# ANNEX









# Overview of group discussions & potential connections





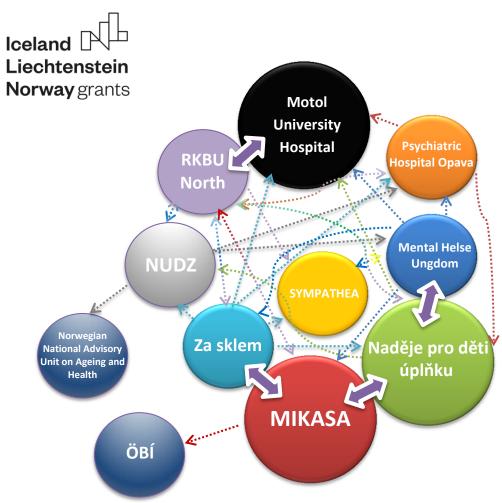




### **GROUP A**

# **Network map - potential connections**





#### Legend



very good match between both entities



partial match between both entities



#### Overview & summary of group A discussions

In group A discussing the area of children's mental health, professionals of 9 different organizations including two representatives from Norway, were gathered. Main topics are summed up in points in the table.

#### • Mental Helse Ungdom (Norwegian Association of Youth Mental Health): Adrian Tollefsen

- helping young people with different projects including mental health
- research on user participation, help seek behaviour among youth
- running participation programme in healthcare

#### • MIKASA z.s.: Sandra Štěpánková

- focus on social rehabilitation, support and assisting people with autistic spectrum disorder
- providing guidance for parents, psychological counselling for parents, carers and professionals
- running a daily stationary for children and youth with combined disabilities
- interested in providing quality social services to children and young people affected by mental disorders on the basis of their individual needs and in a family environment

#### • Motol University Hospital: Michal Goetz

- preparing a pre-defined project with the objective to enhance mental health and well-being of children of school age through the implementation of the 'Incredible Years for Every Child' programme in the Czech Republic
- pilot of Incredible Years (IY) training programme for parents of children of 6-12 years at selected centres across the Czech Republic including research on locations for further dissemination of the programme

#### • Naděje pro děti úplňku z.s. (Children of the Full Moon): Markéta Křečková

- associating parents and other carers of children with severe autistic spectrum disorder (ASD)
- documentary about families raising children with a severe form of autism: https://www.detiuplnku.cz/en/children-of-the-full-moon/movie/#play video
- key activities: analyses, advocacy, awareness raising among public, social care innovation and improvement of the quality of services for children and their families
- interested in piloting of homesharing shared care in community settings

#### • National Institute of Mental Health (NUDZ): Barbora Veselá

- focus on research programmes in social psychiatry: analyses and development of programmes focused on prevention of mental health issues of children (primary school age); mental health of Roma from socially excluded areas in the Czech Republic
- epidemiological and clinical research of addiction
- geropsychology, features of cognitive superaging and impact of settlement size on cognition in older age

#### • Psychiatric Hospital Opava: Jana Bartošová

- providing diagnostic-therapeutic care of psychopathology in children and youth
- focus on complex care, neurodevelopmental disorders incl. ASD, early diagnostics, re-education
- interested in sharing experience and best practise

#### • Regional Centre for Child and Youth Mental Health and Child Welfare: Oddbjørn Løndal

- donor partner of the pre-defined project IY
- focus on evidence based treatment and prevention (conduct and social problems) and implementation of evidence based programs
- providing parent training and support
- offers to help with establishing contacts with relevant Norwegian institutions working in the field

