



Parents of Disabled Children

GUIDE TO HELP AND SUPPORT

A practical *Guide*

Colophon

Parents of disabled children Guide to help and support

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to **parents**

This guide is intended to give you, as parents who are expecting or already have a disabled child, an overview of the main sources of public sector help and support – in other words, the help offered by the social, health, cultural and educational services.

To use the guide, you can look up your child's age or the services and information relevant for you at the moment. The last pages contain a list of the legislation forming the basis of this guide as well as links to more information.

In this guide, the word 'disability' is used as a general term for all forms and degrees of impairment. However, the guide is primarily aimed at parents whose child has substantial, permanent impairment or invasive chronic or long-term condition.

The guide can be downloaded free of charge from The Social Portal:
www.social.dk

Where to find help?

The local authority

When you become parents to a disabled child, you will usually need thorough consultancy. For example, consultancy might deal directly with the child's disability and ways to solve practical problems, or might address future perspectives and respite care options.

Your local authority will help you navigate the various help and support options available. In most cases, a social worker will contact you, but you can also get in touch with the local authority yourselves. If all you want is consultancy, this can be provided anonymously, if you wish.

Your social worker will explain the relevant support services to you and thoroughly discuss your family's overall situation. Your social worker should work closely with you on creating a general plan. You are the ones living with the problems and who are most familiar with your family's situation and daily routines.

Your local authority is obliged to give you information about the effect your child's disability may have on your family. If you need specialist information, the authority can call in consulting specialists from other local authorities or get advisory help from VISO (The National Knowledge and Specialist Consultancy Centre).

FACTS

The local authority is your gateway to public benefits and support. The individual local authority assesses and decides which services you are entitled to.

Support is granted according to an assessment of the family's overall situation. Because each local authority independently determines its service level within the legislative framework, services and options will vary from authority to authority.

VISO offers free specialist consultancy to private individuals and local authorities, although only in the most specialist-requiring and complex cases. Although your local authority will be your main source of help and advice, you can also contact VISO personally for specialist consultancy. Read more about VISO in the brochure 'VISO – A Service Guide for You', which you can download in Danish from: www.spesoc.dk (click VISO).



Organisations for *parents and disabled people*

For most people, becoming parents to a child with a disability is unexpected. Many feel bewildered by the mixed emotions of grief and happiness with which they must cope.

You may find it helpful to get in touch with other parents in the same situation. Many organisations for parents and disabled people run parents' groups, family courses and consultancy services. They can give you information and advice and offer support from others in similar situations. Many parents benefit enormously from meeting other parents, sharing experience and networking.

You will find the names of organisations for disabled people and parents on the websites listed at the end of this leaflet.

The child's *age*

Providing help to a disabled child often requires the concerted efforts of professionals, treatment units, administrative bodies and sectors. To give parents and professionals a clearer picture of the situation, it can be helpful to ask the social worker to arrange a meeting with all the parties involved. Besides the parents and the social worker, the health visitor and a member of the educational psychology advice unit (PPR) could be invited to participate.

Drawing up an action plan coordinating the efforts of the various professionals can be extremely useful. Since an action plan keeps track of initiatives planned and ensures they interconnect, it may be a good idea to ask for one.

As a rule, when your child switches from one day-care facility to another or starts school, your social worker will be responsible for coordinating and planning the transition – together with you. As parents, you need to be involved in the planning process and help provide information about your child and his or her daily routines.

FACTS

A written action plan can help underpin a complete service package for your child. An action plan clearly sets out the roles and responsibilities of all people, authorities and public bodies involved.

The action plan outlines the measures to be initiated, their purpose and duration, and other matters such as aids, day-care facilities and treatment. The plan should be regularly adjusted to ensure that the right support is provided at all times.

Action plans are not a statutory requirement for children and young people under 18 with disabilities. According to section 141 of the Act on Social Services, local authorities are required to offer disabled adults a written action plan.



Before **The birth**

If a pregnancy examination shows that your child will be born with a disability or chronic condition, you may face a difficult decision: Do you want to continue the pregnancy or should it be terminated? In this situation, you need to gather as many facts as possible to help you make a well-informed decision.

As a rule, you and your partner will be advised by the experts at the hospital or clinic where you have your check-ups. You may also receive advice from a genetics unit if your family has a history of hereditary illness.

