The Nordic Centre for Welfare and Social Issues

PILOT PROJECT CONCERNING MENTAL HEALTH FOR FAMILIES WITH A CHILD WITH DISABILITIES

Nordic Centre for
Welfare and Social Issues
&
The Information Office in Kaliningrad

Pilot project concerning mental health for families with a child with disabilities

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Preface

Since 2006 the Nordic Council of Ministers has been conducting a cooperation programme involving the Council, North-West Russia, Kaliningrad and the three Baltic States with a view to improving the situation for children with disabilities and their families. As part of this cooperation programme, parents of children with disabilities in Kaliningrad have attended workshops, seminars and courses. Based on the needs expressed in this cooperation, the decision was taken in 2010 to implement a project financed by the Nordic Council of Ministers.

The project was defined as a pilot project, the primary purpose of which was to help support the general situation of the families through a small number of families defining in close cooperation what concrete measures could help individual families.

One of the project's aims was to identify how to keep the families together and how to support them in becoming integrated in their community.

The secondary purpose of the project was that strong parent involvement in itself could enhance the family's perception of its ability to take control.

There was also a broad aim of influencing the general view of disabilities in a positive direction through the project.

Finally, the aim was to work out a design for the project so that it can be implemented elsewhere in the Nordic countries and surrounding regions.

The project was initiated and overseen by the Nordic Centre for Welfare and Social Issues in the person of Deputy Director Marianne Smedegaard. Lena Birch Christiansen, Section Leader at the "Children's House" residential institution for children with severe disabilities in the Municipality of Svendborg, was appointed project manager, with Mette Zierau Kudsk, formerly a specialist consultant with the Region of Southern Denmark, as project assistant.

The project is embedded in a national/regional steering group, which has been the steering group for the entire cooperation programme. The members of the steering group represent the Ministry of Social Affairs and Labour, the Ministry of Education, the Ministry of Health of the Government of the Kaliningrad Region, the Faculty of Pedagogics and Psychology of the I. Kant Russian State University and NGOs. (Appendix 1)

The project period ran from May 2010 to May 2011. The report was written in April 2011.

The project report was the product of intense, close collaboration, for which we would like to thank everyone involved. A big thank you goes to:

- the participating parents
- the steering group
- Christina Parkhomenko, the project coordinator from the Nordic Council of Ministers' Kaliningrad office
- Marina Yakusheva, the interpreter on the project
- the Zhemchuzhina and Special Child institutions
- Arne Grove, head of the Nordic Council of Ministers' Kaliningrad office
- Marianne Smedegaard, Deputy Director of the Nordic Centre for Welfare and Social Affairs and project manager

Mette Zierau Kudsk & Lena Birch Christiansen

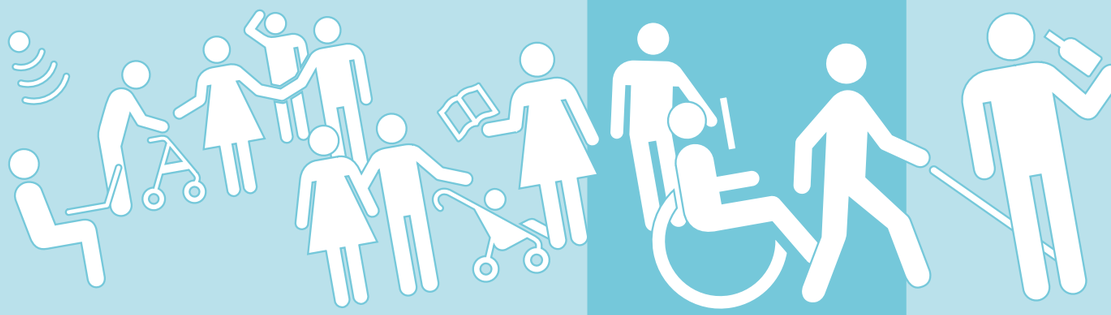
mental health for families with a child with disabilities

The report has been divided up so that the first section contains a number of problems as described by the parents.

The second section contains the parents' suggestions for measures that could improve these problems and make the everyday lives of the families better.

The third section is a detailed process and method description. This section aims to illustrate the process and the reflections that contributed to it with a view to it being possible to implement similar processes in the same or other social areas in Kaliningrad or in other countries.

It was our ambition to be completely open to the parents' perspectives. To be the parents' messenger.



Introduction

How do you find out what is needed to improve conditions for families with a child with disabilities?

You ask them!

The starting point for the project is to use the parents as a knowledge resource, since they know more about their own situation than anybody. By taking the parents' perspective – seeing problems and proposals with their eyes – and taking the parents' wishes and needs as a basis, we will acquire their knowledge and can use it as inspiration for changing practice and improving the present service. In other words, the parents will be seen as experts in their own practice, the practice that is their everyday life as a family with a child with disabilities.

What will we learn if we explore these everyday lives?

If we listen to the family's problems, wishes, needs and suggestions for change openly and whole-heartedly?

What answers will we get if we ask families with children with disabilities what problems they have?

What answers will we get if we ask the parents what initiatives are needed to help with their problems and their life situation with a child with disabilities?

What is important and essential for the parents?

What will we learn if we explore the lives of the families and engage ourselves in their narratives?

Can listening to the parents and involving them provide insights and ideas that can be used as inspiration to change practice?

What is needed to make the work being done even better?

The project report will provide answers to these questions.

The project is based on four families from Sovetsk and four families from Kaliningrad. All eight families have a child with disabilities.

The eight families were interviewed separately about the problems of being a family with a child with disabilities.

Material from these interviews was then structured and brought together in 11 headings.

These 11 headings were presented to the group of parents at seminars in Sovetsk and Kaliningrad held on one day for parents in Sovetsk and the next day for parents in Kaliningrad.

After the presentation the parent groups were asked to prioritise one or two headings that they would like to work on and suggest solutions for.

Both groups chose the heading "education" as their first priority. The parent group in Sovetsk chose "from child to adult" as its second priority, while the parent group in Kaliningrad chose "outreach by public services".

The prioritised topics were then discussed by the parent groups based on the question: "What initiatives are needed to solve the problem?"

Notes were taken throughout the discussions, with the suggested solutions that had been recorded being presented to the parents before the end of the seminar. The suggested solutions were subsequently structured into 23 proposals.

Project description

The following project description was drawn up at the start of the project in May 2010:

Title:
Pilot project concerning mental health for families with a child with disabilities.

Project goals:
To define what concrete measures can help families with a child with disabilities to enhance their situation.

How can the families be supported in
- keeping the family intact
- becoming integrated in the community

Subsidiary goals:
- To take the parent's experiences as a starting point and map them
- To identify the parents' needs
- To map barriers that create frustration
- To map the systems that underpin the families' service experiences
- To analyse what measures are needed to lower the barriers/improve the parents' situation
- To describe the aforementioned measures in concrete terms: who, how, when, how much
- To create a spirit and a space with the parents that inspires them to continue forming networks
- To describe the parents' expected output in these measures
- To tie the two user organisations closely to the project and the project's output
- To build on the results achieved in the three-year cooperation programme
- To structure and describe the project in a model that can be translated to other countries in the Nordic countries' neighbour regions.