#### SYMPATHEA, o.p.s.: Jana Poljaková

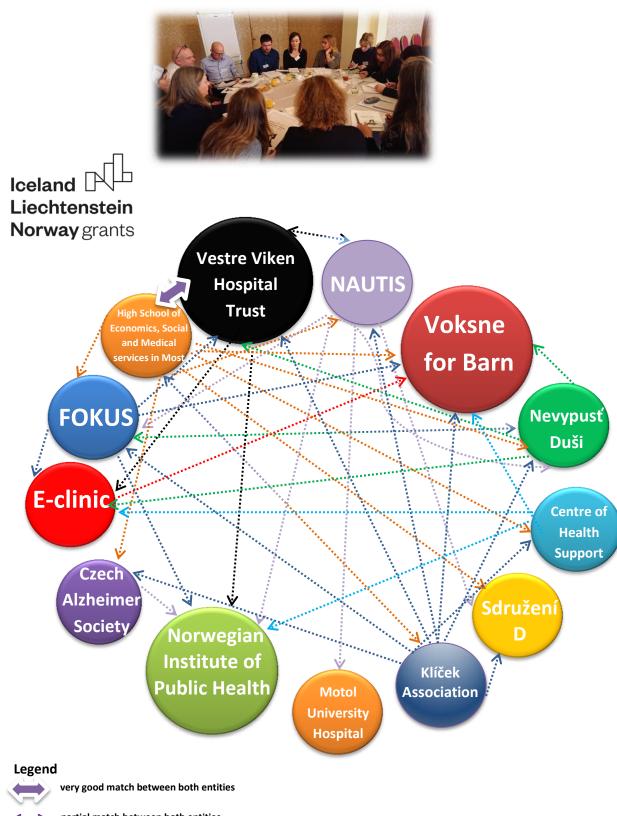
- focus on relatives of mentally ill patients
- providing support, advice on health and social services and social contacts
- running phone counselling (7 days a week)

#### • Za sklem o.s.: Tomáš Hasík

- focus on ASD by providing services for people with ASD in order to be able to live, study and work in standard environment
- supporting the inclusion of children with ASD into society and providing support to their families
- providing expert trainings for teachers and social workers

# GROUP B

# **Network map - potential connections**





partial match between both entities

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#### Overview & summary of group B discussions

In group B discussing the area of children's mental health, professionals of 13 different organizations including three representatives from Norway, were gathered. Main topics are summed up in points in the table.

#### FOKUS České Budějovice: Aneta Vedralová

- activities aimed at destigmatization of mental disorders (schizophrenia, bi-polar disorder or depression)
- interested in extending and developing ongoing activities and implementing destigmatization school programmes focusing on children in various group categories
- intention to learn from partner's experience and/or implement joint activities

#### NAUTIS: Zuzana Daňková

- support people with autism and people around them by wide range of activities
- diagnostic and social services, such as shelter housing or kindergarten
- awareness-raising campaigns for the public
- interested in developing "homesharing" and focusing on early intervention programmes

#### Nevypusť duši: Marie Salomonová

- focus on prevention and raising awareness about mental health and mental illness (anxiety, eating and other disorders)
- implementation of evidence-based school programme for students and teachers
- plan to establish a partnership for the purpose of scaling-up and improvement of a comprehensive certified programme for youth and for teachers
- focus on peer programmes and further empowerment of patients

#### • Centre for the Health Support: Lenka Plzáková

- prevention of obesity and eating disorders, promotion of healthy lifestyle and nutrition of children
- interested in developing primary and secondary prevention activities and implementing services for patients suffering from eating disorders, anorexia or bulimia and their relatives
- focus more on children in excluded localities

#### • The Norwegian Institute of Public Health: Svetlana Skurtveit

- research of causes of mental diseases and problems with addictions
- analysis of data from national health registries
- interested in bilateral research collaboration which would contribute to the joint production of knowledge on what proportion of children suffers from mental disease how well it is treated

#### • E-clinic: Jana Gricová

- dealing with eating disorders and providing of online help to motivate clients to find treatment
- family consulting, awareness-raising and promotion of children's mental health
- intention to focus on children with special needs and further empowerment of patients with eating disorders

#### • Voksne for Barn: Randi Talseth

- expertise in preventive mental health programs at schools for children from 1st to 4th grade
- has implemented the Zippy's Friends programme already on 700 schools in Norway
- plans to move on with Zippy's Friends programme and its further development
- interested in developing a general life skills programme targeting children of all ages

# • High school of economics, social and medical services in Most (VOŠ-SOŠ Most): Hana Elexová

- seeking a partner with experience with implementation of practical educational programme aimed at explaining to adolescents how to deal with their emotions, how to handle stress, etc.
- interested in implementing educational programme for teachers on the various techniques to work effectively with students

