ECHO AUTISM COMMUNITIES

ECHO 4 ECHO Autism

Advancing care together.

autism care network

autism speaks

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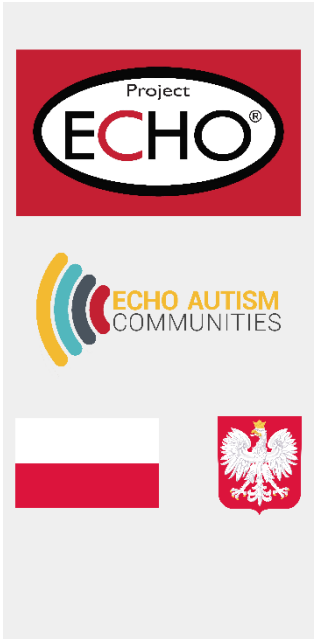
Project ECHO

ECHO AUTISM POLAND



HUB Team

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GDAŃSKI UNIWERSYTET MEDYCZNY

VIS-A-VIS

ProFUTURO

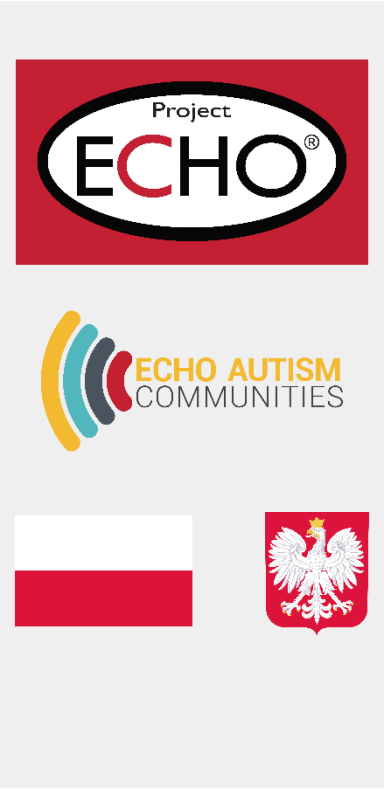
spektrum autyzmu

CENTRUM WSPIERANIA ROZWOJU MOTYL

CDTE AGATA PIENIĄŻEK

Wielkopolskie Centrum Fizjoterapii

ECHO Autism Poland



- The Extension for Community Health Outcomes (ECHO) Autism model is now for the first time introduced in Poland in 2022.
- The consorcium of partners in Poland with College of Medical Sciences, University of Rzeszow as the leader.
- Standard curriculum in medical schools and professional development curriculum for general clinicians in Poland often lacks specificity in core elements of ASD and standardized instruments used in ASD assessment.
- In mid-2022, ECHO Autism Poland, a hub of ECHO Autism Communities, launched a pilot project to increase access to evidence-based practices and specialized trainings in standardized instruments: ADI-R (Autism Diagnostic Interview – Revised) and ADOS-2 (Autism Diagnostic Observation Schedule, Second Edition) for clinicians in Poland.

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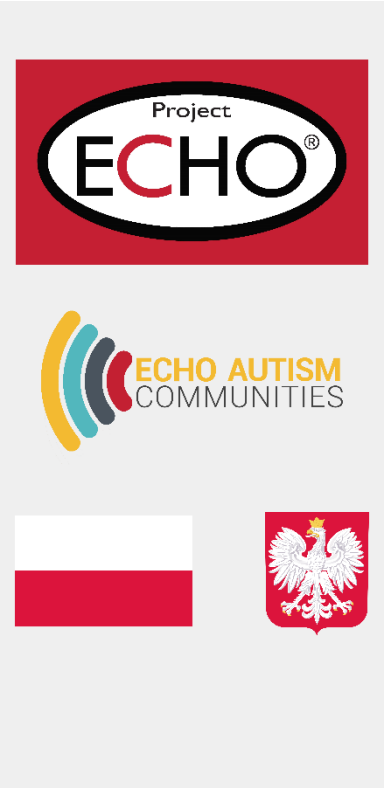
Objectives

- The project aims to train professionals in best-practice care of ASD patients and guided practice on the comorbidities in ASD, with focus on underserved population of autistic females. It also aims to train in the standardized assessments of ADI-R and ADOS-2, creating the meaningful collaboration between global ECHO Autism teams.

