



Summary

The study on the provision of psychosocial services for children with severe illnesses or disabilities and their relatives was conducted by AC Konsultācijas, Ltd. in cooperation with the Children's Clinical University Hospital (CCUH). The study was implemented in 2026, during the period from February to June, within the framework of the ESF+ project No. 4.3.6.3/1/23/I/001 "Establishment of a Support System for Children with Severe Illnesses and Their Family Members."

The aim of the study was to assess the compliance of the psychosocial support services provided by CCUH with the needs of the project's target group, as well as with the objectives of measure 4.3.6.3 and the project, by identifying opportunities for improvement in terms of content, accessibility, and organisation.

The target group of the study consists of:

- ▽ children under the age of 18 who have a severe illness or functional impairments, potential or existing disability, who are admitted to CCUH inpatient care or are under regular outpatient supervision at the time of illness and who require psychosocial support;
- ▽ family members of these children (the child's legal representatives, foster families, or persons living in the same household with the child);
- ▽ project implementation staff (CCUH social workers, psychologists, chaplains, paediatric play specialists, PEP mother (early emotional support provider for parents), and other support specialists such as attending physicians), CCUH project management staff (project manager, coordinator, and other specialists ensuring project management and implementation), as well as representatives of municipal social services, the Ministry of Welfare, the Ministry of Health, NGOs, and the CCUH Parents' Council.¹

Within the framework of the study, the following tasks were carried out:

- ▽ An assessment was conducted of the compliance of the implementation of the psychosocial support service provided within the project with the objectives of measure 4.3.6.3 and the project, as well as with the processes described in

¹ Pašvaldības, ar kurām projekta ietvaros ir noslēgti sadarbības līgumi; bērnu un personu ar invaliditāti tiesības un intereses pārstāvošās nevalstiskās organizācijas.

the handbook “Guidelines for Providing Psychosocial Support to Children with a Severe Diagnosis and Their Family Members.”

- ▼ An evaluation was provided on whether the criteria, procedures, and implementation practices of the personnel specified in the handbook are sufficient to accurately identify members of the target group to whom the psychosocial support service is offered.
- ▼ The accessibility of the psychosocial support service, as well as the adequacy of its scope and content to the needs of children and their family members, and the quality and effectiveness of service provision were assessed.
- ▼ Recommendations were developed to improve the effectiveness, sustainability, and efficiency of the psychosocial support service, to enhance the handbook, to improve cooperation between CCUH and municipalities, and to strengthen cooperation between families and municipalities.
- ▼ A comprehensive empirical study was conducted to address the above-mentioned tasks.

A mixed methodology was used in the study, combining both quantitative and qualitative data collection methods. A survey of children’s parents was conducted (with 289 respondents participating); an in-depth analysis of 250 cases in which individuals had received psychosocial support services provided by CCUH was carried out; an analysis of CCUH recommendations for further support to families was performed; focus group discussions/interviews were held with parents and young people who had received the service; as well as with CCUH specialists involved in the project; representatives of municipal social services; and representatives of policymakers, non-governmental organisations, and the CCUH Parents’ Council. In addition, document analysis was conducted, including an assessment of the national and international policy framework and regulatory environment, as well as an analysis of CCUH documents and compiled statistical data. This approach ensured a multidimensional perspective on service provision.

In the context of the study, the international and national policy framework is significant, as it emphasises the need to ensure person-centred and accessible services for persons with disabilities, anticipated disabilities, functional impairments, and their families. Both the UN Convention on the Rights of Persons with Disabilities and European Union strategic documents highlight the importance of early support, social inclusion, and service accessibility. Latvian policy planning documents emphasise the development of community-based services and cross-sectoral cooperation. Challenges identified in these documents include unequal access to services across municipalities, individuals’ prejudices towards cooperation with social services, and the lack of informational and consultative support provided according to the one-stop shop principle.² In this context, the psychosocial support service

² Apvienoto Nāciju Organizācijas Konvencijas par personu ar invaliditāti tiesībām ieviešanas izvērtējums. Pieejams:

provided by CCUH is an important solution, as it enables families to receive timely and comprehensive assistance from specialists in one place during crisis situations. Furthermore, the work of CCUH social workers – informing families about available support at their place of residence and mediating cooperation with municipal social services – promotes families' openness to engagement and facilitates the initiation of further cooperation with social services.

The psychosocial support service provided by CCUH is a structured, multidisciplinary, and individually tailored support mechanism for children and families. The service is delivered both in inpatient and outpatient settings. Within the framework of the service, support is provided by a social worker, psychologist, chaplain, paediatric play specialist, PEP mother (early emotional support provider for parents), and nanny, and recommendations are developed for further support, including continued assistance at the place of residence.

