# "Too small to be seen"?: Identifying obstacles to the participation of children with mental disabilities in educational and social care decisions and in criminal proceedings

Mojca Urek & Andreja Rafaelič University of Ljubljana, Faculty of Social Work ENTER conference

User participation: An essential element for effective mental health care in the 21st century,

Barcelona, 16th and 17th June 2014

### About the research project

- EU project »Access to Justice for Children with Mental Disabilities" (DG Justice, 2013-2015)
- Main lead: Mental Disability Advocacy Center, MDAC, Budapest.
- The project partnership has a geographical spread across the EU, with 10 partnership members:
  - Hungary, Romania, Bulgaria, Czech Republic, UK, Ireland, Spain,
     Lithuania, Latvia, Slovenia.
- The project addresses:
  - participation of children with mental disabilities in all stages of the legal process, in educational and social care decisions.
- Project objectives:
  - development of a methodology for data gathering; development of standards (in relation to child participation); development of training materials and advocacy actions.

### We are investigating:

- how children with mental disabilities can choose where and with whom they live;
- how they can access inclusive education and get the supports they need; and
- how they are protected by and supported in the criminal justice system as victims, witnesses and defendants.

 Mental disability: term used to refer to children with intellectual disabilities, children with mental health and psycho-social problems, including Autism, Asperger Syndrome, ADHD, and acquired brain injury.

### Main questions

- What is happening with the children with mental disabilities through legal procedures where decisions about their lives are made?
- How do children participate in decisions that affect them?
- Can children access information about their rights?
- Do children have access to free and quality legal aid?
- Do justice systems provide 'reasonable accommodation' for children?
- Are they provided with interpreters and representatives that are trained to understand them and convey their will and preferences?
- Are children provided with the necessary equipment and facilities such as materials in a language or format they can understand?
- Are court hearings adapted so that children with mental disabilities can participate? Are judges, lawyers and others adequately trained?

### Slovene findings

### Methodology

- Literature and legislation review desk research
- Empirical part of the research:
- Semi-structured face-to-face interviews (15 interviews with 17 persons were conducted, such as: Human Rights Ombudsman, professors of Criminal Law, social workers from Center of Social Work, professionals from different institutions for children, a mother of the child with mental health problems, a child with intellectual disability, family judge, state prosecutor, police, NGOs etc);
- Focus groups
- Written requests-questionnaires (for statistical data): to the Supreme court and one to the Ministry of Interior – Police (Criminal Police Directorate).

### General observations

- Through literature review and interviews it became obvious that neither the professionals, nor the people that are trying to do some steps towards children friendly justice in Slovenia, had in mind children with mental disabilities.
- Although there is a progress towards so called "children friendly justice" in Slovenia (such as children friendly hearing rooms with video-conference equipment or children-friendly booklets, such as The Child at Court), children with intellectual disabilities and mental health issues remain virtually invisible in the eyes of the law.
- Law does not specifically apply to children with mental disabilities.
   A general principle applies: every child must be heard. But do the children with mental disabilities receive any additional support in this regard?

- Strong point of our legislation is that the principle of consideration of the evolving capacities of the child is reflected in various Slovene laws. But in the practice, we observed insufficient respect for this right of children to participate and to be heard.
- Children with mental disabilities are often treated in this respect somehow automatically and routinously and they didn't profit much from innovations and improvements in this field.
- Little support is provided to children in general to help them understand very complex justice systems, let alone children in need of extra support and assistance.

- Police, judges, lawyers and other professionals in justice systems are rarely given training on children's rights and even more rarely on needs of children with mental health problems or intellectual disabilities.
- As interviewees they have been surprised when we opened this topic. They have continually talked only about children in general or in the best cases about children on wheelchairs.
- They saw "other professions" (psychiatrists, psychologists, special pedagogs) as only relevant experts to deal with children with different difficult mental health or intellectual conditions.
- There are several national programmes, declarations and laws in place, but the implementation is very poor.

## Decisions where and with whom children with mental disabilities live

- In the care proceedings with outcomes such as entry into institutional or foster care or in guardianship proceedings, there is no legal obligation in terms of obtaining an opinion of the child under age 15 (differently for adoption);
- But it is somehow expected (but not guaranteed!) that somewhere in the procedure child is interviewed and asked for her/his view, opinion.
- This is the matter of the professional concepts, standards and ethics rather than legal obligation.

- Children with »severe disabilities«, as interviewed family judge explained, do not even come to a court, and the judges do not have a direct contact with them. A temporary guardian is appointed to them, but only in the case when parents have opposing interests or their decision is not in benefit of the child. Otherwise they rely on assesment of different experts.
- Not many cases of family desputes over the custody in these cases.
- In the case of children who are placed in an institution, social workers try to achieve their informed consent; the one we inteviewed talks to the child for as long as it takes to achieve this. But she admits that "children with less communication or intellectual capabilities it seems that sometimes we forget that also these children should be asked."
- Her experience is that children are poorly informed about their rights: 

  »If we don't tell them or their parents don't tell them, they are not 
  informed and they do not know«. Sometimes even the parents do not 
  know that their child can also state an opinion, and some parents 
  even do not allow their child to state an opinion. Similarly with the 
  right to oppose the decision about the placement.

