

# RESPONSIVE

**Horizon Europe project: Increasing the responsiveness of social services  
to citizen voice across Europe**

## **Research report**

### **Citizen experiences of taking part in co-creation processes**

**March 2024**

**[www.responsive-europe.eu](http://www.responsive-europe.eu)**



INSTITUTO SUPERIOR  
DE CIÊNCIAS SOCIAIS  
E POLÍTICAS  
UNIVERSIDADE DE LISBOA



UNIVERSITY  
OF WARSAW



AMADORA  
Câmara Municipal



**Yvelines**  
Le Département



**AALBORG  
UNIVERSITY**



**Université  
Paris Nanterre**

Centrum Wspierania  
Aktywności Lokalnej



## Horizon Europe project information

Project acronym	RESPONSIVE
Project name	Increasing responsiveness to citizen voice in social services across Europe
Project number	101095200
Call	HORIZON-CL2-2022-DEMOCRACY-01-02
Call topic	The future of democracy and civic participation
Project start date	1 March 2023
Project end date	28 February 2026
Website	<a href="https://www.responsive-europe.eu">https://www.responsive-europe.eu</a>

## Deliverable information for the European Commission

<b>Deliverable number</b>	D2.1
<b>Title</b>	Research report about citizen experiences of consultative and participatory processes
<b>Lead organisation</b>	AAU
<b>Work package</b>	Work Package 2
<b>Dissemination level</b>	PUBLIC
<b>Type</b>	Report

## History of changes

Version	Date	Comments
1.0	01/05/2024	Initial version from the consortium

## Suggested reference

Müller, M., Rømer, M., & Uggerhøj, L. (2024). Citizen experiences of taking part in co-creation processes. *Research Report 2, Horizon Europe project 'Increasing responsiveness to citizen voice in social services across Europe'* (RESPONSIVE). Available at: <http://www.responsive-europe.eu/>.

## Contacts

If you have questions or would like more information on the research results or RESPONSIVE project, please contact colleagues at the University of Innsbruck.

- Lars Uggerhøj, WP Lead [luc@socsci.aau.dk](mailto:luc@socsci.aau.dk)
- Mette Rømer, WP coordinator [romer@socsci.aau.dk](mailto:romer@socsci.aau.dk)
- Maja Müller, WP coordinator [majam@socsci.aau.dk](mailto:majam@socsci.aau.dk)

## Author list

This report is a collective work. It was compiled by Lars Uggerhøj, Mette Rømer, and Maja Müller at Aalborg University, Denmark, based on research by country teams who are listed in alphabetical order in the following table.

<b>Report Lead</b>	Lars Uggerhøj, Aalborg University
<b>Austria country team</b> (University of Innsbruck)	David Furtschegger Anja Hofmair Florian Ohnmacht Michael Rasell Katharina Streicher
<b>Denmark country team</b> (Aalborg University)	Maja Lundemark Andersen Valentin Hammershøj Maja Müller Mette Rømer Lars Uggerhøj
<b>France country team</b> (Paris Nanterre University)	Andreea Ernst-Vintila Ylias Ferkane Agathe Osinski Léo Parmentier Anna Rurka
<b>Poland country team</b> (University of Warsaw, CAL Association)	Magdalena Kuleta-Hulboj Barbara Lipińska-Zańko Agnieszka Naumiuk Agnieszka Wołowicz Izabela Grabowska Bohdan Skrzypczak
<b>Portugal country team</b> (ISCSP, University of Lisbon)	Ana Esgaio Elvira Pereira Carla Pinto Fernando Serra
<b>Romania country team</b> (CFCECAS)	Lucian Caciamac Adela Şetet Maria Toader
<b>Reviewers</b>	

## Contents

<b>Executive summary .....</b>	<b>6</b>
<b>List of boxes .....</b>	<b>12</b>
<b>List of tables.....</b>	<b>12</b>
<b>Introduction .....</b>	<b>13</b>
Definition of social services.....	14
Co-creation processes .....	15
<b>Part 1. Design and methodology – A participatory approach .....</b>	<b>16</b>
Methodological guidelines as a steering course .....	16
Data analysis.....	21
Sample size .....	23
The co-created research design .....	24
Methodological reflections .....	29
Ethics .....	30
<b>Part 2. Sector-specific findings of experiences of responsiveness.....</b>	<b>32</b>
<b>2.1 Responsiveness in disability services .....</b>	<b>32</b>
Responsiveness at the individual level: Access, awareness, and reliance on social services .....	33
Responsiveness and participation.....	37
Recommendations for the future from citizens who use disability services .....	40
<b>2.2 Responsiveness in child protection services .....</b>	<b>41</b>
Responsiveness at the individual level: Being involved and having an influence.....	42
Responsiveness and participation at the organisational and group levels.....	47
Recommendations for the future from citizens who use child protection services .....	48
<b>2.3. Responsiveness in mental health services .....</b>	<b>49</b>
Responsiveness at the individual level: Access, personal relations, and holistic approaches.....	50
Responsiveness and participation at the organisational and group levels.....	56
Recommendations for the future from citizens who use mental health services .....	58
<b>2.4 Responsiveness in services that work with youth at risk of social exclusion .....</b>	<b>59</b>
Responsiveness at an individual level: Binding relationships and (not) being listened to .....	61
Responsiveness and participation at the organisational and group levels.....	66
Recommendations for the future from young people who use social services .....	69

<b>Part 3. General findings of experiences of responsiveness.....</b>	<b>70</b>
3.1 The experiences of responsiveness are diverse .....	71
3.2. Responsiveness at the micro level .....	72
3.3 Responsiveness on meso and macro levels .....	76
3.4 Drivers and barriers to responsiveness .....	77
<b>Part 4 Conclusion and recommendations .....</b>	<b>84</b>
4.1 Conclusion .....	84
4.2 Recommendations .....	85
Policy level.....	85
Managerial/organizational level .....	85
Professional level .....	86
Keep in mind .....	86
<b>References .....</b>	<b>87</b>
<b>APPENDIX: Country tables showing the numbers of citizen boards and research activities.....</b>	<b>89</b>

## Executive summary

This report presents the results and the analysis of a qualitative empirical study of citizens' experiences of taking part in co-creation processes in social services across six European countries (Austria, Denmark, France, Poland, Portugal, and Romania). The study focuses on citizens' experiences of four different types of social services:

- Community-based disability services
- Mental health services
- Child protection services
- Services for young people at risk of social exclusion

The report is part of the Horizon Europe research and innovation project 'Increasing responsiveness to citizen voice in social services across Europe' (RESPONSIVE) that runs from 2023-2026. It presents results of Work Package 2 in the project "Citizen experiences of taking part in co-creation processes", where the objectives are to:

- Collect the views of diverse citizens about the impact of citizen input in digital and non-digital consultative and participatory structures in social services.
- Analyse participatory events and processes in social services to understand processes of voice, accountability and intersectional inequality in the range and variance in responsiveness to diverse citizen voices.
- Study citizen views on feedback loops, transparency and accountability in participatory actions and if they feel informed about the impact of their input on service development and decision-making.

The report illuminates how citizens experience and/or have experienced responsiveness within the four types of social services and their experiential knowledge of developing social services. The report is structured in four parts that present the methodology, sector-specific findings, general findings and finally the conclusion and recommendations for policy, practice and further research.

### 1. Design and methodology

This study is framed by analysis conducted in Work Package 1 of the RESPONSIVE project (Rasell et al, 2024) of the existing legal, policy and organisational frameworks in the six EU countries for incorporating the voices of citizens into the development and implementation of personal targeted social services.

In Work Package 1, the conceptual framework for the research project was developed by reviewing conceptual and empirical literature about democracy, participation and co-creation. The report presented the concept of 'responsiveness' within social service organisations, defined as *the process of learning from and reacting to the perspectives of diverse citizens who use social services. It ensures that citizen voices have an impact on social services.* The definition is used as a starting point for this report and has been further developed during Work Package 2 by adding the citizens' perspective to the definition.

This report is based on qualitative data design and a participatory practice research process involving approximately 400 users of social services in Austria, Denmark, France, Poland, Portugal, and Romania. They are all users of or have been users of social services related to one or more of the four sectors: disability, child protection, mental health and youth at risk of social exclusion. The data was collected in the period August 2023 to January 2024 and consists of qualitative individual interviews, focus group interviews, observations and workshops with service users of the four target services: Disability; Child Protection; Mental Health and Youth at Risk of Social Exclusion.

This research took a participatory approach that aimed to involve and give voice to citizens on matters of choosing research methods, collecting data and analysing data. Based on democratic principles, citizens with user experiences within the four selected social service sectors took part in 'citizen boards' to give input on the research process.

## **2. Sector-specific findings**

Analysis of citizens' experiences of participating in co-creation in consultative and participatory processes within the four social service sectors (disability services, child protection services, mental health services, and services working with youth at risk) indicates different drivers and barriers to responsiveness across sectors. These are shaped by the welfare services offered across countries, by the vulnerable positions of the different target groups, and by the individual conditions and cases of the participants. The main findings, categorised by sector, are outlined below.

### **2.1 Responsiveness in disability services**

- The support that participants with disabilities can receive is critical to their physical, financial, and health-related situations – leaving them in very vulnerable situations and at risk of social exclusion when the help they need is limited and out of reach.
- Inadequate provision of community-based services for independent living and inclusion limit the participation of persons with disabilities in democratic processes and developing social services by leaving them primarily preoccupied with their own individual case.
- Paternalistic attitudes towards citizens with disabilities and fear of losing services are counterproductive to citizen experiences of responsiveness.
- Against the significant barriers to raising voice, citizens with disabilities often find it useful to draw on support from other – parents, next of kin, friend(s), or others from their network – to achieve responsiveness.
- An open-door institutional policy facilitates responsiveness and participation.
- Citizens need more information about available social services and how they are organised.

## **2.2 Responsiveness in child protection services**

- Responsiveness was foremost related to being involved in and positively influencing the citizen's/children's case.
- Responsiveness is lacking if there is little information, if rules are too rigid and non-negotiable, and if there is less flexibility to include children's suggestions.
- There are fears of complaining when rights are violated and that acting in a negative way might influence relationships with social workers.
- There is little or no experience with responsiveness on the meso level – taking part in, for instance, Children's Councils, boards, or any kind of group meetings. If participating in councils, boards, or meetings, the citizens' focus was still connected to their individual cases.
- A few experiences of responsiveness at the macro level centred on 'advocacy' and contributing to a group, forum or discussion about improving child protection above the service level. These made citizens feel truly heard and included in decision-making.
- Responsiveness is difficult and almost coincidental in individual cases unless there is a specific structure, method, or approach.
- Structural approaches that rely on close relationships support responsiveness and inclusion.

## **2.3 Responsiveness in mental health services**

- Mental health participants' experiences with responsiveness primarily concern their own case, namely access to relevant services, medical treatment and therapy.
- Good mental health is a basic need and the most important problem to solve before citizens are able to concentrate on other things (e.g. participating in democratic processes).
- Experiences of responsiveness are linked to being listened to, recognised, and respected as human beings.
- The experience of responsiveness or lack thereof is linked to a feeling of stigmatisation based on citizens' mental health issues.
- The asymmetric relationship between staff and service users is a major barrier to responsiveness.
- There is a general fear of voicing oneself.
- There is a feeling of being labelled as a 'group' whose voices are not valid.
- The few reported experiences of participation and involvement in peer work entailed horizontal empowerment, social relationships, and affiliation with a group that understands the citizens.



## 2.4 Responsiveness in services working with youth at risk of social exclusion

- Youth at risk are affected by several challenges – the transition to adulthood, poverty, social exclusion, mental health, housing, addiction – that make it difficult to focus on responsiveness, co-creation, and participation.
- Responsiveness is related to experiences of being listened to and involved in decision-making.
- The relationship with the frontline staff is a key factor in experiencing responsiveness.
- Staff deciding and acting *with* and not *against* young people and taking their wishes and needs seriously is valued as a participatory experience.
- Trust is essential for the young participants.
- Some of the participants mentioned that they experienced a lack of responsiveness due to their (young) age and being viewed by professionals as ‘children’ without a legitimate voice.
- To establish responsiveness, youth at risk must be heard by the services, establish personal contact, and be treated with an understanding of their perspectives. Staff should ensure a sense of security and respect the right of youth to independently make decisions.

## 3. General findings of experiences of responsiveness

One of the introductory questions towards the interviewed citizens was how they understood and experienced responsiveness in the social services they were using. Across countries and sectors, it became evident that responsiveness is an unclear and for some unknown concept with many different meanings. The experiences and perspectives of citizens suggest the following definition of responsiveness in social services:

**Responsiveness in social services is the process of learning from and reacting to the *voices and actions* of citizens facing diverse social challenges. It aims for citizens’ *voices* and lived realities to have an impact on their individual situations and influence on social services.**

The general findings outline how citizens from the six countries and within the four different social services experience responsiveness. The findings are analysed both with focus on cross-country and cross-sector analysis. The analysis focuses on patterns and nuances in the experiences and identifies responsiveness on different levels - micro, meso and macro followed by identification of drivers and barriers to the experiences of responsiveness.

The main findings of the citizens’ experiences of responsiveness shows that the participants across countries and sectors are focused on:

- Gaining support to solve their individual challenges and cases. Democracy and democratic processes within social services are therefore fundamentally connected to people’s lives.
- The relationship between themselves and the social service professionals

- Being seen, listened to and acknowledged as human beings by the professionals and the organisational structures of social services (*being truly heard and taken seriously*)
- Having the possibilities to choose services, support and treatment (*making decisions in their case*)
- Dialogue with professionals who should listen to their needs, not stigmatize them and have a holistic approach towards their problems.

Findings regarding the experiences of responsiveness at meso and macro level show that:

- Activities where citizens using social services have experienced responsiveness at local and national levels are: house meetings, open door policies, open spaces for participation, boards, peer-to-peer-meetings, peer-working, in campaigns, political fora and user organisations.
- The majority of research participants have had no or very little experience with responsiveness at the meso level.
- Responsiveness from social services and voice at these levels is closely connected to participation in local or national actions, in organizations of people who use social services and in community-based NGOs.
- Research participants have few and frustrating experiences in macro-level participation where they do not see concrete changes or reactions from social services as a result of their input
- Particularly in child protection services and in some countries also youth at risk services, many citizens have never been invited to participate in anything beyond the collaboration with the case worker.

## **2.1. Drivers and barriers to responsiveness**

In the participants' narratives about their experiences of responsiveness it becomes clear that different conditions and mechanisms influence the experiences of responsiveness. These are in the following split into drivers and barriers of responsiveness.

Drivers of experiences of responsiveness:

- A close, trustful, and respectful relationship between people using social services and staff (availability, attentiveness, adaptability and accompany)
- An organizational and professional structure facilitating participating and co-creation processes with clear democratic aims (establishing structures and spaces for citizen participation, methods and approaches to facilitate democratic processes as boards, house meetings and 'open door' access to the management etc.)
- Being trained and voicing one's own situation by supportive empowerment processes at different levels – both individually both also in groups supporting peer-networks and sharing experiences building communities and affiliation

- Supporting persons as families, friends or lay representatives from organizations who can help give citizens a voice.
- Skilled professionals (having tools and knowledge about participation, trustful relationship, democratic processes)
- Resources to carry out participatory and responsive processes.