Consultancy will include the information available about your child's disability and treatment options. The experts will also try to explain how the disability may affect your child and your family as a whole. Their advice will also inform you about how to qualify for public benefits as well as about where to find consultancy outside the healthcare sector. For example, the consultants can put you in touch with a relevant organisation for parents or disabled people.

Later in the pregnancy, you can get advice and guidance from your GP, health visitor or your local midwife centre. You can also attend ordinary prenatal education sessions and midwives' consultations to help prepare yourselves for the birth and parenthood.

FACTS

What do you do if the child of your dreams is less than perfect? You can find more information in Danish about your particular situation, prenatal diagnosis and related topics on www.fosterdiagnostik.lev.dk. The site contains useful links and refers to a hotline where you can talk to people with personal experience of having a disabled child.

You can find details about prenatal diagnosis and risk assessment on the Danish National Board of Health website: www.sst.dk/informeretvalg.



Your child *0-3 years*

Like all other families, you will be offered visits by a health visitor after the birth of your child. You can discuss all aspects of your child's life: breastfeeding, care and nutrition, development, stimulation, health and illness. You can also talk to the health visitor about all aspects related to your family's health and well-being: everyday problems, parental roles, responsibility, grief and crisis. Your needs will determine the number of visits. The health visitor can continue visiting you until your child reaches school age.

If your child is born with a disability, your local authority has a duty to advise you about your help and support options. If necessary, your social worker can also contact other relevant experts who can advise and guide you.



Your preschool child *3-7 years*

Before your child reaches kindergarten age, you and your social worker need to decide how best to balance your child's needs and development with the available resources. You need to consider whether your child should attend ordinary kindergarten or needs a special facility. As parents, you must be involved in describing your child and his or her needs.

Facilities and options vary between local authorities. Some have kindergartens with 'disability groups' – either in the kindergarten or attached to it. These facilities are typically intended for children with minor impairments. If your child needs special stimulation or care, the local authority must provide the necessary support, such as a support teacher.

Transition to preschool and school

You should start planning your child's year of preschool well before the time comes, preferably one or two years in advance. You should also determine the person who will coordinate the transition between kindergarten and school and get him or her involved. This contact will normally be your social worker or a member of the educational psychology advice unit (PPR).

The PPR will be able to advise you on your choice of school and the start of your child's school life. The staff is familiar with the various relevant educational options available.



FACTS

The Danish Centre for Rare Diseases and Disabilities (CSH) has published a handbook about starting school: 'A good start to school life – for children with rare disabilities' (in Danish only). The book describes how parents can take an active part in planning their child's introduction to school life. It offers good insights, tips and ideas for parents (also for parents of children without a rare disability). The book can be downloaded from: www.csh.dk.



Your schoolchild *7-14 years*

Children with disabilities are encompassed by the Act on primary and secondary education and are – like other children – required by law to receive instruction. The local authority must ensure education is provided for your child (in an ordinary school, with support or in a special school or special class, if necessary).

The PPR assesses whether your child needs special education and special teaching assistance. Special teaching assistance is not limited to strictly educational needs and can take the form of speech therapy.

Once your child's educational needs have been determined, you can contact the PPR for information and advice about your options and choice of school. As parents, you will be consulted on the choice of school, and your wishes must be clearly stated on the school referral form. Make sure that you are involved in describing your child's situation and needs.

Ē If your child is referred to a special school, the placement is valid for one year at a time. This gives you a yearly opportunity to adjust your child's education in the event his or her needs change.

Ē If you choose a private school for your child, you should still contact the local authority's educational psychology advice unit for advice on the special rules regarding payment, financial support and after-school facilities.

Schools must provide aids, also for helping at home with homework. The school must also offer other necessary support, such as a support teacher or personal assistant.

School and after-school facilities

Once your child's schooling is in place, the next step is to find the right after-school facility – local authority after-school facilities (SFO), an after-school centre, or a club.

In some cases, the child may need a special arrangement, for example at an after-school centre together with other disabled children and young people. If the child attends a special school, the school may have after-school facilities attached.

FACTS

The local authority is responsible for meeting your child's educational needs – even if your child needs special education and special teaching assistance. If the authority cannot provide relevant educational facilities, it must offer your child a place in another local authority or one of the specialised regional facilities.