Description/understanding the problems:
Problems in the families:
- high divorce rate
- problems caused by low income
- feeling excluded – lack of inclusion in the community
- the families do not know what support they are entitled to
- support is not coordinated
- the parents feel they are fighting a lonely battle

Project description:
The project is a bottom-up project:
- The families are knowledge suppliers,
- describing their situation as it is today
- helping to draft future solutions
- The families are co-developers
- The families provide qualified inspiration because the knowledge they generate is:
- Based on concrete reality
- Based on what is normal/typical

Method:
The work takes elements from:
- Systemic questioning
- Dream scenario
- Qualitative interview method
- Citizen-centred innovation

Use is made of:
- Quiet reflection
- Reflection in groups
- Group interviews
- Individual interviews

Authors Mette Zierau Kudsk (left) and Lena Birch Christiansen flanking interpreter Marina Yakusheva in Kaliningrad

Phases

- The project is divided into the following phases:
  - Phase 1: Preliminary visit
  - Phase 2: Introduction to the parent group
  - Phase 3: Individual interviews
  - Phase 4: Analysing, prioritising and des cribing concrete measures
  - Phase 5: Discussion of results, evalua- tion
  - Phase 6: Report writing
  - Phase 7: Presentation seminar

Output:

- Project report describing results from the project's phases and the final results in the form of concrete measures that can help families with a child with disabilities to en- hance their situation. The results will be written in a form that can be translated to other regions/countries.
- Process report describing the project proc- ess in such a way that the model can be translated to other regions/countries.
- The parents being inspired by the process to form networks.

Team and resources:

- Overall project owner: Marianne Smede- gaard, Deputy Director, Nordic Centre for Welfare and Social Affairs
- Project manager: Lena Birch Christiansen, Head of Section, Municipality of Svendborg, Denmark
- Project assistant: Mette Zierau Kudsk, Con- sultant, Denmark
- Local contact in Kaliningrad
- Russian/English interpreter
- Eight families with a child with disabilities
- Members of the steering group, including the Apparel and Maria user organisations

Project period:

- May 2010 – May 2011

Section 1

Problems and patterns from parent interviews in Sovetsk and Kaliningrad

Interview data:

The children:
4 girls and 4 boys aged 9 – 10 – 11 – 11 – 14 – 14 – 17 – 19 years

2 children with severe cerebral palsy (recumbent)
2 children with purely physical disabilities
6 children with communication problems
1 child with ADHD

The families:
Interviews with the children's primary carers: 6 mothers, 2 fathers and 1 grandmother
We define the primary carer as the person who looks after the child most.

3 families divorced. 4 families not divorced.
In 1 family the father was dead.

Work:
2 of the mothers interviewed were not in work. 6 primary carers worked.

Physical circumstances:
2 families live in a house.
6 families live in an apartment.
In several families a grandparent lives in the household.

Education:
1 child receives home schooling.
5 children receive no schooling (one of them has been offered home schooling).
1 child receives schooling at a private school.
1 child attends a special school.

Disabled organisations:
2 parents do not know of the disabled organisations.
2 parents used to be members of the Association for Disabled People.
3 parents have been a member of disabled organisations (either Maria or Apparel).

Residential care:
3 families have been offered a residential place, but decided against it because of condi- tions in the residential institutions.

Problems – Patterns

A pattern of 11 problem headings emerged from the eight family interviews. They are listed and enlarged on below. Direct quotes from the interviews have been added. The 11 headings are not in order of priority.

- Outreach by public services
- Knowledge and guidance
- Education
- Finances
- Child's social development
- Parents' ability to take paid work
- Help with communication
- Inclusion in the community
- Disabled organisations
- From child to adult
- Assistive technology

Outreach by public services

The families are in need of outreach by public services regarding help for the family.

- Parents have to seek help themselves.
- Parents lack knowledge regarding where to seek help.
- The help the family receives is down to chance and depends on whether the family knows someone who knows what help the family is entitled to and how to obtain it.
- Parents feel rejected by the system when they make inquiries.
- Parents lack knowledge of what is on offer (e.g. special nurseries, disabled organisations, etc.)

It's hard to find out what's on offer, because you don't know where to look

I heard about the special nursery somewhere

We sought the help we've received ourselves

Knowledge and guidance

Parents lack knowledge and guidance on being parents of a child with a specific disability.

Parents are in need of

- Better information on where they can learn about their child's disability.
- Knowledge and guidance (from an educationist, for example) on how they should act/what they should do in relation to their child with a specific disability.
- Courses and seminars for parents of children with the same disability.
- Literature on children with disabilities. Literature on diagnoses. Literature providing information.
- Advice from doctors and other specialists.
- Better information on the rules for support services. Information on changes in the rules.
- An accommodating attitude on the part of public bodies and institutions.
- Greater general awareness in the area of child disabilities.

It's as if there's very little interest in children with disabilities

It was learning by doing – and it was hard work

We've had to fight hard for everthing we've got. We weren't offered anything.

Education

Parents are in need of education provision for children with disabilities.

- Some children are regarded as unsuitable for education. They are not offered any form of schooling.
- There is no education provision for children with no spoken language.
- Parents lack education provision that does not take the form of traditional schooling, but is customised.
- Education provision is not adapted to the individual child's disability.
- Parents lack teachers who know about their children's special individual needs.
- Parents are not given the chance for children with physical disabilities to attend mainstream schools.
    - The physical conditions at the school are not adapted for children with disabilities.
    - Children who are unable to sit cannot be taught in school.
- Some children are offered home schooling. When they are taught at home, children do not have the chance to take part in the normal social life of school.
- Parents lack provision for physical exercise and massage.
- Transport to a special school is often difficult, especially for children with physical disabilities (there are a lot of bus changes or the children are carried by their parents).
- Parents are in need of communication teaching.
- Parents do not have the chance for their child to be taught/guided to change behaviour.
- In general parents describe it as a problem and tough that they as parents should have to teach their child everything and be responsible for their child's whole education.

> It's such a shame that there isn't a group where she could spend time with other children at her own level of development

> It's been difficult that he wasn't entitled to go to school and it's our responsibility to teach him something all the time

> If an educator could come and instruct him and teach him something. He's developing

> Parents have to carry their children to the special centre or push them in bad wheelchairs

Finances

- Parents lack money for the relevant treatment they would like, e.g. operations.
- Parents lack money for a special diet.
- Some families pay for services for their children themselves (speech therapy and massage).

Child's social development

- As there is no provision for education in school, children do not have the chance to meet other children there.
- Parents lack the opportunity for their children to spend time with other children with the same problems and at the same level of development – in a small group if necessary.
- More and more children are going to day care. Children with slight disabilities are given priority, which means that provision is being cut back for children with more severe disabilities or disappearing altogether.
- Transport to day care is difficult. Children with severe disabilities have to be carried there.

Parents' ability to take paid work

The child either has no day care or day care that is of shorter daily duration than a working day. The mother therefore has to remain outside the labour market, work part time or work in the child's special needs provision. This means that the families of children with disabilities are often worse off financially than families without children with disabilities.
The families choose or adapt work to suit everyday life with a child with disabilities, e.g. working nights as a security guard or shifts.
Most families are reliant on family help to look after the child when the parents are at work.