ECHO Autism Poland Hub



- Subject matter experts of Polish hub include psychiatrists, pediatricians, child and adolescent psychiatrists, speech and language pathologists, educators, physical therapists, psychologists additionally to adult autistic individuals, their parents, grandparents and sibling which constitutes the fundamentals of this model.

ECHO AUTISM
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- In the first 2-months circle of implementation of the project over 200 Polish professionals were trained in ADI-R and ADOS-2 by certified, internationally recognized trainers. The trainings were free of charge to all participants. Participants emphasized the opportunity to be able to develop strong multidisciplinary networks and collaborative partnerships across the sites.

ECHO Autism Poland
INSAR 2023

Implementation of the ECHO Autism Model in Poland

Agnieszka Rynkiewicz[1,2], Artur Mazur[3], Katarzyna Plata-Nazar[4], Izabela Łucka[5], Agata Ossolińska[6], Agnieszka Słopień[7,8], Agata Pieniążek[9,10]

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Background

The Extension for Community Health Outcomes (ECHO) Autism model is now for the first time introduced in Poland (Rynkiewicz et al. 2022; Sohl et al. 2022). ECHO Autism is disseminated globally due to its flexibility in adapting to local and regional differences in social norms and constructs. The model supports local professionals working with patients with autism spectrum disorder (ASD) from childhood to late adulthood. ASD is more common among males than females where autistic females still represent a highly underestimated and underserved group of ASD patients. Especially adult autistic women, are particularly affected by insufficient knowledge and shortage of trained specialists (Karavidas & Visser, 2022; Moseley et al., 2021). Standard curriculum in medical schools and professional development curriculum for general clinicians in Poland often lacks specificity in core elements of ASD and standardized instruments used in ASD assessment. In mid-2022, ECHO Autism Poland, a hub of ECHO Autism Communities, launched a pilot project to increase access to evidence-based practices and specialized trainings in standardized instruments: ADI-R (Autism Diagnostic Interview – Revised) and ADOS-2 (Autism Diagnostic Observation Schedule, Second Edition) for clinicians in Poland. Both instruments have been available in clinical practices in Poland only in recent years: ADI-R since 2021, ADOS-2 since 2017. Subject matter experts of Polish hub include psychiatrists, pediatricians, child and adolescent psychiatrists, speech and language pathologists, educators, physical therapists, psychologists additionally to adult autistic individuals, their parents, grandparents and sibling which constitutes the fundamentals of this model.

(...) The financing of the ECHO project reflects its intention to help those in need, therefore the ECHO model programs cannot charge any fees or benefit from it. The ECHO Autism model in Poland is financed/funded like the programs from the USA and other countries in the world, for example from grants, competitions and other forms that may financially support the dissemination of diagnostic standards and best practices and medical care for patients with ASD (...). (Domarecki et al. 2022; Rynkiewicz et al. 2022; Sohl et al. 2022).

Objectives

The project aims to train professionals in best-practice care of ASD patients and guided practice on the comorbidities in ASD, with focus on underserved population of autistic females. It also aims to train in the standardized assessments of ADI-R and ADOS-2, creating the meaningful collaboration between global ECHO Autism teams.

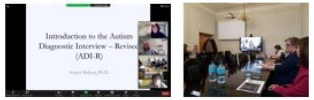
FULBRIGHT

Results

In the first 2-months circle of implementation of the project over 200 Polish professionals were trained in ADI-R and ADOS-2 by certified, internationally recognized trainers. The trainings were free of charge to all participants. Participants emphasized the opportunity to be able to develop strong multidisciplinary networks and collaborative partnerships across the sites.

Conclusions

For the first time, to our knowledge, the activities and results of ECHO Autism model in Poland are presented. This model has already created the network of collaboration among the local partners in Poland and global partners. ECHO Autism in Poland shows great promise to create the opportunities for meaningful collaboration between global teams and valuable cross-cultural learning.



