

SUPPORT OF SOCIAL PARTICIPATION OF PEOPLE WITH DISABILITIES

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CONTENT

- ✘ aims and activities of EUCERD (European Union Committee of Experts on Rare Diseases)
- ✘ research – conclusion from interviews with young people with Williams Syndrome
- ✘ social services supporting the social participation of people with disabilities

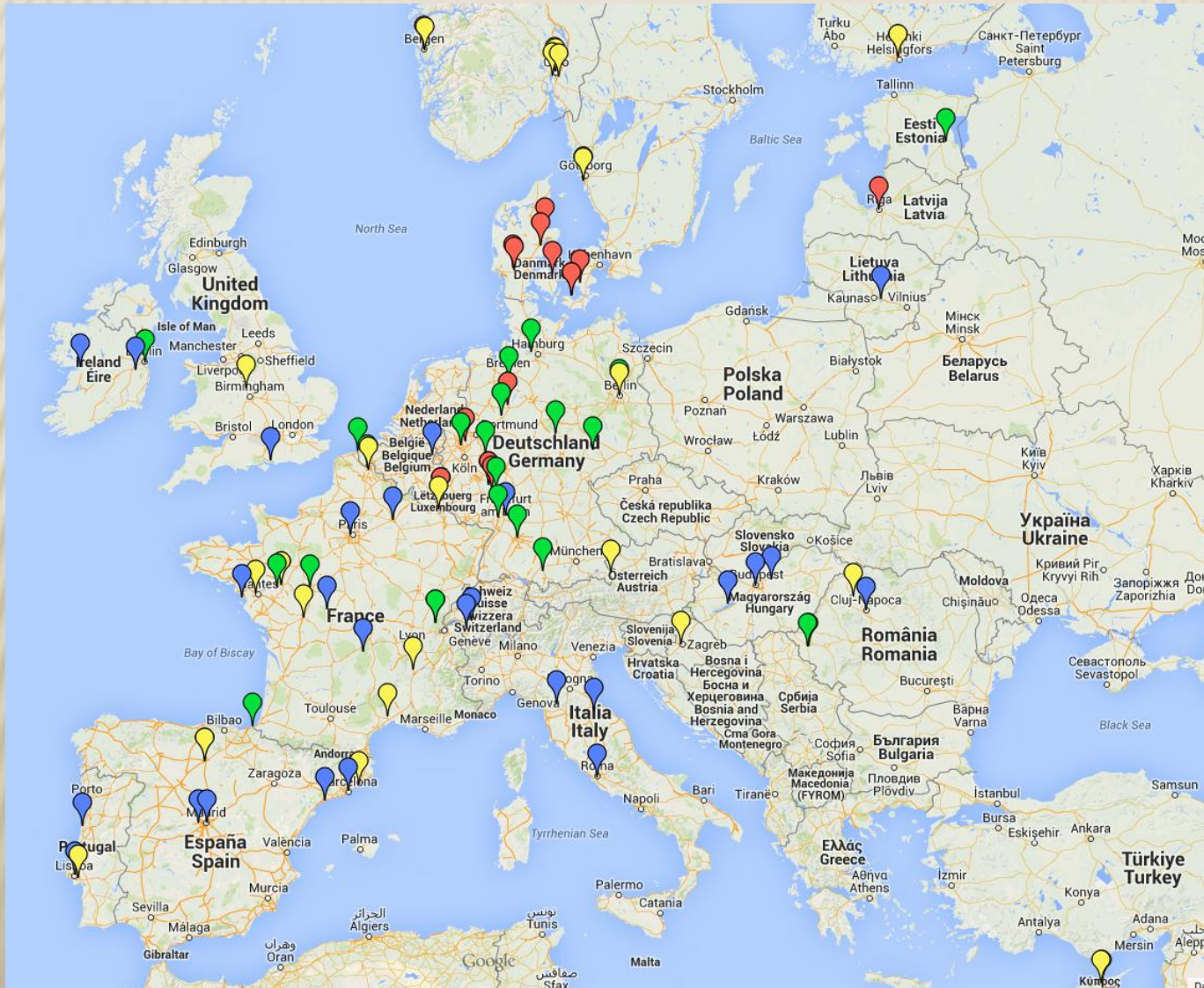
AIMS AND ACTIVITIES OF EUCERD

- ✘ to facilitate access to information on specific social services for RD patients and their families;
- ✘ to define guiding principles for Member States and stakeholders on why and how to develop training sessions for social services providers;
- ✘ to promote the integration of RD into social policies and services
- ✘ to implement the plans and strategies for rare diseases at national and international level
- ✘ and...