- Care provision for children with disabilities and the labour market are not a good fit. The special centre closes before the working day ends and/or care is only available at the special centre every other day.
- Parents need
    - Jobs that offer the necessary flexibility day to day.
    - Jobs where shorter hours can be worked.
    - Longer opening hours for special needs provision.
    - The option of day care every day.

Help with communication

Parents and children develop their own language.

- This internal language helps to reinforce the child's dependence on its mother.
- There is no help for parents in the form of information on total communication or assistive communication technology.

When we're out, we're asked so many questions about the child that it's tiresome. People aren't used to seeing children with disabilities

Inclusion in the community

Opportunities for parents to socialise outside the home.

- The primary carer cannot leave the home. There are no minding options for the child.
- People are not used to seeing children with disabilities, so it is difficult for parents to be around other people with the child.
- Parents of children with severe spasticity are reliant on family help to move the child.
- Families need a respite option to enable the primary carer to work on ordinary terms.
- Families need a respite option to enable them to do things together in their spare time.

There's a lot to do and no spare time for socialising, plus I can't leave the child alone at home for any length of time

The whole family can't go out together very often

Disabled organisations

Membership or awareness of disabled organisations.

The disabled organisations can help with the following:

- Summer camps for children without their parents – respite for parents.
- Interesting talks
- Good outings
- Experience sharing
- Friendships

The disabled organisations lack knowledge of children with severe disabilities and have no provision for parents of children with severe disabilities.

The organisations – they're not interested. It's mortifying. They don't know what the problems are and so can't understand them.

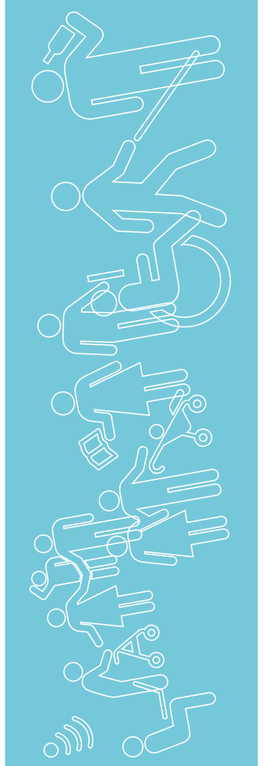
From child to adult

Parents express doubts and uncertainty about the future.

- In the short term:
    - Activity provision disappears completely at 18.
    - The children are getting heavier and harder to move.
- In the longer term:
    - What will happen to the child when the parents die?
    - Doubts about whether the child will cope socially (risk of social exclusion).
    - What is going to happen health-wise.
    - How will the young person cope without close contact with his/her primary carer (dependent on primary carer)?
    - Where will the young person live when s/he leaves home?

Assistive technology

- Moving around at home
- Transport



Section 2

Suggested solutions

The 11 headings were presented to the Sovetsk and Kaliningrad parent groups at half-day seminars held in Sovetsk and Kaliningrad.

After the presentation, the parents were asked to prioritise one or two headings that they would like to work on together and suggest solutions for.

Both groups chose the heading "education" as their first priority.

The parent group in Sovetsk chose the heading "from child to adult" as its second priority, while the parent group in Kaliningrad chose "outreach by public services".

No suggested solutions were put forward on the topic of "from child to adult" for reasons of time.

Both parent groups mentioned that it was difficult to prioritise because all the topics are intertwined.

The prioritised topics were then discussed by the parent groups based on the question: "What initiatives are needed to solve the problem?"

Notes were taken throughout the discussions, with the suggested solutions that had been recorded being presented to the parents before the end of the seminar.

Through the discussions it became clear that the attitude to children with disabilities is a problem that overarches the 11 problems described.

There follows a list, in no particular order, of the suggestions made by the parent groups in Sovetsk and Kaliningrad with regard to the initiatives that would solve or at least ease their problems with education and outreach by public services.

Education

- Home schooling / a special teacher at home.
- Respite for a few hours a day, when the child can go somewhere and education can be offered.
- Training special teachers to teach children with different disabilities.
- A communication group for children who are unable to communicate with spoken language. This would make a great difference to their experience of being in a group where there is alternative communication.
- Option for parents to pay for a special group.
- Further education for intelligent children who cannot attend a normal school because of a physical disability.
- Financial support for expansion of the existing special centre (Zhemchuzhina) so that it can offer provision for all children.
- If their child-minding needs were covered, parents would have a better chance of working full time.
- More financial help with medical treatment.
- Provision of psychological help for parents with children with disabilities.
- Centre where parents can go for help and support.
- Publicising the problems involved in having children with disabilities. Any publicity should take account of the vulnerability of individual families.
- Parent groups/network groups.
- Joining forces makes a bigger impact.
- Focusing on attitudes to the parents.
- The parents being treated with respect when their problems are being dealt with in the public systems. Staff being aware of the parents' problems.
- Greater sympathy and accountability on the part of public offices.
- Parents being entitled to a free choice of school/education for their child while the child lives at home – so that the child is not excluded from the home. There are various suggestions for how this can be achieved:
    - A school in the immediate environment.
    - There are examples of children with Down's syndrome attending a normal school – primary school (up to year 4/age 9). It is suggested that this should be extended to children with more disabilities and to secondary school.
    - Home schooling.
    - This would be a step towards the children receiving schooling every other day.
- The decision as to what schooling the child should be offered and where should be taken on an individual basis.
- A professional with knowledge of the child should be in attendance when assessments are made by the Medical Board. There should be a report from the person who knows the child.
- The parent organisations should write to the ministries about their need for support.
- An information system should be set up so that parents know where they can obtain information about their legal rights.
- A parent seminar at which parents can meet representatives of the ministries and tell them about their problems and what they need.
- A ministry should be set up for people with disabilities, among other things to make it easier for citizens to know where to make inquiries. And/or a special government department for people with disabilities. This would give people with disabilities equal representation – and therefore the possibility of equal rights in society.
- More publicity, which could help to change the general attitude to people with disabilities.

Outreach by public services

- A coordination centre within the public sector like the one that Kant University tried to set up with a Polish donation. A centre where parents can find out where to get help and what help they are entitled to. It would have:
    - an advice hotline
    - trained coordinators
    - helpers to give families individual assistance
    - helpers who are employed at the centre (so it is not reliant on volunteers)
    - professional legal advice

- Guide for parents.
  The "Guide for parents of children with disabilities. Help and support" is expected to come out in May.
  The guide for parents will provide a summary of public support services and voluntary organisations in Kaliningrad.

Section 3

Process and method description

The description of the process and methods used will cover the following:

- Division of the project into phases
- Selection of parents
  - Methods used
    - Presentation
    - Interviews
    - Structuring
    - Group discussions
- Ethical considerations
- Evaluation

Division of the project into phases

Right from the start of the process the project was structured in phases with a description of content and timeframe.
The phase description guided the project throughout the process, but the number of phases and implementation dates were adjusted as changes were made in the project content.
Each phase started in Kaliningrad with a kick-off meeting with the project coordinator.
Each phase ended in Kaliningrad with a steering group meeting for reporting, feedback and securing continued support.

