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Taming the adulthood

Training program for specialists working with individuals with intellectual disabilities

1. Who is this innovation for?

- for experts working daily with individuals with intellectual disabilities at the occupational therapy workshops, social welfare centers, community self-help centers: therapists, instructors and caregivers
- for individuals with intellectual disabilities attending occupational therapy workshops, social welfare centers, community self-help centers

2. What social problem does it address?

UN Convention on the Rights of People with Disabilities defines minimal requirements in respect to the rights of individuals with disabilities and points to goals that are to be achieved. The UN General Assembly adopted general norms pertaining to protecting disabled individuals and providing them full and equal access to enjoy basic freedoms and human rights.

From research on sexuality and parenthood among individuals with intellectual disabilities conducted over the period of last several decades we've learned that intellectually disabled persons want to start families, want to become parents, experience their sexuality and do engage in sexual activities.[1]

Training program *Infant simulator use in the work with intellectually disabled individuals* is a grassroots initiative by parents of intellectually disabled individuals, stemming from needs and problems such as:

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[1] A. Czusz, W. Otrębski, *Seksualność osób niepełnosprawnych umysłowo – wyzwanie dla metodologii badań i praktyki psychologicznej* [w:] *Oblicza psychologii klinicznej*, Sopot 2014; A. Żyta, *Małżeństwa i rodzicielstwo osób z niepełnosprawnością intelektualną – wyzwania współczesności*, Edukacja Dorosłych, vol. 2, 2013.; I. Fornalik, *Osoby niepełnosprawne – niektóre właściwości rozwoju i funkcjonowania seksualnego*, [in:] *Człowiek niepełnosprawny. Rodzina i praca*, ed. by M. Kościelska, A. Bassam, Bydgoszcz 2004; U. Bartnikowska, A. Chyła, K. Ćwirynkało, *Kobiety z niepełnosprawnością intelektualną w roli matki: perspektywa zagrożeń*, Niepełnosprawność, vol. 13, 2014.

- a deficit of established practices and methods when working on sexuality and parenthood with intellectually disabled individuals
- a lack of a textbook containing a work schedule that incorporates infant simulator practice that's designed with intellectually disabled in mind
- a stereotypical and infantilizing perceptions of persons with intellectual disabilities and their parenting potential
- a common denial of intellectually disabled individuals' ability to become parents, or fulfill themselves as close relatives (as aunts or uncles)
- a need for creating an open and inclusive society and environment that levels the plane for everybody

photo: Tomek Meuś

3. Description

Where did the idea come from?

It's a fact that individuals with intellectual disabilities want to perform the same social roles that they observe in their everyday lives. They have the same sexual needs as people without any disabilities and want to start their own families.

Therapists, educators, social workers and family assistants who work at the occupational therapy workshops, social welfare centers and community self-help centers and other institutions every day struggle with the question of how to best work with their patients to make the human sexuality something easily understandable. Experts often lack training that would increase their competences in that area, as well as tools necessary to conduct workshops that would familiarize individuals with intellectual disabilities with the role of a parent.

Taming the Adulthood innovation was created on the basis of many professional and personal experiences of innovators connected to the Gdynia based Dom Marzeń Foundation, who collaborated with Dr. Izabela Fornalik and used their own resources to create a training program that expands competences of experts working with intellectually disabled patients in that area.

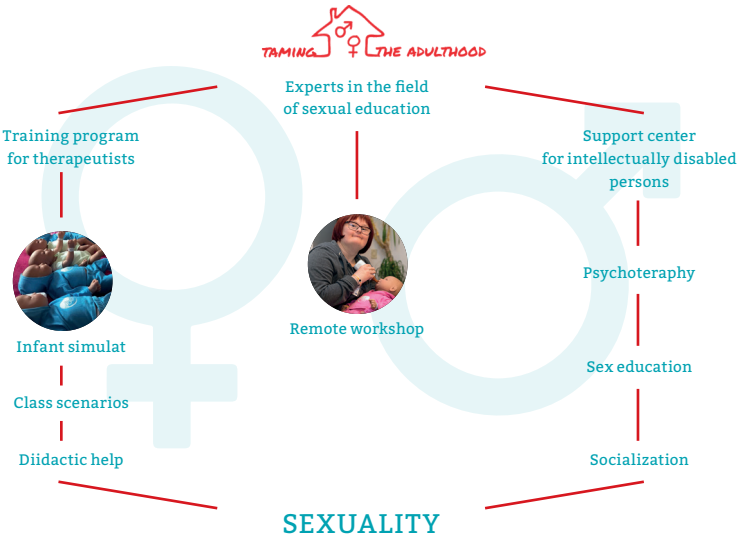
Essence of the innovation

The essence of the innovation is a training program preparing therapists for working with intellectually disabled individuals, using an infant simulator. Simulator is a doll with a mini-computer built in and equipped with special software that imitates infant behaviors. Simulation of infant care is an educational method that reproduces reality of child care in artificially created conditions, which enables trainees to experience the role of a parent and caregiver, while preparing them for a responsible transition into a real-life care of an infant. The therapist/educator/caregiver is the operator of the simulation. He or she chooses the correct variant of software and can assess progress by looking at the readouts of the simulation results.

Taming the Adulthood innovation consists of:

1. Training program for experts and specialists working with intellectually disabled individuals provides fundamental information regarding parenting and sexuality for persons with intellectual disabilities, maintenance and usage of the simulator, therapeutic work applications and class scenarios.
2. Remote workshop – training offer dedicated for experts working with intellectually disabled persons, as well as intellectually disabled individuals.
3. Consultation center – work realized by the experts in the field of sexual education, who were trained using the innovation. Consultation center organizes individual consultations, therapy, as well as can diagnose intellectually disabled persons in the sphere of sexual disorders and provides group trainings and classes at support centers for intellectually disabled persons.