ACKNOWLEDGEMENTS
We would like to thank our Global ECHO Autism Communities Liaisons, the other ECHO Autism Poland Hub Members & Supporters: Kristin Sohl, Alicia Curran, Somer Bishop, Robin Hardesty, Aneta Radoczyńska, Patryk Domarecki, Marta Bieńko, Joanna Pleskot-Kaczmarek, Agata Bloż, Anna Kostiukow, Aneta Wojciechowska, Jan Potkański, Gabriela Klecha

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Treatment of menopausal vasomotor symptoms (VMS) and sensory issues: A case-based approach in a 53-year-old Caucasian autistic woman

Agnieszka Rynkiewicz[1,2], Nouchine Hadjikhani[3,4], Rachel Moseley[5], Julie Turner-Cobb[5], Agata Ossolińska[6], Izabela Łucka[7]

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Background

Adult autistic women are still under-recognized (Rynkiewicz et al. 2019). Of more than one billion women aged 50 and over, it is unknown how many are autistic and experiencing menopause. Still considered a taboo topic in many societies, little research exists on how menopause affects autistic women's health and well-being. Existing studies suggest this often-difficult transition period is associated with many unmet health needs, a frustrating lack of knowledge and support from healthcare professionals, and an absence of resources dedicated to this population (Karavidas & Visser 2022; Rynkiewicz et al. 2022; Moseley et al. 2021). Menopausal vasomotor symptoms (VMS), or hot flashes and night sweats, are cardinal symptoms of menopause. While VMS are experienced by most women during menopause, in autistic women such symptoms may intensify and worsen sensory sensitivities (Groenman et al. 2022). Recently, more adult women without intellectual disability have pursued a formal autism diagnosis to define their own autistic identity. This often helps them learn to more effectively recognize warning signs of sensory difficulties and meltdowns, and can lead to the self-discovery of unexpected strength, resilience, and confidence in advocating for their needs.

Methods

53-year-old Caucasian autistic woman, diagnosed with ASD at age 43 by a trained psychiatrist, no ID, currently experiencing menopausal symptoms. Anxiety and depression previously recorded and treated pharmacologically, currently no other comorbidities or somatic illnesses and no medications at the start of recording. Examinations and tests completed or retrived from the patient's medical record over the period of 7 months of the study: transvaginal, breast ultrasound and cytological exams; hormonal lab testings; magnetic resonance imaging (MRI) of the pituitary gland; ADOS-2 (Module 4); ADI-R (retrived codes under Interests & Behaviors: the items 67-79); a modified version of GQ-ASC/Q-ASC (Girls' Questionnaire for ASC) for adult women (Attwood, Garnett, Rynkiewicz [measurement instrument 2011] modified by Brown et al. 2020); SCQ Lifetime; AQ; and MENQOL. The patient participated in the Mindfulness sessions. Hormone replacement therapy (HRT) was introduced to ameliorate symptoms of estradiol and progesterone deficiency.

Objectives

To investigate menopausal vasomotor symptoms (VMS) experienced by an autistic woman and examine whether symptoms were linked to autistic traits and sensory issues.

Results

- **Magnetic resonance imaging (MRI) of the pituitary gland:** smooth-bordered oval focus with dimensions of approx.4.5x3x4mm in the anterior part of the frontal lobe = **microadenoma**. A fluid focus of approx.2.5mm between the upper parts of the pituitary lobes = like that in Rathke's pouch cyst.
- Initially, **hyperprolactinemia** was diagnosed with a level of 1425.25 mU/l (normal range: <557.1), and in the MCP test, there was no increase in prolactin concentration; levels of 1176.4 and 1033.1 mU/l - suggestive of prolactinoma.
- The initial **cortisol concentration** was **normal** at 360.2 nmol/l with an appropriate ACTH concentration of 13.3 pg/ml, and there was complete cortisol suppression at 32.7 nmol/l in the 1g DXA test.
- **Normal IGF concentration** of 130.9 ng/**ml.**
- **Normal electrolyte balance, blood glucose levels, TSH, FT3, FT4.**
- **Breast ultrasound:** Cysts, Ø approx. 4.2 to 11mm visible in both breasts. **Transvaginal ultrasound and cytological exam:** both unremarkable.
- **Difficulties in functioning and unusual sensory interests:** ADOS-2 (Module 4) SA+RRB (11), D1(2)/D2(1)/D4(2)/D5(1); SCQ Lifetime (26), AQ (33), I&B in ADI-R.
- **MENQOL:** hot flashes, night sweats, foggy thinking, vaginal dryness, mood swings and anxiety decreased while aching in muscles and joints, low backache, feeling tired, worn out persisted after HRT implementation.
- The patient **responded positively to Mindfulness meditation** and continued regular sessions beyond the project.
- Treatment: **Systen Conti** (3.2mg Estradiolum + 11.2mg Norethisteroni acetas) - 1 patch twice a week. Vitamin D3 supplementation; **Devikap 4000 IU** - 1 tabl./day. **Dostinex** (Cabergolinum 0.5mg) ½ tabl./week for the hyperprolactinemia, well tolerated by the patient.