Here follows a description of the individual phases.
The complete phase description can be found in Appendix 2.

Phase 1:
14-16 June 2010
Presentation of project to the steering group
The steering group expresses support for the project.
Importance is attached in the project to parents outside the city of Kaliningrad taking part too. This is because there are often different options and more resources in a large city, and the intention is that this project should also cover areas with fewer resources.
For transport reasons it is not considered realistic for parents who do not live in the city of Kaliningrad to take part if the project is not run locally. It is therefore decided to split the project, with part of it taking place in Sovetsk and part in Kaliningrad.
The number of families is also increased from eight to ten. Five in the Sovetsk area, five in the city of Kaliningrad. This is because a group of four in each place would be very vulnerable if anyone were to drop out.
The steering group says that the proposed method involving individual interviews in the home can be used.
It is agreed that a confidentiality agreement will be drawn up and interpreting will be taken care of by a single interpreter throughout the project.
Great importance is attached to the ethical basis for the project being given high priority.
Practical agreements on local partners are entered into.
It is agreed that the members of the steering group will be in charge of selecting parents based on closely defined criteria.
It is agreed that each phase in Kaliningrad will end with a meeting of the steering group so that the steering group can monitor the project closely with regard to follow-up and feedback.

Phase 2:
20-23 September 2010
Presentation of project to the parent groups
Four parents from Sovetsk meet in Sovetsk and four parents from Kaliningrad meet in Kaliningrad. One family from Sovetsk and one family from Kaliningrad did not want to take part in the project.

The project – including goals and timetable – is presented to the parents.

The parents introduce themselves to each other.

Expectations for participation in the project are coordinated.

A confidentiality agreement is handed out and several parents sign immediately.

Eight parents make it know that they would like to take part in the project.

Phase 3:
18-21 October 2010
Interviews with four primary carers in Sovetsk. Individual interviews that take place in the home.

Phase 4: 15-18 November 2010
Interviews with four primary carers in Kaliningrad. Individual interviews that mainly take place in the home.

Phase 5: 21 – 24 March 2011
Group discussions in Sovetsk and Kaliningrad.
The four parents from Sovetsk meet for a half-day seminar at which the structured problems from the interviews are presented. The group prioritises and discusses what concrete measures could enhance their situation.
Two parents from Kaliningrad meet for a half-day seminar at which the structured problems from the interviews are presented. The group prioritises and discusses what concrete measures could enhance their situation.

Phase 6: March – April 2011
Report writing

Phase 7: 17 May 2011
Project presentation

Selection of parents

It is agreed at the first steering group meeting that the steering group will be responsible for selecting the ten parents who are to be offered the chance to take part in the project. This is done on the basis of the following selection criteria:

- Five families in the city of Kaliningrad – or so close to the city that it will be possible for the families to attend meetings in Kaliningrad.
- Five families from Sovetsk – or so close to Sovetsk that it will be possible for the families to attend meetings in Sovetsk.
- The families must have a child with a disability.
- The child must live at home.
- The child must be between 0 and 18 years of age.
- Single parents can take part. If there are two parents in the family, it is desirable for both parents to take part in interviews and meetings.
- Different disabilities must be represented in the group of children.
- Children with severe disabilities should be well represented.
- Different ages must be represented in the group of children.

Two of the ten parents did not want to take part in the project.

Methods used:

Presentation
The project involved several types of presentation:

- project to parents
- parents to us
- us to parents
- parents to each other
- project and process to steering group

Presentation of the project to the parents
We attached importance to presenting the project in such a way as to create confidence in the project among the parents. Great trust is required to take part in a project where parents have to talk about their very personal, private problems. Where intimate problems are brought out into the open.

It is also necessary to create a high degree of trust when parents are taking part in in a project where they are expected to describe possible developments and suggested solutions themselves. This is not the more traditional sort of project in which help is provided with solving problems. The participants have to play an active role in suggesting solutions, while the role of the project staff is to facilitate the parents' problems and suggestions.

From the first meeting it was stressed to the parents that it was their project and we were their messenger. We stressed that they possess the knowledge needed to suggest changes.

Presentation of us to the parents and the parents to us
By agreeing to take part in the project, the parents showed great faith in us and entrusted us with an important task.
Talking about problems to do with their own child and family usually makes people feel very vulnerable.
The first meeting is vital in determining how the interviews with the parents will go. They must feel that they are being treated equally and with dignity, and that the dialogue is being conducted on their terms.
When two people work together on such a task, it is part of the preparation to clarify the importance of the different phases of an interview. The division of roles needs to be discussed, as both cannot have the same weight, e.g. who kicks off and how to complement each other during the interview.

It was important for us to establish a relationship of trust with the parents based on:

- ensuring anonymity
- being sympathetic and giving them our full attention
- respecting the parents' reactions and statements
- not being judgemental
- creating space for confidences
- making time for informalities (coffee, looking round the house, etc.)
- being a team that knows where we and each other are - accommodating complexity and maintaining calmness, control and a sense of security, both individually and together, when unexpected situations or strong emotional responses occur.
- radiating respect for each other in our cooperation – "walking your talk" when we work together, with our "talk" being about respect, understanding, security, giving each other space.
- In the individual situation we set the direction based on a coordinated understanding, because we share perceptions, impressions and considerations with each other all the time and use this for joint reflection and critical feedback.

Presentation of the parents to each other
It was important to create an atmosphere in which the parents felt secure about opening their hearts to each other.

Presentation of the project and follow-up to the steering group
We attached importance to describing the parents' problems and suggestions honestly, keeping to our role as their messenger.

Interviews
Eight interviews of the children's primary carers were conducted individually at home.
The interviews were conducted using the qualitative method, which aims to gain an insight into the interviewees' experience of their own situation.

Home interviews were chosen for several reasons:

- Talking to the parents in context improves the chances of understanding the family's situation, including in particular the opportunity to meet the children.
- The security for the parents of being on their own ground.
- At our first meeting with the parents in phase 2 we gained the distinct impression that it can be difficult for the parents to leave the home.

The interviews were conducted using an interview guide (Appendix 3) that had been drawn up based on the methods of the semi-structured research interview, the purpose of which is to understand the topics described from the interviewees' perspective and the form of which means that the interviewer follows up the avenues opened up by answers during the interview.

In the dialogue with parents there is a need to balance communication so that the desired information is obtained, while the parents feel that there is time and space to say what is most on their minds.

There were two dimensions to the interviews. Firstly there was a question guide, which formed the basic element in the study, and secondly there was a free, open dialogue with the parents, where they were given time to speak freely about subjects of most relevance to them.

The interview was conducted by one project worker, while the other made notes. These roles were reversed from interview to interview. A structured interview record was produced after each interview.

The interview started with a short briefing on the project and establishing contact. This was followed by the interview, which ended with the interviewee having the opportunity to ask questions and being told about the further course of the project.

Two families were interviewed each day.
With all the visits we were expected, contact was established quickly and the interview stuck to the subject. All this meant that the two hours scheduled for each interview proved ample and appropriate.