Barriers to the experience of responsiveness:

- Lack of services and support leaving the participants in vulnerable positions in risk of social exclusion not being able to fulfil basic needs and with no energy to participate in democratic processes.
- Lack of information on rights to support and democratic processes.
- Fear of potential negative consequences from social services if they voice dissatisfaction or try to interfere in the work of their case.
- Asymmetric relationships between staff and service users – where power and expert roles among professionals result in the devaluing and reducing citizens to “users” and “patients”.
- Stigmatization where the professionals and society label citizens with disabilities, mental health problems or young people, making their voices less valued and legitimate.

#### **4. Conclusion**

Responsiveness seen from the perspective of users is far from being practiced in social services. There are elements of responsiveness in individual practice of social services staff and in some institutional settings and community-based organizations, but it is experienced as random and seldom built on strong organisational cultures and structures.

Citizens' experiences of responsiveness in social services show that they are focused on:

- their individual challenges and cases – making their situation central in their understanding of responsiveness
- the relationship between themselves and the social service professionals – being seen, listened to, being acknowledged as a whole person, being truly heard and taken seriously – is the basis for having and giving a voice, being listened to and being supported.

For the majority of the citizens giving voices to experiences of responsiveness, the focus is to receive as high-quality and relevant support as possible. Citizens' individual challenges and aims are thus a pivotal and important starting point for responsiveness and participation, and the basis for democratic governance processes.

## List of boxes

Box 1: Definition of personal targeted social services (EU 2022: 21–22)	14
Box 2: Inspiration for interview guide for individual/group interviews	20
Box 3: The thematic code tree	22

## List of tables

Table 1: Sample size in each country and across REPONSIVE countries	23
Table 2: Sample size across sectors and countries	24
Table 3: Research activities across sectors and countries of the RESPONSIVE project	25
Table 4: Citizen boards across countries	26

## Introduction

This report presents the second part of the Horizon Europe research and innovation project ‘Increasing Responsiveness to Citizen Voice in Social Services across Europe (RESPONSIVE) – Citizens’ Experiences of Taking Part in Co-creation Processes’. The research project, which runs from 2023 to 2026, aims to investigate and increase *responsiveness* in social services in vulnerable areas, i.e. to increase the involvement and participation of vulnerable citizens in the development of public and private services. The project assumes that people who use personally targeted social services often face high levels of structural vulnerability and exclusion from key societal and political structures and that their voices have so far had only limited weight and influence in the development and implementation of social services. This risks undermining democracy, trust, participation, and the effectiveness of social work’s support for vulnerable citizen groups.

The RESPONSIVE project aims to increase the impact of citizens’ voices in the development and implementation of personal targeted social services, focusing on the following:

- Community-based disability services
- Mental health services
- Child protection services
- Services for young people at risk of social exclusion

The RESPONSIVE project is being implemented by a consortium that includes universities, social work training organisations, local authority social services, NGOs, and the International Federation of Social Workers Europe in six European countries: Austria, Denmark, France, Poland, Portugal, and Romania.

The overall purpose of the RESPONSIVE project is to enhance the responsiveness of Europe’s social services to input from diverse citizens. It aims to increase the impact of citizen voice on the approaches, organisation, and delivery of four types of social services: disability, mental health, child protection, and services for youth at risk. The project will help social service staff and EU policy-makers better understand, utilise, and innovate with the knowledge, experiences, and ideas of citizens.

Work Package 2 focuses on service users’ experiences of taking part in co-creation and participatory processes in social services. This is explored and analysed in a qualitative research project conducted in Austria, Denmark, France, Poland, Portugal, and Romania.

This report compiles the findings of the research project in Work Package 2, which has the following objectives:

- Collect the views of diverse citizens about the impact of citizen input in digital and non-digital consultative and participatory structures in social services.
- Analyse participatory events and processes in social services to understand processes of voice, accountability, and intersectional inequality in the range and variance in responsiveness to diverse citizen voices.

- Study citizen views on feedback loops, transparency, and accountability in participatory actions and if they feel informed about the impact of their input on service development and decision-making.

The report is based on qualitative data from six European countries. The data were collected between August 2023 and January 2024 and consist of qualitative single interviews, focus group interviews, observations, and future workshops with service users of the four target services.

Part One of this report presents the design and methodology, Part Two the sector-specific findings, Part Three the general findings of the qualitative research project, and finally, Part Four the conclusion and recommendations. Based on the citizen experiences linked to the different sectors of social services and the citizens' degree of vulnerability, the analytical focus is to unfold the concept of responsiveness and point out the drivers of and barriers to responsiveness in social services across the six European countries.

### Definition of social services

In terms of social services, the project draws its understanding from a recent analysis for the EU (2022) that provides a baseline definition that distinguishes between 'personal targeted social services and social services that are provided more generally, including health, education, and employment'.

Personal targeted social services address particular needs and seek to strengthen social inclusion; they encompass the four types of social services studied in the RESPONSIVE project.

#### **Box 1: Definition of personal targeted social services (EU 2022: 21–22)**

Social services can be defined as services provided to the public that offer support and assistance in various life situations. Social services differ from other services of general interest, as they are person-oriented, are designed to respond to human vital needs, and are generally driven by principles related to solidarity and contributing to the protection of universal human and social rights, upholding democratic principles, religious and/or cultural values, and socio-economic objectives.

Social services can be provided both universally ('general interest') and to specific target groups in society with particular needs, vulnerabilities and/or special situations in order to strengthen their social inclusion. Examples of services focused on strengthening social inclusion include the following:

- activities with preventive functions aimed at preventing or reducing the risk of social exclusion of persons in vulnerable situations due to financial, health, or other problems;
- activities with a reductive function aimed at reintegrating persons already experiencing social exclusion (e.g. homeless persons, persons with addictions, ex-offenders).

Social services may also be provided in a personalised (targeted) way, in which the type of service offered is determined in a flexible way by the service provider.

Social services are provided by public, private-commercial, third, or informal sector organisations and actors and are further shaped by the users and their needs.

### Co-creation processes

As indicated by the title of the research report, 'co-creation' is understood as an important notion in the identification of meaningful responsiveness. Co-creation, often used interchangeably with co-production, is understood as citizens' involvement in the production of public services (Ostrom, 1996). Pestoff (2012: 5) later defined co-production as 'the mix of activities that both public service agents and citizens contribute to the provision of public services'. Co-production/co-creation emphasises the importance of service users' involvement as 'partners' throughout the processes (Farr, 2013; Jæger, 2013). Co-creation involves citizens as co-designers and initiators, whereas in co-production they are involved as co-implementers in the delivery of services (Voorberg et al., 2014: 15). In this report, co-creation is connected to the use of 'participation' and 'involvement' in the data collection; however, co-creation goes further. Similar to translating 'responsiveness' mainly to 'being listened to', co-creation is not shown to its full advantage if translated only into 'involvement' and 'participation'. Co-creation goes beyond the fact that someone (social services) involves somebody (a citizen). Co-creation is a partnership in which a phenomenon is created in close and more equal collaboration between participating partners.

## Part 1. Design and methodology – A participatory approach

This research report is based on a qualitative research design and a participatory practice research process involving users of social services (Andersen et al., 2020; Uggerhøj, 2011). The qualitative design included individual interviews, focus group interviews, future workshops, and observations to study citizens' experiences of responsiveness and co-creation processes across the four RESPONSIVE sectors.

The participatory approach aims to involve and give voice to the research participants on matters of choosing research methods, collecting data, and analysing data. Based on democratic principles, citizens with experiences within the four social service sectors of the RESPONSIVE project were involved as research participants in what the project called 'citizen boards' to support researchers in planning the research activities as well as collecting and analysing how to grasp citizens' experiential knowledge of responsive social services (Beresford and Croft, 2001).

In this chapter, we outline the methodology of the research designs, beginning with how research questions and methodological guidelines were formulated to act as a steering course for the research teams as well as the sample size and methodological reflections on the research approach.

### Methodological guidelines as a steering course

To make sure that research teams had the same object of study across the six RESPONSIVE countries, the following two research questions were formulated at the very beginning of the work package:

- How do citizens experience and/or how have they experienced responsiveness within social services?
- What experiential knowledge of responsiveness do citizens have regarding the development of social services?

Additionally, to make the participatory approach dynamic as well as transparent, methodological guidelines were developed for *Selecting participants*, *Forming citizen boards*, and *Developing research methods*, including those for *future workshops*. The methodological guidelines were developed as an overall framework and facilitation tool that granted space for researchers to connect to local contexts and be experimental and open when negotiating the final research activities – methodological approaches and analyses – with the citizen boards.

### Selecting participants, including research participants

The criteria for selecting participants for the project was basically to recruit citizens who had current and/or past experience within the four sectors of the RESPONSIVE project: disability, child



protection, mental health, and youth at risk of social exclusion. A guideline for selecting participants was made to support research colleagues in accessing relevant citizens in different ways. The guideline included the following two possible approaches:

- access through *target services*, i.e. access through contact with front-level workers in social services, and
- *access through citizens' organisations* representing target groups/services at the national or local level.

The approach of the guideline was left open to allow for later inclusion of other ways to reach research participants, i.e. citizens who have experience of responsiveness or co-creation within social services.

#### Forming citizen boards

The guidelines for citizen boards specified that research participants were to be involved from the very beginning of the project period (September and October 2023). The timeline for forming a citizen board and the involvement of the research participants was as follows:

- to be set before 1 September 2023,
- to be invited to the first meeting in the first half of September, and
- to be invited to multiple meetings during Work Project 2.

It was further highlighted in the guidelines that the number of meetings could differ from country to country as well as sector to sector but should at least include the following:

- one meeting focusing on the development of the selected research approaches,
- one meeting focusing on interview guides and the development of future workshops,
- one meeting focusing on analyses, and
- one meeting focusing on the research report and the practical guide for citizens.

The guidelines for establishing citizen boards also included the following two suggestions for the composition:

- one main citizen board containing four sub-groups with one to two citizens from each sub-group/target service;
- four citizen boards related to each target service/sector with three citizens on each board.

These suggestions were ways to be methodologically experimental in merging and partnering with research participants from different sectors and research participants related to a target group/service.

### The participatory role of citizen boards

The participatory role of citizen boards included the following matters related to choosing research methods, collecting data, and analysing data:

- discussing and developing the specifics of the chosen research methods (interviews, focus groups, observations, and future workshops),
- discussing interview guides,
- developing and planning future workshops,
- (possibly) participating in focus group interviews and future workshops,
- participating in the analyses of the collected data, and
- participating in structuring the research report and the practical guide for citizens, as well as the content of both.

The participatory role of citizen boards was to support researchers in developing, qualifying, and finalising the stated research activities, including the process of collecting and analysing data. In addition, a logbook template was developed to document citizen board meetings in a transparent and systematic way.

### Developing Research Methods

A 'toolbox' of research methods was chosen beforehand to aid in the formulation of research methods for the RESPONSIVE project. Hence, the citizen board helped to refine the approaches (e.g. interview questions, themes for the focus groups) and how they could be applied to grasp citizens' social service experiences. The 'toolbox' included *interviews*, *focus groups*, *observations*, and *future workshops*, which were selected to focus on the citizens' experiences of responsiveness in the social services, including *when*, *where*, and *how* they were involved and experienced being listened to, as well as their experience of influencing the social services they received. The *future workshop*, on the other hand, is a group work method that was constructed to put participants' experiences and recommendations at the centre of planning for change.

### Interview

Individual interviews were specifically aimed at listening to the voices of the citizens to gather information about their experiential knowledge of responsiveness – both in their present situation and from past experiences. This facilitated the creation of a timeline of their life experiences of responsiveness as citizens in their specific country context.

Different types of interviews (e.g. structured, semi-structured, and unstructured/open-ended) were included in the toolbox to gain insight into the citizens' experiences. It also outlines suggestions for conducting interviews in various mediums, such as face-to-face interviews, phone interviews, virtual interviews (Brinkmann and Kvale, 2018).

### Focus group

Focus groups consisted of citizens who were willing to clarify their (shared) experiences of responsiveness. These groups were constructed of citizens from various populations, such as the following:

- from *within* a single target service,
- from *across* target services within target groups,
- from *across* target groups, and
- from *across* target services and target groups.

### Observation

Ethnographic observation (Hammersley and Atkins, 2007) is a method of observing relevant interactive activities, such as residential meetings where citizens can experience open forms of responsiveness and digital and non-digital structures within disability, mental health, child protection, and youth services. The observation might focus on any of the following questions.

- Involvement of citizens – how, when, and who is involved?
- In what kinds of activities are the citizens involved?
- How is the interaction between the staff and the citizens?
- Are citizens encouraged to express their experiences and understanding?
- Are there any talks about the development of social services?

Different types of observations were included, such as structured observation, participant observation, unstructured observation, and digital observation.

### Developing interview and observational guides

Due to the nature of this participatory research project, it was necessary to develop interview and observational guides in collaboration with the citizen board, as described above. However, to grasp the object of the study, a guideline was made to ensure thematic focus on the following:

- citizens' backgrounds (biographical facts), and
- experiences of responsiveness within services in the *past*, *present*, and *future*.

As a starting point, the following interview and observational guides were developed to inspire discussion and negotiation with the citizen boards.

## **Box 2: Inspiration for interview guide for individual/group interviews**

### **1. Introduction and presentation of background information**

- Age, use of social services, etc. (digital/non-digital)

### **2. Experiences of responsiveness (with social services and in developing social services)**

- Unfolding of the concept of responsiveness – what does it mean to you?
- Descriptions of situations of being listened to and of having influence (a voice) – these might be in individual meetings, online forums, or group activities related to social services.
- Description of when it is important to be listened to and to have influence (accountability)
- Experiences of drivers of and barriers to having a voice and being heard related to social services (accessibility)
- Description of specific situations with drivers of and/or barriers to being listened to or having the desired influence (e.g. intersectional inequality)

### **3. Participation in individual and group activities related to social services (design, innovation, implementation, and improvement)**

- Description of participation in activities/meetings related to social services
- Experiences of access to and support of participation in activities related to the development of social services (accessibility and support)
- Description of the outcome of participating – experiences of influence of and response to citizen input
- Description of drivers of and/or barriers to participation and gaining influence (support and attention to gender, diversity, and intersectionality)

### **4. Wishes and suggestions for the future**

- Description of when and how citizens' wish to gain more voice and influence
- Suggestions related to improving responsiveness in social services

Interviews were recorded and transcribed, and field notes were made from observations and future workshops. Any pictures or other relevant material used in or developed through, for instance, future workshops were also collected.

## **Future Workshops**

The creation of future workshops is a creative method that was used in this study to put the participants' experiences, wishes, and recommendations for the future at the centre of planning for change. As an approach, the future workshop emphasises critique, learning, teamwork, democracy, and empowerment as means to support oppressed groups who are struggling to achieve a better quality of life and society. Future workshops usually focus on a local issue, challenge, or action related to a particular development (Jungk and Müllert, 1987). Future

workshops are, in other words, a group method that includes the citizens as participants in the democratic process by putting their experiences and wishes for the future at the centre of planning for change.

