

ITHACA Board Meeting 2020

2020 December 10 - 12

Patient Council Meeting : December 10th

14h00 - 17h00





Exploring transition from childhood to adulthood through co-working between families and professionals to enhance practice and participation – workshop.

KATARZYNA ŚWIECZKOWSKA, TOMASZ GRYBEK

Patient Council Meeting : December 10th



Exploring transition from childhood to adulthood through co-working between families and professionals to enhance practice and participation – workshop.

32nd European Academy of Childhood Disability Annual Meeting.

- The EACD is an academic association of professionals working with children with disability throughout Europe.
- At present the academy has over 500 members who are paediatricians, neuropaediatricians, physiotherapists, occupational therapists, speech therapists, psychologists, nurses, social workers and special-needs teachers.
- Over 35 countries are represented.
- The main goal of EACD is to promote teaching and facilitate sharing of information, research and good practice.
- 32nd European Academy of Childhood Disability Annual Meeting - Poland
- Exploring transition from childhood to adulthood through co-working between families and professionals to enhance practice and participation – workshop

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32nd European Academy of Childhood Disability Annual Meeting.

Goals:

1. Allow families to gain and share information in relation to transition.
2. Allow professionals to share experience about transition.
3. Allow parents and the people concerned to share and contrast their views with those of professionals reciprocally to improve practice and understanding of the transition process.
4. Improve knowledge and favor appropriate decisions for the welfare of people living with disabilities and facilitate the transition into adulthood

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PART 1

Users and professionals separately:

Most common concerns of

- people in transition
- family of people in transition
- professionals involved with transition
- Transition from children's to adults health care system (lack of path for smooth transition, little knowledge on rare diseases)
- Services are not family centred
- Discrimination and lack of participation and inclusion
- Lack of respect for individual autonomy including the freedom to make one's own choices, and independence of persons
- Lack of money
- Sexuality
- Lack of proper support in COVID-19 pandemic

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PART 2

Users and professionals together

Solutions:

- Preparing a path for smooth transition from children's to adults health care system (patients' passports, coordinated health care)
- Family/person centred approach in providing services, building users – professionals partnership
- Promoting personal assistance
- Promoting inclusion and participation
- Circles of support approach
- Educating users and professionals on persons with disability sexuality
- Sharing of information, research and good practice in supporting people with disability in COVID-19 pandemic

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Rare Disease Centre of Gdansk – Conference „Rare Disease – Together into adulthood”

Basics:

2 Days online event: **1st Day:** Conference (7 presentation & Speakers) | **2nd Day:** Workshop „From Childhood 2 Adulthood”

Workshop stats:

26 participants:

- **13 Users** (RD Patients & Caregivers representing **8 different RDs**).
- **13 Professionals** (HCP, Psychologists, Pedagogics, Physiotherapists, Authorities Officers).

6 Moderators (ePAG Adv., HCP, Therapist, Special-needs teachers, Med. Univ. Student) of **6 Workshop Groups**.

4 hours via Zoom

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Main Challenges:

- Deficit of autonomy in everyday life
 - Limits of disabilities - self acceptance and empowerment
- Growing with age lack of understanding in social, educational, professional environment
 - Nascent sexuality of persons with disabilities
- Transition of care – independence & subjectivity vs. limits & challenges of HCS (shortage of time, lack of care coordination, limited knowledge and access to expertise network outside big metropolis)
 - Disease–Life Balance (pursuit of reaching golden mean in daily life)

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Key Solutions:

- Lifelong assistance & support of RD patients
 - Psychological systemic support for persons and his family in the concept from the diagnosis till adulthood
- Social Awareness & Inclusion Policies – campaigns, education on all levels, small scale initiatives „me & my ecosystem”
 - Sexual Awareness Educational Programs & Campaigns
- Coordinated, networked, IT supported, patient-centred specialised health care implemented by evolution not revolution
 - Holistic empowerment & life companionship – cooperation of all stakeholders on all levels