#### Overview & summary of group B discussions

#### • Klíček Association: Markéta Královcová

- support for parents of children in hospitals
- effort to set up independent facilities throughout the Czech Republic to secure overnight stays and complementary services for parents of hospitalized children
- development of support for families of the deceased children
- raise awareness and promote family-centred care and concept of Play Workers

#### • Sdružení D: Pavel Němeček

- preventive mental health campaigns in schools based on format of creative drama
- works with children in need and in foster care, various group activities
- interested in sharing experience with creative drama and collaborate in developing programmes for children from children housings to support their mental wellbeing

#### • Czech Alzheimer Society: Lucie Hájková

- provides support for people with dementia and carers
- conducts activities for early detection of dementia (radio advertisements, memory testing)
- interested in sharing of good practices with similar institutions from abroad
- establish centres for early detection of dementia, implement awareness raising campaigns

#### • Vestre Viken Hospital Trust: Bror Just Andersen

- mental health interventions in schools VIP programme (Very Important Problems)
- need to talk about problems of daily lives and what mental health means with kids at schools
- achieve universal prevention at schools and diagnose mental problems among students
- further develop and implement awareness raising programmes for youth in bilateral partnership

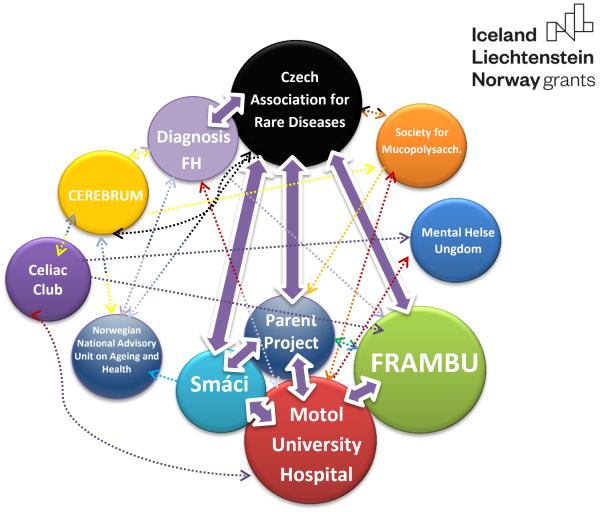
#### Motol University Hospital: Světlana Havlíčková

- expertise in various fields (prevention, diagnostics and treatment of children mental disorders; rare diseases and other specializations)
- interested in implementation of new diagnosis procedures in the field of mental health, therapeutic methods and/or creating multidisciplinary teams
- experience with participation in bilateral projects (also from the EEA and Norway grants)

### **GROUP C**

# **Network map - potential connections**





#### Legend



very good match between both entities



partial match between both entities



#### Overview & summary of group C discussions

In group C discussing the area of patient empowerment and prevention of diseases, professionals of 11 different organizations including two representatives from Norway, were gathered. Main topics are summed up in points in the table.

#### - Czech Association for Rare Diseases: René Břečťan

- Focus on implementation of holistic high quality complex care for RD patents Planned activities of the organization within EEA Grants:
- Operation of help-lines for patients with rare diseases;
- Develop early diagnosis of rare diseases via education doctors and medical students;
- Provision of palliative care as part of complex care for RD patients.

#### - Diagnosis FH: Kristýna Čillíková

- Support of patients with familiar hypercholesterolemia via negotiations with relevant stakeholders;
- Within EEA Grants projects Diagnosis FH aim at implementation of preventive educational campaign (e.g. educational brochures, educational camp for GPs, awareness weeks, etc) in cooperation with similar organization from Norway that would represent patients with FH.

#### - CEREBRUM: Jana Dobrkovská

- Focus on provision of support to clients who have suffered serious brain injury;
- Within EEA Grants projects CEREBRUM aim at developing homecare for patients (-> looking for a partner organization with experiences from provision of homecare) and provide counselling for caregivers and carers.

#### - Smáci: Václav Hradilek

- Organization associating patients with Spinal muscle atrophy and their families;
- Looking for partner organization that would help with creation of patient questionnaire for SMA patients.

#### - Celiac Club Brno: Helena Pernicová

- Focus on support of celiac patients both adults and children;
- Intend to create a union associating regional celiac patient organization in the Czech Republic
- Create an advisory panel of professionals instead of volunteers.