Youth *14-16 years*

Well before the last year of school (9th or 10th grade), you should start discussing your child's future. You need to clarify expectations and possibilities so that you can plan ahead. You should think about the long-term prospects for education and leisure time – or for housing and work.

From the 6th grade until the last school year, your child – like all other children – will write an education logbook at school, possibly with your help. Starting in the 9th grade, an education plan will be made with a view to clarifying the young person's wishes and choices for the future. The education plan helps identify relevant options in good time. Your next step will be to involve your social worker in the planning process and, together, meet with the relevant professionals.

The young person is entitled to an offer of education after 9th grade, whether school (10th grade, higher secondary school, commercial college, etc.), a traineeship or an occupational opportunity. The young person should have access to all educational institutions. The various training institutions must provide the necessary compensatory support.

Other educational opportunities for young people include continuation school, folk high school, transition education (guidance and teaching) or adult vocational training offers. In some cases, sheltered occupation can be an option as well as other activities or educational facilities.

FACTS

The job of Youth Guidance Centres (Ungdommens Uddannelsesvejledning) is to guide young people in their choice of education and occupation in the transition from school to youth training programmes and between training programmes.

Centres offer guidance for young people from the 6th grade of lower secondary school up to the age of 25, and they work at the local level. Find out more about the training guide on: www.ug.dk (where you can also read more about the education logbook and plan).

Further information about access to educational opportunities can be found on The Ministry of Education's portal on education and disability:
www.tilgaengelighed.emu.dk.



Transition to adulthood *16-18 years*

Different rules apply after the age of 18, so you should receive consultancy about your teenager's future situation well before he or she turns 18. Your child comes legally of age at 18 and is therefore assigned a personal social worker. After this, you will need your child's consent to participate (as the child's advocate) in meetings with the social worker.

Once your child turns 18, the social worker must offer to prepare a written action plan together with the young adult. The plan will address such issues as the young person's income base, housing and education.

The transition to adulthood affects the services, options and routines that have been part of your daily life so far. For example, you will no longer be compensated as a family; the young adult's situation will be assessed according to the provisions that apply to adults. For these reasons, you should consider how these changes will affect you as a family well before they do so. Your social worker can give you advice.

If the young adult has a severe impairment, you may consider applying to the Regional State Administration for guardianship. Advice and guidance about guardianship is available from the Regional State Administration.

Personal attendance

Like all young people, young disabled people living at home need to enjoy activities of their own choice outside the home – without their parents.

Young disabled people (16-18 years) are entitled to have a personal attendant from the local authority for 15 hours monthly, provided they meet the scheme requirements. If the young person does not appoint a personal attendant, the local authority will provide one. As necessary, the personal attendant's job is to help the young person manage such activities as putting on outer garments and using aids and a wheelchair. Generally, the young person pays the cost of the personal assistant's transport, admission fees and café visits, but expenses up to a certain annual limit can be refunded.

The young person decides on the social activities for which she or he needs an attendant. Examples range from visiting the cinema and friends to joining in club activities and meetings. Getting out and about with a personal attendant can enhance the young person's independence and give him or her an opportunity to establish and maintain social contacts and friendships.

FACTS

Find out which Regional State Administration you belong to at the www.statsforvaltning.dk website.

Help for *your family*

According to the social services legislation, you will be compensated as far as possible for the consequences of your child's disability. You must be able to live as normal a family life as possible, either through help provided to your child or to your family as a whole.

Ě Respite care

Most parents of disabled children need respite from everyday routines. Respite care can enable you to spend time with your other children – or give you time for each other. Respite care may be the key that gives you enough resources to carry on a working life.

Respite care can be provided inside or outside the home. Various forms of respite care are available at weekends or on weekdays, for example:

- Ě Personal and practical help in the home
- Ě Respite care in a residential facility
- Ě Respite care in a respite institution
- Ě Respite care in a foster family

Your social worker will assess whether you qualify for respite care and the amount to which you are entitled. The assessment will take into account the degree of your child's disability and your family's situation as a whole. This makes it important for you to put your particular needs into words.

Ě Residential placement

If you are unable to care for your disabled child at home, various residential options are available for your child: foster families, special care centres and residential facilities. You will continue to have parental responsibility.