DOM MARZEŃ FOUNDATION IN GDYNIA



Innovation step by step

1. **Recruitment**
   - candidates for experts working with intellectually disabled persons
   - individuals with intellectual disabilities

2. **Trainings**
   - Theory training for experts at Pomeranian Science and Technology Park in Gdynia in sexual education
     Training program begins with familiarizing the experts (therapists/caregivers/educators) with operations of the infant simulator, its technical specifications and rules guiding its functioning. It constitutes a necessary foundation for proper remote workshop.
   - Remote workshop for individuals with intellectual disabilities and experts in sexual education
     Individuals with intellectual disabilities, who learn new skills working with the simulator, as well as experts (therapists, caregivers, educators) who learn how to support their patients, take part in the workshop. Organizers must make sure that the intellectually disabled participants have access to psychologist's and psychotherapist's support at all times. An important part of the workshop is working through emotions that accompany the care over the infant simulator, so that they don't provoke negative results. We should remember that the entire program is meant to be educational.

3. **Training program**
   - Realization and analysis of one's own research
   - Tools and didactic help, class scenarios
   - Film

Innovators prepared six class scenarios while testing the innovation during the remote workshop. The firs one is about how the infant simulator works and each following scenario focuses in detail on different aspects of sexuality, care, relationships, assertiveness, security, personal hygiene and becoming independent.

photo: Dom Marzeń Foundation

Acquiring new skills is documented in participant's workshop log. That's where intellectually disabled participants assess their own work with support of their caregiver, who can help them express their feelings accurately.

The entire process can be very emotional and the emotions can positively influence social functioning of intellectually disabled individuals, as well as help build a relationship between them and their caregivers. The relationship can become more partner-like and based on great trust. That's a powerful foundation for further work.

True emotions that accompany the innovative training, as well as mature and responsible attitude of individuals with intellectual disabilities towards certain, particular problems related to care, their reactions in times of stress and fatigue, are a proof of full engagement in the realization of a task – care for the infant simulator.

I've been working with intellectually disabled persons for many years and this remote workshop has been a new experience for me. I knew that my patients function better on trips, but this workshop proved that they can be independent, caring and responsible as caregivers of the infant simulator. Despite all these years of work they still surprise me.

Remote workshop coordinator

Despite it being another activity with a simulator, it was the first time I had an opportunity to observe work with psychotherapists. I observed how they approach a disabled individual in a crisis, how the conversation looks like, and observe their approach.

An expert

That training was exceptional. It gave us proficiency in using simulators and we were able to learn from one another.

An expert

I worked with the simulator for the first time, but what's important is that we could exchange observations with others and we could live through it together. Because it's not just another job you do. We were in it non-stop, together with the participants.

An expert

We, the parents, still fail to understand that our disabled children are capable of many things. For example, after the workshop we were able to solve a problem with our daughter that we were unable to solve for the past six months, simply because we started treating her like an adult and told her she needs to make an adult decision. And for the first time we observed our child consistently following her decision, one that she made after a long and serious consideration.

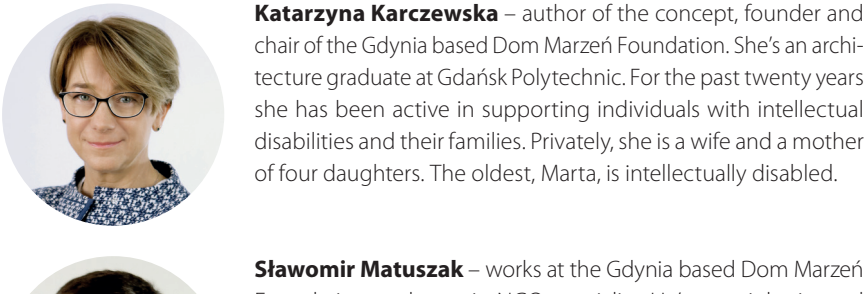
Parents of individuals with intellectual disability

photo: Tomek Meuś

The original goals for the project were preparing a training program and bringing in four experts who would serve as trainers. The program, the specialists and the training offer were supposed to be the main result of our innovation testing. One of the testing stages was the remote workshop that included both individuals with intellectual disabilities and expert candidates, Dr. Izabela Fornalik, and the innovators. As a result of the workshop, instead of planned, stationary training offer, an offer for remote workshop trainings was created that would include both therapists and their patients. Realizing this innovation became an inspiration for further actions by the Gdynia based Dom Marzeń Foundation in the area of sexuality of intellectually disabled persons. The consultation center is the fruit of that inspiration.

4. Who's behind it?

Authors and coordinators of the project are individuals working at the Gdynia based Dom Marzeń Foundation. One of the statutory goals of the foundation is initiating and supporting all the innovative solutions across different spheres of social life, particularly in protecting human rights and freedoms and in the sphere of family life and social prophylactics.



Katarzyna Karczewska – author of the concept, founder and chair of the Gdynia based Dom Marzeń Foundation. She's an architecture graduate at Gdańsk Polytechnic. For the past twenty years she has been active in supporting individuals with intellectual disabilities and their families. Privately, she is a wife and a mother of four daughters. The oldest, Marta, is intellectually disabled.

Sławomir Matuszak – works at the Gdynia based Dom Marzeń Foundation as the main NGO specialist. He's a sociologist and a pedagogue by training. For the past 13 years he's been working with individuals with intellectual disabilities, combining passion with work as a music therapist. He served as a chair of an NGO dedicated to development and promotion of culture for eight years.

photo: Iwona Wojdowska

Other experts engaged in building the program are: **Dr Izabela Fornalik, Anna Janowska, Paulina Nowogrodzka, Anna Pułjan-Laudańska, Marta Wilamowska.**

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