Conclusions

Intensity of the menopausal VMS symptoms were observed in relation to strength of sensory issues. HRT alleviated majority of VMS experienced by the patient. Sensory perception and intellectual processing appeared to influence how VMS symptoms were interpreted, labeled, and reported. Since gynecologists often lack fundamental knowledge on ASD, this highlights the need for further research to inform treatment plans, including HRT and non-pharmacologic approaches that could be offered to autistic women during menopause.

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Ministry of Education and Science Republic of Poland

Funded by Ministry of Education and Science Republic of Poland (MEiN), grant SKN/SP/535279/2022 and the institutional funds of College of Medical Sciences, University of Rzeszow, Poland. Approved by the Ethics Committee of College of Medical Sciences, University of Rzeszow (KB-2022/093).

ACKNOWLEDGEMENTS
We would like to thank our Global ECHO Autism Communities Liaisons and Supporters: Kristin Sohl, MD, FAAP, Alicia Curran, BS, Grad. Cert., Robin Hardesty, Somer Bishop, PhD, Artur Mazur, MD, PhD, Dorota Darmochwał-Kolarz, MD, PhD

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ECHO AUTISM COMMUNITIES

ECHO Autism Poland
AUTISM EUROPE INTERNATIONAL CONGRESS 2022

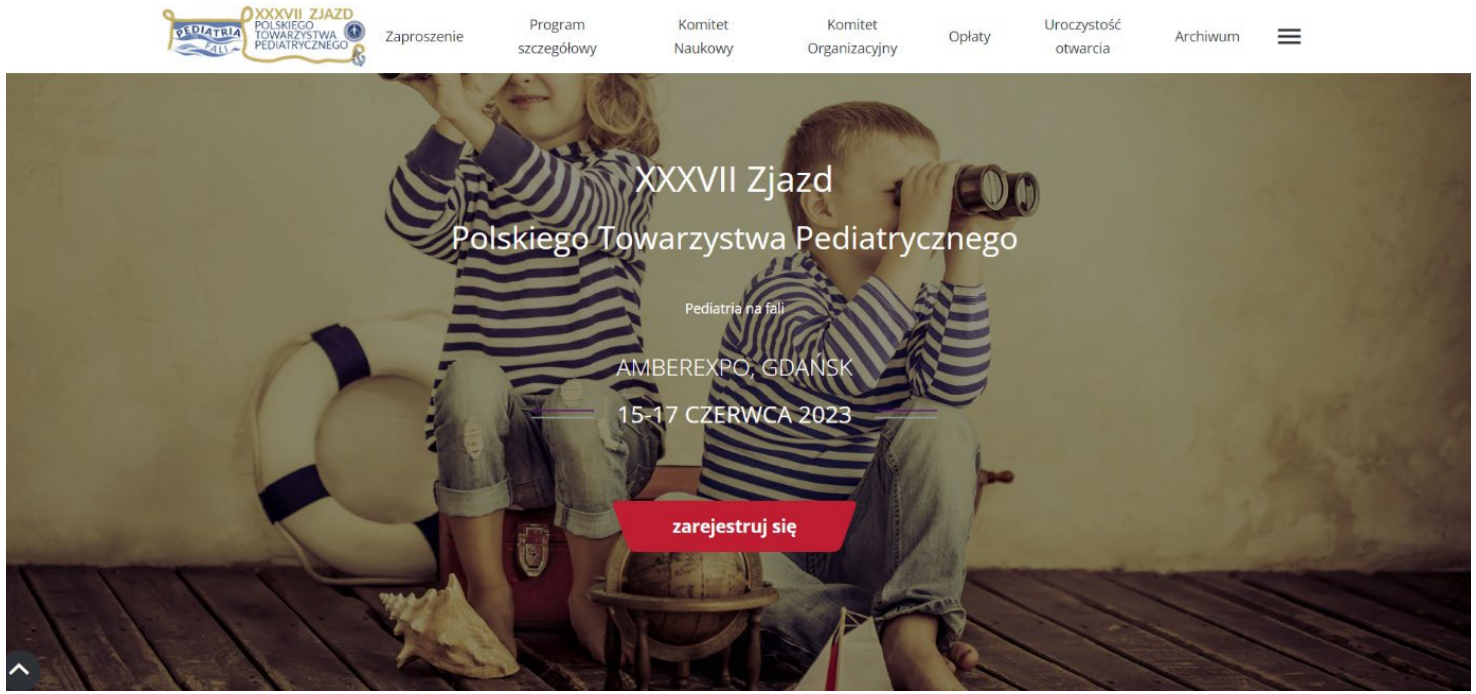
ECHO Autism Communities

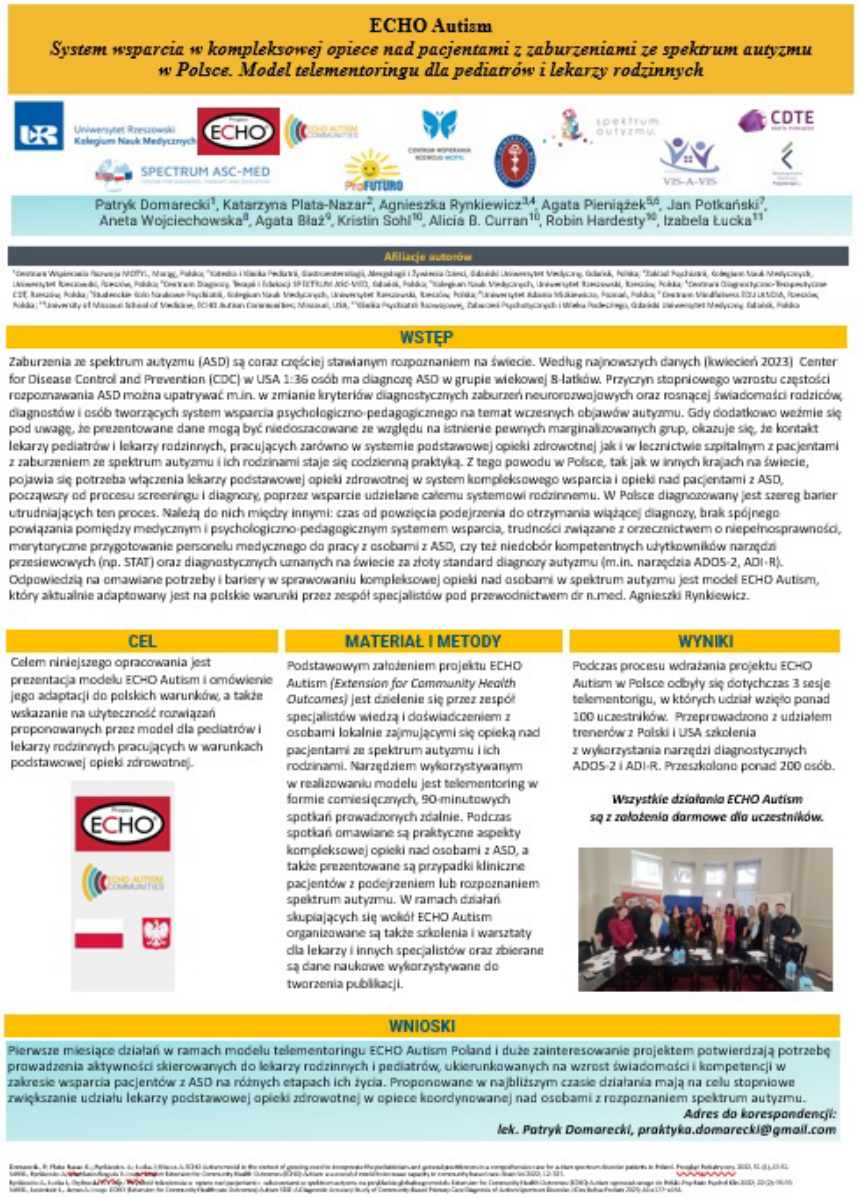
Global scale ECHO Autism model enhancing healthcare for females with autism spectrum disorder (ASD) during their transition into adulthood