Future workshops were facilitated by the researcher – if possible, in collaboration with citizens from the citizen board – with a focus on the following:

- Experiences with responsiveness – when have they felt listened to and when not?
- Experiences and identification of good examples of responsiveness
- Ideas to strengthen responsiveness

The future workshops entailed round table talks with the participants and posters on which the participants wrote their wishes and recommendations within the three themes of focus. The workshops were usually about four hours long; the times and dates were discussed with the citizen board beforehand.

### Data analysis

The collected data consisted mainly of interviews, which were first transcribed into the local language before translation into English. The data analysis consisted of a thematic coding made in English at the country level followed by feedback from citizen boards on the findings, both before and after writing up the country reports on the four different sectors. Based on the four sector reports, each research team conducted a cross-sector analysis at the country level. The synthesis of country-level reports on different sectors from the six consortium partners was made by the research team at Aalborg University in Denmark (work package lead), who conducted the cross-country analysis and generated the general findings presented in this report. In addition to the citizen boards reviewing the country reports, the draft of the final report was reviewed by the country teams and project colleagues external to the research process to check the validity of the findings.

### Guideline for country reports

As part of the analytical strategy, a *guideline for country reports* was formed to make the data analysis systematic and transparent. To ensure an accurate comparison of differences and similarities at the country level and across countries in this report, the guideline outlined the following structure for country-level reports:

- An introductory description of the target group and the social service(s) context
- A methodological section describing how citizen boards were established, the outcome of the collaboration, and how the processes worked out, including a description and reflections on the chosen research methods and tools
- A description of data, numbers of interviews, field notes, etc.
- A thematic analysis of the findings

Each of the six consortium countries created a country report on each of the four social services/target groups – disability, mental health, child protection, and youth at risk – and these were finally compiled into a national cross-analysis report. In all, 30 sub-reports act as the foundation of this overarching research report, which aims to merge the findings across sectors and countries to identify differences and similarities.

#### The analytical strategy

This report's thematic analysis strategy was built upon the development of a thematic code tree (see Box 2) based on the definition of responsiveness that was formulated in the desk study of the former work package of the RESPONSIVE project:

Responsiveness is the process of learning from and reacting to the perspectives of diverse citizens who use social services. It aims at citizen voices having an impact on social services.

### Box 3: The thematic code tree

#### **Responsiveness**

*This can include the following:*

- Experiences of being (or not being) involved, being listened to, and having influence
- Drivers of and barriers to being listened to, involved, and having the desired influence

#### **Participation in individual and group activities related to social services**

*This can include the following:*

- Experiences of participation in activities/meetings related to social services on different levels (micro/individual, meso/institutional, and macro/political)
- Outcome of participation
- Drivers of and barriers to participating and gaining influence on different levels (intersectional inequality)

#### **Wishes and suggestions for the future**

*This can include the following:*

- When and how do citizens wish to gain more voice and influence?
- Suggestions to improve responsiveness in social services

The operationalisation of the thematic code tree included a focus on grasping the research participants' experiential knowledge of responsiveness (i.e. their subjective experiences of being or

not being involved and listened to and of having or not having influence). The operationalisation also included a focus on gathering experiences of participation actions at different levels: the individual (micro) level, the group or community (meso) level, and the political or national (macro) level.

Micro level: the processes in the actions of and collaboration between the citizen and a social worker or other persons representing social services.

Meso level: the institutional, organisational, or community level where citizens participate in institutional meetings, are involved as members of boards or councils, or take an active part in initiatives in local communities.

Macro level: the overall organisational and/or political level where citizens participate in national events and processes.

The third priority of the operationalisation was to clarify the drivers of and barriers to responsive processes, as well as citizens' wishes and suggestions as a basis for developing recommendations for change.

The thematic code tree was developed to ensure that the research teams' explorations of the participants' experiences of responsiveness as a basis for developing the concept of *responsiveness*. The synthesis of the results across the six consortium countries was coded based on the thematic code tree at the country level, within sectors and across sectors, as well as across countries. The thematic code tree allowed research teams to, if necessary, include new aspects of responsiveness that were not included in the desk study.

### Sample size

Country research teams across the six RESPONSIVE partners involved approximately 423 research participants in different research activities across the four sectors of disability, child protection, mental health, and youth at risk of social exclusion (see Table 1).

**Table 1: Sample size in each country and across RESPONSIVE countries**

Austria	Denmark	France	Poland	Portugal	Romania	Number of Participants
65	60	52	112	66	68	<b>423</b>

All participants had experience using social services within at least one of the sectors. A few had experiences using services from two or more sectors but are representing the sector in which they had the most recent and significant experience.

### Sample size across sectors

Table 2, which lists the distribution of participants across sectors and countries, shows that the child protection service sector had the least participants in the sample, which is indicative of the research team's challenges regarding getting access and motivating citizens to participate in the research project as well as the limited amount of participatory mechanisms in child protection compared to other sectors (see the Work Project 1 report). The samples within the mental health and youth at risk sectors are roughly equal in terms of size, closely followed by the disability sector.

**Table 2: Sample size across sectors and countries**

	Austria	Denmark	France	Poland	Portugal	Romania	Numbers of participants across countries
Disability	18	12	24	21	13	26	101
Mental health	31	5		38	23	12	119
Child protection	16	10	10	21	30	16	78
Youth at risk		33	18	32		14	117
Total	65	60	52	112	66	68	423

It is important to highlight two deviations. First, participants in two sectors in Austria, France, and Portugal were integrated into one (see Table 2). These are divided by the two sectors in the calculation of the approximate number of participants. The merging of the two sectors was caused by the fact that the social programmes and services, including the legal framework, were closely connected and difficult to detach from each other in terms of target service and target groups. The integration across two sectors is not considered a bias, as the focus is on citizens' experiences of responsive social services and not the matter of their personal diagnosis or social problems as such.

The second deviation was caused by the selection of both parents and children as participants within the sector of child protection. For example, the researchers in Romania interviewed children and young adults (most of them under 18 years old), who were currently placed in two residential social services. In Poland they interviewed young adults (former care recipients who now live independently or were in the process of gaining independence after leaving care) and parents whose children were in child protection institutions and trying to regain custody of their children. The Austrian sample was a mix of (former) care leavers with an approximate age of 23 and persons still in care with an approximate age of 18. In Denmark parents representing a wide range of social issues were interviewed. Consequently, the child protection sector sample demonstrates a diversity of voices from varying parent and child perspectives.

### The co-created research design

Table 3 demonstrates how interviews and focus groups constituted the most applied research activities and how observations were only scarcely applied. Future workshops were also held in all countries except France. So, the final co-created research design included multiple methods. See the appendix for the research activities in each country.



**Table 3: Research activities across sectors and countries of the RESPONSIVE project**

	Individual Interviews	Focus Group Interviews	Observations	Future Workshops
<b>Austria</b>	35	0	0	4
<b>Denmark</b>	28	1	2	2
<b>France</b>	25	4	0	0
<b>Poland</b>	38	4	1	2
<b>Portugal</b>	21	4	4	2
<b>Romania</b>	17	6	0	1
<b>Total</b>	164	19	6	12

#### Participant recruitment

In the recruitment of participants, researchers in all countries have, to different extents, made use of multiple approaches to access and contact citizens with experiences within the four sectors. Citizens were approached through *target services* (mainly in Denmark, Romania, and Poland) and through *organisations and associations led by users or practitioners* (mainly in Austria and Portugal), as outlined in the guideline. Whereas the researchers in Denmark mainly recruited through target services, those in France sought to diversify the sample by recruiting informants from different services, organisations, and geographical locations. Researchers in all countries made use of snowballing (i.e. gaining access to citizens through the citizens they had made contact with already; Parker, Scott, and Gedes, 2019).

Due to the multiple approaches to recruitment, the research participants were characterised by experience with a wide range of social services, programmes, and interventions. Even though a few had experiences from the same social services or programmes, they illustrate diverse experiences in diverse organisational settings, which is seen as a methodological strength. The multi-method research design and varied sample size are not intended to produce conclusions that are generalisable to all social services but rather results with applicability to a wider range of settings.

Research teams experienced various challenges in recruiting participants, for instance, getting access through target services only to be met by unmotivated citizens, working with target service workers who were not willing to connect them with citizens, and getting access to citizens in spite of the services' thick line of managerial layers. However, most of the research participants expressed a willingness to participate and to share their experiences and opinions, as well as a genuine interest in the research topic and project. Some of the research participants expressed appreciation and valorisation of the work involved in these kinds of research studies – they expressed their willingness to continue participating in this and other research and hoped that the results of the study could be used to improve the social services' responses and to benefit other people.

### The formation of formal and informal citizen boards

In all, 13 citizen boards were established across sectors and countries (see Table 4). The characteristics of the established boards differ in terms of the number of participants (2–13) and the structure, as permitted in the guideline for citizen boards.

**Table 4: Citizen boards across countries**

	<b>Number of Citizen Boards</b>
<b>Austria</b>	3
<b>Denmark</b>	1
<b>France</b>	2
<b>Poland</b>	3
<b>Portugal</b>	3
<b>Romania</b>	1
<b>Total</b>	13

The majority of the 13 citizen boards were established in alignment with model 1 of the guideline (one citizen board related to each target service/sector). Only three citizen boards consisted of two or more sub-groups. For instance, this occurred in Romania, where citizens had multiple vulnerabilities and were representing different target services across sectors, and in France, where citizen boards were established across the sectors of mental health/disability. The diversity of formation was related to the successes and challenges in getting access to citizens within sectors.

In general, multiple factors shaped participation. Several research participants were challenged by illness or severe individual or family issues. This made it difficult for citizens to allocate time for participatory research activities and to participate in planned meetings. In some cases, researchers perceived a lack of interest in discussing research methods or other research-based items, which turned out to be hindering. In general, research participants seemed to be more interested in discussing findings and analyses than in designing the research methodology. A lack of confidence towards the researchers and the way data was handled, as well as a lack of knowledge regarding the research purpose of the citizen board, were also observed. Consequently, the learning outcomes of the establishment of citizen boards are as follows:

- To gain citizens' trust and authentic participation in citizen boards takes time – this is especially true of the most vulnerable citizens.
- To train research participants to participate in a democratic process as co-creators on citizen boards requires clarity and focus from the researcher (which is in line with the research results).
- It worked quite well when citizens played a consultative role (i.e. when the research team came up with concrete proposals to discuss and gather feedback on). More open brainstorming sessions were less effective (France).

- Participants like to focus more on interpreting results than on planning the interview questions and research methods (Austria).
- Research participants are willing to participate in meetings in the form of a focus group interview (youth at risk in Denmark); instead of utilising planned processes, they can be informally asked to participate in developing an interview guide and research methods.
- Citizen board participation in research was a new process for service users from the most vulnerable groups (Poland).

Overall, it is the experience of the research teams that citizen boards play a vital role in understanding service users' perspectives during planning research activities. Also, the citizen board serves as a co-creation platform for citizens with a two-fold aim: to learn of responsiveness through participation and benefit from expertise through experience. An Austrian female participant expressed that, due to being involved in the co-creation process, she had gained a large amount of insight, knowledge, and awareness about different dimensions of participation that she had not known before because she 'was so inside the system'. This is an interesting quote, considering that such information should be provided by the social services. It is important to note that, if citizens in vulnerable situations are to be included, the engagement process requires significant empathy, flexibility, and listening skills (responsiveness of researchers) to create an environment where the learning process of moving from fear to empowerment and sharing one's voice is a necessary aspect of going beyond 'participation and engagement' for citizens.

#### Final research activities: Interviews, focus groups, and observations

The final research activities included, as demonstrated in Table 3, individual interviews, focus groups, and observations.

#### *Interviews – Individual and focus groups*

In all, approximately 164 individual interviews and 19 focus group interviews were conducted. The majority were face-to-face interviews. To better fit with the participants' lives and to reduce travel time and distance while diversifying the sample, online interviews (via Teams and Zoom) were conducted in Portugal and France. In general, face-to-face interviews took place in the informant's private home, in the institutional settings of the social service, or in a third place agreed upon by the research participant. Focus groups were, according to the guidelines, held *within* a single target service (Denmark, Poland, and Romania), *across* target services within target groups (Austria, Romania, and Portugal), *across* target groups, and *across* target services and target groups (France).

Based on the recommendations from the citizen boards (or if content simply did not work out with specific groups and/or individuals), questions in the interview and observational guide (Box 1) were further developed by either being rephrased or being replaced with new questions. In some cases, questions from the guide were not asked, as the researcher had to adapt to the situation and discourse of the research participants during the interview.

In general, the interviews – individually and in focus groups – provided a wealth of information and insights through which to grasp co-creation experiences in (non-)responsive social services. However, not all interviews or focus groups yielded the same quality or quantity of information. For example, a 14-person focus group on mental health/disability was not very manageable, given the large number of participants (a choice outside the control of the research team); only a few questions were discussed, and those with little depth (France). In general, the focus group setting was not well adapted to some of the informants with physical and mental disabilities. Similarly, some of the interviews conducted in France with youth on the streets were challenging to conduct (given the lack of privacy, etc.).

### *Observations*

Few observations were made, and when they were, the focus was usually on observing the interactions in focus groups, self-representation groups (Poland), or future workshops (Denmark and Portugal). In addition, observation was applied during everyday participatory events between citizens and social service representatives in two different centres within the disability and youth at risk for exclusion sectors. At a residential home for people with intellectual disabilities in Denmark, observations were used to facilitate interaction between the research team and citizens living independently, as well as to motivate participation in the research project. The small number of observations is partly related to the (short) period of the research study (September 2023 to February 2024) and partly to a lack of relevant events to observe.

### *Future workshops*

Future workshops were carried out differently across sectors and countries due to different challenges. However, despite the varying approaches, settings, and contexts, citizens consistently contributed with wishes and recommendations for developing social services. For instance, in Denmark the challenge was getting parents in child protection to attend appointments, even though they had previously given their consent to participate. However, building trust at The Young House (Denmark) made the young residents interested in attending, and consequently, seven of the residents participated in the future workshop. The three research participants who participated in future workshops within the Danish disability sector knew each other well and felt comfortable around each other after, respectively, 13, 18, and 25 years at the social enterprise. They expressed pleasure and satisfaction with the workshop, as they learned new information about each other regarding placement at the same public institution in their youth, which contributed to more extended experiences of participation and responsiveness (than those within the current social service at the social enterprise). Moreover, they found inspiration during the activity in which participants write their experiences and wishes on sticky notes and post the notes on a big board on the wall. Together, they decided that this activity could be adopted as a democratic tool in the User Council at the social enterprise. This is despite the fact that one of the research participants could not write himself and depended on the research team to write on the sticky note.

In Poland two future workshops were conducted in two different ways: as a separate meeting for youth and as a meeting after a break from a previous session that focused on group interview topics (with parents of children in care). Although the settings, times, and contexts differed, the same questions were asked. The youth expressed more personal biographic stories, while the parents were more focused on changing the system.

Future workshops were not used in the fieldwork conducted in France due to practical and logistical challenges. It was difficult to gather groups, and when it happened, other challenges emerged: either the group size was too large to conduct a future workshop (mental health/disability) or the setting did not permit it (spontaneous focus group on the street) or language/literacy obstacles made this method inappropriate.