If you accept an offer of residential care, you may benefit from the advice and support offered by organisations for parents and disabled people (see the list in this leaflet). Most people find talking to other parents in the same situation an enormous relief.

Ē Home modification

When you welcome a disabled child as a new member of your family, you may need to extend or redesign your home to adapt it to the family's changed circumstances. In very exceptional cases you may get help finding another home.

If you want to redesign your home, you should seek the help of your local authority. You must apply before you start making changes or looking for somewhere else to live. Please note that housing cases can take a long time to process. Ask your authority how long you should expect the case processing to take.

When providing assistance for home modification or for another home, the local authority does not take your financial circumstances into account. Whether you live in a rented flat or own your home is also irrelevant

Ē Psychological support

If you or your child has mental problems that are best treated professionally, or if you need help getting on with your life, various psychological support options are open to you.

The options vary, but you can ask your social worker for guidance about the services provided by your local authority. These may include consultancy from the education psychology advice unit (PPR), the social services or the authority's specialist consultants.

If you are going through a serious crisis, you can get assistance to pay for therapy through a referral from your own doctor. Furthermore, some hospitals may offer psychologist services if your child is frequently hospitalised for long periods.

Help for your child

Beyond examinations and treatment, the health sector also offers other forms of help for families with a disabled child. Examples of such help include physiotherapy, various technical aids and preventive health services. The preventive health service means that while your child is of school age, he or she is entitled to additional consultancy and extra preventive examinations from the nurse or doctor.

Ē **Therapeutic devices and technical aids**

If your child needs therapeutic devices as part of his or her ongoing hospital treatment, the hospital must provide you with this equipment. Your child may have a temporary need for a wheelchair, a special bed or respiratory equipment. In these cases, the devices will normally be provided until the child's condition has stabilised. The hospital may also help provide devices prescribed for permanent use or as part of ongoing hospital treatment, for example, oxygen apparatus or an insulin pump.

If your child has a material need for aids to alleviate the permanent consequences of the disability, the local authority will provide support to buy them. Aids can also be provided to make day-to-day home life significantly easier for the family. Aids qualifying for support include wheelchairs, orthopaedic footwear, special beds, hearing aids or special IT aids. Help is not provided for consumer items normally found in an ordinary household.

Support for aids can be granted as items on loan or free of charge, or as a cash allowance. The local authority usually has a physiotherapist or ergotherapist who will give you guidance in choosing and adapting aids.

Ē **Physiotherapy**

If your child needs physiotherapy, support is granted for doctor-prescribed treatment. If your child has a permanent and severe physical disability, certain diagnoses will entitle him or her to free physiotherapeutic treatment or riding therapy. The aim of therapy is to improve or maintain physical functionality or postpone functional deterioration.

FACTS

The website of The Danish Centre for Assistive Technology: www.hmi.dk.
You can order or download the National Board of Health guidelines for free access to physiotherapy for physically disabled people on: www.sst.dk (in Danish only).

Supplements to *family finances*

Ē **Additional expenses**

As a family, you can receive assistance to cover necessary additional costs that are directly attributable to your child's disability. This means you have to pay ordinary expenses just like everyone else, but the cost of additional expenses arising from items such as special diet, dietary foods, medication, special clothing, extra laundry and special toys will be covered, in addition to fees for relevant courses for parents and other relatives.

If your child is hospitalised because of the disability, and you have to stay with your child, you can get assistance with additional expenses incurred as a result, for example, overnight stays, board and transport expenses.

Your social worker will, together with you, assess which additional costs you are entitled to have covered. The amount must exceed a minimum amount and is neither taxable nor means-tested. You can ask your social worker for more details about the conditions applying to additional expenses.

Ē **Loss of earnings**

If one of you cares for your child at home because it is the most practical solution and an unavoidable consequence of your child's disability, you can claim compensation for loss of earnings. The period of time for which compensation can be paid ranges from a few hours a week to compensation for loss of full-time work over several years. Compensation can also be paid for a few hours or days in connection with doctor's visits and similar.

Before deciding to claim compensation for loss of earnings, you will need advice from your social worker regarding your various options and the possible consequences of absence from the labour market

FACTS

The pilot project 'Help for families with disabled children' has published a brochure in Danish on loss of earnings. It can be downloaded from: www.vfb.dk

Ē Subsidy for a car

If your child has difficulty getting around without a car, you can apply for support to buy a car on your child's behalf. You can also apply for exemption from vehicle tax and assistance for such car modifications as a hoist, ramp or seat. In very exceptional cases, an interest- and instalment-free loan may be granted for a more expensive car.

