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I Ty masz prawo być sobą!



Comprehensive support for caregivers to people with disabilities and/or with the spectrum of autism



FUNDACJA
DLA GIGANTÓW

'I Ty masz prawo być sobą!' is a comprehensive support programme for individuals taking care of people with disabilities and/or with the autism spectrum disorder. It is a cycle of eight workshops conducted by means of the proprietary 4-O method – otwieranie, ogarnianie, odpoczywanie, odkrywanie (opening, managing, resting, discovering). Apart from offering a breather and an opportunity to come out of social isolation, such meetings have one more goal – to learn how to help yourself and others who are in a similar situation. Workshops serve as a starting point and the key component of the self-help group creating process.

Authors of the innovation have created it based on their own challenging experience of taking care of people with disabilities and the autism spectrum disorder. They have experienced the lack of support in all areas themselves. Their dissent to this situation was a trigger to introducing changes in their own life and to inspire others to do it.

Who is the innovation is targeted at?

The innovation is targeted at individuals taking care of people with disabilities and/or the autism spectrum disorder. This group is often left all alone, burdened with both physical and mental effort, while those who belong to it often drop out of professional, social, public or even family life.

The innovation is meant for those who take care of others, having no time or space to take care of themselves, to rest, to stay in good health, to be socially active, to keep in touch with others, to develop or pursue their hobbies.

Who can implement the innovation?

The innovation can be implemented by:

- NGOs supporting people with disabilities and their caregivers;
- public institutions that direct their activities to a varied extent at this group of beneficiaries, including welfare centres, district family support centres, as well as educational, psychological and pedagogical facilities;
- places of local activity and neighbour homes.



What problems does the innovation address?

The innovation addresses challenges faced by caregivers, such as:

- not having their basic life, health, and social needs satisfied, even to a minimum extent,
- sense of constant fatigue, lack of energy, lack of understanding or mental support and immediately available therapeutic care,



- no access to free respite workshops at times and dates convenient to them,
- no relaxation, rest, normal social life (trips, family vacation, discussing daily problems with another person, walks, going to cafés),
- poor availability of assistants to people with disabilities what would allow caregivers to devote their time to satisfying their own needs,
- discrimination and social exclusion, isolation, no opportunities to learn new skills or utilise the ones already acquired, e.g., related to one's profession or hobby,
- no opportunities for easy networking for caregiver groups which could be a starting point to mutual self-help in the future,
- no habit of perceiving themselves in the context of their own autonomy as an individual, of giving themselves the right to take care of themselves and their health, to cater for their needs – cutting themselves for a longer while from the person with disabilities and their needs related to it.

How was the innovation created?

The innovation was established on the initiative of 5 individuals – caregivers of people with disabilities and the autism spectrum disorder.

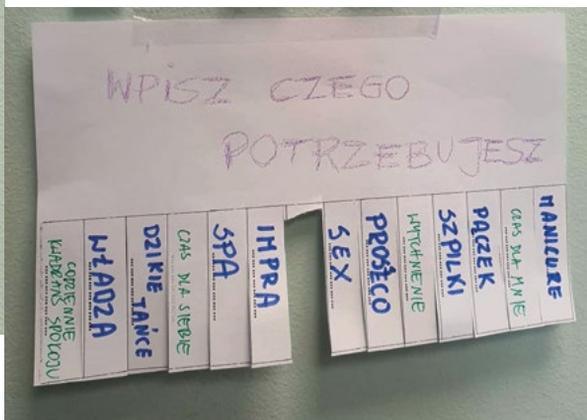
The experience of extremely challenging motherhood turned their life upside down, it excluded them from work, social life, and had negative impact on their psychophysical condition due to the lack of proper and fast support as well as years of no access to therapeutic help.

Due to the lack of proper public support system available to caregivers to people with disabilities in Poland, they had to become 'multi-professionals'

filing these system gaps (therapists, teachers, nurses, drivers). Not agreeing to lose their subjectivity, over the years they have established self- self-care and self-keeping methods, and when looking for support for themselves, they also created the foundations of self-help.