Structuring
After the eight interviews we produced a joint interview compilation and structured compilation made up of 11 headings with explanatory text.
Direct quotes from the parents were added because it would have blunted the content if we had tried to paraphrase.
After the group discussions the suggestions were compiled in structured form.

Group discussions
The parents met in group contexts twice:
At the presentation of the project and the presentation of the parents and ourselves to each other in phase 2.
At the presentation of the structured problems and discussion of solutions and suggested improvements in phase 5.

The purpose of the group discussion was:

- joint information
- for the parents to inspire each other by discussing shared problems and solution models
- for the parents to get to know each other, providing a basis for possible network forming

In the group contexts where the parents met it was important for us:

- to create a congenial, confidential atmosphere
- that the parents should meet in an open dialogue with a respectful, positive approach to each other
- that there should be confidence between the participants
- that everyone should contribute to the discussions on topics openly and honestly

Ethical considerations
We took great care to focus on ethics in the process.

It was important to be able to ensure the parents' anonymity in the project. A written form describing the project was drawn up. This form was signed by parents and project staff.
Importance was also attached to the same interpreter doing all the interpreting for the project.

From the first interviews we realised that we found ourselves in a moral dilemma. The children were present during the interview in all cases. Sometimes because the children were curious about what was going on. At other times because it was the only practical option. Where we thought it practically possible, we encouraged the parents not to have the children present owing to the subject matter of the interview.

We told the parents about our ethical dilemma of talking about the children while they were present, as it is part of our view of the world to differentiate between what children should and should not be a part of.

Evaluation
At the end of phase 5 we asked the parents to answer two questions in writing. The questions were handed over and we received five completed evaluations.

The evaluation questions were as follows:
What was the most important thing about taking part in the project for you?
What was the experience of taking part like for you?

In the evaluation the parents attached importance to the following:

- It was good that attention was being paid to the area
- It had been good:
  - to be able to talk about their problems openly
  - that someone listened and showed an interest in their problems
  - to have the chance to talk to other parents in the same situation
  - hat the atmosphere in meetings was always positive, friendly and professional
  - that being able to share problems, express pain and receive moral support is of great psychological importance
- Several mentioned that taking part had given them hope for the future

Conclusion

Eight families with children with disabilities described their problems. The problems were thematised in 11 headings.
The parents concluded that all 11 problems are important and no one problem can be seen in isolation.

One of the problems that cropped up in all the interviews was ”attitudes to people with disabilities”. The parents feel that they have to fight for their children to get special support and help.
Some parents feel that they are looked down on when they go into social contexts with their children, because people are not used to respect for and openness surrounding people with disabilities.

The parents drew up a catalogue of solutions and suggested solutions for one prioritised area in particular, ”education”. Solutions were also suggested with regard to ”outreach by public services”.

The families expressed satisfaction with taking part in the project. They say that being asked makes them feel listened to, and being taken seriously and having the opportunity to express their needs and wishes gives them hope for the future.

This report and its results are hereby submitted to the steering group.

Putting into perspective

During the process the parents made the following suggestions for follow-up projects:

- Communicating with children with severe communication problems
- Seminars for parents on subjects like: From child to adult – how should parents tackle it?

Bibliography

We took inspiration from the following books for the project work:

Steinar Kvale: InterView. Introduktion til et håndværk (InterViews: Learning the Craft of Qualitative Research Interviewing). 2009.

Christian Bason, Sune Knudsen, Søren Toft: Sæt borgeren i spil. Sådan involverer du borgere og virksomheder i offentlig innovation (Put the citizen into play: How to involve citizens and businesses in public sector innovation). 2009.

Mette Zierau Kudsk
She is a speech and language therapist by profession since 1973. Alternative communication from different perspectives is her line of education: Hahnen therapist, Marte Meo, course leader in Total Communication at Vikom - (The Danish Resource Centre on Communication and Multiple Disabilities concerning Children and Young People without Spoken Language).
AVT therapy (auditory-verbal-therapy).
She has worked for 39 years with children, young people and adults with severe communication disabilities as a result of congenital or acquired brain disorders.

Lena Birch Christiansen
Since 1997 she has been head of department at Byhaven Børnehuset in Svendborg, a 24-hour care centre for children with severe physical and mental disabilities.
She is a social educator by profession since 1982 and has widespread experience within her field of expertise. She has worked with psychiatric patients in Greenland and on a disability project for ”MS ActionAid Denmark” in Kenya.
She has been associated with several projects as an educator or project worker, in e.g. Poland, Estonia, Lithuania and Kaliningrad.

The authors

Appendices

Appendix 1 - Members of the steering group:

Marianne Smedegaard
Per Gunvall
Lena Birch Christiansen
Arne Grove
Christina Parkhomenko
Larisa Barkovskaya
Alexey Goncharov
Natalya Tikhonova

Svetlana Shpilevaya
Natalia Starovoyt
Natalia Nikulina
Zoya Kochetkova
Alla Osipova
Sergey Kiseliov
Anna Kovalchuk

Appendix 2

Phase description.
Pilot project concerning mental health for families with a child with disabilities.

Phase	Act. No.	Country	Activity heading
1	2010-1	Ru	Project introduction for steering group

Preparation
Draw up project and phase description for submission to the steering group. Including questions for clarification by the steering group.

Time	Part	Yr	Mth	Wk	Day	Description
1 day	A	2010	6	24	15	Meeting with the steering group: Present the project to the steering group. Discussion and feedback.
	B					Enter into agreements with the two user organisations, Apparel and Maria, on the selection of 8 families with a disabled child. In the selection Apparel and Maria will make sure that the families know the terms and are motivated to take part.
	C					Make practical agreements for: interpreter, premises, catering for the families during the project, local contact/organiser (possibly Christina).

Participants
Lena Birch Christiansen, Marianne Smedegaard, Arne Grove, members of the steering group, including members of the Maria and Apparel user organisations

Expected output
Project presented to the steering group. Feedback from the steering group and expression of support for the project. Maria and Apparel, the two user organisations, have committed to active participation in the project. The two user organisations have undertaken to select the eight families to take part in the project and the understanding of how the families are to be selected has been coordinated. A local contact/organiser has been appointed who Lena can contact and ask to arrange invitations, premises, catering and transport, etc. Various questions concerning project content have been clarified, e.g. whether it will be possible from a purely practical point of view to organise individual interviews with the parents and whether it will be practically possible for parents from rural areas to take part (which is desirable).

Goal achievement indicators
The support of the steering group has been secured. User organisations Maria and Apparel have taken on the task of selecting the eight families. Maria and Apparel have committed to active involvement in project follow-up. A local organiser/contact has been appointed.

Results
The project was presented to the steering group, which gave it strong support.
To ensure that parents outside Kaliningrad can take part, it has been decided that part of the project will take place in Sovetsk and part in Kaliningrad. The number of families is also being increased from eight to ten.
The steering group has undertaken to select the ten families on the basis of defined criteria, which will be sent to the members of the steering group.

