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Research plan: Access to Justice and Realization of Rights of People with Epilepsy

1. Introduction

There are over 60 million people living with epilepsy worldwide. It means that one in every hundred people has epilepsy. People with epilepsy have a lot of problems with realization of rights and access to justice. According to the WHO (2022), although the social effects vary from country to country, the stigma and discrimination that surround epilepsy worldwide are often more difficult to overcome than the epileptic seizures themselves.

There has been discussion in the research literature about legal status and legal problems of people with epilepsy. For a long time in history people with epilepsy couldn't get married and it is still difficult in some countries. People with epilepsy have legal problems in many areas of their life like education, employment, insurance, driving, and typically they meet discrimination.

Our research team in the Center of Law and Welfare at the University of Eastern Finland has established a research project on the rights of people with epilepsy (https://uefconnect.uef.fi/en/group/realization-of-the-rights-of-people-with-epilepsy-in-the-welfare-state/). In the end of year 2022 our research team together with Epilepsy Association of Finland conducted a (internet)survey of realization of the rights for the people with epilepsy (n=237). The survey had questions of well-being, everyday (legal) problems, perceived prejudices, discrimination in working life, and experience of the activities of Epilepsy Association. There were also open questions. In the year 2023 we have also conducted interviews (n=38) for people with epilepsy, health care personnel and employees of Epilepsy Association.

The theoretical background of our project is socio-legal access to justice perspective. Access to justice research has pointed out that it is not enough to have formal rights in legislation. Rights must also be realized in society. Key topics of access to justice research are legal needs or legal problems, barriers of access to justice and remedies and solutions. The aim of the study is to get information about the realization of the rights of people with epilepsy and to improve their position in society.

According to the preliminary results people with epilepsy have the most problems with healthcare, working life, housing, family and mistreatment. People with epilepsy experience prejudice in all areas of life like in work and study, services both in public sector and private sector, in hobbies, everyday life and in close relationships. An important research result is that seizures have a clear connection to problems as well as well-being of people with epilepsy (see figure 1).

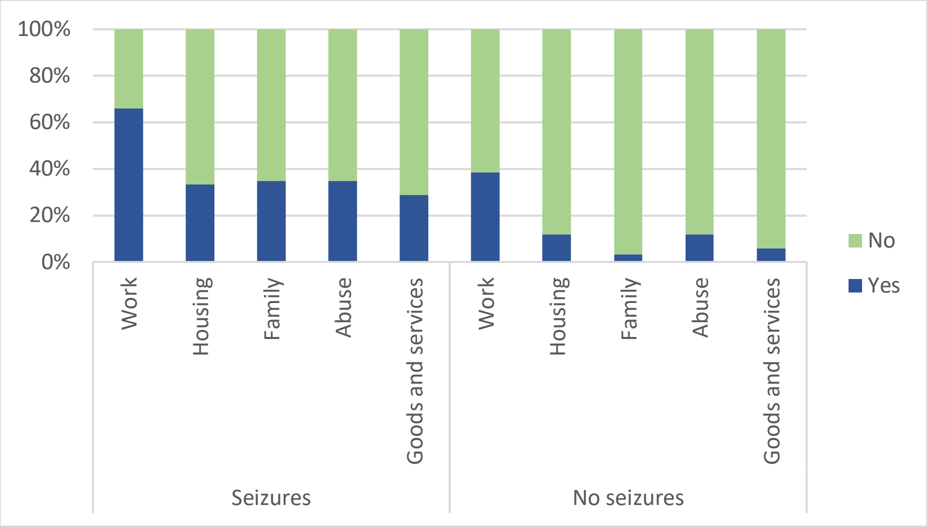

Figure 1 Everyday (legal) problems of people with epilepsy (n=237)

According to our study, epilepsy and seizures, stigma, discrimination, legal problems, and quality of life of people with epilepsy are connected to each other (see figure 2).