Agnieszka Rynkiewicz[1], Kristin Sohl[2], Roma A. Vasa[3], Alicia Brewer Curran[2], Adeline Lacroix[4], Gabriela Klecha[5], Jakub Klecha[5], Katarzyna Plata-Nazar[6], Izabela Łucka[7], Artur Mazur[8]

ECHO Autism Poland

Congress of Polish Pediatric Society 2023





ECHO Autism

System wsparcia w kompleksowej opiece nad pacjentami z zaburzeniami ze spektrum autyzmu w Polsce. Model telementoringu dla pediatrów i lekarzy rodzinnych

Patryk Domarecki[1], Katarzyna Plata-Nazar[2], Agnieszka Rynkiewicz[3,4], Agata Pieniążek[5,6], Jan Potkański[7], Aneta Wojciechowska[8], Agata Błaż[9], Kristin Sohl[10], Alicia B. Curran[10], Robin Hardesty[10], Izabela Łucka[11]

Afiliacje autorów

WSTĘP

Zaburzenia ze spektrum autyzmu (ASD) są coraz częściej stawianym rozpoznaniem na świecie. Według najnowszych danych (kwiecień 2023) Center for Disease Control and Prevention (CDC) w USA 1:36 osób ma diagnozę ASD w grupie wiekowej 8-latków. Przyczyn stopniowego wzrostu częstości rozpoznawania ASD można upatrywać m.in. w zmianie kryteriów diagnostycznych zaburzeń neurorozwojowych oraz rosnącej świadomości rodziców, diagnostów i osób tworzących system wsparcia psychologiczno-pedagogicznego na temat wczesnych objawów autyzmu. Gdy dodatkowo weźmie się pod uwagę, że prezentowane dane mogą być niedoszacowane ze względu na istnienie pewnych marginalizowanych grup, okazuje się, że kontakt lekarzy pediatrów i lekarzy rodzinnych, pracujących zarówno w systemie podstawowej opieki zdrowotnej jak i w lecznictwie szpitalnym z pacjentami z zaburzeniem ze spektrum autyzmu i ich rodzinami staje się codzienną praktyką. Z tego powodu w Polsce, tak jak w innych krajach na świecie, pojawia się potrzeba włączenia lekarzy podstawowej opieki zdrowotnej w system kompleksowego wsparcia i opieki nad pacjentami z ASD, począwszy od procesu screeningu i diagnozy, poprzez wsparcie udzielane całemu systemowi rodzinnemu. W Polsce diagnozowany jest szereg barier utrudniających ten proces. Należą do nich między innymi: czas od powzięcia podejrzenia do otrzymania wiążącej diagnozy, brak spójnego powiązania pomiędzy medycznym i psychologiczno-pedagogicznym systemem wsparcia, trudności związane z orzecznictwem o niepełnosprawności, merytoryczne przygotowanie personelu medycznego do pracy z osobami z ASD, czy też niedobór kompetentnych użytkowników narzędzi przesiewowych (np. STAT) oraz diagnostycznych uznanych na świecie za złoty standard diagnozy autyzmu (m.in. narzędzia ADOS-2, ADI-R). Odpowiedzią na omawiane potrzeby i bariery w sprawowaniu kompleksowej opieki nad osobami w spektrum autyzmu jest model ECHO Autism, który aktualnie adaptowany jest na polskie warunki przez zespół specjalistów pod przewodnictwem dr n.med. Agnieszki Rynkiewicz.

CEL

Celem niniejszego opracowania jest prezentacja modelu ECHO Autism i omówienie jego adaptacji do polskich warunków, a także wskazanie na użyteczność rozwiązań proponowanych przez model dla pediatrów i lekarzy rodzinnych pracujących w warunkach podstawowej opieki zdrowotnej.