### *Methodological reflections*

The research teams from the six consortium countries all followed the methodological guidelines for the dynamic practice research approach involving research participants on citizen boards. Despite difficulties in gaining access in some countries and difficulties in categorizing citizens due to multiple issues, the data are characterised by a strong tie between interviews within and across different types of services and across countries. There were no outliers or interviews that did not provide useful and qualified data. Workshop results, interview data, and citizen board input suggest validity in terms of triangulated perspectives.

### *Responsiveness as a lingual challenge*

A challenge and possible bias in the data collection is that the English notion of ‘responsiveness’ is difficult to translate into all six languages. Either the word is not translatable or recognisable (Poland, Portugal, and France) or it is an old-fashioned word (Denmark). In all countries, it was necessary to translate ‘responsive’ and ‘responsiveness’ into more mainstream words. Three main words recur in the national translations: ‘being listened to’, ‘involvement’, and ‘participation’. Although these words characterise part of important democratic processes, they lack one important part of ‘responsiveness’ – what could be called the ‘re-’ in responsiveness. That is, all translations miss the part of responsiveness that involves acting/reacting/responding to what services have learned from citizens. Hence, alternative and synonym words were used to describe responsiveness in a way that places some focus on the act of responding. For this reason, the collected data include both experiences of being listened to (or not being listened to) and experiences related to the kinds of reactions the participants received from social services when voicing their opinions or becoming involved in some other way.

### *Experiences are not general or comparable*

The analytic aim of the RESPONSIVE project was to illuminate differences and similarities in research participants’ experiences of responsiveness in social services and in co-creation processes related to developing social services across the six consortium countries. Hence, the RESPONSIVE project goes beyond comparative welfare state research, analysing the differences and similarities of research participants’ experiences within the four sectors of disability, child protection, mental

health and youth at risk of social exclusion (Kettunen and Petersen, 2011). The research purpose was not generalisation but to identify patterns in experiences of responsiveness and developing social services at the country level, as well as across the six EU countries, as a basis for exploring and developing the concept of responsiveness in social services from the perspective of citizens.

### Limitations

There were some limitations of the dynamic participatory research approach in this RESPONSIVE project:

- Forms of digital participation were identified in only one case (in Romania with the Mobile Team).
- In the recruitment of interviewees, categories indicating intersectionality were not included.
- In terms of gender, the sample was not fully gender-sensitive in terms of asking specific questions in interviews. No research teams explicitly asked participating informants about the gender with which they identified (if any). It appears that the sample in Austria, Denmark, Poland, and Romania had a small overrepresentation of women, and France and Portugal had an overrepresentation of men. A small group of transgender individuals were, however, present within the sector of youth at risk of social exclusion in Poland.
- In terms of ethnic background, research teams did not explicitly ask for this information, as it was deemed inappropriate for cultural sensitivity; thus, this socio-demographic data was not collected. However, we know from the research activities that the majority of the participants in Austria, Poland, and Romania were ethnically white. In Denmark a few citizens within the child protection services had an ethnic background, including indigenous Greenlanders. In France at least one-fifth (10 informants) of the total sample size were born outside of France and had immigrated from countries in the global South, mainly from Africa. In Portugal approximately half of the participants were partially white, and approximately 10 participants were African or Roma of origin. Overall, intersectionality did not emerge very strongly in the data collection.

### Ethics

The RESPONSIVE projects have followed the ethical EU clearance and the ethical clearance of the Board for Ethical Issues at the University of Innsbruck in Austria (project lead) by formulating information sheets about the project and consent forms to ensure voluntary and informed consent. The information sheets were developed to explain that personal data and identities would be anonymised and that participation in the research would not affect individual cases (for service users) or professional practice (for practitioners). Likewise, as involvement with social services is often connected to personal difficulties that may be sensitive to discuss, all research participants were reassured that they could skip questions if desired.

The research participants were invited to express accessibility requirements and preferred location and format for research activities (online, face-to-face, written, or oral) to ensure opportunities for diverse citizens to participate, regardless of disability, communication style, and mental and

physical health conditions. For young people aged 14–18 who were involved in the research, both individual consent and parental approval were required. In addition, research participants were asked if they would like to receive the results and information bulletins. Last, the time contributed by research participants was, in some countries, compensated with a voucher at a rate of €25 per hour (adjusted by the country coefficient for the cost of living in other countries). Transport expenses were likewise refunded.

## Part 2. Sector-specific findings of experiences of responsiveness

In this second part of the report, the findings of citizens' experiences of co-creation in consultative and participatory processes within the four sectors – disability services, child protection services, mental health services, and services working with youth at risk – are analysed and illustrated with empirical examples from each area. This part of the report offers an in-depth description and analysis of service users' experiences of responsiveness within the specific sectors. Each section can be read in isolation, depending on the interests of the reader.

Each sector's section includes a cross-country analysis of the findings on responsiveness and participation. In each section the main findings are depicted in three main subsections that focus on *citizens' experiences of responsiveness at the individual level, how responsiveness is connected to participation at the group and organisational levels, and any recommendations related to responsiveness that service users have for the future*. Factors that influence experiences of responsiveness are analysed and highlighted within each subsection, including structural conditions that facilitate or prevent responsiveness.

The analysis is based on empirical data (cf. the methodology section) from the six participating countries, and the findings are analysed in a cross-country analysis that focuses on patterns and nuances across countries. In each section, the context of the different areas is briefly introduced. These contexts are further described and analysed in the report from Work Package 1: *Normative, policy, legal, and organisational contexts shaping the responsiveness of social services to citizen participation* (2024). That report compares and contrasts the contexts of the social services in each country and sector.

### 2.1 Responsiveness in disability services

Following the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; 2006), disability is defined and understood 'as long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder [a person's] full and effective participation in society on an equal basis with others'. Consequently, following the UNCPD, this report focuses on barriers to participation and, in line with the social model of disability, does not see impairments as the causal force. The citizens who shared their experiences of co-creation processes in community-based disability services are adults with different impairment(s) and various needs for support and assistance.

The UNCRPD constitutes a central context of the co-creation processes of the participating countries, as it has been ratified by the EU and all six RESPONSIVE countries. These countries have obliged themselves to implement the principles of participation, self-determination, and independence in law and practice. The deinstitutionalisation of services for persons with disabilities is another key contextual element that frames the context of disability sectors across



the six countries. Even though the countries are in different phases nationally in implementing the principle of the UNCRPD and ending institutionalisation, broader legal participation structures exist in all six.

The participating citizens are users of a wide range of social services offered by diverse organisations (in the public, private, and third sectors). Hence, the sample is comprised of individuals with not only various impairments, mixed genders, and ages that range from 20 to 55, but also various experiences of disability services, including with community-based support for independent living, including personal assistance, institutions and/or accommodation units, sheltered employment and activity and socialising programmes, and civil society organisations for the defence of the rights of people with disabilities. Some informants had spent periods on social services, others had been institutionalised from birth and never experienced responsiveness (Romania), and others had been living independently with support from personal assistance.

Some of the participants from Austria and Portugal had experience defending the rights of people with disabilities (beyond their individual cases) through civil society and user-led organisations. The participating citizens in Poland and France were users of both social and (mental) health services. The input from the Polish participants was dominated by a health perspective, and they mainly discussed rehabilitation services, specialist doctors, and psychological services, as well as vocational support related to social services.

#### Responsiveness at the individual level: Access, awareness, and reliance on social services

Almost all of the interviewees heard the word 'responsiveness' for the first time during the explanation of the objectives of the RESPONSIVE project. It was difficult for informants to grasp the term because it is not known or used in everyday language in most countries. Even though responsiveness was presented as a 'process of learning from and reacting to the perspectives of diverse citizens who use social services', it was difficult for citizens to relate to the concept.

Across countries, the research participants adopted a general focus on their individual cases and challenges when talking about their experiences of responsiveness. Within this focus, there was a mixed review of experiencing responsiveness. *Negative* responses were related to getting access to social services and the insufficiency of national social services. As the process of deinstitutionalisation continues, countries such as Poland, Romania, and France are not only lacking in social services but have people living in institutions or citizens living at home with family members without support from social services. In Denmark and France, citizens with disabilities can wait for months or even years before being offered adequate services:

I didn't do anything at all. I sat alone in my flat for 8 years or something. And did nothing. I sat there by myself. And I made the days go. It wasn't a problem. But the reason why I was sitting there was a lack of offers ... They had [name of centre]. And it was my clear impression that it was all or nothing (Danish participant).

When citizens responded with adequate or (for some) any kind of social services, the responses were categorised as *positive*. Some citizens did not know what to expect, what a social service should look like, or what the determinants of quality are. Consequently, these citizens did not refer to any generally accepted quality standards or norms for citizen involvement; instead, they evaluated services intuitively, often being satisfied that they received any service. As one informant pointed out, 'One should be happy with any service because there is always something to be gained from them' (Polish participant). This lack of information regarding social services demonstrates how power inequalities in the relationship between services and citizens hinder democratic co-creation processes and thus responsiveness. Others with an awareness of their legal right to be involved and influence their individual case (due to, for instance, Austria's personal assistance agreement) demonstrated diverse experiences and tacit knowledge of the dynamics that correspond with 'responsiveness' as a 'process' or 'practice'; some deemed it a 'familiar' experience but did not know it as 'responsiveness'. As one participant stated, '*It [responsiveness] is like a "thing without a name"*' (Portuguese participant).

A citizen's awareness and knowledge concerning social services has an essential influence on developing social services in the role of co-creators. How can you navigate if you are not informed about the (changing) services or you do not understand or are not aware of how you were offered social services?

If everyone – institutions and those outside institutions – would unite and get along with each other – because as a person I sometimes come across things I can't understand. I've said it at work, and I'm saying it here. In Romania, if you don't have someone behind you, you are nobody, wherever you go. As a person, I can say that I have a clear mind, I judge very well, but ... here, in Romania, if you don't have someone behind you, you can't make it! I've been there (Romanian participant).

Across countries and citizens with disabilities, reliance on social services and the resulting relationship of dependency was a key dynamic in the relationship between disability services and the people who use them. Dependency, in terms of the support citizens receive, is essential for ensuring that physical, financial, and health-related basic needs are met. For example, this citizen had experiences of long-term institutionalisation:

For me, things have changed because I found people with whom I can collaborate because, in various centres I mentioned, I was not listened to. If I knocked on a door, nobody listened to me. Since I arrived here and started calling them, they would ask me, 'Angela, how do you find it here, in ... [city name]?' I feel much better; I am much more listened to, and understood, whereas back then when I knocked on a door – excuse my language, the fact that I wasn't listened to meant I had to take my pants down to pee so they would take me and send me to the crazy ward. That's what I experienced in various homes. Here, since I arrived, I started to be listened to, started

to be understood, [and they] have patience with me. So, I feel that a lot has changed (Romanian participant).

Besides reliance on physical and practical help to overcome disabling barriers, dependence on representative laypeople in meetings with the authorities was also identified across countries among citizens with intellectual disabilities. To be listened to and responded to in meetings with the authorities, the majority of the citizens experienced the need to bring representatives – parents, next of kin, friends, or others from their network – in the hope of being respected and thus listened to and responded to. One citizen strongly stressed, for instance, the need to bring in his cousin, a trained social worker, as a representative in his case to help him negotiate with the municipality after officials misinformed the citizen about his opportunities (Danish participant). Connected to the dependency on representatives, a lack of memory about or understanding of being involved their own case was identified among citizens who did not bring a representative to meetings with the municipality.

In opposition to citizens who had experienced responsiveness in their individual consultative cases, other participants did not remember how or why they had come to live in their current home. The individuals in this group lived in accommodation units, and their everyday lives were often built around trust in the frontline social workers/professionals at the residential and/or job employment centre to help them achieve their needs. Consequently, responsive services are characterised as follows:

- those that are welcoming and sensitive to citizens' problems,
- those that respond quickly,
- those that try to communicate clearly, facilitating access for people with disabilities to official information,
- those who try to reduce the burden of bureaucracy by making the application of rules more flexible, as far as possible, and
- those that help people grow and overcome disadvantage

These characteristics of responsiveness all aim to ensure that citizens are listened to and reacted to, no matter the issue or situation of the citizen or the organisational setting.

#### Relationships: Attentiveness and attitudes

Although the research participants across the six countries were diverse, a common characteristic identified as relevant for responsiveness in social services is *the ability of professionals to listen to the problems posed to them and be proactive in resolving them by looking for an alternative or innovative solution together with the users*. The citizens distinguished the attentiveness and ability of professionals to listen to and relate with them on two levels: (1) interactions with the practitioners (social workers and/or 'educators') working directly with them, and (2) interactions with the social service more broadly (i.e. the practitioner's supervisors and decision-makers, such

as statutory case workers, directors, and other professionals involved in the management of the social service). Across countries, the results of this study showed that the quality and subjective 'feeling' of individual relationships between service users and staff/management cannot be underestimated. So-called 'horizontal' relationships and attitudes (persons collaborating and interacting as equals) are particularly appreciated by service users, as these seem to favour openness and transparent communication. Additionally, personalised attentiveness and positive professional attitudes can act as a basis for developing a trustful and equal relationship:

...we had such summer trips. You know, there, you just got into such personal relationships with the doctors during those summer trips. In addition, they got very emotionally involved and gave a lot of themselves as well (Polish participant).

In general, when citizens experience attentiveness by being heard and reacted to by professionals, they experience an increase in their effective freedom of choice – even if it is only in small steps and despite their difficulties and obstacles and the energy that is needed to be mobilised daily to live a 'normal life'.

#### Barriers to responsiveness: Paternalistic attitudes and fear as a coercive factor

Despite the positive experiences of responsiveness, there were also contrasting experiences of paternalistic attitudes, which made the citizens feel that they were being reduced to their position as 'users' and 'patients', not being listened to, and not being valued:

...When she first saw me, I remember very clearly that she looked at me from head to toe. I don't think she had any idea what autism was. She had her own idea. She really looked at me like a curious animal, which made me very uncomfortable. I don't think she knew what to expect, but I had the impression that she thought I was going to scream at her at any moment, jump down her throat, behave completely inappropriately, or even that I had an intellectual disability. I don't know. And then, at the interviews – there were only two – there was nothing but contempt and judgment. It was worse, in fact' (French participant).

These so-called 'vertical' relationships stand in opposition to the previously mentioned 'horizontal' relationships. In some cases, citizens expressed fear of openly expressing their opinions as social service users due to the possibility of being excluded from the social service in retaliation. Others learned to handle their fear when they witnessed a peer being sanctioned for standing up for their rights:

Participant: ...Because another user expressed her disagreement with a staff member. And when she expressed her disagreement, she was the one who was suspended for a month. She had no right to support for a month.

Researcher: Wow, OK. Is that something that worries you?

Participant: Yes, because I don't express myself in the same way as she does. I'm not as outspoken as she is, but I think, if there's something wrong, I have the impression that the structure will protect itself and not listen to me, in fact (French participant).

Further examples include fear of conflict or deteriorating relationships with social services staff (French research participant) and a marked lack of confidence in the effectiveness of reporting violations and mistreatment (Polish research participant). In general, the reason for fear is the possibility of reduced accessibility to services in the future, which underlines the dependency on representatives and others to stand up for citizens when their rights are being violated. An interesting initiative in Poland is the movement of self-advocates, i.e. people with intellectual disabilities who advocate for people with intellectual disabilities as well as institutional defenders of rights, such as the ombudsperson for patients and citizens, which raises awareness of the procedures for reporting violations.