#### - Norwegian national Advisory Unit on Ageing and Health: Midtboe Kari Kristianses

- Provides competency building and guidance within the area of ageing and health;
- Focus on guidance and advice in connection with the development and testing of new models for treatment and care for people with dementia.
- Example of activities: educational programmes, day care activities, prevention and awareness

#### - Motol University Hospital: Milan Macek

- Develop the basis for the CZ rare diseases resource centre;
- Intention to create and implement undiagnosed rare diseases programme with the EEA Grants;
- Focus on specific needs of CZ Roma population.

#### - Frambu Resource Centre for Rare Disorders: Julie Lisen Mohr

- Focus on gathering, developing and disseminating knowledge regarding rare and unfamiliar disabilities with patients, their families and the professionals;
- Aiming at provision of quality life to patients with RD to be able as normal life as possible. Focus on empowerment of patients with RD and their families.

#### - Parent Project: Karolína Podolská

- Focus on better health care for patients with muscular dystrophy;
- Intention to create a group/team of specialists (psychologist, social worker, nurse) that would be providing homecare/consultations to patients. Provide this team with training and best practices sharing with specialists from Norway, Iceland or Lichtenstein.

#### Overview & summary of group C discussions

#### - Ranveig Stava: Mental Helse Ugdom

- Focus on work with variety of minority groups in danger of mental disorders (e.g. young farmers, indigenous people like sami population, etc.)
- Interested in cooperation within project focused on similar target groups -> young people in danger of mental disorders and/or poor mental health.

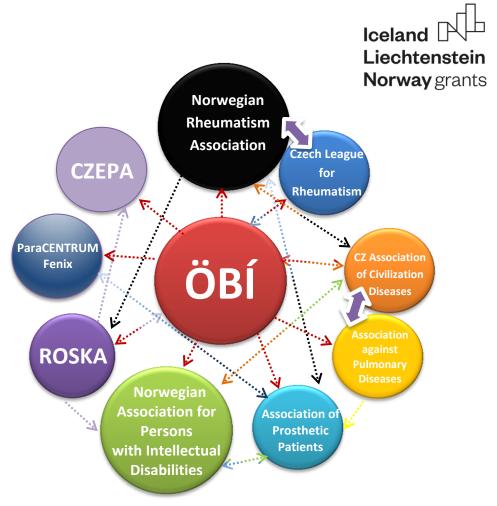
#### - Association for Mucopolysaccharidosis: Petra Tomalová

- Focus on providing support for families of children with MPS from the very first detection of illness;
- Intention to increase the support of parents with seriously ill children via creation of teams of doctors and social workers in hospitals.

### **GROUP D**

# **Network map - potential connections**





#### Legend



very good match between both entities



partial match between both entities



#### Overview & summary of group D discussions

Group D consisted of representatives of wide range of Czech patient organizations and three representatives from the donor countries organizations.

#### • Association of Individuals Afflicted with Civilization Diseases in the Czech Republic: Marie Říhová

- preventive programs, exercise program
- volunteers/local office, cooperation with university
- raising awareness campaigns

#### • Association of Prosthetic Patients: Olivie Lánová

- medical services and online activities
- support patients, helping them to defend their rights

#### Czech Association of Paraplegics – CZEPA: Veronika Friebová

- peer mentoring -> train mentors to help clients
- extend the usage of application and social network "VozejkMAP"

#### Czech Civic Association against Pulmonary Diseases: Stanislav Kos

- patient empowerment and strengthening role of patient organization
- raising awareness about lung and civilization diseases
- participation in research

#### • Czech League for Rheumatism: Edita Müllerová

- raising awareness activities focused on patients, medical professionals, public
- online activities
- self-management and helping patient in their every-day-life
- peer to peer activities

#### • Dobré místo: Tereza Klenorová

- helping people with mental disorders
- raising awareness

#### • Nedoklubko: Lucie Žáčková

- parent organization for parents with preterm born children
- psychological support for parents
- research causes and prevention
- peer support

#### • Norwegian Association for Persons with Intellectual Disabilities: Gunn Strand Huthinson

- support to patients with intellectual disabilities and their families
- working on better living conditions for people with mental disabilities

#### • Norwegian Rheumatism Association: Anna Fryxelius

- implementation of exercise and self-help programs
- organizing peer support
- involved in PDP Patient HUB