MATERIAŁ I METODY

Podstawowym założeniem projektu ECHO Autism *(Extension for Community Health Outcomes)* jest dzielenie się przez zespół specjalistów wiedzą i doświadczeniem z osobami lokalnie zajmującymi się opieką nad pacjentami ze spektrum autyzmu i ich rodzinami. Narzędziem wykorzystywanym w realizowaniu modelu jest telementoring w formie comiesięcznych, 90-minutowych spotkań prowadzonych zdalnie. Podczas spotkań omawiane są praktyczne aspekty kompleksowej opieki nad osobami z ASD, a także prezentowane są przypadki kliniczne pacjentów z podejrzeniem lub rozpoznaniem spektrum autyzmu. W ramach działań skupiających się wokół ECHO Autism organizowane są także szkolenia i warsztaty dla lekarzy i innych specjalistów oraz zbierane są dane naukowe wykorzystywane do tworzenia publikacji.

WYNIKI

Podczas procesu wdrażania projektu ECHO Autism w Polsce odbyły się dotychczas 3 sesje telementoringu, w których udział wzięło ponad 100 uczestników. Przeprowadzono z udziałem trenerów z Polski i USA szkolenia z wykorzystania narzędzi diagnostycznych ADOS-2 i ADI-R. Przeszkolono ponad 200 osób.

Wszystkie działania ECHO Autism są z założenia darmowe dla uczestników.

WNIOSKI

Pierwsze miesiące działań w ramach modelu telementoringu ECHO Autism Poland i duże zainteresowanie projektem potwierdzają potrzebę prowadzenia aktywności skierowanych do lekarzy rodzinnych i pediatrów, ukierunkowanych na wzrost świadomości i kompetencji w zakresie wsparcia pacjentów z ASD na różnych etapach ich życia. Proponowane w najbliższym czasie działania mają na celu stopniowe zwiększanie udziału lekarzy podstawowej opieki zdrowotnej w opiece koordynowanej nad osobami z rozpoznaniem spektrum autyzmu.

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ECHO AUTISM COMMUNITIES

ECHO Autism Poland sessions

- The launch session took place in March 2023.
- The first open session in Polish language took place in April 2023. We have almost 400 registered participants.
- About 80-100 people connected to us in each online session.

ECHO AUTISM COMMUNITIES

Participants

- Sex: 89,1 %- female, 10,4 %- male
- Age: 20-69 years (most between 20-50)
- Profession: pedagogue, psychologist, psychiatrist, doctor of another specialty, teacher, parents of a person with ASD
- Experience working with people with ASD: 5-10 years
- Expectation: access to professional care, current knowledge about ASD, current possibilities of diagnosis and therapy of people with ASD

ECHO AUTISM COMMUNITIES

ECHO Autism Poland - Didactics

April 2023	Comprehensive support system for families of people with autism spectrum disorders
May 2023	Screening tools used in the Diagnosis of autism spectrum disorders Part 1
June 2023	Screening tools used in the Diagnosis of autism spectrum disorders part 2
July 2023	STAT- Screening test for autism for young children - possibilities of use in Poland
August	ADOS-2 and ADI-R as the gold standard in the diagnosis of autism spectrum disorders

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ECHO Autism session- cases

- The cases of children with ASD and adult women with ASD were presented during the session.
- The discussion and developed recommendations supported the family, specialists, and teachers.

- We are waiting for more cases…

ECHO AUTISM COMMUNITIES

After the session…

- Most of the participants believe that they gained new knowledge during the session.
- Most session participants believe that they will be more effective in diagnosing autism.
- Most participants believe that during the session, they learn best practices for caring for people with ASD.
- Most participants think they will be more able to assess comorbidities with ASD.
- Most participants respect the opinion and opinions of other professionals.
- Most of the participants believe that the trainers allowed free expression of their opinion.

ECHO AUTISM COMMUNITIES

Promotion ECHO Autism Poland

- Facebook
- Websites of cooperating organizations
- Trainings organized by the ECHO Autism Hub
- Scientific press
- Conferences
- Meetings with students, faculty at the universities, schools, pre-schools, resident medical doctors, health care professionals in the hospitals and clinics
- Meetings with families of people with ASD

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Advancing care together.

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Project ECHO

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School of Medicine
University of Missouri Health