### Responsiveness and participation

The above experiences of social service responsiveness are based on citizens' lived experiences with a broad range of services and are not related to structural conditions that facilitate or prevent responsiveness. The following sections analyse examples of citizens' participation and experiences of responsiveness within structures that facilitate democratic support (i.e. provide space for co-creating processes in developing social services). Citizens across countries recounted mixed experiences of participation in social services and of responsiveness linked to that participation, from being included in co-production in a limited way to experiences of being reduced to a user, patient, or client without a voice.

### Participation in own individual case

Based on a long history of disability rights activism that fights against an even longer tradition of institutionalised care and support for disabled people, Austria has – as an illustrative example of participatory processes – begun to introduce 'personal assistants'; this change grants service users far greater control over the selection and activities of their staff and is based on a model initially developed by disability rights organisations aligned with the independent living movement. Similarly, the Tyrol Participation Act 2018 established a mandatory advisory board of people with disabilities who use disability services and receive direct payments to facilitate people with disabilities taking ownership of their social services by managing their personal assistance. A facilitating example of responsiveness is when a service carefully matches its support (e.g. a personal assistant) to the needs of the disabled person, highlighting the importance of responsiveness in each individual case:

Um, I said I needed someone who was ... competent, and they really looked for someone for me and found them .... So, they were really active, um, they networked,

and that went really well ... um, that's a very good example, the implementation also worked out (Austrian participant).

Although participants stated the general issue of staff shortages as a major barrier to using their voices as co-creators and to being listened to when choosing qualified personal assistants, they regarded personal assistance as a more participatory service than the traditional services in Austria. The switch from a traditional care service to a personal assistance system was described in terms of the freedom to choose their own care workers, given the intimate nature of the support:

Because they really were people I chose – that's simply having autonomy over your own body. And if you can't have control over your own body, that makes you ill in the long term. It's unhealthy. It's – it's actually abuse. Not actually – it's a – you're permanently in an abusive situation, but you still have to talk yourself out of it. And for me, that's the bottom line. Choosing the people who touch my body ... who support me on my skin, but who also know my whole life. Who – well – yes, who knows everything about me? I would like to have my hand over that (Austrian participant).

However, full user control was not possible in the personal assistant model of support. Citizens explained that in principle, it is possible to make own decisions within social services that offer personal assistance, but there is always a coordinator from the service in between. Based on the example of personal assistance, a key feature of responsiveness, beyond being listened to and reacted to by the professional/case worker, is equality and maintaining autonomy in relation to the professionals.

#### Participation and responsiveness at organisational and group levels

Whereas forms of social service delivery such as personal assistance allow citizens to shape their own support, the example of social services offered by a social enterprise in Denmark shows how citizens can be co-creators at the group level. Social enterprises are not typical of social services in the Danish welfare state, where the majority of social services are offered by public authorities. A social enterprise is a service provided by a private organisation with the primary objective of creating social improvement for people with disabilities (rather than generating profits) through democratic processes that involve disabled citizens to reduce disabling barriers. The democratic processes are divided into the following formalised structures that allow citizens to raise their voices and thus be listened to and reacted to within the service structure of Staff Development Dialogues (SDDs) and User Councils (UCs).

The individual SDD – a dialogue with the managing director of the social enterprise – formalises the opportunity for citizens to raise any individual or organisation issues with the services directly to the managing director. Likewise, the UC is a democratic body in which citizens raise, discuss, and decide upon suggestions related to developing the service of the social enterprise:

‘If anyone has any ideas, they can write them on a note to put in the mailbox. Then the mailbox will be emptied when we have our User Council meeting [and we will] discuss whether it’s a good idea or a bad idea’ (David and Victor)

The decision is made by a show of hands and presented to the manager. It is the participants’ experiences that the SDD and UC give them a feeling of being listened to and reacted to – and not least, of having influence and impact in developing the social services of the social enterprise within an institutional setting. Citizens did not recount constraints on proposing themes that were ‘outside’ the allowed parameters of the service level, which has been identified in other settings across countries (e.g. in Austria).

The home services for adults with disabilities provided by the Mobile Team in Romania likewise include a formalised (digital) structure for improving feedback from the co-creators who receive the social services:

In the past, we didn’t get any social services, but since the Mobile Team was set up, they have started to support us more in making decisions as disabled people. They take us to the places we need to go, like the doctor, to get money, we do counselling, and they look for work if needed for those who don’t have a job. This support is only provided by the Mobile Team (Romanian participant).

The Mobile Team stay in contact with the citizens through an online group where they communicate about various initiatives, shared activities, or participation experiences: *‘So, we have a team! We have a WhatsApp group, and we get messages about everything that’s happening, events, and so on.* Through digital communication on WhatsApp citizens feel they have a channel for being listened to and are also given forms to fill out for improvements of the services as well as are being instructed on how to act in difficult situations: *‘For example, we also had calls, like in the pandemic, and the activities weren’t outdoors because you couldn’t, but someone came online and explained to us in details, in everybody’s understanding, what was going to happen and then it happened’.* The Mobile Team not only applied the digital platform of WhatsApp as a structure for feedback to influence the development of social services. During COVID-19 and in everyday activities, they apply the online platform to instruct the citizens to make decisions in their independent living and give voices on the service of the Mobile Team. The social services of the Danish social enterprise and the Romanian Mobile Team demonstrate formalised participatory structures at the organisational level where the services are instructed and educated in participating in democratic processes, but, mainly within the structures of the existing services.

#### Participation in policy-level participatory processes

All citizens who participated in the study in Portugal were, in various ways, part of civil society organisations dedicated to defending the rights of people with disabilities. As all organisations were

reference organisations participating in disability policy advocacy and consultation processes in Portugal, they had experience with participatory structures on meso and macro levels. To be listened to and react to demands, as stated by this Portuguese citizen, but also knowledge and education to interact and make an impact on public policies at the national level as well as in supra-organisational bodies:

People [with disabilities] have to know how to ask the right questions: ‘But then why am I not entitled to this?’ ‘Why are you telling me that I have extra income (because I filled out a certain form and didn’t put the cross in the right place...)?’ ‘You have to explain to me why!’ And I won’t leave without explaining to me why things happen ... and this is work, this is tiring, but this then brings great satisfaction (Portuguese participants).

However, several participants in Austria had significant experience taking part in policy-level participatory processes at the regional or national level, which they criticised as often tokenistic. They encountered paternalistic and patronising attitudes towards people using social services and a lack of institutional responses to participatory input:

And in general, if you want any changes to the law, in the discussions you usually end up with something like ‘Yes, actually you can be grateful that you’re allowed to breathe’. So I don’t think that participation is really desired. And if it is, then only in the way the state would like it to be. So actually, I think we as [users] are only there so that the state can say that we involved them and they all thought it was great – which is not the case, not at all (Austrian participant).

Participation was thus experienced as ‘an alibi activity’, as a pretext in which users are consulted but their perspective does not always lead to change, and as an institutional strategy to maintain the status quo. Hence, achieving responsiveness at this political level requires a change in the attitudes towards citizens with disabilities, not only on the political level but in society. A change in attitudes was a common wish for the future among the participating citizens in all six countries.

### Recommendations for the future from citizens who use disability services

As a part of the individual and focus group interviews and the future workshops, research participants were asked how social services can improve responsiveness. The following section is a presentation of suggestions to improve the responsiveness of disability services:

- ***Actively teaching how to participate and co-decide.*** Across countries, citizens condemned that participation and co-decision are not taught or practised in other spheres of life (e.g. at school). They pointed to the need to encourage and learn participation elsewhere and not limit it to the sphere of social services or electoral politics.



- **Better and more information for service users in multiple channels.** For instance, something like the Romanian Mobile Team or an ‘information centre on social services’ were requested to provide personal information, advice, and support. Moreover, it was emphasised that channels and processes for providing feedback should be explicit, given that learning, deciphering, or assuming ‘implicit’ procedures are energy-consuming and uncomfortable.
- **Changes in attitudes towards citizens with disabilities.** Participants highlighted that this must occur both within social services and in society in general.
- **Holistic approach and support.** This specifically regards support of the autonomy of people with disabilities, as well as the facilitation of a process through which every person with a disability can feel liberated after decades of heavy institutionalisation.
- **Open door concept.** The open-door concept is a premise for responsiveness in a democratic organisation. The participants voiced a wish to adopt and keep an open-door concept that allows all citizens to approach managers without a scheduled meeting – including the head of the programme. This creates a nearness to the manager, which citizens appreciate.
- **Service user groups and self-organisation.** More participatory groups for people with lived experiences in social services were suggested, especially groups facilitated by peer workers.

## 2.2 Responsiveness in child protection services

The child protection area is diverse, and it can include all other target groups – disability, mental health and youth at risk. Likewise, child protection can encompass children, youth, and parents. This diversity is visible in the data – some were collected from children, some from young people, and some from parents. Child protection is carried out differently and by different agencies in the six countries: state-based, regional-based, municipality-based, or NGO-based. Initiatives from authorities can be preventive or aimed at specific challenges. Scrutiny is often closely connected to initiatives within the child protection area – to describe the challenge or problem, to estimate the severity of the problem, and to present a possible solution. The reason for including different kinds of scrutiny and investigation is that social services often have specific responsibilities towards children and young people under 18. Scrutiny thus connects closely with different forms of control and underlines one of the main dilemmas in social services: the same authority, sometimes even the same people, must simultaneously offer support and execute control. The fear of authorities interfering in family life or even ‘removing children’ from the family naturally influences the collaboration between professional/social services and citizens, as well as citizens’ reflections about responsiveness.

The child protection area is connected to various laws and approaches to child protection in the six countries. In Austria child protection and youth at risk are covered by the Federal Child and Welfare Act; most responsibilities for child protection are delegated to regional authorities. In Poland there are no separate child protection services. Instead, local, regional, and national NGOs exist to support and enhance the child protection system. In Romania social services for children are divided into two main categories, residential services and non-residential services. These can be provided by state institutions or NGOs at both the county and local levels. In France the aim of

child protection services is defined in the Code de l'action sociale et des familles, which guarantees the fulfilment of children's basic, fundamental needs and aims to support their physical, emotional, intellectual, and social development and preserve their health, safety, morality, and education while respecting their rights; the Child Welfare Agency assumes authority for these goals. In Denmark child protection is based on the Consolidation Act on Social Services, which includes different kinds of support for children, adolescents, parents, and families. The main actors are regions and municipalities – with the most responsibility and burden of action placed on the municipalities – which offer a large number of services to families. According to the law, families must be involved in the investigation process.

### Responsiveness at the individual level: Being involved and having an influence

In general, the citizens mostly focused on their individual cases and challenges when talking about their experiences, which made responsiveness at the micro level the most common and important experience. The majority of the participants had little or no experience with responsiveness on the meso level, and even when citizens had experienced meso- or macro-level responsiveness, their individual cases and challenges remained of specific importance – as exemplified by the participating citizens from Romania. When reflecting on experiences related to being members of the Children's Council, which can be viewed as a meso-level activity, their experiences of participating in the Council were closely connected to their experiences of being listened to and involved in their own cases. None of the citizens in the Denmark sample had participated in boards or other kinds of group meetings, although 9 out of 10 expressed interest in participating in a user board in the social service if they were invited. Citizens in institutional settings are often automatically participating in 'house meetings', 'planning meetings', or 'resident meetings', and hence, their participation is part of their everyday activities and tends to connect to meso-level activities. Few of the involved citizens had experience at the macro level; however, approximately half of the interviewees in France had experienced macro participation or advocacy (i.e. contributing to a group, forum, or discussion about improving child protection above the service level). The findings from Portugal were distinct from those of other countries, as the participants primarily spoke about responsiveness on the meso level, followed by the macro level. It is, however, important to note that the young citizens in Portugal were selected from organisations that support youth participation and encourage them to use their voices.

The data underline the necessity of establishing structures for responsiveness. The findings show that responsiveness is difficult to achieve and almost coincidental in individual cases unless there is a specific structure, method, or approach that facilitates it. The Danish 'relational welfare' approach/method used in individual cases seems to have changed the experience from not being listened to or involved into an experience of being included and listened to. In institutional settings where house meetings, residents' meetings, and other kinds of joint meetings are a natural part of everyday activities, the structure strengthens participatory processes. Although not applicable in all institutional settings, the pre-organised processes and activities make it easier to accomplish responsive and participatory processes. Likewise, organisations with the specific goal of supporting

and educating citizens to encourage them to participate and use their voices – and trying out the processes in real-life settings with citizens – operate with micro- and meso-level responsiveness.

### Positive experiences of responsiveness

Research participants reported both positive and negative experiences of trying to achieve understanding and make changes within social services. Children and young people interviewed in Portugal explained that they have experienced being listened to and involved in activities and decision-making. They felt respected, valued, and ‘truly heard’ within the social services/organisations; their ideas and opinions were taken into consideration and put into practice when possible. These positive experiences were closely connected to ongoing involvement in local organisations in which voicing oneself and participating in local and national actions are built into the support. In other social services, the young people in Portugal felt that their participation was not valued – especially because they are young. The respondents in France noted that the support received from child protection services was clear, conscious, and deliberate, and they said that the support they had received had improved their lives. It is important to emphasise that experiences among the French informants were quite diverse and that several informants had negative or very mixed experiences. Citizens in Austria emphasised the beneficial consequences of a relationship that is dialogical, trustful, and cooperative, but they also highlighted the importance of service workers meeting individual needs.

I’ve been in a lot of facilities, and now since I’ve been in [social service], I really have the feeling that if you say something and if something bothers you, nobody gets angry; they take you completely seriously. They say, ‘Okay, how can we find a solution?’ and not, ‘It’s your fault’ or something or go against you. I think they’re completely with us. ... Or if I say, ‘Okay, I’ve taken this and that’, then they say, ‘Thank you for your trust, thank you for saying that.’ And that just gives me the feeling, okay, I can always talk about it, I can say if I’ve just overdosed, I can say if I’ve used it the wrong way, I can always call a carer because nothing will happen to me. And I think that’s really great (Austrian participant).

When focusing on vulnerable children, interestingly, being listened to and involved supports more than democratic perspectives: it catalyses a sense of empowerment. Several citizens expressed that being involved, participating in group activities, and increasing involvement in political actions were empowering for their self-esteem and approach to their own problems.

Parents in the Danish interviews felt that they were generally listened to by family case workers, that their suggestions and comments were considered, and that they could say no to offerings from the social service. The experiences were, however, closely connected to the time when the department started using a specific approach – relational welfare – the point of departure of which is how citizens understand their own problems.

## Negative experiences of responsiveness

Most citizens interviewed for the project had experienced feeling that they were not being listened to, that the 'support' was often intrusive, inappropriate, and misleading, and that citizens often miss information about rights, as well as about decisions within and the process of their case (France). In general, the interviewees' experiences indicated a lack of or low level of responsiveness from the social services with which they collaborate (Poland).