# The rejection of children with more complex and combined difficulties from the side of institutions

- We came across of few specific problematic areas:
- Children's institutions (re-education, reformatory) recently tend to avoid having bad reputation of being repressive places and have started to advertise themselves as children friendly places where the child is accepted only on a voluntary basis.
- At first glance this seems positive, but it is actually very problematic practice. Namely, these institutions have started to set high criteria for admission. A high-threshold for admission usually means the rejection of children with more complex and combined difficulties, such as addiction, mental health problems, difficult emotional-behavioural problems.
- It happens frequently that children's institutions give up over a child with more complex difficulties and simply "returns" the child back to the Centre for Social Work without any further solutions.

- Actually only one of the institutions, reformatory home Planina is known to accept such children (they have so called therapeutic union with psychiatrist s employed), which means again segregation of children with the most difficult situations in one place which is not likely therapeutic. Institution got I award for innovation their special intensive unit.
- A story: A reformatory home was closed over the summer (they only keep one unit open). A girl that they could not send home over the holidays as well as the fact there was no space for in the open unit was sent to a psychiatric hospital and left there. When she had a check up by the psychiatrist, he wanted to send her back to the reformatory home. But they just left her in the psychiatric hospital and there was nobody to come and pick her up in the end of the summer. So the only other option was to call the institution for children with intellectual disabilities that is open all year round to come and take her. Two years after this incident the girl is still in the institution for children with intellectual disabilities even though her intellectual capabilities are normal.

- Another problematic area:
- A lot of attention is paid to domestic violence, while the violence in institutional care remains hidden and unaddressed.
- None of the reporting mechanisms in place in Slovenia are particularly focused on children with disabilities (or children generally).
- Advocates would be needed in institutions for the care and re-education of children and adolescents with emotional and behavioural problems and in so called "Education, work and care institutions" for children, with intellectual disabilities.
- But none of existing advocates scheme covers the advocacy in these types of institution or in peadopsychiatry.
- Existence of isolated institutions for children with mental disability is of course a problem for itself.

- Statutory advocates for users' rights in mental health could have been extent their work on peado-psychiatric hospital (as a matter of fact Mental Health Act doesn't mention children psychiatric facilities specially, but it also doesn't prohibit advocates to work there), but they never did.
- On other side, professionals, who are working as advocates for children rights (through Ombudsman Office), reported that children with mental disabilities are currently not widely included in their advocacy practice.
  - CSWs reported that last 5 years they often appoint the advocate of the child's rights when parents are in mutual conflict and when they deal with special traits in the child (behavioural or emotional problems, mental health issues), which helps the child articulate his or her statement which is used in the court or in front of other bodies.
  - Obstacle: lack of training and communication skills, as some of the children with mental disabilities can't talk or they do communicate in more nonconventional ways.

### Decisions where the child should be educated

- Segregated education is still preferred to mainstream for children with intensive support needs.
- Committee for the Placement of Children with Special Needs which works under the National Institute of Education is responsable for assessment of the child.
- Disability statuses are an obstacle for entering ordinary schools and integrated education / existence of parallel education system for children with disabilities.
- The whole educational system is based on diagnosis. Without it you are not entitled to any support and with it you are entitled to the support that your diagnosis is entitled to.
- If Slovenia really wants an inclusive education, first off all the double-tier system of education should be abolished. It does not make any sense to keep segregated schools open if we decided to follow the principle of inclusion.
- Also it is impossible to really integrate and include all children with mental disabilities in mainstream schools if most of the funding and trained professionals flow to special schools.

- Regarding the decision making process of where a child with disabilities should be educated it is obviously too administrative and bureaucratic.
   It does not give the child the opportunity to participate and express their views.
- Usually when there is a rule stating that they should be able to express their opinion it is just on paper. In practice there are rare occasions when children's views are listened to and even rarer when they are taken in consideration.
- The biggest concern regarding these types of procedures is probably the possibility for any party in the process of placement of children with metal disabilities to decline the child.
- The school can decline to accept a child with mental disability, the teacher can decline to teach a child with mental disability and lately it has been shown that even other parents of children without disabilities can decline for a child to be in contact with children with disabilities.
- Therefore it is all on the parents, their involvement, knowledge and connections. This is what in practice really decides how and where a child is to be educated.

