

# SUPPORT OF SOCIAL PARTICIPATION OF PEOPLE WITH DISABILITIES

PhDr. Lucie Procházková, Ph.D.  
Bc. Lenka Kratochvílová  
Masaryk University, Faculty of Education, Brno (Czech Republic)



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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

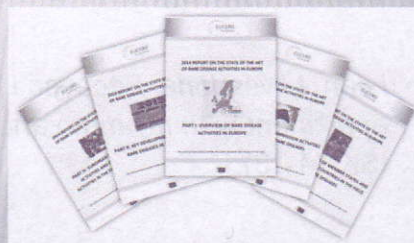
Resource Centres (RC) - yellow

[www.eucerd.eu](http://www.eucerd.eu)

## 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

online available:  
[www.eucerd.eu](http://www.eucerd.eu)



## 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!

PhDr. Lucie Procházková, Ph.D.  
[prochazkova.lucie@ped.muni.cz](mailto:prochazkova.lucie@ped.muni.cz)  
Bc. Lenka Kratochvilova  
[kratochvilova.len@seznam.cz](mailto:kratochvilova.len@seznam.cz)



PEDAGOGICKÁ FAKULTA  
Masarykovy univerzity