When I was still in the family home, for example, and the coordinator was with us, he didn't get involved at all. For example, after all, I was 12 years old at the time, and I had a four-years-younger sister with a disability (cerebral palsy), for example, when my parents wouldn't open the gate, well because they were drunk, for example, he never showed any desire to get into the house. He just always ignored it and left, and all in all, this situation lasted for several years, so it wasn't that someone said: 'It's bad, we're taking the child away'. The same with my brother. He lived in the house for seven years, seven years, nothing changed in those seven years and nobody helped him (Polish participant).

There were few definitive responses from citizens, although the most dominant statements were critical. This is exemplified by the responses collected in Austria, where some citizens expressed that social services do not reflect their rights but rather emphasise the rules that they must follow. On the other hand, other participants mentioned that they were informed from the beginning that they had the right to speak freely. A more consistent lack of transparency was linked to financial aspects. A majority of informants did not receive information about the financing of the service.

In general, the citizens reported experiencing a lack of suitable information (Portugal and Poland). They noted frequent changes in staff and a lack of stability of services, which made it difficult to establish a good relationship. Additionally, disengaged staff and wrong or no suitable support were reported to influence the experience of responsiveness and the relationship (Poland). The children and young people interviewed in Romania expressed that their opinions have not always been taken into account and that they have observed providers expressing intentions to follow up on feedback without any concrete or visible actions or changes. In general, these informants did not feel that they had any influence on their relationship with adults in the social service. A main topic in the Romanian interviews was participation in and the outcome of the Children's Council – an activity that could be regarded as a group or meso initiative. The purpose of the Council was to propose activities for implementation, and attendance was mandatory for all children in the residential centre. On the one hand, membership in the Council seems to have supported their self-confidence – feeling that they had a special responsibility – and helped them adopt a mentor-like role. On the other hand, the children were not prepared for the role in any way, and it seems like the Council is experienced more like a formality than a step towards increasing the responsiveness of social services.

Rules are often experienced as rigid and non-negotiable. There is a lack of flexibility and openness to children's suggestions. Adults do not provide adequate attention to the needs of each child and enough interaction time in social care (Romania). Instead of 'gatekeepers', citizens seem to need 'gate-openers'; several informants in Denmark emphasised that it is difficult to make services listen to and understand their challenges at the very start of the collaboration, as explained by this mother:

The first time I approached [the Department of Social Services] was in 2014. They didn't want to do anything because [they found] the children were thriving. So, there was no help to get .... And then the following year, in 2015, I tried again. And they didn't want to help there either because the children were still thriving. In the end, I was so burnt out. In 2016, when the children had to go to orphanages because I was so burnt out .... Then I was supported. And I have been supported ever since ... if I had gotten help when I asked for it, then they [the children] wouldn't have ended up in an orphanage.

The experience of not being listened to and not being understood in the very beginning has impacted citizens for a long time – also after their problems were 'accepted'. It seems that there is a general need for responsiveness, especially regarding being heard when citizens are in transition – from not having had support to applying for it, from being a child/young adult to becoming an adult, and from changes in the type of support, for example, when children and young people undergo the transition from being in residential care to being on their own (Portugal).

Although school is often the place where problems are discovered and where children and young people spend much of their time, neither children/young people nor parents felt that schools have the skills needed to understand and act upon issues in their lives; multiple children, young people, and parents noted that it is challenging to collaborate with schools. According to the interviewed parents, it is difficult to make schools understand the extent of the child/family problem and the consequences for the families and to make them act upon these problems. According to Danish citizens schools do not have the necessary skills to communicate with and support children and their parents in solving problems. This lack of knowledge and understanding was underlined by one of the Danish mothers, who claimed that the 'odd' kids are too challenging for the school and that the schools would rather get rid of them.

#### Dimensions of responsiveness: Relationship and fear

A crucial element – and a basis for the possibility of supporting responsiveness – that was stressed by most citizens is the relationship between the citizen and the social worker. As emphasised by the Polish participants, 'everything depends on people'; it is rare to find examples of experiences unrelated to interpersonal contacts. A healthy relationship makes it possible to build trust and for social workers to understand problems from the perspective of the citizens. A positive and trusting relationship with the staff and management of child protection services was deemed crucial for

facilitating citizens' expression and participation (France). A warm and enduring relationship was, according to the Austrian participants, regarded not only as an important part of participation but also as decisive for improving their situation – they even compared the social workers with a 'mother' or a 'friend-like' person. On the other hand, a lack of positive and trusting relationships makes it difficult to voice ideas, needs, requests, or even rights. Social workers and citizens need not become buddies; rather, they should build what the French team defined as a horizontal relationship – a feeling of closeness and a friendly relationship between equals. Some participants reported that social workers provided consistent, solid, and professional support, showed no fear, and sought to connect with youth as equals:

There was an immediate bond. She didn't make the educator–child connection, she made the 'We're buddies, but I'm still your educator' connection right away (French participant).

Likewise, children in Romania mentioned having a secure relationship with social workers that included trust.

However, fear stands out as a major barrier to responsiveness. Some citizens expressed fear of potential negative consequences if they voiced dissatisfaction or tried to interfere in the work of their own case. Fear of negative consequences or even sanctions from social workers appeared as a driver of several French, Polish, and Romanian citizens' decisions regarding whether to act or how to act. In France the participants expressed a fear of speaking, in Poland a reluctance to make complaints and a fear of being accused of being overdemanding, and in Romania a fear of speaking their opinion.

Children are afraid of what adults will say because you express your opinion, and it comes out totally different... (Romanian participant).

The only reason I don't want to do it now [make a complaint] is because if I do it now, I feel I will make it worse for myself. ... As long as I'm going down this path and things are going well, I just don't want to escalate the situation for now. When I get the child back, then I can start (Polish participant).

Data from the research participants suggests that citizens from both groups (foster care leavers and biological parents) were generally reluctant to make complaints when they felt their rights were being violated, and others mentioned that they did not want to voice their opinions because they were afraid of being seen as troublemakers. Even if the informants did decide to make a complaint, several had never been informed about how to do it.

Another side of the same phenomenon, which came up in several interviews, is the feeling of having to please the social worker by remembering to write 'thank you for a good meeting' or 'yes, it was nice that you listened' (or etc.). Participants in Denmark noted that it is important not to

appear to be a grumbler, to behave properly, to act co-operatively, and to primarily exhibit one's 'good qualities'.

### Responsiveness and participation at the organisational and group levels

The experience of responsiveness, as mentioned above, is even clearer if the institutional setting specifically aims to implement democratic processes. Research participants from Portugal were especially satisfied with the way they are listened to and supported in voicing themselves and the challenges they are facing. This is likely because they are involved in community-based organisations that seek to support young people, adopt clear democratic aims, and create citizen boards, which make it possible for the young people to participate in sessions with political representatives and decision-makers on both local and national levels.

One thing that was important for me, throughout this entire project, was when I went to speak to [name of the organisation]. I had written a text talking about what I liked about [name of the social service], why I felt heard, and what changed about me. ... And I remember that that day had a big impact on me because for me it was something .... Suddenly, extremely important people will stop for a moment, sit there, and then listen to me. What am I going to say? ... I was very nervous; on top of that they had invited my mother to come and see me. ... I went up on stage, read the text I had written, and then suddenly I started speaking. It was as if I was feeling again everything I had written .... At first, I thought I was going to read the text and talk a little because everyone has their own things to do ... but suddenly I started talking and people started listening to me, and then they started to ask questions, and I already felt super comfortable. I didn't even remember that I was talking to people I didn't know and who would be important or not. So I really felt heard and then at the end people applauded, and my mother was super proud, and they came to ask me questions and make some project suggestions .... And that's something that really resonates with me. To this day, I still have that text, and I reread it (Portuguese participant).

This outcome was also reported in the disability and youth at risk sectors, where some Danish citizens are enrolled in institutional settings in which they automatically become members of boards, have regular meetings, and have open door access to the management. Likewise, community-based organisations in Portugal were reported to support involvement and bolster empowerment. In those organisations children and young people participate in the design, implementation, and evaluation of specific activities and projects. Only a few children and young people were, however, continuously involved in activities, projects, or boards. In that sense, the participants suggested strengthening social services coverage and the diversity of activities.

Several citizens within child protection (and for some countries also youth at risk) had never been invited to participate in anything beyond the collaboration with the case worker. None of the



research participants from Poland had been invited to take part in any consultations, evaluations, or other meso-level activities related to social services. This was also the case for the parents in Denmark, despite the relational welfare approach.

In France some informants described experiences of social services avoiding bringing users together in collective spaces, sometimes even explicitly refusing this request from participants. On the other hand, more than half of the interviewees in France had had experiences of macro participation or advocacy, that is, of contributing to a group, forum, or discussion that aimed to improve child protection above the service level. These experiences, which included partaking in research projects or representing youth in political fora, were generally perceived as positive.

### Recommendations for the future from citizens who use child protection services

As a part of the individual and focus group interviews and of the future workshops, research participants were asked how social services can improve responsiveness. This section presents suggestions to improve the responsiveness of child protection services.

- ***Offer more and accurate support.*** An important general facilitator to support responsiveness in the future is to offer citizens more and accurate support based on their own experience of specific problems. This does not mean that any other more general initiatives – on meso or macro levels – have to wait for individual challenges to be solved or defined. Actions can very well be parallel. Being able to participate on a meso level seems, however, to be based on experiences of being listened to when it comes to individual challenges. In other words, being listened to on the individual level makes room for responsiveness on higher levels. Accurate support entails the adoption of a holistic approach that responds to a citizen's entire person and life course, not just their immediate needs or wishes.
- ***Develop social services competencies.*** Responsiveness on micro, meso, and macro levels calls for additional development of social services' and workers' competencies in communication based on listening; they must also understand what participation and responsiveness are and how they are practised.
- ***Be attentive, available, adaptable, and accompanying.*** Social workers should behave in an 'attentive and enabling' (rather than restrictive) manner towards the voices of citizens in child protection. Social services and social workers should be more available, especially regarding physical presence (regular, continuous, etc.). They should be able to work with children, youth, and parents, which will allow them to observe and understand the current situation in the person's life; they should also be able to adapt and respond to unforeseen challenges. And they should accompany – understood and walk together with – children, youth, and parents towards autonomy and emancipation.
- ***Focus on relationships.*** An important part of being responsive and believing in responsiveness is the relationship between citizen and social worker, which should entail trust, empathy, and respect.



- **Support citizen resources and capital.** Unfair though it is, it is necessary to have resources and capital to be able to receive the right support. Or, to put it another way, citizens often need to know their rights and to be strong to make responsiveness work. Educating citizens about participation could help them to succeed.
- **Invite citizens to be part of the considerations and decisions.** A parent needs to be able to discuss and consider their situation and possibilities. Hence, responsiveness entails not only listening but also facilitating open discussions, including debate and giving and receiving feedback. Such openness appears to make parents less alert and hence, reducing the fear reported by several citizens in various countries.
- **Emphasise approaches that lead to democratic competencies.** Supportive approaches help young people who use social services learn the important democratic competencies of speaking, debating, and arguing in public spheres. Individual rules and exceptions can only be applied and accepted if concerns and explanations are communicated within a trustful atmosphere.
- **Underline the 're' in responsiveness.** An overall positive experience of collaboration with social workers is based on (1) the possibility of being listened to and (2) the co-creation elements in responsiveness. Responsiveness entails not only listening to, but also responding to, what citizens are saying – the co-creation process between social services and citizens.
- **Ensure schools are communicative and understanding.** Schools invariably constitute an important environment for experiences of responsiveness and should therefore be more supportive, communicative, and able to understand and address complex problems.
- **Take action.** Being responsive is also about taking action – realising that citizens are facing multiple issues and challenges in life and sometimes struggle to play an active role in the collaboration with social services.
- **Bring a lay representative.** Several citizens addressed the problem of being alone at important meetings, of forgetting what happens, of losing the overview, etc. – a lay representative is very helpful in those situations.

## 2.3. Responsiveness in mental health services

This section focuses on how the responsiveness of social services is experienced by citizens with mental health issues across the six participating European countries. The section compiles the analysis of the empirical data from interviews and focus groups with citizens who are or have been users of services in the mental health sector.

A shared characteristic across the countries is that the mental health participants' narratives mostly focused on experiences with access to the health sector, medical treatment, and therapy. This relates to the fact that mental health sectors are often integrated into – and therefore shaped by – either the health sector or the disability sector in the given country. Furthermore, the health and social sectors seem, in practice, very much divided, with little organisational or professional

overlap or collaboration. The analysis highlighted that for a citizen with mental health issues, the focus is primarily on how to get responses, support, and help regarding their health conditions. This relates to the vulnerability that mental health issues cause and to the citizen's life conditions and ability to act. Thus, there seems to be a hierarchy of needs in which the individual health condition is a basic need and the foremost problem to solve before the participants can concentrate on other issues. This is in line with the report from Work Project 1, which emphasises that the existing research and practice landscape in the mental health area is mainly psychiatrically focused and less informed in the areas of social work research, care research, or social science perspectives in general. In practice, this means that citizens with mental health disorders often have to navigate multiple sectors to receive services and support regarding their mental health situation. Their needs will often fall into the interface between the health and social sectors.

The target group in this section is citizens with mental health issues, including people who are diagnosed with a mental disorder and those who are or have been users of mental health services. Furthermore, there were participants in both the interviews and the future workshops who have been or still are peer workers or members of peer boards, etc. (Austria and Denmark). These participants had unique experiences with participatory processes, whereas other participants had been hospitalised in psychiatric wards and did not have any experiences of co-creation in consultative and participatory processes in the mental health sector (Romania). Thus, the participants' experiences were wide-ranging. The following presentation of the findings focuses on their experiences of responsiveness and the patterns and nuances across countries.

#### [Responsiveness at the individual level: Access, personal relations, and holistic approaches](#)

At the individual level, the participants' experiences of responsiveness in the mental health sector were primarily characterised by the struggle to achieve access to assistance with their health condition – either medical or therapeutic. Their experiences of responsiveness were linked to being listened to, recognised, and respected as human beings.

Responsiveness at the individual level was described by the participants as those responses related to basic needs such as receiving treatment. There are varying experiences of access to the health sector, but in general, there are long waiting times for appointments with a psychiatrist, and in some countries, such as Poland, Denmark, and France, access to psychiatrists and psychologists is very limited and is characterised by inequality based on economic capital and social network. This pushes people to use the private sector – those who can afford it – to achieve responsiveness and quality in the service, as the following participant noted:

I gave up on public healthcare because I think that the quality is always lower there. It's also like, when you pay, you get more, you get more (Polish participant).

Thus, responsiveness is – in the view of the mental health service users – very much related to access and the likelihood of getting treatment. Some participants described the concept as almost synonymous with availability in the health sector.