### Positive stories

- When we heard the stories about children staying in mainstream education it mainly was not because the justice system protected them but because their parents were very involved and resistant to the system of directing children. Usually they are labeled as too difficult, non-realistic, too ambitous..., but rarely get efficient support unless they accept to put child in special school.
- There has been a case when the mother never allowed her daughter to be diagnosed. It was obvious that the girl had elements of Down syndrome.
- The mother allowed her to be tested like all children get tested in the first grade. The test has shown a total zero. But throughout her whole education a team was working, trying to support her. She went to secondary constructions school. They did not have a lot of students and were fighting to survive, so they took her. They adopted their ways to her and she managed to finish her secondary school. At the end she even managed to do her A levels.
- Because she was so hard working she has also managed to get employed.
- If she went thought the diagnostic process, she would end up in a special school. Her mum somehow prevented that, and the school as well because we joint her mums opinion. They created a support network and taken an individualised approach.

### **Criminal proceedings**

System of juvenile criminal justice in Slovenia has many very strong points, such as:

- Protective approach to child offenders.
- Proceedings for offenders younger than 14 years are very well regulated. They have even more procedural rights than victims.
- Children with intellectual disabilities can hardly be categorised as offenders.
- For children between 14 and 16 only educational measures are possible.
- Involvement of social services in the entire duration of the criminal procedure.
- There are alternatives to criminal proceedings in place.
- Measures against secondary victimisation, such as the implementation of duty lawyers for victims of sexual abuse, family violence and human trafficking, paid by the state.

### However, we identified some gaps

- In the law children are a unified category. No group of children is specified. Maybe an internal guidelines would be needed, the so called »soft-law« - instructions about how to act in these special cases.
- Additional training and specialization of judges, prosecutors, duty lawyers for work with children with disabilities is urgent need, expressed by all interviewees.
- The list of additionally trained specialised duty lawyers, as well as the one of advocates for children's rights should be available. Not just anybody is suitable, as much damage can be done to the child.

- The proceedings should be faster and carried out as priorities. Parents of children with mental disabilities point out that due to the involvement of experts in such cases, the proceedings not only become prolonged for over twice the time, but also drag on very much. The professional recommendation is not to appoint several experts; only one expert should be appointed with one opinion in order not to overburden the child.
- The risk that the child with mental disabilities is considered in a patronising way, too protectively, that their subjectivity is not acknowledged, and their possibility to make judgements and decisions for themselves (the risk of an overprotective system).
- It is not enough only to appoint a duty lawyer for juvenile victims of violence. Along with this the children need immediate – while the proceedings are still in progress – urgent psychosocial help. There is no bridge (coordination) between judicial and nonjudicial institutions in the cases of sexual abuse.

- The social worker we interviewed recounted the following story of the boy officially diagnosed with mild intellectual disability, but actually with many mental health and emotional difficulties.
- He lived at the Special Education Centre and attended a special school which
  is part of this centre's facilities. When he was about 13 years old he once
  brought a gas pistol to school, which caused a panic in the school and
  importantly changed a picture the staff members had about him. They
  started to perceive him as a dangerous person.
- He was later sent to the re-formatory and re-educational institution Planina.
- Definitely nobody asked him or his parents about their opinion on this. In the special education centre he had a key person, who knew him better, but she was also overlooked in this procedure, she did not have any impact on the decision on his replacement.
- The social worker, who has recounted the story, remembered that she started to work with him when he was about 14 years old. She needed about a year to prepare him to communicate with her, he did not articulate anything clearly for a whole year, he only cried and yelled. After a year, he was able to tell her what was happening to him at home, about his impulsive and aggressive father, abuse and other things.

### Conclusions

- In general the legislation and the international documents that Slovenia ratified entitle children with disabilities to a variety of rights, the main issue is that the government is not concerned with them.
- For example, UN convention on the rights of persons with disabilities, says that all people with disabilities should be supported to live independently in the community, but as we see:
- there have been several steps taken in Slovenia but almost none is embodied in the law. Most of the steps have been taken thought projects and by voluntary NGOs.

- When asked about cases when a child with mental disabilities was effectively protected by the justice system professionals often told us stories when children went to segregated education or ended up in institutions.
- Slovenia is building new closed institutional settings for "difficult" children.
- For example, most children diagnosed with a psychosis are placed in the pedopsychiatric unit. But sometimes when the staff at that unit cannot handle them they are placed in the enclosed unit with adults in the psychiatric hospital. The National mental health plan tries to solve this question. They will create a new closed unit especially for children.
- There are often discrepancies between the views of different professionals (for example between judges and social workers) and even bigger ones between parents and children with mental disabilities and professionals on other side on how the things work in the practice.
- Difficult journey. We had often a feeling that we are composing a sort of a puzzle and at the times also as we would enter into the swamp of violation of the basic children's rights, invisibility or institutional mistreatment.
- Next stages: training and advocay actions.

#### Website

http://www.mdac.info/en/access-to-justice-forchildren

### Thanks!

Mojca.Urek@fsd.uni-lj.si
Andreja.Rafaelič@fsd.uni-lj.si