During the analysed period (2024–2026), the service was received by more than 1,600 children and nearly 2,000 family members, demonstrating the significant role of the service within the social rehabilitation system. Most frequently, the service was provided to families in which children had been diagnosed with: endocrine, nutritional, and metabolic diseases (15 %); mental and behavioural disorders (14 %); certain conditions originating in the perinatal period (14 %); congenital malformations, deformations, and chromosomal abnormalities (10 %); and diseases of the nervous system (9 %). The age structure of children during the analysed period indicates that the psychosocial support service is relevant across all stages of child development – from the neonatal period to adulthood.³

The results of the study indicate that:

- ▼ The psychosocial support service provided by CCUH corresponds to the objectives of the project, as it ensures crisis intervention and multidisciplinary specialist support for children and families in accordance with their situation.
- ▼ The psychosocial support provision process defined in the handbook is generally followed.
- ▼ Support is provided to children and families that meet the project's target group criteria. At the same time, the study found that the selection criteria exclude certain target groups, such as children from residential child care institutions; children who have reached adulthood but continue treatment at CCUH; family members during the bereavement period following a child's death; as well as children receiving palliative care and their family members, if the family has not signed an agreement with the Children's Palliative Care Society.

https://www.lm.gov.lv/sites/lm/files/data_content/biss_gala_zinojums_lm_ano_konv_30062020red_13_072020_1_11.pdf

³ BKUS statistika par sniegto psihosociālā atbalsta pakalpojumu par laika periodu no 2024. gada 1. jūlija līdz 2026. gada 12. februārim.

- ▼ Most families consider the information about the service to be clear and timely. However, in crisis situations it is often perceived in a fragmented way, and therefore families do not always initially gain a full understanding of the scope, duration, and sequence of the service. Moreover, case analysis shows that families have not always recognised specialist consultations – particularly those provided by social workers – as part of the psychosocial support service. This indicates the need to continue explanatory work about the service and its content.
- ▼ The views of both the target group and CCUH specialists, social services, and other stakeholders confirm that the service is useful. The main benefits are associated with emotional support, the feeling that the family is heard and understood, as well as practical support and information about further support options.
- ▼ Only in a small number of cases is the support assessed as not useful (in 8 % of cases for the child and in 9 % of cases for family members). The reasons given for such an assessment include the fact that the service is still in progress, the child is waiting in line, or the service has not been started, including due to the lack of cooperation with the municipal social service; the family was referred to receive support outside CCUH. In such cases, the support objectively could not have produced the expected results. Some families indicate that the service was offered at an inconvenient time, for example, at a time when the child would have to miss school; the child was unable to establish contact with the specialist; the amount of consultations received was, in the family's view, insufficient (for example, only one consultation); due to waiting lists, there was a break in support, which reduced the continuity and effectiveness of the process.
- ▼ The accessibility of specialists involved in the psychosocial support service at CCUH inpatient care is generally high. In the outpatient phase, the main challenge is the availability of psychological consultations, which is more limited. This is related to insufficient human resource capacity at CCUH. Appointment times for specialist consultations generally do not pose challenges for families; however, in certain cases, they may limit the ability of children/families to attend consultations in person in the outpatient setting.
- ▼ Recommendations for further support are prepared in all cases when a child has completed inpatient treatment or when a family assessment has been carried out on an outpatient basis. Analysis of the content of the recommendations indicates that they are clear, include contact information, and specify deadlines. All recommendations include advice to contact a CCUH social worker if necessary. In most cases, consultations with various CCUH specialists within the psychosocial support service are recommended. The suggestion to contact municipal social services is generally formulated in broad terms, without specifying particular services. This approach is linked to

an agreed practice between CCUH and social services, whereby decisions on specific support are made at the municipal level, taking into account the family's individual situation and available resources. At the same time, although CCUH generally provides additional verbal explanations about the possibilities for receiving further support, the use of such a general written formulation means that some families do not have a sufficiently clear understanding of what kind of support could be provided to them and what benefits they can expect from contacting the social service. This may be related to difficulties in fully processing verbally provided information at that moment, which can be affected by emotional state, fatigue, the amount of information, as well as a possible language barrier and other factors.

Services outside CCUH or municipal social services are recommended in a minority of cases.

- ▼ Case analysis shows that in a minority (16 %) of cases, families provide consent for cooperation with social services. In cases where such consent is given, cooperation with social services is initiated in 89 % of cases. At the same time, a similarly large proportion of families (17 %) have cooperated with social services without providing consent to CCUH for data exchange. This indicates that some families establish direct cooperation with municipalities outside the framework of the project. One possible explanation is that consultations with CCUH social workers have strengthened parents' understanding and motivated them to seek support from municipal social services.
- ▼ Information is shared with social services both through the SOPA system and via direct communication. Although CCUH social workers inform municipal social services that recommendations will be uploaded, the lack of automatic notifications in the SOPA system prevents municipalities from immediately identifying when recommendations regarding a target group individual have been entered into the system.
- ▼ The main challenges in service provision and in the overall support system are not related to the quality of services at CCUH, but rather to the accessibility of support outside the hospital. Access to services varies across municipalities. An additional challenge is the relatively low level of family engagement in cooperation with municipal social services. Only a small proportion of CCUH prepared recommendations are forwarded to municipalities with family consent, and some families do not initiate cooperation with social services at all. The main reasons include stigma, lack of trust, negative previous experiences, and insufficient understanding of available support.
- ▼ Another significant challenge is the discontinuity of support after a child reaches adulthood and during the bereavement period following a child's

death. In these cases, the need for psychosocial support remains or even increases.

The study's recommendations focus on improving access to information and support in the regions, including emphasising the need to develop a unified minimum service package and to strengthen the involvement of non-governmental organisations and parent support networks. The recommendations also aim to potentially expand the content of psychosocial support services and to enhance cooperation among stakeholders. Specific recommendations are provided for the possible improvement of the handbook.

In conclusion, it is important to continue the provision of psychosocial support services to the target group, while clearly defining the service financing model and priorities in cases where available funding is limited.