Long waiting times and lists and the need to use the private sector were presented as barriers to responsiveness, while meeting key persons in the health and social sectors and personal relationships were highlighted as facilitators. In some countries, such as Poland, the importance of having access to the right network and gatekeepers is so profound that the participants there concluded that one needs to have family and friends to effectively undergo treatment. In Denmark the general practitioner was identified as the gatekeeper to treatment at the psychiatric ward as well as to other types of services offered by the municipality, including unemployment and social benefits. The way the general practitioner – and other professionals – are meeting the participants and reacting to their mental health conditions influences the experiences of responsiveness. A young Danish woman explains in the following quote how her general practitioner sent her to the psychiatric ward immediately after she consulted him about her mental health situation and condition – he even paid for her taxi to the hospital:

I remember using this image. I feel like I'm in a pool, and I want to get out of it. But I just can't stretch my arms .... And then I sit down and talk to the doctor ... and I say, well, I'm having a lot of suicidal thoughts, and I feel that I physically can't cope with anything. And then he just looks at me after we've talked a bit, and then he says, 'I'm going to order a taxi.' And then you're taken to the psychiatric emergency department, and then he says, 'and then you have to promise me that you'll accept all the offers they give you.' Um .... Well, because I'd never had contact with the system before. And he's actually paying for this taxi. So I had, I feel like it was big. He took it very seriously, in a way, but it was also powerful for me that he took it so seriously. Because it kind of said something about, okay, he thinks I feel so bad.

This participant's story recounts how she was met with acknowledgement of her condition by the general practitioner. No critical questions were asked as to whether she was sick or not. Responsiveness is here connected to both being listened to and that the professional acts on her behalf – he 'responds' to her needs and condition. This was a common understanding of responsiveness across the countries. As it is described in the French report. Responsiveness is *understood by the informants as an attitude, behaviour, or action that is adaptable, open, and flexible to what service users need and want* (France Work Project 2 report).

In the Danish case above, the professional also acted with a caring and personal approach (e.g. paying for the taxi). Meeting key persons who either help with access to treatment or act in a particularly supportive way plays a significant part in the participant's experiences of responsiveness at the individual level. The human component of interaction with social workers was strongly emphasised by the participants across the countries (especially Poland, France, and Denmark). Responsiveness was connected to approaches that are holistic and '*human-centred* –

*taking into account that there is a human being on the other side, not just a medical case'* (Poland Work Project 2 report). Some participants in each of the countries spoke about how it is necessary to have a personal relationship with the professionals to get human treatment.

A lot of times I've gone beyond the 'patient–doctor' relationship with the doctor lady. She understood some things, and she saw my human side. ... In this process, the percentage should not be 99% medical and 1% the human side. It's quite 'primitive'. On the social side, they should work much better because the human mind...how shall I say...it's useless to 'drive it crazy' with drugs if you don't influence it from the human point of view (Romanian participant).

Similarly, a Danish participant described how a nurse acted emotionally (human) towards him by taking his hand and hugging him when needed when he was hospitalised. Human actions and holistic approaches had a big impact on users' experiences of responsiveness; these professionals were described as key persons in the participant's narratives about their experiences with social services. The professionals' holistic approaches towards the service users become very important regarding the experience of responsiveness. In Portugal the professionals who were identified as facilitators of responsiveness were described as those who were most *human, willing to listen and respond, flexible, respectful, empathic, understanding, and committed to addressing requests*.

#### Asymmetric relationships, power, and fear of losing the services

In contrast to positive experiences in which they were treated as human beings, the participants also called attention to experiences in which they felt devaluated and reduced to 'users' and 'patients' in their relationships with the staff. Across countries, there were several examples of participants who reported negatively about their experiences of responsiveness, especially of being involved. They focused on non-participation in decisions about their individual (personal) cases, and they recounted interactions with professionals who stigmatised people with mental illness. A Portuguese participant reported the following: *'The strength of our opinion is linked to the state of our mental health'*. Across countries, participants spoke about different dimensions of being devalued due to their mental illness, and in Austria, one participant compared this with being treated like a child, an 'idiot' or an unreasonable outlier:

Especially people who haven't been completely knocked out by tablets, who still have a brain that they can use. Adult people who are treated as if they were 5-year-old children in a facility like – sorry to say this by name – in [residential facility in Austria].

The experiences of being devalued and not being involved in decisions were further illustrated by examples of lack of autonomy and experiences of exercise of power, for instance, in the psychiatric hospitals where some of the participants were hospitalised due to their mental health conditions.

They took me to the hospital against my will, out of my house, out of my bed, where I was sick – and I ended up in a room with about 20 beds with some people with much more serious problems than me... (Romanian participant).

An abuse of power by staff in facilities that offer services in the mental health care system was also mentioned by participants in Poland and Denmark. Analysis uncovered that this was especially evident in the narratives of individuals who had experienced stays in psychiatric hospitals, where the doctor was portrayed as the highest authority, upon whom everything depends. A Polish patient described it as follows:

Since 2008, I've been in a psychiatric hospital eight times. I never appealed to anyone. I didn't file a complaint. Can you imagine writing a complaint in a camp about one of the camp officers? You probably wouldn't. And if you complain, you might get even worse treatment, so it's better not to do it. You just have to endure.

This statement indicates a lack of agency, which can be understood as the lack of power of the patients to take action, make decisions, and control their stay at the hospital. This lack of agency was also linked to a fear of losing the help, treatment, and support – which is why the Polish patient concludes: *'You just have to endure.'* This is also a consequence of the fact that in the mental health sector, for many users the support they receive is essential for physical, financial, and health-related reasons, and many of the participants have waited a very long time to get help. In some cases, informants felt 'lucky' to get any help at all.

In France the asymmetric relationship between social service users and the staff or services that support them in the mental health and disability sectors was characterised as one of dependence: without those services, some individuals would not be able to ensure that their basic needs were met, nor could they ensure access to certain rights. This dependence, combined with the fear of losing access to the services, was why the users felt they were not able to express their desires, needs, and requests. Some participants reported that their lack of agency was linked to a fear of being punished in treatment if they raised their voices. One interviewee reported the following situation as an example:

Because another user expressed her disagreement with a staff member. And when she expressed her disagreement, she was the one who was suspended for a month. She had no right to support for a month (French participant).

Others experienced a lack of responsiveness and abuse of power in the health sector regarding their diagnosis and medication when they were hospitalised in the psychiatric ward. Two of the Danish participants pointed out how they did not experience responsiveness when they were diagnosed – they felt they were wrongly diagnosed, but the system was so powerful that it was difficult to fight against it. A young woman described how she – because of a conflict with her case worker – was labelled and diagnosed on that basis:

And that episode leads to the fact that at my next meeting with a psychiatrist ... he looks at me and says: 'We don't think you're depressed at all.' I was admitted to the affective ward, and I was very severely depressed. Then he looks at me and says, 'We actually think we will remove this antidepressant ... because we think you have a personality disorder.' Because I've had this one episode with a case worker. Then I say, 'I just don't agree with that.' And then he looks at me. He looks me directly in the eyes and says, 'The way you're reacting right now, that you're so reluctant. It just proves to me that we're right. That this is the right diagnosis.' And then I said, 'This doesn't make any sense to me. I can't see myself in this diagnosis. It doesn't make sense *at all*.' ... But it provokes me a lot. And I always had this feeling that I really had to hold back on myself. And show that I was cooperative. ... This diagnosis, I simply don't think it's right (Danish participant).

This quote describes the powerful position the employees are placed in regarding service users with mental disorders and how employees can use this power. In this case, the use of power is an illustration of the lack of citizen involvement and responsiveness in the diagnosis of mental illness. In this process, the participants felt stigmatised as *people to whom the employees did not listen* because of their mental illness. The way the Danish participant put it, she must act in a special way to be listened to in this setting; *she must be cooperative and hold back on herself*.

This case indicates that responsiveness is embedded in restrictions and that it refers to an asymmetric relationship in which responsiveness depends on whether the citizen acts in the 'right' way. This relates to fear; if they do not act in the way the 'systems' lead them to, they are afraid of how it will influence their further treatment. Here, it is worth mentioning that the mental health sector is known for using power by direct coercion at psychiatric hospitals. There are cross-country examples of this in the data (especially in Denmark, Poland, and Romania), and there are reports of a lack of consent regarding medication and placing patients at psychiatric hospitals without the patient's consent, which are extreme manifestations of a lack of responsiveness and examples of how the expert-patient relationship in the medical and/or institutionalised setting can prevent responsiveness.

This is actually the annihilation of your sense of agency, that you can even think about something. Because everyone around knows better, right? The psychologist knows better, the doctor knows better, you don't know, you talk nonsense (Polish patient).

This quote illustrates the asymmetric relationships in the mental health area, especially between doctors and patients.

## Stigmatisation and lack of voice as a group

Besides the individual experiences of being undervalued due to the staff's expert roles and being devalued as only 'patients', participants in each country also pointed out the stigmatisation of persons with mental illness as a group of persons you cannot rely on. Across countries, there were reports of experiences of being labelled as mentally ill persons with voices that were not recognised as valid. One of the Danish participants talked about how she needed a spokesperson to advocate on her behalf to get the right support because she felt the professionals did not listen to people like her – those with a diagnosis of bipolar and borderline personality disorders. This was also noted in Austria, where social workers were sometimes perceived as an insurmountable 'wall' of experts who were unwilling to allow users to co-decide and provide expertise for their cases. The participants' experiences of being labelled due to their mental health conditions are not just a matter of singular staff members' non-responsive actions in the mental health services but an expression of structural mechanisms that maintain a fictional duality between experts/non-experts and rationality/irrationality. While there are examples of participants who experienced responsiveness in their individual cases and who felt they could voice their concerns to individual staff, there appeared to be a lack of opportunity for collective expression and exchange among service users across the six countries. In Austria a workshop participant expressed it this way:

Well, I think we can leave this topic out because nobody ever listens to our ideas. We have to accept everything; there are no ideas from us.

In France informants reported a lack of collective spaces for participating in the management and delivery of social services in the mental health sector. Most consultations were organised in individual spaces, despite the importance and potential of being part of a group, as expressed by one of the participants in the study:

I needed to go to group activities because it was the only way of getting in touch with other users. Otherwise, everything was done individually. But it's through the group that you realise the different challenges. ... That was lacking. It would have been useful. You feel better as a group than as an individual because you can find recurring issues (French participant).

Having a voice as a group and taking part in group activities can develop democratic and bottom-up processes, which can lead to horizontal empowerment that emphasises the development of powerful inward and downward networks between actors at the same level, e.g. between patients (Bilfeldt, Jensen, and Andersen, 2014). Thus, the most frequently mentioned results associated with group activities in Portugal did not relate to specific changes in services or responses (although there were some references to possible changes). The participants mainly focused on the possibility and worth of interaction and sharing experiences and/or on their contributions to both increased visibility/recognition and decreased stigma.

## Responsiveness and participation at the organisational and group levels

Most of the participation and communication described by the research participants tended to take place in informal spaces and was often an expression of individual rather than collective participation. In some of the countries, none of the participants were able to recollect any form of organised participation to provide feedback, consultation, or information gathering from the perspective of those assessing social services for change or improvement in the mental health sector (cf. Romania, Poland, and France). In France a majority of the participants had little experience with formal spaces for voicing their views, and none of the participants had experienced delegation of power and decision-making – either as an individual or as a collective. In other countries, including Portugal, Austria, and Denmark, a diversity of experiences of participation in activities related to the development and evaluation of mental health services were found – at both the meso and macro levels and from no participation to frequent participation.

Participation at group levels to provide input and influence services for people with mental health issues was reported across countries. This included peer working, board membership to represent patients with mental illness, and/or being a volunteer in or an ambassador/spokesperson for self-help groups.

Many of the participants, as mentioned earlier, had experienced stigmatisation, and the participants who had experiences with group-level activities were often preoccupied with breaking down taboos about mental disorders or starting peer groups for people like themselves. Others did peer work to make sure that their peers were getting the best help and support, and some were members of peer boards (etc.) to be spokespersons on behalf of people with mental disorders. It can be difficult to decide whether these activities to achieve responsiveness should be categorised as individual activities or activities at the meso or macro levels. Both why they participated in the activities and what they achieved regarding responsiveness are highly variable.

Participants from Austria, Denmark, and Portugal reported participation in *peer work* and *peer boards*. This indicates that in these countries there are increasing efforts by some social services in the mental health area to facilitate or expand new participation structures. The interviewees emphasised that a particularly positive form of responsiveness is facilitated when social services enable peer work, and some of the research participants with these experiences mentioned an institutional change from informal structures of responsiveness to formal, transparent structures. Acting as a peer worker or joining a peer board opened up new forms of participation for the interviewees. However, even though this path to citizen participation and democratic processes was well established, peer workers were not always welcomed, and some participants experienced being perceived as intruders in the system's status quo:



So, I was told by one of the managing directors of [organisation] about a well-known psychiatrist who told [the organisation]: 'Don't hire peer employees under any circumstances. Because you'll bring the illness into the organisation.' So, this idea of 'We are the healthy ones', so to speak, 'and there are the sick ones.' And if you bring in the employees, then the whole organisation gets ill (Austrian participant).

The idea of mental health services being 'infiltrated' and 'infected' by participatory mechanisms reveals an issue of pathologizing the involvement of service users. In Denmark, too, participants with peer work experiences described negative experiences of responsiveness. Both individuals ultimately resigned from their roles as peer workers because they found it too difficult to gain influence and be accepted as persons with expertise:

I found myself in a hopeless inefficiency in the system. For one thing, I found that patients were demanding my services more than they were demanding the services of the nurses. But the reason I quit was because I wasn't being listened to. And because I had to fight for a new professionalism. Peer work was a new profession. And very, very little recognised (Danish participant).

The research participants in general indicated token participation, and the Austrian participants suggested that participation was purposely designed for promotional purposes while decision-making processes remained hidden, meaning that it is the services 'or the social workers who decide in the end' (Austrian participant). Members of the advisory board also emphasised these aspects and added that even if a participatory structure somewhat exists, there is often no awareness of or belief in it.

Other participants in Denmark embraced participation via peer-to-peer work in self-help groups or by being spokespersons rather than acting as peer workers. One participant spoke about how he experienced responsiveness from peers more than professionals:

Here I am not met with professionalism. I am met by a humanity with people who have lived experience on their own bodies. And a framework of understanding where I am not assessed with checklists (Danish participant).

Peer-to-peer work is, in this context, not about influence on the vertical or political levels but about community and social relationships, about being part of a group that understands you. Being viewed as a human being by peers creates horizontal empowerment and responsiveness. Another variant of this type of participation is acting as a spokesperson on behalf of those with a given mental disorder. For example, an ongoing initiative in Denmark, which only recently began to receive governmental support, focuses on giving a voice to citizens with mental disorders via a campaign entitled ONE OF US. This national anti-stigma programme seeks to improve life for all by promoting inclusion and reducing the stigma and discrimination connected to mental health conditions. To achieve this, ambassadors with lived experiences of mental disorders speak at

events to break taboos and shed light on the lives of citizens with mental health issues<sup>1</sup>. Two of the participants in the Danish study were or had been in the process of becoming such ambassadors. For one of the participants, that position has been an important part of her identity and given meaning to her life:

I've had something bigger than myself. I've had something that made sense. I've had something that I considered to be the meaning of my life. Where others might go to work and find meaning in it. Then it was my purpose to be where I was.

Regarding what motivated her, she spoke about how she had previously felt alone; telling her story and seeing that she was not the only one gave her motivation and meaning. This indicates a kind of responsiveness at a group or societal level – experiences of responses to her situation. Being a spokesperson has *'taught me that my voice is worth just as much as everyone else's. It's given me something in my backpack that I wouldn't have had otherwise.'*

These varied types of participation illustrate that there are diverse structures in place in the six European countries and that the participants in the study, as such, have experienced both their opportunities to participate and their participation differently.