A project coordinator from the Nordic Council of Ministers' Kaliningrad office has been appointed, Christina Parkhomenko.
An English/Russian interpreter has been appointed, Marina Yakusheva. Importance is attached to Marina Yakusheva acting as interpreter for the entire project.
Importance is attached to the project being conducted with ethical considerations in mind, such as the parents being guaranteed anonymity. A statement of consent must be drawn up.
The steering group has agreed that the proposed method involving individual interviews can be used.
It is agreed that each phase will end with a steering group meeting for follow-up and feedback.

Phase	Act. No.	Country	Activity heading
2	2010-2	Ru	Project presentation to parent group

Preparation
Edit and finalise project and phase description based on input from steering group meeting. Draw up selection criteria to send to the members of the steering group. Draw up confidentiality agreement (informed consent statement). Draw up detailed programme for phase 2. Make practical arrangements for meeting premises, catering, transport, accommodation, working group meeting. Draw up presentation of the project. Draw up question guide for parent presentation.

Time	Part	Yr	Mth	Wk	Day	Description
3 days	A	2010	9	38	21	Project presentation for 5 sets of parents in Sovetsk. Context clarification with the parent group. Parents introduce themselves to each other.
	B					A shared social experience to create a good spirit in the parent group.
	C					Transport from Sovetsk to Kaliningrad.
	D				22	Project presentation for 5 sets of parents in Kaliningrad. Context clarification with the parent group. Parents introduce themselves to each other.
	E					A shared social experience to create a good spirit in the parent group.
	F				23	Meeting with the steering group for status report and feedback.

Participants
Lena Birch Christiansen, Mette Kudsk, Marina Yakusheva, Christina Parkhomenko. 10 sets of parents, the members of the steering group, including members of the Maria and Apparel user organisations.

Expected output
The objectives and framework for the project have been presented to the parents. The parents have introduced themselves to each other and shown that they are comfortable about opening their hearts in the group. A good atmosphere of trust has been created in the group. Agreement has been reached on participation and project follow-up by the user organisations. Continued support from the steering group.

Goal achievement indicators
We have gained an impression of the families and their problems. A good, confident spirit in the parent groups, where the parents have shown an interest and desire to take part in the project as knowledge suppliers and co-developers. Active parent participation and engagement in the form of questions and comments. Commitment on the part of the user organisations to participation and follow-up.

Results
The project was presented to five families in Sovetsk.
The families are represented as follows: One couple, two single mothers, one grandmother who is bringing the child up, one single father. Two parents brought their child with a disability to the meeting.
The parents arrived in dribs and drabs. They had been told little or nothing about the project when they were selected. They all thought that the project included medical treatment.
The purpose and framework of the project were presented with the emphasis on the project giving the parents the opportunity to publicise their problems and suggestions for change, and it being the parents who would determine the content of the project. The parents contributed questions and comments.
The parents introduced themselves to each other. The atmosphere was one of trust and people communicated with great openness. The five families were given the project contract, which includes a confidentiality agreement. Four families signed on the spot. One mother had to leave before the meeting finished and took the contract home with her. The four participating families were open and accepting with regard to the home interviews.
Lunch had been planned for after the meeting and the parents invited. They all declined because of having to go home to their child with disabilities.

The project was presented to three families in Kaliningrad.
Two families were represented at the start of the project presentation in Kaliningrad. One parent had said in advance that she would be late, but did not turn up. We contacted two families by phone. They were unwell. One of them came along later after all and was given a presentation. The parents were represented as follows: One couple and two single mothers.
The atmosphere was one of trust and the parents introduced themselves in an open manner. They contributed questions and comments. Here too the project was presented with the emphasis on the goal being to publicise problems, potential and the parents' suggested solutions. The three families signed the project contract on the spot.
All the parents were very accommodating regarding the interviews to be held in the home.
Lunch had been planned for after the meeting and the parents invited. One couple accepted. Two parents declined, firstly because they needed to get home to their child with disabilities and secondly because one mother was clearly unwell. At lunch there was a relaxed dialogue about their child.

In total written agreements were signed with families for seven children regarding participation in the project. The goals and framework for the project were presented. Two days before the presentations we were told by the project coordinator in Kaliningrad that several parents had not been given the written description of the project and that several in Sovetsk were very sceptical about participation the project and had to be talked into attending the presentation. Our focus and goal for this phase was therefore changed from clarification and supplementary information regarding the project to providing fundamental information on the project and, in particular, generating confidence and trust in the project. We therefore consider it to be a great success that all five families attended the meeting in Sovetsk, with four of the families signing the participation documents on the spot.

We gained an impression of the families, including some problems that we can use in our interview preparation.
The parents were told when we expected the individual interviews to take place and how the specific arrangements would be made.

The "Guide to parents with a child with disability" was mentioned.

A meeting was held with Arne Grove, Director of the Nordic Council of Ministers' Kaliningrad office, and Christina Parkhomenko, the project coordinator from the office, regarding the project status.

A steering group meeting, at which the project status was presented, was held with ten participants, including representatives of the Maria and Apparel user organisations. The steering group gave feedback and expressed continued support for the project.
It was proposed and agreed at the meeting that the question guide that was being prepared would be presented to the steering group for its information before the parent interviews.

Phase	Act. No.	Country	Activity heading
3	2010-3	Ru	Individual parent interviews

Preparation
Collate and structure the parent presentations. Produce interview guide. Draw up detailed programme for phase 3 and make practical arrangements regarding interview times, transport, accommodation, steering group meeting.

Time	Part	Yr	Mth	Wk	Day	Description
3 days	A	2010	10	42	19	Visit two families in Sovetsk and interview them about their life situation and need for support.
	B					Interview collation
	C				20	Visit two families in Sovetsk and interview them about their life situation and need for support.
	D					Interview collation
	E					Transport from Sovetsk to Kaliningrad
	F				21	Meeting with the steering group, including representatives of the user organisations, for status report and feedback

Participants
Lena Birch Christiansen, Mette Kudsk, Marina Yakusheva, Christina Parkhomenko, four sets of parents, members of the steering group, including members of the Maria and Apparel user organisations

Expected output
Material briefly describing each family's life situation. Material identifying the problems, need for support and barriers that create frustration defined by the individual sets of parents based on their experiences. Material mapping the systems that underpin the families' service experiences. Interview material collected in a good atmosphere of trust.

Goal achievement indicators
Interview record from four family visits with the emphasis on the families' problems and needs in relation to having a child with disabilities. The parents being open about their problems and needs in the interviews. Continued support from the user organisations.

Results
Four families in Sovetsk were interviewed about problems and needs in relation to having a child with disabilities.
Four structured records of the interviews were produced.
All the families showed great openness when telling their story, including their problems, thoughts and wishes.

Method:
The interviews were held individually in the families' homes. Home visits were chosen for several reasons: 1) In order to talk to the parents in context, which improves the chances of understanding the family's situation, including in particular the opportunity to meet the children. 2) The security for the parents of being on their own ground. 3) At our first meeting with the parents we gained the distinct impression that it can be difficult for the parents to leave the home.