Ē Subsidy for transport

If your child receives treatment from a specialist doctor or at a hospital, you are entitled either to be driven to the place of treatment or to receive transport allowance. You should contact your local patient counsellor for information about support for transport

Ē Special nutritional needs

If your child has to be tube fed or needs other special nutritional products, you are entitled to support. If the doctor has prescribed the product, the Health Act entitles you to a certain amount of support. According to Danish social legislation, you will be compensated for the user-paid part of the additional costs. Again, your social worker is the key to getting support

Culture *and* leisure

All children need to feel part of a community whether at school, an after-school leisure facility or other social activity. Leisure activities help to strengthen children's social relations and their contact with the world about them.

- Ē All local authorities provide a range of recreational options such as clubs, youth schools, after-school leisure facilities (SFO) and sports and hobby activities. Each authority determines whether to offer special recreational options for children and young people with disabilities.
- Ē Joining in social activities with peers boosts a child's self-confidence – they will benefit from not feeling different, at least once in a while. For this reason, you as parents might consider looking into ways of getting your child together with other disabled children. Organisations for disabled people also offer a variety of activities. Opportunities for disabled people to take up various types of disabled sports are also increasing.
- Ē An overarching principle of Danish disability policy is that, as far as possible, people with disabilities should be accorded the same opportunities as the rest of society. This means, for example, that the activities offered by a community should be accessible to people with social as well as physical and communication disabilities.

FACTS

Information about accessibility: The Equal Opportunities Centre for Disabled Persons – www.clh.dk

The Danish Council of Youth Organisations of People with Disability – www.dsiungdom.dk

The Danish Sports Organisation for the Disabled – www.dhif.dk (see Youth Sports under Activities [in Danish only])

Case processing

Your social worker is pivotal to your relationship with the local authority. Successful case processing greatly depends on you and your social worker cooperating to find the optimum solutions. Clarifying possibilities and expectations promotes a productive partnership. For example, you can contribute by:

- ☒ Describing what you expect from the cooperation
- ☒ Describing your child in detail
- ☒ Describing your family's overall situation in detail

One way in which the social worker can contribute is by answering the following questions:

- ☒ What forms of help and support are viable?
- ☒ What is the legal framework for the provision of support?
- ☒ How is the public system structured?
- ☒ How will case processing progress?

To plan the best possible provision of support for you, your social worker needs full information about your family. Conversely, you must have a chance to have a say in your case. Your social worker should plot your child's course to include your involvement.

If you do not speak or understand Danish, you are entitled to free interpretation assistance. In other words, a qualified interpreter must be present every time you have a meeting with your social worker or attend a parents' meeting, consultation and similar. The local authority or public body in question has a duty to provide and pay for the interpreter. The same rules apply if you have a child with a communication disability (impaired hearing, sight or speech).

Furthermore, everyone has the right to take a relative, friend or other person – a child educator or doctor for example – to meetings with the public authorities (as observers).

FACTS

The Impartial Consultative Service for People with Disabilities (Den Uvildige Konsulentordning på Handicapområdet, DUKH) offers counselling and promotes the legal status of disabled people. DUKH can provide information about Danish legislation and legal rights, services, appeal rights and case processing. DUKH can also facilitate cooperation between the individual and the social authority (www.dukh.dk).

Rules of appeal

Ě Social sector

Read about the general rules of complaint and appeal for cases involving the social services and about your rights during case processing in these brochures published by the Ministry of Social Affairs: 'If you want to make a complaint' and 'How your case is processed'. The brochures, in Danish, can be downloaded from: www.social.dk.

On www.social.dk you can also find information about case processing and about complaint and appeals in social cases. The site contains references to the relevant sections of Danish legislation.

