“ block in which I was able to stay: At the moment, the theme there is „exciting scientists and their work“.



© Familie P.



The following station themes are offered: „Leonardo da Vinci - artist, researcher, universal genius“; „Historical scientists - detective superintendents who investigate the past“; „Things that change the world“; „Like LANGUAGE SCIENCE“; „Awards, doctorates and really curious things“; „Places of science - from thick ice to a depth of 20 metres“; „Danger - race to the South Pole“ and some additional stations. All topics include an extensive range of tasks from which the children can choose. In addition to personal support, the cooperation pupils also receive differentiated tasks. An example that shows the differentiation: an additional station consists of assigning newspaper articles from the „Wissen“ page of the Hamburger Abendblatt (newspaper) to different generic terms. This can be done by reading as well as by looking at the pictures (animals, people, technology). At all stations, work can be done either on a very abstract-linguistic level or on a concrete-objective level. All the children work on one subject at their own learning level.

In the meantime, Nico is in Grade 8, he feels very comfortable and we can say that this co-op model is a good way of schooling for him. With regard to his heart disease, we also have one less worry here, because downtime due to doctor's visits or hospital stays can be absorbed without any problems, and the subject matter is always adapted to the respective learning and performance level.

Of course, the cooperation model does not only have advantages: as in every type of school, the implementation of the concept stands and falls with the respective class teams. Each lesson requires a lot of preparation and organisation from all involved. The timetable is tight and demands a high level of concentration, not only from the special needs children. And, last but not least, the children in the regular class must be willing to learn together with the special needs children - with all the advantages and disadvantages. We have made the experience that this model can be an opportunity for heart children who „do not fit into any drawer“!

Seevetal, November 2014
Ulrike P.



© Familie P.

Addendum to the report:

Meanwhile - in 2021 - Nico has arrived at work. I would like to tell you briefly how Nico's path has continued:

The final stage of the special school for mental development (grades 9-12) took place in classes at the main school, i.e. the cooperative lessons with the regular school class had ended. Practical life lessons were now on the curriculum (instead of mathematics, e.g. shopping and accounting for purchases) in order to prepare the special needs children for as independent a life as possible after school.

In grade 12, Nico was recommended by an expert's report to work in a workshop for disabled people (WfbM), as he cannot do an apprenticeship with a special school certificate and a job on the general labour market is too strenuous for him. After graduating from school in July 2019, Nico started a vocational training measure at the WfbM of "Lebenshilfe Lüneburg-Harburg" in the office/reception field in September 2019. There, he will be trained in the professional profile of an office assistant. This measure ends after 2 ¼ years in November 2021. From December 2021, he will switch to the working field of "Lebenshilfe". The head office there employs handicapped people at its own reception who have been trained in this vocational training scope. After a successful internship, Nico has been accepted for a job there, which is very is very fortunate for us.

The activities correspond to his abilities without overtaxing him and bring him fun.

There is no pressure to perform there either; downtime due to hospitalization, for example, is not a problem. It is, so to say, work in a protected setting. We are very happy that we found this way for Nico. A big part comes from persistent research - and there was also a bit of luck involved, but we are confident that Nico will find his way in the future, too.



© Familie P.



© Familie P.

Checklist for teachers/educators

Name of the child: _____

Heart defect: _____

Concomitant diseases: _____

1. Medicines: No Yes, when, how often: _____

Support necessary? _____

Keep in school (out of reach of other children), refrigerated or similar:

Teacher-child protocol in place? (p. 16): Yes No

Administration by teaching staff agreed? (private courtesy, without liability)

Yes No

Side effects: e.g. increased urination, increased risk of bleeding:

2. Allergies, other health peculiarities:

3. Particularities during emergency measures: (e.g. observe Fontan circulation during ventilation, risk of bleeding after falls/injuries):

4. Emergency numbers: parents' mobile number _____

attending doctor: _____ hospital: _____

5. Release of the doctor from the duty of confidentiality by parents is available: Yes No

6. Disadvantage compensation (p. 9) agreed: _____

7. Restrictions in sports (p. 12 ff): No Yes, which _____

Agreement on grading in sports: _____

8. Report contagious diseases in class (e.g. diarrhoea) to parents (such as transplanted children): Yes No

9. Additional comments: _____

Date, Signature: _____

Especially for children and teenagers:

Understandable information about congenital heart defects.