Their need to get support from other people in a similar situation led to social cooperation with NGOs and organising help not only for themselves but also for other caregivers.

Authors of the innovation want to stress how important but at the same time how neglected group caregivers are. Just like any other group, they have considerable potential and the right to keep and develop it. They also have the right to 'be themselves'.



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

The innovation is a cycle of respite workshops conducted by means of the proprietary 4-O method – otwieranie, ogarnianie, odpoczywanie, odkrywanie (opening, managing, resting, discovering). They can be implemented in the format in which they were tested and developed, with the use of detailed class scenarios available, but it is also possible to introduce modifications, depending on the profile of the group and its interests, and the host's capabilities. Workshop coordinators should have personal or professional experience in the field of disability or supporting individuals with the autism spectrum disorder.

When pursuing particular activities, it seems advisable to seek support from:

- friends having skills useful in running workshops planned by the organiser,
- coaches or specialists known to organisers from the therapeutic, rehab or educational setting (e.g., physiotherapists, rehab specialists, music therapy specialists),
- local social organisations that often have teams of animators, experts, and technical resources, e.g., office equipment, overhead projector,
- local entities that might be interested in cooperation in a spirit of social responsibility including dance schools (e.g., salsa classes), sports clubs (e.g., tai chi, yoga).

The workshop is inspired by four universal human needs described by psychologist Marshall Rosenberg. According to his theory the change of habits, even if it is extremely difficult, allows people to constructively approach the satisfaction of their needs and to live a life full of sense.

Hence, the workshop is broken down into **four modules (the so-called 4-O)**. The first encourages you to notice yourself, your needs, dreams, and the fourth, the last one, to come back to passions and interests that have been put aside or to look for new ones.

Module 1: Opening

It is to help caregivers remember what they need and want for themselves as autonomous individuals. This can be a workshop devoted to emotions accompanying raising a person with disabilities or with the autism spectrum disorder.

Module 2: Managing

It teaches participants how to organise family life and to see why it is good to give up excessive duties to find time for themselves. It can be a workshop devoted to managing tasks and duties in daily life.

Module 3: Resting

Within this module caregivers learn how to take care of their physical and spiritual wellbeing and experience the impact of leisure on their body and mind. During the pilot innovation, caregivers participated in a tai chi class, learned about the impact of stress on their organism, and the consequences of experiencing it in the body in the context of physiotherapy.

Module 4: Discovering

The objective of the last module is to show and remind caregivers that regularly pursuing their passions, hobbies or new activities can be the source of respite, joy, sense of satisfaction and fulfilment. Within this module, they can take part in dance or arts&crafts workshop or other activities aimed at self-actualisation.



An important assumption behind this work method is the focus on caregivers' situation and needs – their wellbeing is in the centre of organisers' and coaches' attention. Apart from letting their participants take a breath and come out of social isolation, such meetings have another goal – they help them learn how to help themselves and help others who are in a similar situation.

Workshops are a starting point and the key element of creating **self-help groups** that can be of virtual character (e.g., a group on Messenger or WhatsApp). They are chiefly to help eliminate caregivers' social, personal and emotional isolation. Because of their similar needs and problems, participants gain the sense of security and understanding which they are unable to experience among people not affected by disability. Self-groups are based on mutual support and exchange of experience and information – in a safe and judgment-free setting. Initially, a virtual group can be moderated by organisers, for instance via:

- a nice morning greeting to group members (sending a photo of a coffee mug, flowers, a nice view, etc.),
- boasting about little achievements in finding time to rest (e.g., visiting a bookshop, café, movie theatre, or a hairdresser).

Over time, participants will initiate contact within the group on their own and will share both good and difficult moments. Full acceptance and the lack of judgment will give them the sense of security and enormous relief.

To strengthen the process of establishing self-help groups, it seems a good idea to propose an informal ice-breaker meeting, e.g., going to the movies, to a café.