#### • ÖBÍ-National Organisation of People with Disabilities in Iceland: Stefán Hjaltalín Vilbergsson

- linking the health and education system of childcare
- raising awareness about children with mental disorders
- working with schools and the way how they work with children with mental disorders

#### • ParaCENTRUM Fenix: Ladislav Loebe

- services for people after SCI (spinal cord injury)
- preventive programmes for schools, families
- wide spectrum of services and complex care

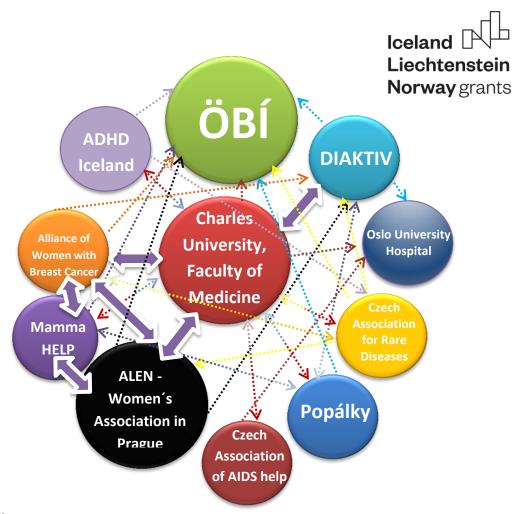
#### • ROSKA Union - Czech Society for Multiple Sclerosis: Jiřina Landová, Radoslav Hýl

- Intention to set up a helpline
- introduce MS specialist nurses (as in the United Kingdom)
- raising awareness through social media and peer groups
- long-term goal: establish a second nursing home for MS

# **GROUP E**

# **Network map - potential connections**





#### Legend



very good match between both entities



partial match between both entities



#### Overview & summary of group E discussions

Group E consisted of representatives of wide range of fields, mostly representatives from patient organizations, but also representatives from medical institutions.

#### • ADHD Samötkin (ADHD Association Iceland): Hrannar Arnarsson

- Helping people (and their families) with ADHD diagnosis and other disorders;
- Raising awareness about ADHD;
- Education of professionals teachers, social workers and others.

#### • ALEN - Women Association in Prague: Daniela Mikulejská

- Helping women with breast cancer;
- Organizing group meetings, rehabilitation exercises and healing stays;
- Helping women with returning into ordinary life.

#### • Alliance of Women with Breast Cancer: Mirka Phillips

- Support for patients and their families;
- Coordinates almost 50 patient organizations;
- Focus on prevention, campaigns and education.

#### • Charles University - Faculty of Medicine in Hradec Králové: Kateřina Javorská

- Raising awareness about non-communicable and chronic diseases;
- Greater involvement of patients in health care;
- Education, prevention, healthcare in social excluded areas.

#### • Czech Association for Rare Diseases: Monika Němcová

- Raising awareness about rare diseases;
- Education and support of patients (e. g. through help line);
- Would like to found complex centre for rare diseases.

#### • Czech Association of AIDS help: Július Szabó

- Providing services for patients and active in the field of HIV prevention and destigmatization;
- Focus on prevention and HIV testing, education, harm reduction.

#### DIAKTIV CZECH REPUBLIC: Pavlína Mirschová

- Works with patients with diabetes;
- Raising awareness in groups of patients and their families;
- Education, mostly about type 1 and type 2 diabetes.

#### Mamma Help: Jelena Burianová

- Helping women with breast cancer;
- Consultations (e. g. with psychologist about how to tell children about mothers diagnosis), online consultations, rehabilitation;
- Helping women with returning into ordinary life;
- Intention to focus more on education and raising awareness.

#### • ÖBÍ-National Organisation of People with Disabilities in Iceland: Þórdís Viborg

- Linking the health and education system to childcare;
- Raising awareness about children with mental disorders;
- Working with schools and the way how they work with children with mental disorders.

#### Oslo University Hospital: Stig Tore Bogstrand

- Focus on harmful consumption of alcohol/drugs and its consequences;
- Implementing activities in the field of research, intervention, raising awareness.

#### • Popálky: Jana Tlustá

- Working with burned patients;
- Consultations in hospitals, workshops, preventive programs, camps for child patients.