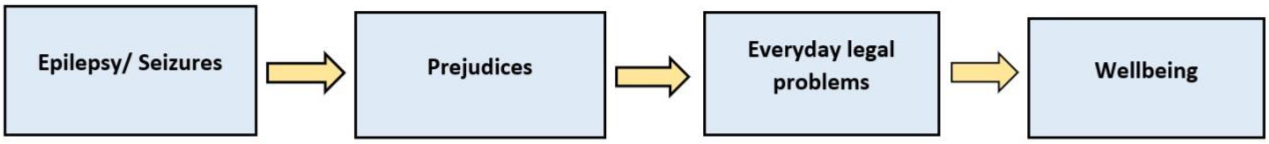

Figure 2 Epilepsy and (legal) problems in Finland: The overall picture

2. Comparation between Finland and Sweden

In the end of year 2024 we will conduct comparative study between Finland and Sweden of realization of rights of people with epilepsy in Finland and Sweden. Finland and Sweden are culturally very similar countries. The aim of the study is to get information of the similarities and differences of the socio-legal position of the people with epilepsy in Finland and Sweden. We will conduct same survey in Sweden together with Swedish Epilepsy Society which we conducted in Finland. We would probably get more than 200 answers in Sweden as well.

We have had an ethical preliminary assessment by the research ethics committee of the University of Eastern Finland for the survey in Finland. In the year 2024 we will have an ethical preliminary assessment also in Sweden (https://etikprovningsmyndigheten.se/en/).

A realistic schedule could be the following: Project planning and translation of the survey into Swedish spring 2024; implementation of the survey autumn 2024; analyzing the data autumn 2024/ spring 2025.

Center of Law and Welfare is part of the Law School at the University of Eastern Finland. Our research team belongs also to the Neuroscience Research Community at the University of Eastern Finland.

3. Research team

Kaijus Ervasti (LL.D.) is a professor of law and society at UEF. He is one of the leading law and society and access to justice researchers on theoretical as well as empirical level in the Nordic countries. He has experience of managing research projects at both national and international level. He is leading project *Shadows in paradise? rights of the people with dementia in the welfare state,* funded by Kone Foundation 2022-2025; project *Access to Justice for marginalized groups of older people in ageing society* 2023-2027, funded by Research Council of Finland and project *Realization of rights of people with epilepsy* 2023-2027 funded by Rights for Patients foundation and Angelini Pharma Nordics AB. Tasks and roles in the project: PI of the project.

Mervi Issakainen (Doctor of Social Sciences) is a postdoctoral researcher in social psychology at UEF. Her research focuses on the health and well-being of different age groups. She has used various qualitative methods to explore subjective experiences related to sensitive research topics, such as depression and early onset dementia (incl. access to rights for people with EOD). She is currently studying the well-being, rights and access to justice of older people and people with dementia during the pandemic (WELGO project), funded by Strategic Research Council. Tasks and roles in the project: analysing empirical research material.

Reetta Kälviäinen (MD, PhD) is the Full Professor and Chair of Neurology in the University of Eastern Finland and the Director of the Kuopio Epilepsy Center in the Kuopio University Hospital. She leads an active clinical epilepsy research group and large epilepsy biomarker study in Kuopio. She serves in the executive committee of the European Reference Network for rare and complex epilepsies EpiCARE (of which Kuopio Epilepsy Center is a full member) and in the management group of the Epilepsy Scientific Panel of the European Academy of Neurology. She is the member of the board of the Neurocenter Finland. She has been active in patient-public-involvement activities and is an honorary president of the Finnish Epilepsy Association.

Anna Mäki-Petäjä-Leinonen (LL.D.) is a professor of Law and Ageing at UEF. She is also a director of the Center of Law and Welfare. She is leading Elder Law researcher in Finland. Her research focuses on Elder Law combining jurisprudence with social and medical sciences. She has experience of management research projects at both national (MeRela) and international (MCI@work) level. She also leads a research team “Neuro-Ethics and Law” at the UEF Neuroscience Research Community. Tasks and roles in the project: legal comparison between Finland and Sweden.

Minni Teerikangas (Master of Social Sciences) is doctorand at the University of Eastern Finland. She will make her doctoral thesis of the financial abuse of older people. Tasks and roles in the project: analysing empirical research material.