The interviews were conducted using an interview guide that had been drawn up based on the methods of the semi-structured research interview, the purpose of which is to understand the topics described from the interviewees' perspective and the form of which means that the interviewer follows up the avenues opened up by the answers during the interview.
The interview was conducted by one project worker, while the other made notes. These roles were reversed from interview to interview. A structured interview record was produced after each interview.
The interview started with a short briefing on the project and establishing contact. This was followed by the interview, with the question guide acting as a framework, within which the order and wording of questions were adapted to the individual's history. The interview ended with information on the further course of the project and the parents having the opportunity to ask questions.

Two families were interviewed each day, one in the morning and one in the afternoon.
Each interview involved transport to and from the family and writing the interview up. Priority was given to writing a structured record immediately after each interview to keep the individual interviews separate.
Christina Parkhomenko, the project coordinator from the Nordic Council of Ministers' Kaliningrad office, had made appointments with the families for the interviews prior to the visits. They were told that we were flexible about the time of each interview, as we considered it important that the time should be convenient for the families.

With all the visits we were expected, contact was established quickly and the interview was structured on the basis of the question guide. All this meant that the two hours scheduled for each interview proved ample and appropriate.
Each family was given a box of chocolates as a thank you for taking part in the interview.

From the first interviews we realised that we found ourselves in a moral dilemma. The children were present during the interview in all cases. Sometimes because the children were curious about what was going on. At other times because it was the only practical option. Where we thought it practically possible, we encouraged the parents not to have the children present owing to the subject matter of the interview.

A steering group meeting was held with four participants, including representatives of the Maria user organisation, the Ministry of Education and the university. A status report on the project was given. The steering group asked amplifying questions regarding methods and results and expressed its continued support for the project.

A status and planning meeting was held with Christina Parkhomenko, the project coordinator from the Nordic Council of Ministers' Kaliningrad office.
A meeting was held with Arne Grove, Director of the Nordic Council of Ministers' Kaliningrad office, to give an update.

Phase	Act. No.	Country	Activity heading
4	2010-4	Ru	Individual parent interviews

Preparation
Structure interview records. Draw up detailed programme for phase 4. Make practical arrangements for transport, accommodation, working group meeting.

Time	Part	Yr	Mth	Wk	Day	Description
3 days	A	2010	11	46	16	Two interviews of families in Kaliningrad regarding their life situation and need for support.
	B					Interview collation
	C				17	Visit two families in Kaliningrad and interview them about their life situation and need for support.
	D					Interview collation
	E				18	Meeting with the steering group, including representatives of the user organisations, for status report and feedback

Participants
Lena Birch Christiansen, Mette Kudsk, Marina Yakusheva, Christina Parkhomenko, four sets of parents, the members of the steering group, including members of the Maria and Apparel user organisations.

Expected output
Material briefly describing each family's life situation. Material identifying the problems, need for support and barriers that create frustration defined by the individual sets of parents based on their experiences. Material mapping the systems that underpin the families' service experiences. Interview material collected in a good atmosphere of trust.

Goal achievement indicators
Interview record from four family visits with the emphasis on the families' problems and needs in relation to having a child with disabilities. The parents being open with regard to their problems and needs in the interviews. Continued support from the user organisations.

Results
Four families in Kaliningrad were interviewed about problems and needs in relation to having a child with disabilities. Three interviews took place in the family's home. One interview took place at the Nordic Council of Ministers' office at the mother's request.
Four structured records of the interviews have been produced.
All the families showed great openness when telling their story, including their problems, thoughts and wishes.

The interview phases are now complete.
The original starting point for the project was to interview eight families. At the preliminary steering group meeting in June 2010 this was changed to ten families.
Two families declined to take part: one family from Sovetsk and one from Kaliningrad.

The complete interview material is now based on interviews with eight families, four families from Sovetsk and four from Kaliningrad.
2 families selected by NGO Maria
2 families selected by the Ministry of Social Affairs and Labour
1 family selected by NGO Apparel
2 families selected by the Ministry of Health
1 family selected by the Ministry of Education
Of the two families who did not wish to take part, one was selected by Apparel and one by the Ministry of Education.

A total of four structured records of the interviews have been produced.
A pattern of common themes emerges with regard to problems.

Method:
The same interview methods as described for phase 3 were used.
Based on experiences from phase three, half an hour longer was set aside for writing up the interview after each visit (an hour and a half in total). The journey time to/from the families was longer (by taxi/bus) than in Sovetsk.

Status meetings:
A steering group meeting was held with five participants, including representatives of the Apparel user organisation, the Ministry of Education, Kant University and the Nordic Council of Ministers' Kaliningrad office.
The steering group asked amplifying questions regarding methods and results and expressed its continued support for the project.
It was discussed at the meeting how the results of the report can be used. The concrete dilemma of child minding in the next phase was solved.
The content for phase 5 was presented.
There are separate minutes from this meeting.

Phase	Act. No.	Country	Activity heading
5	2011-5	Ru	Parent group discussions

Preparation
Collation, analysis and structuring of interview material. Structuring of needs. Questions and process guide for selecting problems and group discussions on possible solutions. Letter to the Special Child and Zhemchuzhina institutions concerning help with child minding. Practical arrangements with local contact.

Time	Part	Yr	Mth	Wk	Day	Description
3 days	A	2011	03	12	22	Meeting with parents in Sovetsk. The needs identified in the interviews are presented to the parents in structured form. The parent group prioritises and selects the needs/problems/barriers that they want to work on/suggest solutions for.
	B					The parent group suggests possible solutions and works out measures for improving their situation. The measures are described in concrete terms: (who, how, when, how much).
	C					Transport from Sovetsk to Kaliningrad

	D				23	Meeting with parents in Kaliningrad The needs identified in the interviews are presented to the parents in structured form. The parent group prioritises and selects the needs/problems/barriers that they want to work on/suggest solutions for.
	D					The parent group suggests possible solutions and works out measures for improving their situation. The measures are described in concrete terms: (who, how, when, how much).
	E				24	Meeting with the steering group, including representatives of the user organisations, for status report and feedback.

Participants
Lena Birch Christiansen, Mette Kudsk, Marina Yakusheva, Christina Parkhomenko, eight sets of parents, members of the steering group, including members of the Maria and Apparel user organisations

Expected output
All the needs produced through the interviews were presented to the parents. The parents discussed and prioritised the needs. The parents drew up suggestions for concrete possible solutions and measures. A spirit was created in the parent group that inspired the parents to continue network forming.

Goal achievement indicators
Material with concrete, realistic suggestions for possible solutions and measures produced by the parents. An emphasis on possibilities in the parent group. The parents talking to each other about problems and solutions. Incipient network forming.

Results
All four families in Sovetsk attended the seminar in Sovetsk.
The seminar was scheduled to run from 9 am to 3 pm. We were aware beforehand that it was difficult for the parents to attend meetings outside the home for several hour because of their child having to be cared for. Through Natalia Starovoyt from the Institute of Modern Education, Kant University, we arranged for volunteers from the university to look after the children. We contacted the Zhemchuzhina and Special Child day care centres and asked for their assistance. We asked if they could make a room available for the children and volunteer helpers. We also asked whether staff from the centres could help the volunteers with the specialised care that would be needed.
The child-minding arrangements did not come off.
The parents told us that they would only be able to take part in the seminar for ½ - 3 hours for reasons of work. The programme was adapted to these circumstances.
The seminar ended with a light meal, which two parents were able to stay for.