Ě Education sector

Various rules of appeal exist in the education sector. If you wish to complain about the general education service provided by your local authority, contact your local council. If you are dissatisfied with the special education services, you can complain to the Board of Special Education Complaints (Klagenævnet for vidtgående specialundervisning). You can also lodge an appeal with the appeals board if your local authority refuses to refer your child to a special education option such as a special school or special class. Read more about rules of appeal on www.klagenævnet.dk. Appeals should be addressed to:

Klagenævnet for vidtgående specialundervisning
Styrelsen for Evaluering og Kvalitetsudvikling af Grundskolen
Snaregade 10
DK 1205 Copenhagen K
Tel. +45 33 92 62 00

Ě Health sector

The health sector has a series of appeals bodies. Contact your local patients' office or patients' counsellor for guidance. The website of the Patients' Appeals Board (Patientklagenævnet), www.pkn.dk, contains information about avenues of appeal against the health services, as well as the downloadable brochure 'Do you want to complain about the health service?' (in Danish).

Relevant *legislation*

The list below is a summary of the most important legislation applying to the various topics covered in this guide.

Ē **The Public Administration Act**

Observers	Section 8
Interpretation assistance	Section 7

Ē **The Act on Legal Protection and Administration in Social Matters**

Citizen involvement is a must	Section 4
Time limits for decisions	Section 3

Ē **The Act on Social Services**

VISO – National Knowledge and	Section 13
Specialist Consultancy Centre	
Respite care	Section 20, 32, 41, 44, 52(2), 84
Interior design and home relocation	Section 116
Day-care facilities and special day-care facilities	Section 20, 32
Subsidies for day-care facilities	Section 29
Residential care facilities	Section 67(2)
Action plans for adults	Section 141
Aids	Section 112
Club facilities and special club facilities	Section 33, 36
Personal attendance	Section 45
Extra costs	Section 41
Local authority counselling	Section 11
Subsidies for cars	Section 114
Loss of earnings	Section 42

Ē **The Health Act**

Special preventive health services, children and youth	Section 122, 123
Subsidies for dental care	Section 127
Subsidies for transportation	Section 170
Subsidies for nutritional products	Section 159
Subsidies for physiotherapy	Section 67
Subsidies for psychological counselling	Section 69

Ē **The Danish Act on Primary and Secondary Education**

Complaints provisions	Section 51
National and regional educational provision	Section 20(3)
Special education assistance for preschoolers	Section 4
Special education assistance for schoolchildren	Section 3(2)
Special education and special education assistance	Section 20(2)

Get *more* information

Ë Books and leaflets

A host of books and leaflets have been published on the subjects described in this guide. Ask your health visitor or social worker if they know of any literature or other information about your child's particular disability. The library is another place to find help.

Ë Local authority websites

Your local authority website will inform you about the range of services offered – and about whom to contact. Find your local authority on www.kommune.dk.

Ë Organisations for parents and people with disabilities

www.handicap.dk – The Danish Council of Organisations of Disabled People (DSI) is an umbrella organisation for the Danish organisations for people with disabilities. The website contains links to organisations for parents and people with disabilities, tel. +45 36 75 17 77.

Ë consultancy and information

www.spesoc.dk – The National Board of Specialist Consultancy and Social Service. The Board consists of the Social Service Centre and the Specialist Consultancy Centre (VISO).

VISO (The Specialist Consultancy and Knowledge Centre) offers free specialist consultancy to private individuals and local authorities in the most exceptional and complex cases.

The Danish Centre for Assistive Technology, The Danish Centre for Rare Diseases and Disabilities (CSH) and the former county authority knowledge centres are among the bodies affiliated with VISO.

www.tilbudsportalen.dk - The facilities portal ('tilbudsportalen') gives an overview of social options in the disability sector: special day-care facilities, residential facilities and clubs. Members of the public and social workers can use the site to compare the options, their teaching methods, physical facilities and special services.

www.social.dk – The Social Portal (information and review of the area covered by the Ministry of Social Affairs).

www.csh.dk – The Danish Centre for Rare Diseases and Disabilities (advice and information about rare disabilities and diseases), tel. +45 33 91 40 20.

www.dukh.dk – The Impartial Consultative Service for People with Disabilities (counselling and guidance in complex individual cases) tel. 76 30 19 30, text tel.: +45 76 30 19 39.

About the guide

This guide is intended for parents who are expecting or already have a disabled child. It outlines the main sources of public sector help and support – in other words, the help offered by the social, health, cultural and education services.

The guide can be downloaded from The Social Portal: [**www.social.dk**](http://www.social.dk).