AIMS AND ACTIVITIES OF EUCERD

- ✘ to identify and to map the existing specialised social services and to identify good practices
- ✘ Specialised Social Services identified at EU level:
 - + Therapeutic Recreation Programmes (TRP)
 - + Respite Care Services (RCS)
 - + Adapted Housing (AH)
 - + Resource Centres (RC)

SPECIALISED SOCIAL SERVICES IN EUROPE



Therapeutic
Recreation
Programmes
(TRP) - blue

Respite Care
Services
(RCS) - green

Adapted
Housing (AH) -
red

Resource
Centres (RC) -
yellow

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REPORTS ON THE STATE OF THE ART – 2014

- ✘ Reports on the state of the art of rare disease activities in Europe – 2014 edition, 5 parts
- ✘ Individual reports on the activities in each country

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RESEARCH ON PEOPLE WITH WS

- ✘ Main aim: to analyse the extent of participation of people with WS in society
- ✘ Focus on adults with WS
- ✘ Interviews with people with WS
- ✘ Modified to intellectual disability

AREAS OF INTEREST

- ✘ Family and relationships – own family, independent living
- ✘ Productive activities – education, job, volunteering
- ✘ Social activities – free time, hobbies, leisure time activities, dreams

RESPONDENTS

- ✘ Czech Republic – 3 respondents (M21, W22, M23)
- ✘ Slovak Republic – 3 respondents (W34, M23, W30)
- ✘ Germany – 3 respondents (M30, W20, M43)

FAMILY AND RELATIONSHIPS

- + Good relationships with close and distant family
- + Two of them live alone (sheltered living)
- + Three of them have a partner
- + Most of them want a partner, perhaps to get married
- + None wants a child

FAMILY AND RELATIONSHIPS

- ✘ *No, definitely not. I wouldn't manage it, because I need to be taken care of, no I wouldn't manage it. (SK, W 34)*
- ✘ *I can't live alone. Because I bought an apartment with my mum and I live with her. (SK, M 23)*

FAMILY AND RELATIONSHIPS

- ✘ *Maybe we would have the same kids as we are. (CZ, M 21)*
- ✘ *Because he has the WS, so my mum said that we can't. It could be disabled and I wouldn't manage to take care of it at all. (CZ, W 22)*
- ✘ *I can't have a boyfriend, nor relationships, nor children, unfortunately. (SK, W 30)*

FAMILY AND RELATIONSHIPS

- ✘ *Sometimes I even miss it when I see somebody holding hands with a boyfriend but I say what a pity I can have just friends. But friend is better than boyfriend. (SK, W 30)*
- ✘ *Because I would like to have a friend or girlfriend and go out for cola with her. Then for example concerts and so, listening to music. (SK, M 23)*

FAMILY AND RELATIONSHIPS

- ✘ *My father died three years ago. He was 51. He was severely ill and he had a stroke. (G, M 30)*
- ✘ *It was a shock. I didn't even know that she wouldn't have hair. So I started to cry when they told me.*
- ✘ *Later. They knew it in the family that she will loose hair but they didn't want to tell me because I would freak out. (CZ, W 22)*

PRODUCTIVE ACTIVITIES

- + Three of them have a job (sheltered labour market), one has a part-time job
- + Three of them still visit the school
- + Two of them have volunteered

PRODUCTIVE ACTIVITIES

- ✘ *I would like to have a job. My mum asked a friend if there is some sheltered work, where I could work but there are not any in my area. (SK, M 23)*
- ✘ *No, I would rather be at home. I am used to be at home and I wouldn't like if I had to go somewhere far away. (SK, W 34)*

PRODUCTIVE ACTIVITIES

- ✘ *Right now I visit one woman, I am a volunteer.*
- ✘ *I go to the senior centre. She can't move her body, just her head. So we talk and I ride the wheelchair and it is great. (CZ, W 22)*

SOCIAL ACTIVITIES

- + Activities on internet
- + Going out with friends
- + Music
- + Travelling
- + Sport

SOCIAL ACTIVITIES

- ✘ *I rather sit at the computer and write to my friends and play games, am on Facebook, Skype, everywhere. (SK, W 34)*
- ✘ *I visit art school and I play drums there and I´m good at it. (SK, M 23)*

SOCIAL ACTIVITIES

- ✘ *A lot. I am away. Mondays I go to an adult club, which is Monday from 16:45 till 19:30. Meanwhile I leave earlier from the club because on Mondays evening I sing in a choir. That´s why I have to go earlier. Tuesdays I have skittle (bowling) every four weeks. Wednesdays I am either at home or sometimes I also go out. Thursdays I am out with the adult club. We go on trips or we go to the pub or we go bowling or play miniature golf or for a walk to the city, shopping and so on. (G, M 34)*

SOCIAL ACTIVITIES

- ✘ *I like to go to the playground, outside, cycling. Visiting friends and so on.*
- ✘ *Then swimming and I play the piano. (G, W 20)*
- ✘ *Music, reading, travelling. (G, M 43)*

CONCLUSION AND RECOMMENDATIONS

Situation (not only) in the Czech Republic

SITUATION IN THE CZECH REPUBLIC

- ✘ Czech Association for Rare Diseases – 2002
- ✘ The Act of Social Services Nr. 108/2006
 - + Social counselling
 - + Services of social prevention
 - + Services of social care
- ✘ Non-profit-organisations essential
 - + Občanské sdružení Willík

THERE IS... → THERE SHOULD BE...

- ✗ Support of people with disabilities
 - + gaining of independence
 - + education – preparing for adult life – There is life after school... but it doesn't begin after school.
 - + job – transition programme
 - + living, leisure time, partnership, money...
 - + social skills and competencies (plan-decide-organise-find-support)
 - + social services – obtainable, available

THERE IS... → THERE SHOULD BE...

- ✘ Support of the parents and families
 - + information – rights, possibilities (school, support...)
 - + letting to become independent
 - + „everlasting child“
 - + social services – obtainable, available
- ✘ Awareness of the society
 - + „let them participate on everyday life“

THANK YOU FOR YOUR ATTENTION!

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