In Kaliningrad the seminar was attended by two families.
Two families were absent owing to illness.
As the number of participants was halved, the programme was adjusted so that it ended at 12 o'clock and was followed by lunch at a restaurant. One of the parents stayed for lunch.

The programme for the two seminars was identical:
- Presentation of the structured interview material, which consists of 11 headings with explanatory text and direct quotes from the interviews.
- Prioritisation of the one or two headings that the parents wanted to discuss and suggest solutions for.
- The parents' joint suggestions for solutions.

- In both Sovetsk and Kaliningrad the reaction to the interview material was that it is very accurate, with several parents feeling touched when it was presented.

In both places it was difficult for the parents to prioritise, as all the problems are important and intertwined.
In Both Sovetsk and Kaliningrad top priority was given to the theme of "education".
The parents were then asked to discuss what initiatives were needed to solve their problems with regard to education.
In Sovetsk in particular it was difficult offhand to make suggestions because, as someone put it: "If we knew what could be done, we would already have done it".

The subsequent dialogue produced a number of suggestions for improvements, e.g. individual approach to a child's education provision, groups providing training in communication, education for all.

In Sovetsk the theme of "from child to adult" was chosen as second priority. It was not discussed for reasons of time.

In Kaliningrad the theme of "outreach by public services" was chosen as second priority.
The dialogue generated suggestions for improvements.

In the course of the discussions it became clear that the attitude to children with disabilities overarches all 11 headings.

For evaluation purposes all the parents received two written questions, which they were asked to answer in writing:
- What was the most important thing about taking part in the project for you?
- What did you get out of taking part in the project?

Among other things, the answers stressed the importance:
- of being able to talk about your problems freely, of someone listening and showing an interest in your problems, of having the opportunity to talk to other parents in the same situation
- of the atmosphere in the meeting always being positive, friendly and professional, with being able to share problems, express pain and receive moral support being of great psychological importance
- Several mentioned that taking part had given them hope for the future

The gathering of material for the project report is now complete.
The following are available:
- Structured interview material with problems
- Structured group discussion material with suggestions for improving problems
- Process and method description in the form of detailed phase descriptions and records from each phase

Status meetings:
A steering group meeting was held with ten participants, including representatives of the Apparel and Maria user organisations, the Ministry of Education, Kant University and the Nordic Council of Ministers' Kaliningrad office.
A record of the process and content of phase 5 was provided.
The steering group asked amplifying questions and gave feedback.
Information was provided on the next stage, which consists of report writing. The report will have a section that describes the results of the project and a section that describes the method of listening to citizens.
The report will be completed in Danish by 15 April. It will then be translated into Russian and printed.

Arne Grove informed the meeting that the project report would be presented at a conference on 17 May 2011.

There are separate minutes from this steering group meeting.

Preparation

Phase	Act. No.	Country	Activity heading
6	2011-6	Ru	Report writing

Time	Part	Yr	Mth	Wk	Day	Description
5 days	A	2011	4			Writing project and process report

Participants
Lena Birch Christiansen, Mette Kudsk

Expected output
A project report describing results from the various phases of the project and the final results. The results will be written in a form that can be translated to other regions/countries. A process report describing the project process in such a way that the model can be translated to other regions/countries.

Phase	Act. No.	Country	Activity heading
7	2011-7	Ru	Project presentation

Time	Part	Yr	Mth	Wk	Day	Description
1 day	A	2011	5	20	17	Presentation of project report

Participants
Lena Birch Christiansen, Mette Kudsk, the eight participating parents, the members of the steering group, Arne Grove, Marianne Smedegaard.

Expected output
The report has been delivered to the relevant parties in Kaliningrad.

Goal achievement indicators
A seminar was held and attended by relevant parties. Interest was shown in the report by the relevant parties invited deciding to attend the seminar. Interest was shown in the project at the seminar.

Appendix 3

Pilot project "Mental health in families with a child with disabilities in the Kaliningrad region"

Phase 3 - Individual interviews with the families from Sovetsk - 18-21 October 2010
Phase 4 - Individual interviews with the families from Kaliningrad - 15-18 November 2010

Interview guide

We employ a questioning technique in which we use an interview guide that lists the topics to be covered and suggestions for questions.

We follow up on parents' answers and responses. This means that in each interview we assess how many of the questions - and which ones - we need to ask to throw light on the topics. During the interview we use our intuition and flexibility to throw light on the topics. The interview guide contains ***suggestions*** for questions. We do not necessarily ask all the questions from the guide, and we may ask other questions. It depends on the individual interview.

TELL US ABOUT YOUR FAMILY How many members are there in the family? Where do you live? Do you have a job – what is it? TELL US ABOUT YOUR CHILD WITH A DISABILITY How old is the child? How much is your child able to do for itself? Who takes care of the child most of the time? How do you communicate with your child? Do you know other families with a child with a disability? Are you involved in organisations for parents with children with disabilities?	

PARENTS' NEEDS How do you experience your situation and the support you get for you and your family? How does your life differ from families without children with disabilities? Being a parent of a child with a disability often means problems in the family. What problems have you experienced? If you are divorced because of the child with a disability, what was the reason for the divorce? Is integration in the community a problem for your family? What have been the worst difficulties of having and living with a child with a disability? What support do you receive for the child with a disability?	
What positive experience do you have of the support you have received? Are there experiences that are worth emphasising and why?	

Can you imagine what will happen if you don't receive the support you need?	
What initiatives are needed to solve the problem?	
What can you do yourself?	
How do you envisage the initiatives required to solve the problem?	
What difference will it make to you and your family if the problem is solved?	
Who is going to do what, when and how?	
Is the goal realistic?	

Nordic Centre for Welfare and Social Issues

The Nordic Centre for Welfare and Social Issues – an institution under the Nordic Council of Ministers
We seek to stimulate development and clarify different aspects of the Nordic welfare model.

The aim of our work is to promote the inclusion of vulnerable groups, with equality, social solidarity and also accessibility and quality in issues connected with social services.

The three main objectives of the Nordic Centre for Welfare and Social Issues
Knowledge
We gather and coordinate experience from the Nordic countries in the field of welfare policy.

Dissemination
We pass on knowledge and experience of good examples though our activities and network.

Dialogue
We set up dialogues between politicians, researchers and field workers.

Our work covers the following areas:
- Alcohol and drug issues
- Inclusion in the labour force
- Deaf-blind affairs
- Questions of functional disorder
- Social services
- The welfare model
- Welfare technology

Our organisation
The institute's head office is located in Stockholm, with branches in Denmark and Finland. The Nordic Centre for Welfare and Social Issues is led by a committee of representatives from the five Nordic countries. The Committee is appointed by the Nordic Council of Ministers.

Our operations are linked to a network of Nordic institutions and experts. Their task is to integrate our work into practice and pass on the results to decision makers and field workers.

A significant proportion of our work is carried on internationally. We collaborate with international players in the health and social area, including the European Union, the European Council and the United Nations.

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