



March 2021, ASrid

## REPORT

### **The contributions of the intermediate organization -MHLW's "daytime activity support" to revise the fees for welfare service for persons with disabilities:**

On February 4, 2021, the Ministry of Health, Labour and Welfare (MHLW) published an overview of the revision in the remuneration of welfare services for persons with disabilities for fiscal year 2021 ([https://www.mhlw.go.jp/stf/newpage\\_16573.html](https://www.mhlw.go.jp/stf/newpage_16573.html);  
Document 1: <https://www.mhlw.go.jp/content/12200000/000734439.pdf>).

The revision provided details on the establishment of "daytime activity support" (Reference 1, page 11: "Strengthening the acceptance system of medical-type short-term care facilities" and "Evaluation of daytime activity support" (in Japanese)).

In line with the new service, individuals involved in medical-type short-term care facilities are considered stakeholders in the field of pediatric intractable diseases. As such, they have been engaged in various related activities in the field for over several years. This substantial accomplishment was made possible through the voicing of opinions by stakeholders in the field. Again, I would like to congratulate everyone involved in this effort.

In response to a request from the aforementioned parties, the Advocacy Service for Rare and Intractable Diseases (ASrid), a non-profit organization conducted a survey on daytime activities, such as "play and learning," for children undergoing medical care and their families residing in medical-type short-term residential facilities. The survey was conducted during the May of 2019 and April 2020, in collaboration with the National Center for Child Health and Development (NCCHD).

Previous studies on daytime activities have been scarce, and many unprecedented challenges have been faced, such as the evaluation of the quality of life (QOL) of children involved, play and learning that occur in facilities, and ethical aspects of recruiting children in medical care as participants of the research.

Nevertheless, the survey items and procedures were finalized through discussions with Mr. Katsuyasu Uchida and other concerned parties at the Momiji House of the NCCHD.



Furthermore, questionnaires were distributed to, and interviews were conducted with, the children, facility staff, and experts based in four facilities in Japan.

Based on the questionnaires and assessment of the children's parents, the QOL of the children improved after admission to the facilities, and the enrichment gained through play and learning activities in these facilities contributed to such results. In addition, the results of the interviews generated a large quantum of first-hand information regarding the significance of play and learning activities for children in medical care facilities, ideas on improving such activities, and concerns and conflicts observed during the implementation process. I believe that each participant had a valuable voice that was unheard until that moment.

This survey taught us several lessons. We also recognize the opportunities for improvement in terms of its design. However, we firstly believe that we were successful in obtaining basic figures and the valuable opinions of the people involved.

ASrid is an intermediary organization. However, even when we directly met the needs of the people involved, we only reached our goal through their direct, subsequent efforts.

The report proposes several items deemed necessary for the future, such as "Recommendations for Additions and Grants" and "Recommendations for Additional Fees and Subsidies." In addition, we propose a list of medical institutions and medical-type short-term care facilities considered lead organizations (directly related parties). We intend to pass the baton to these organizations.

The results have been further utilized by the parties involved in the study as well as the Ministry of Health, Labor and Welfare, who responded to the exchange of opinions. We received and passed on the responsibility and decided on furthering the goal of the people involved. We believe that this should be the ideal structure of an intermediary organization.

We hope that the establishment of the new "daytime activity support" program under the revised remuneration system will enable: (a) children with medical care needs in short-term residential facilities to play and learn to the fullest and (b) parents to leave their children with medical care needs in such facilities with peace of mind.

Our activities will continue based on the results of this research in the next fiscal year and beyond. As an intermediary organization, we will move forward with the goals of *enhancing social security for the sustainable operation of short-term medical care*



*facilities and increasing awareness of the importance of “play and learning” for children in short-term medical care facilities.*

Finally, we express sincere gratitude to JCR Pharma Inc. for supporting the research and other non-profit activities of the organization.

Reference material: Report on the results of the research (<http://urx.red/bcdV>).

The results will be summarized in a paper.

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