Visit and experience for yourself!



www.herzklick.de



Adresses - Your local contact

Herz-Kinder-Hilfe Hamburg e. V.

c/o Inge Heyde
Wolsteinkamp 63 - 22607 Hamburg
Tel. 040-82 29 38 81
i.heyde@herz-kinder-hilfe.de
www.herz-kinder-hilfe.de

Marfan Hilfe (Deutschland) e.V.

Postfach 0145 - 23691 Eutin
Tel. 0800 - 76 13 34 4
kontakt@marfanhilfe.de
www.marfan.de

Herzkinder Ostfriesland e. V.

c/o Jörg Rüterjans
Suurleegdenweg 5 - 26607 Aurich
Tel. 04941-60 44 316
info@herzkinder-ostfriesland.de
www.herzkinder-ostfriesland.de

Kleine Herzen Hannover e.V. Hilfe für kranke Kinderherzen

c/o Ira Thorsting
Wirringer Str. 21a - 31319 Sehnde
Tel. 0 179-50 97 103
ira.thorsting@t-online.de
www.kleineherzen.de

JEMAH e.V. Bundesverein Jugendliche und Erwachsene mit angeborenem Herzfehler e.V.

Am Exer 19a - 38302 Wolfenbüttel
Tel. 05331-92 78 48 50
info@jemah.de
www.jemah.de

Aktion Kinderherz e. V. Düsseldorf

c/o Gabriele Mittelstaedt
Goethestr. 41 - 40670 Meerbusch
Tel. 02159-91 26 44
aktionkinderherz@arcor.de
www.aktionkinderherz.de

Noonan-Kinder e.V. Deutschland

c/o Susanne Brombach
Ludwig-Richter-Weg 17 - 40724 Hilden
info@noonan-kinder.de
www.noonan-kinder.de

Elterninitiative herzkranker Kinder Dortmund / Kreis Unna e.V.

c/o Mechthild Fofara
Vorhölderstr. 63 - 44267 Dortmund
Tel. 02304-89 540
fofara@t-online.de
www.herzkinder-dortmund.de

Herzkinder Oberhausen und Umgebung e.V.

c/o Andrea Ruprecht
Babcockallee 7 - 46049 Oberhausen
Tel. 0176-72 38 80 48
herzkinder-oberhausen@t-online.de

Herzranke Kinder e. V.

c/o Julia Ensel-Eckerth
Pottkamp 19 - 48149 Münster
Tel. 0251-85 70 43 57
info@herzranke-kinder-muenster.de
www.herzranke-kinder-muenster.de

Fördermitglied im BVHK

Herzpflaster Coesfeld / Bunter Kreis Münsterland e.V.

c/o Johanna Kemper
Poststraße 5 - 48653 Coesfeld
Tel. 02541 - 89 15 00
herzpflaster@bunter-kreis-coesfeld.de
johanna.kemper@bunter-kreis-coesfeld.de

Kinderherzhilfe Vechta e.V.

c/o Corinna Krogmann
Sonnenblumenweg 12 - 49377 Vechta
Tel. 04441-15 99 638
info@Kinderherzhilfe-Vechta.de
www.kinderherzhilfe-vechta.de

Elterninitiative herzkranker Kinder, Köln e.V.

c/o Ute Braun-Ehrenpreis
Quettinger Str. 42 - 51381 Leverkusen
Tel. 02171-55 86 92
info@herzranke-kinder-koeln.de
www.herzranke-kinder-koeln.de

Herzkrankes Kind Aachen e. V.

c/o Jörg Däsler
Jülicher Str. 373 - 52070 Aachen
Tel. 0241-99 74 10 74
info@herzkrankeskindaachen.de
www.herzkrankeskindaachen.de

Elterninitiative herzkranker Kinder und Jugendlicher Bonn e.V.

c/o Christian Behre
Postfach 190204 - 53037 Bonn
Tel. 02 28-61 96 80 99
vorstand@herzkinder-bonn.de
www.herzkinder-bonn.de



Kinderherzen-Fördergemeinschaft Deutsche Kinderherzzentren e.V.

c/o Jörg Gattenlöhner
Elsa-Brändström-Str.21 - 53225 Bonn
Tel. 0228 422 800
info@kinderherzen.de
www.kinderherzen.de