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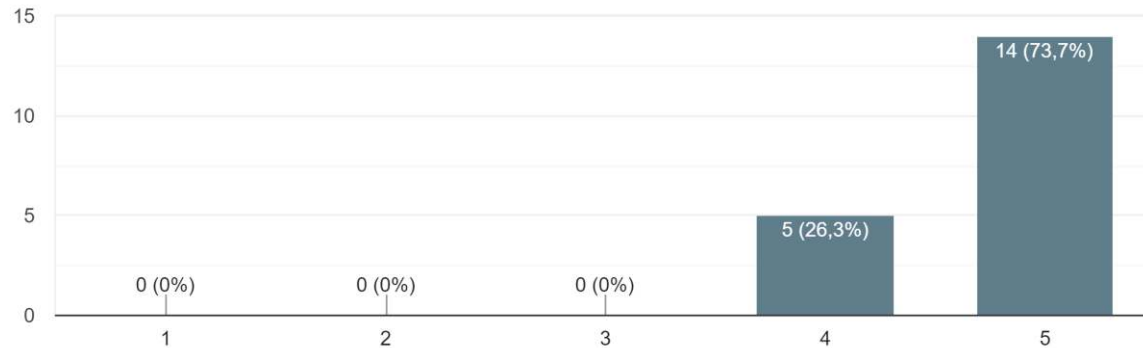


Rare Disease Centre of Gdansk – Conference „Rare Disease – Together into adulthood”

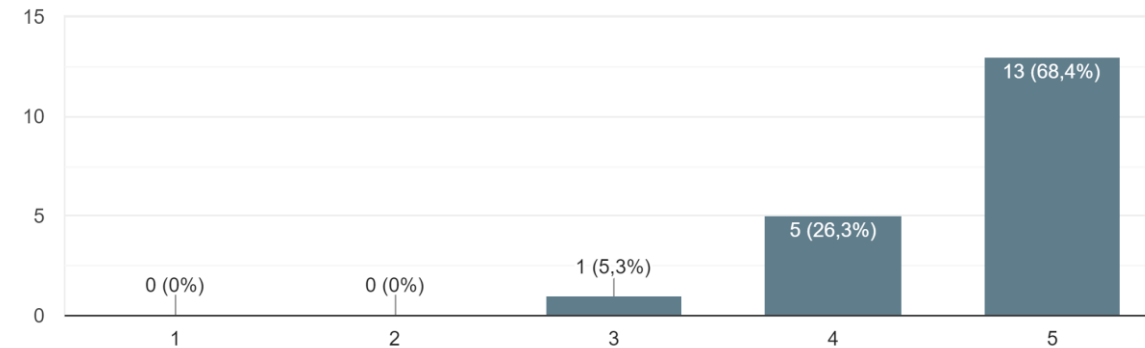
Evaluation – early conclusions:

Basics: anonymous online survey, response rate: 73% (47% Professionals, 53% Users):

Rating of organizational level



Rating of substantive level



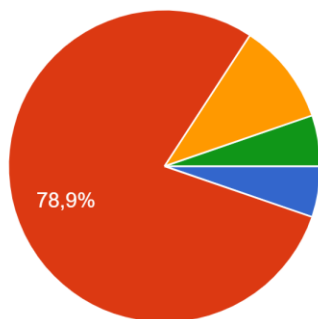
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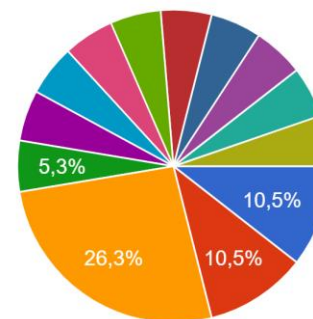
Evaluation – early conclusions:

Which part of workshop was the most valuable?



- Praca w grupie jednorodnej (tylko OzN/Rodzice lub tylko Profesjonaliści)
- Praca w grupie mieszanej (połączone grupy tylko OzN/Rodzice i Profesjonalistów)
- Sesja plenarna podsumowująca pracę w grupach
- Wszystkie części były dla mnie wartościowe

Which part of workshop was the least valuable?



- Praca w grupie jednorodnej (tylko Uży...)
- Praca w grupie mieszanej (połączone...)
- Sesja plenarna podsumowująca pracę...
- brak
- brak najmniej wartościowych
- wszystkie sesje były bardzo cenne
- trudno powiedzieć
- nie było takiej części warsztatów

▲ 1/2 ▼

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Evaluation – early conclusions:

Substantive aspects:

- Important & current topic
- Great concept of mixed groups: bilateral perspective on challenges & solutions
- Next step challenge – how effectively and efficiently implement solutions?
 - conference & workshop concept should be continued and repeated
- Key success factor lays in comprehensive, diverse selection & allocation of participants

Technical aspects:

- Shortage of time
 - Moderation and taking notes – room for improvement
- Limits of allocation – the less diverse the less comprehensive approach

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Thank you for your attention!

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