



inkubatorpomyslow.org.pl

Powitalnik



A guide for parents facing the child's diagnosis



'Powitalnik' is a tool to support parents who have had their children diagnosed with disabilities or severe conditions. It comes in the form of a kit handed over to parents at obstetric wards. The kit is made of a psychological and legal guide, a contact base to parents-guides sharing similar experience, worksheets facilitating communication between parents and other meaningful persons important to the child, as well as recordings and descriptions of techniques reducing stress in crisis situations.

'Powitalnik' has been prepared based on the experience of over 60 mothers who have shared their experience of having disability diagnosed in their child. Innovators have also gathered a group of 20 guides ready to support parents receiving 'Powitalnik'.

Who is the innovation is targeted at?

The innovation is targeted at:

- Parents who are provided with the diagnosis of their child's possible disability or severe condition at hospital; it is a highly diversified group, with different personal, financial or health situation, often sharing the sense of confusion or terror when confronted with their child's diagnosis;
- The staff of obstetric, neonatal, and paediatric wards: midwives, nurses, psychologists, lactation consultants, and physicians accompanying parents in facing their child's diagnosis.



Who can implement the innovation?

The innovation is targeted chiefly at hospital wards managing children's diagnostic process, including ob-gyn, neonatal, paediatric, and neurological units.

At a later stage, the innovation can be implemented at offices of healthcare professionals diagnosing severe conditions or disabilities in children, at psychological and pedagogical centres, by disability evaluation boards, welfare and family support centres, rehabilitation centres, and by NGOs supporting people with disabilities and their families.

What problems does the innovation address?

There are around 10,000 children with disabilities born in Poland every year. Healthcare professionals informing parents on their children's diagnosis often do not have the right tools to effectively support them at this critical moment of their life.

Parents facing the child's diagnosis experience various emotions such as the sense of confusion, terror, lack of hope for happiness, grief, aversion to their child, fear about the future or the sense of solitude. 'Powitalnik' helps them understand these feelings, providing them with reliable knowledge about the available forms of support at the same time.

How to implement the innovation at your end, step by step?

If you work at a medical facility or a different organisation supporting parents facing their child's diagnosis and want to provide them with a paper copy of 'Powitalnik', contact directly the Mudita Association that has developed this publication (powitalnik@stowarzyszeniemudita.pl).

If you are a parent or another person who wishes to read 'Powitalnik', you can download its electronic version from <https://stowarzyszeniemudita.pl/powitalnik>. Apart from the publication as such, the website also features templates of useful documents and recordings of anti-stress exercises.

'Powitalnik' is available in a machine-readable and a Braille alphabet version. At the time being, the publication is being translated into Ukrainian.

Does it work? How does the innovation help its beneficiaries?

Parents having their children diagnosed, confirm that 'Powitalnik' is an effective source of support when facing this problem. Many talked in particular about the sense of helplessness and solitude accompanying them after having been informed on their child's health challenges. They believe that 'Powitalnik' can be of great help at this difficult moment.

I experienced facing the diagnosis myself. I hope that other parents can have more support. It is an absolutely needed and beautiful publication.

Had I read it after the diagnosis, I would have felt taken care of in every way.

Enormous support for parents who face their child's diagnosis after the birth. I would like to thank the Mudita Association on my behalf and on behalf of all parents that need support.

I consider this guide highly needed. I remember how lost we were, and how many things we did not know about! There was constantly something new that we had to learn about along the way. This project is worth the Nobel Peace Prize. I bloody missed it two years ago.

Healthcare professionals, psychologists and therapists stress high usefulness of 'Powitalnik' which is a tool that specialists supporting parents in the diagnostic situation did not have access to before.

Parents, grandparents and other people who are close to a child with a newly diagnosed disability tend to ask me what to do, what to start from. I recommend this very source of information.

'Powitalnik' is an excellent support tool for parents confronted with the information on a possible disease, disability, or other special needs of their newborn child.

This is one of initiatives the introduction of which has made us realise how needed it has always been.



How much does it cost?

The electronic version of the publication is available for free.

The estimated cost of printed copies looks as follows:

- Publication printing – ca. PLN 50 per copy,
- Shipment – PLN 20–40 (depending on the number of copies).

Authors of the innovation are striving to obtain means to print more copies of 'Powitalnik' to offer it for free to those in need.

Even though the access to psychological care is free during hospitalisation (and at the same time can be either hindered or insufficient in many facilities), then right after the discharge, the cost of a one-hour therapeutic session for a parent confronted with the child's diagnosis can amount to ca. PLN 150 gross. At the same time, the labour cost of an official responsible at a welfare centre for informing parents on available support options starts from PLN 30. Considering all that, 'Powitalnik' is a low-cost solution that can temporarily fill the system gap in supporting parents of children with disabilities until more comprehensive solutions are implemented.



Who are the authors of the innovation?



The Mudita Association develops support networks and offers respite psychological, informational and legal help to make the life of families of people with disabilities better.

The Association offer includes:

- a free helpline for relatives of people with disabilities providing them with an opportunity to talk to psychologists and psychotherapists;
- support groups for relatives of people with disabilities to share their experience in a safe environment;
- support in daily household chores or childcare duties provided by volunteers;
- a point providing information on formal and legal issues related to taking care of people with disabilities;
- support in finding specialists from different areas of expertise;
- relax zones at which mothers and caregivers can take a rest from everyday duties, have hot coffee or tea, relax, chat, enjoy a massage or other pleasant activities, while their children take part in interesting classes or are under professional care.

The publication has been prepared with the assistance of a wide group of female specialists: midwives, psychologists, therapists, and lawyers.

The innovation also includes a guide for healthcare professionals, a website and a base of materials for parents-guides.

'Powitalnik' was tested in five hospitals and additionally by 15 midwives and organisations utilising the publication in their work.



Magdalena Kolczyńska – project coordinator, international law, human rights, humanitarian law and philosophy graduate. On a daily basis, she is involved in monitoring and evaluating social programmes run by the EU and UNICEF. She had her first encounter with the community of people with disabilities and their families thanks to the Spes Association from Katowice when working as a volunteer during summer integration camps for individuals with intellectual impairments. She started her cooperation with the Mudita Association in 2020, organising support for parents provided with their children's disability or severe condition.

She will be happy to answer all the questions, suggestions and ideas regarding 'Powitalnik' and support parents confronted with their child's diagnosis.

Contact details and additional information

Magdalena Kolczyńska

powitalnik@stowarzyszeniemudita.pl

731 669 862

Maria Lewandowska-Woźniak

Idea incubator run by the Stocznia Foundation

innowacje@stocznia.org.pl

(+48 22) 378 39 73

For more information visit www.powitalnik.pl and <https://inkubatorpomyslow.org.pl/innowacja/powitalnik-przewodnik-po-rodzicielstwie>.





idea incubator

Uncommon solutions to common problems

Text: Julianna Łoboda

Translation: Aleksandra Płażewska-Tabor

Photos: Magdalena Kolczyńska (cover), Centrum Zdrowia Dziecka Team, Warsaw (pages 3 & 7), Karolina Prusińska (page 10)

Design and typesetting: Kotbury, www.kotbury.pl

October 2023