Hypoplastische Herzen Deutschland e.V.

c/o Birgit Höveler
Elisenstr. 12 - 53859 Niederkassel
Tel. 02208-77 00 33
b.hoeveler@hhdev.eu
www.hypoplastische-herzen-deutschland.de

Herzranke Kinder Kohki e.V.

c/o Sigid Schröder
Westring 241 - 55120 Mainz
Tel. 06131-48 79 421, Mobil 0163-78 21 206
kohki-herz@web.de
www.kohki.de

Regionalgruppen:

Aschaffenburg
Berlin-Brandenburg
Bremen
Frankfurt-Darmstadt
Franken
Fulda
Koblenz-Westerwald-Taunus
Leipzig
Mainz-Bad Kreuznach
Pfalz-Rhein-Neckar
Stuttgart
Südbayern
Thüringen
Wiesbaden-Rüsselsheim
Pumpis für Herzis

Kleine Herzen Westerwald e.V.

c/o Günter Mies
Hirzbach 9 - 56462 Höhn
Tel. 02661-82 87
info@kleine-herzen-westerwald.de
www.kleine-herzen-westerwald.de

Kinderherzen heilen e.V. - Eltern herzkranker Kinder - Gießen

c/o Ruth Knab
Am Söderpfad 2a - 61169 Friedberg
Tel. 06031-77 01 63
kontakt@kinderherzen-heilen.de
www.kinderherzen-heilen.de

Herzkrankes Kind Homburg/Saar e.V.

c/o Dr. jur. Alexandra Windsberger
Universitätsklinik des Saarlandes - Gebäude 33
Villa Regenbogen - Kirrberger Strasse
66421 Homburg
Tel. 06841- 16 27 466
info@herzkrankes-kind-homburg.de
www.herzkrankes-kind-homburg.de

Elterninitiative Herzkranker Kinder e. V., Tübingen, (ELHKE)

c/o Mita Ettischer
Königstraße 77 - 72108 Rottenburg
Tel. 07472-96 95 024
info@elhke.de
www.elhke.de

Herzkinder Unterland e. V.

c/o Heidi Tilgner-Stahl.
Leinburgstr. 5 - 74336 Brackenheim
Tel. 07135-96 13 41
vorstand@herzkinder-unterland.de
www.herzkinder-unterland.de

Herzklopfen Elterninitiative Herzranke Kinder Südbaden e.V.

c/o Petra Huth - Geschäftsstelle-
Lutherkirchstr. 1a - 79106 Freiburg im Breisgau
Tel. 0761 - 47 746 444, Mobil 0159 0633 2814
info@herzklopfen-ev.de
www.herzklopfen-ev.de

Junge Herzen Bayern

c/o Michael Brandmayer
Holzfeldstr. 24 - 85457 Würth - Hörkofen
Tel. 08122-95 63 22
info@junge-herzen-bayern.com
www.junge-herzen-bayern.com

ARVC-Selbsthilfe e.V.

c/o Ruth Biller
Fastlingerring 113 - 85716 Unterschleißheim
Tel. 0163-18 47 521
info@arvc-selbsthilfe.org
www.arvc-selbsthilfe.org

Ulmer Herz Kinder e.V.

Saulgauer Straße 9 - 89079 Ulm
Tel. 0731-14 41 83 79
info@ulmer-herzkinder.de
www.ulmer-herzkinder.de



**Information brochure
Children with heart disease at school**

Bundesverband Herzkrankte Kinder e.V. (BVHK)

Vaalser Str. 108, 52074 Aachen

✉ info@bvhk.de ☎ 0241-91 23 32
💻 www.bvhk.de 📠 0241-91 23 33
💻 www.herzclick.de
📘 facebook.com/herzkrankte.kinder
▶ youtube.com/bvhkde
📷 instagram.com/bvhk.de



Deutsches
Zentralinstitut
für soziale
Fragen (DZI)
**Zeichen für
Vertrauen**

Donation account

Bank: Sparkasse Aachen
IBAN: DE93 3905 0000 0046 0106 66
BIC: AACSD33

Understandable information about congenital
heart defects - visit and experience for yourself:

Redesigned,
even better,
click in now!
herzclick.de



**Bundesverband
Herzkrankte
Kinder e.V.**

**Federal association
for children with
heart disease**