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

The purpose of the workshop is to empower participants on their way to changing their attitude to themselves, in particular to acquire new skills to function more efficiently and more easily with their loved ones' disability.

Participation in the workshop:

- Teaches self-care, self-keeping, and self-help – promotes changing old habits and building new ones. It allows for understanding the organic need to ensure daily rest, strengthen the body and mind, give up excessive tasks. It encourages and boosts confidence to either return to or maintain life activity.
- It is a starting point to creating self-help groups, releasing natural motivation and primal need to seek and offer support.
- It provides concrete and simple tools and lifehacks, practical knowledge necessary to understand the needs of the organism and each individual's limited resources to bring changes into life.
- It motivates caregivers to enjoy devoting time only to themselves as an integral individual, separate from



the role of a caregiver-parent, and teaches them to notice and satisfy their basic daily needs of a human being, which in turn helps change the life of the entire family for the better.

Due to its opening and motivating character, the participation in the workshop can also have positive long-term consequences. At the pilot innovation stage, some participants made vital decisions they believed to be initiated by their participation in the workshop, such as:

- starting university education,
- taking up therapy (in the case of caregivers),
- turning to a specialist for help (e.g., psychologist),
- seeking additional specialist care for the participant's child,
- changing jobs.

How much does it cost?

Authors of the innovation shared materials allowing for running some classes on one's own, requiring the purchase of some basic items. Their cost is determined by the organisers' capabilities and ideas for classes. If it is possible to arrange a space for the workshop free of charge and recruit hosts among caregivers or among friends and relatives, the cost might be low.

Who are the authors of the innovation?

Introducing authors of the innovation:



Iwona Kapturzak – leader of the team working on the innovation, originator of the idea, social activist. For the last ten years she has been cooperating with social organisations. Participant of numerous projects supporting people with disabilities, for instance within the Chcemy Całego Życia and Nasz Rzecznik initiatives and work teams by the Office of the Commissioner for Civil Rights Protection. Support group, stress self-management, breathing and self-regulation coach. Within the pilot innovation, she is responsible for coordinating all events, coach and assistant recruitment. Author of the 'Dream Map' workshop. Privately a mom of two sons, including a teenager with autism, epilepsy, and intellectual disability.



Alicja Wiśniewska – social activist, participant of numerous training on NGOs. Graduate of the first edition of the Wydział Innowacji by the Stocznia Foundation. Within the pilot innovation responsible for coordinating workshops, recruitment process, and compliance with data protection. She works as a programmer, privately she is a mom of a teen with Asperger syndrome and oppositional defiant disorder.



Danuta Musiał – social activist, involved in the Nasz Rzecznik initiative, member of work teams (e.g., on people with disabilities and their caregivers) by the Office of the Commissioner for Civil Rights Protection. During the pilot innovation, she is responsible for the coordination of workshops, promotion, and managing its Facebook profile. Author of workshops on family life organisation, letting go, and arts&crafts. Works in the marketing sector, privately she is a mom of teen twins – including one with the autism spectrum disorder, epilepsy and intellectual disability.



Justyna Rowińska – social activist, involved in the Nasz Rzecznik initiative, member of a work team by the Commissioner for Civil Rights Protection. During the pilot innovation, she is responsible for the coordination of workshops, promotion, and managing its Facebook profile. Works in the marketing sector, privately a mom of a teen with the autism spectrum disorder and intellectual disability.



Dagmara Wójcik – social activist. During the pilot innovation, she was responsible for workshop coordination, photo documentation, production of promotional films and managing Instagram and TikTok profiles. Author of the arts&crafts workshop. Working in the hospitality sector, privately she is a mom of a teen with the autism spectrum disorder and intellectual disability.

More information

<https://inkubatorpomyslow.org.pl/innowacja/i-ty-masz-prawo-byc-soba-kompleksowe-wsparcie-dla-opiekunow-osob-z-asd>

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