### Recommendations for the future from citizens who use mental health services

As a part of the individual and focus group interviews and the future workshops, research participants were asked how social services can improve responsiveness. The following section presents suggestions to improve responsiveness in mental health services.

- Better collaboration between the health and social sectors
- Institutional frameworks and principles for collaboration between mental health centres and entities that provide social support
- A holistic approach
- More use of the non-governmental sector to fill the gaps in the public sector
- An extensive catalogue of available services
- Community-based and mobile support teams
- Self-help communities whose members can share information about illness and treatment options
- Restriction upon the number of individuals subject to placement in psychiatric hospitals
- More respect for a person's own view of their mental health situation – more involvement and responsiveness in the process of diagnosis and medical treatment
- Less use of power in the psychiatric ward
- Careful regard of (listen to) citizens' wishes for the future
- Better opportunities to participate in activities that can give meaning to one's life if one cannot work

---

<sup>1</sup> <https://www.sst.dk/da/en-af-os/ONE-OF-US/Ambassadors-in-ONE-OF-US>

- More information about and more breaking down of the taboos surrounding mental disorders
- Textbooks written by citizens about their experiences, especially within the system(s), of having a mental health disorder; these should be used in educational settings to qualify professionals' perceptions and understanding of citizens

## 2.4 Responsiveness in services that work with youth at risk of social exclusion

This section presents the findings of the experiences of responsiveness among youth at risk of social exclusion across the six countries. Youth at risk of social exclusion are understood as young people who have been or still are users of social services. Services for youth at risk represent a wide category in the RESPONSIVE project, including alternative and residential care, substance abuse treatment, vocational training, probation, reintegration, specialist educational and outreach programmes.

Youth at risk of social exclusion face various kinds of social problems, such as risk of poverty, NEET categorisation (not in employment, education, or training), mental health issues, homelessness or housing issues, and addiction problems. The category youth at risk is often understood as individuals between 15 and 29 years old (cf. EU), but most of the participants involved in this study were young people aged 18–29. These constituted a group of users of social services who were in a temporary crisis and at risk of social exclusion.

The young people who participated in this research project were vulnerable to institutionalisation from an early age, various types and degrees of mental and physical disabilities, drug abuse, lack of protection from parents, and other risk situations. They were in many cases characterised by their vulnerability to multiple parameters in their lives and dealt with a complex combination of issues (e.g. mental illness, substance abuse, homelessness, criminality, a challenging upbringing, family issues, and a lack of education).

There were, of course, various significant differences among the research participants and the challenges they faced, but a common issue seemed to be that they found themselves in a transition position where they were trying to sustain an independent life. Most of the participants had never lived alone; if they had, they had not managed it well. They were all in some way dependent on social services and support.

This target group is unique within the social services because some countries offer a variety of special services for young people at risk of social exclusion, while in others only a limited selection of such services is available (cf. Romania). However, there are similar services in each of the participating countries that adopt a focus on young people who are leaving the child protection system, especially those who have been placed in children's homes or raised in foster care. These

young people have the welfare systems' attention because of their obvious vulnerability during their transition from youth to adulthood and because they are about to enter the adult services systems.

Most of the research participants in this category were older than 18 years and were (legally) considered adults; however, they were still regarded 'young' because they were in the transition from youth to adulthood. For most young people, the transition out of childhood can be a difficult period, but for these young people, who may have been placed in care or struggle with family problems or other social stressors, it is particularly challenging. Due to their background, youth at risk of social exclusion have a significantly lower chance of completing secondary education and becoming self-supporting, and they often require substantial support in their transition to adulthood. The fact that these young people are often legally considered children until they turn 18 places them in a particularly difficult situation, as the demands and expectations of navigating adult life are thrust upon them all at once when they turn 18.

The social services that were assessed by the young people in this study are provided by institutions in the fields of social work, education, and social rehabilitation. Due to compulsory education until the age of 16 and the obligations of care organisations until the age of 18, these are primarily public institutions. Youth and families also reported the use of the services of non-governmental organisations (paid and unpaid) and private (paid) specialist services. The following services were assessed:

- Residential social services, including family-type homes and sheltered housing
- Therapeutic, resocialisation (social rehabilitation), educational, and other programs that support young people in difficult situations or in crisis on a long- or short-term basis
- Mentoring/assistance for life independence, including the assignment of mentors who are available to help young people through situations of personal crises and in personal, educational, and professional development
- Psychological and psychiatric support (access to psychologists, psychotherapists, and psychiatrists)
- Vocational programs, including courses, internships, training, and job placement assistance
- Family support to aid families and young people through counselling, as well as family therapy, material support, and support of social workers
- Integration programs that help young people succeed in various types of extracurricular activities, youth clubs, and other activities
- Addiction prevention and treatment programs for drug, alcohol, and gambling addictions
- Legal assistance programs to provide legal support for young people and their families, especially those at risk of legal problems or of breaking the law (e.g. criminal, property, or family law)
- Safe places programs that offer safe housing for young people who may be struggling at home

- Outreach programme for young people in the street
- Educational support programs that offer additional help with learning, tutoring, and remedial classes for young people with learning difficulties; programs on dealing with emotions and teamwork

The data collected from the six countries were quite diverse. In some countries, the young participants used multiple kinds of targeted social services, while in other countries specific projects or NGO projects were approached and utilised as gatekeepers by the participants. The latter case resulted in participants who often had unique experiences with participation at the group level because the NGOs work directly with democratic processes. For instance, the citizens in Portugal were selected from organisations that support youth participation and encourage young people to use their voices. These varied types of services likely influenced the data collection and the kinds of perspectives that were gathered. In Austria and Portugal the youth at risk category was merged with child protection services in the qualitative study.

#### Responsiveness at an individual level: Binding relationships and (not) being listened to

The Work Project 1 report pointed out that while the youth sector in general often offers broad participation possibilities for young people, the desk research suggested that young people at risk of exclusion are more likely to be confronted by formalised, top-down, and exclusionist interventions. This is due to a general neglect of disadvantaged persons in democratic approaches and, more specifically, to a lack of attention to power imbalances between marginalised youth and practitioners in social services.

Generally, the young people did not recognise the concept of responsiveness. The term was explained in the interviews and focus groups in a simplified way and then further discussed if necessary. The subsequent analysis of the interview statements determined that responsiveness appeared to be related to experiences of getting support regarding the respondents' individual problems and situations and whether *the frontline workers* had acted upon (responded to) the needs and problems the young people had described to them.

#### Binding relationships

Responsiveness was related to the young participants' experiences of being listened to and involved in decision-making. The participants' reports on their experiences were quite varied. Among the young participants in Portugal, there was a general experience of being listened to and involved in the activities, projects, and decision-making within the social services they were connected with. They felt respected, valued, and 'truly heard', and they noted the long-term authenticity they felt from the professionals and the empathy those professionals conveyed about their situation as a whole. They felt seen beyond their 'user' status: *'I realise that I'm talking and people are really listening to me, they're not pretending to hear me'* (Portuguese participant). Similar experiences were noted by participants from Austria and Denmark. In Romania the young

participants also reported that their opinions were taken into account when they accessed social services; however, there were varying perceptions of whether their opinions were truly heard. In Austria and Denmark some of the participants pointed out increased responsiveness in their present social service compared to experiences with former services. In the Danish case a phrase like 'here the staff is listening' was common in the interviews (indicating a change from prior experiences). This was often followed by an example of how the staff was helping them with big and small issues.

But here, from day one they have welcomed me and helped me. And they're after you.... Well, not after you, but they help you get through the day. They teach us to stand on our own two feet with cooking, washing dishes, doing the laundry, and cleaning our room. Things like that.... Other places don't do that, either (Danish Participant).

The comment shows how the young service users emphasised the beneficial consequences when the relationship was dialogical, trustful, and cooperative. The uniting element of staff acting and deciding *with* and not *against* young people, taking their wishes and needs seriously, was valued as a participatory experience. Trust was essential for young participants across countries –both service users and staff were encouraged to express their needs, wishes, and expectations. Indeed, a greater exchange of information is the foundation for learning about and meeting individual needs. Thus, such dialogical relationships are not just pleasant for service users but also lead to better care and more effective services. In general – across countries – the participants indicated the following primary needs: to be heard by the services, to establish personal contact, to be treated with an understanding of their perspectives, and to be granted a sense of security and respect regarding their right to independently make decisions.

The individual relationship with one's case workers appeared to be an important channel for participating in decisions – both regarding one's own trajectory as a social service user and regarding the functioning of the social service more broadly. Individual relationships that were viewed positively were, in the French data, characterised by the professional's continued presence and a build-up of trust between the young person and the social worker. In the Portuguese data, several young people stated that they had an affective connection with the professionals and that they feel the professionals 'like them'. This suggests the development of strong binding relationships, so much so that some participants, both in Portugal and in Denmark, stated the following about their living situation (e.g. sheltered housing): '*It's like home to me*' (Portuguese participant). Long-term, almost family-like, relationships with some of the guardians and educators were emphasised in the Polish data:

I don't have very good memories from the orphanage, apart from one teacher with whom I still keep in touch. Every time I need help, vent, or whatever, she's there.

The young participants held their close relationships with professionals in the services they were linked to in high regard, referring to familiar relationships and calling it *like home*, which in some cases may have been influenced by these young people's lack of a personal network and/or troubled family relations. Thus, some of the participants in Portugal also mentioned experiences that fell outside their relationship with the social services. In the context of the family, other social services, and even the employment market, they felt that their participation was not valued, since they are 'too young' and do not 'know anything about life'.

#### Not being listened to and understood

The Polish research notes that sometimes it was easier for the young participants to identify what was *not* a responsive service, to point out errors in communication, and to objectify the treatment of young people as users of pre-defined services that were misfitted to their real needs. The experience of responsiveness or the lack thereof was also defined by some of the participants (across countries) according to whether the services they were offered could help them with their social problems or other issues, such as financial stressors or addiction. Some of the participants reported experiences of being exposed to 'wrong' interventions and of not being listened to or involved in decisions related to specific interventions or types of support. A young Danish participant explained how he was placed at a residential facility for adults with addiction problems when he turned 18. He was guided – by the case worker – to move away from home and his family, as he was seen as a troublemaker who was having a bad influence on his little sisters:

But then when I was about, I think, 18, I started to get a lot of pressure from the municipality to move out. Then it ended up that I was thrown into moving away from home and forced to find a place to stay. That's how it is. It's probably the most contact I've had with the municipality. Until then. ... I was very much against moving away from home because I wasn't ready for it at all ... I definitely feel that a huge mistake was made right there. Our needs as a family and our needs as citizens were simply not taken into account.

This Danish participant further explained that he did not feel that the case worker had any understanding of what he wanted and that he had difficulties explaining it because he had been feeling unwell. He was not ready to move away from home, and this and the family's needs were not taken into account in the decision-making, which is why this illustrates an experience of unresponsiveness. In this situation, the (non-)relationship with the professional played a significant role in the experience of (un-)responsiveness, which was also the case in the other sectors explored in the RESPONSIVE project (mental health, disability, and child protection). These findings call for a more holistic and comprehensive approach towards young peoples' situations, which is also a point of focus in the Polish analyses, where it is repeated several times.

When informants were asked about their experiences of (not) being listened to and (not) having influence, they responded with both examples of *individual cases (micro)* and *organisational-*

*institutional (meso)* examples. The former were related to interactions with social service staff and instances of (not) being given a choice between individual support offers and activities. The meso-level experiences consisted of taking part in house meetings, writing inquiries or complaints, and the way social services frame and react to user feedback in these formats.

#### Marginalisation and social exclusion of youth at risk: Being labelled as 'too young'

Regarding young people's experiences of using social services and participating in the co-creation of those services, the Polish report states that the existing problems and barriers were similar to those that have been analysed more broadly as a source of young people's lack of participation (Brzozowska, 2017). They are primarily caused by adults' (service decision-makers') low levels of knowledge about the current, real needs of young people and the real sources of their crises, as well as by the inflexible approaches adopted by the services themselves, which are generally directed, top-down, to young people. These barriers can be linked to some of the young participants' experiences of being labelled as both troubled and too young to be involved in decisions. Similarly, some of the interviewees recounted experiences of being labelled as a 'group' that, because of their age (and social problems), do not have a legitimate voice. Even though many positive experiences of responsiveness were related in the Portuguese data, several obstacles to participating and gaining influence were also identified. One of these was related to adults' disbelief in children's and young people's skills and ideas, which was one of the transversal aspects mentioned in the interviews and focus groups.

...but what do you know about life? Because we hear this a lot. Ah, you're just a girl, you're only 22 years old, and you still have a lot to live for. ... And sometimes I felt that way. Ok, I really don't know what I'm talking about, I'll let someone who knows or has more experience... (Portuguese participant).

The participant's age, especially being viewed as a 'child', was also mentioned as a cause of professional disregard and neglect of participant opinions:

Sometimes, when some people ask certain questions, they already have in their heads the type of answer they want to hear. And then what happens is that the answer will be completely flawed because it is a very personal answer (Portuguese participant).

...she conveyed it in a way that I am a child, and I have my moods. ... That the problem is not what her parents do or the environment, but that she is young, and that's how she is, and she will get over it (Polish participant).

These quotes indicate that the participants were sometimes judged to be too young to offer input, which was why their participation and opinions were not valued. This was often, as already mentioned, linked to services without trustful relationships, and while interacting with such



service providers, *the interviewees felt that their participation was not valued because they are 'too young' and they do not 'know anything about life'*. These experiences of labelling and feeling worthless were also expressed by youth with migrant backgrounds in France, where informants deplored the strict eligibility criteria for accessing certain social services. While they had been able to seek support from NGOs dealing specifically with migration-related issues and access shelters to spend the night, other services were not available to them. Thus, their requests for support went unanswered – a barrier that made issues related to participation and other forms of responsiveness ultimately irrelevant to the group.

As soon as you come in, they ask you, 'Ah, how are you?' They ask your name, and your situation, and when you say, 'I'm in such and such a situation', they tell you, 'Here, it's not for that, it's for that.' They don't even give you the time to talk about the situation you're in. They tell you straight out, just like that. Sometimes it hurts your heart (French participant).

Furthermore, some youth – both from France and from Poland – suggested or explicitly declared that they felt that social services and staff/management did not especially care about them. As one young person put it, *'I think there was also a lack of interest in me.'* Another focus group participant put it a little differently:

For them, dude, you're just a discount number buddy; they don't give a shit about you. At night, dude, they come home, don't worry, they've got their wives, their kids, dude, their problems, don't worry, they don't give a fuck about you, they don't give a fuck about you, buddy (French participant).

These quotes indicate both experiences with unresponsiveness and feelings of inferiority and of being marginalised as a group of youth at risk of being excluded by society. Some participants thus pointed to structural factors, including migration policies and eligibility criteria (which affect the accessibility and availability of social services for certain groups), an insufficient budget, and a lack of personnel and other important resources (e.g. space).

### Turning 18 – The transition from youth to adult

Another significant challenge that was indicated by young people across different countries was the sharp demarcation of 18 years of age as the stage of transition to adulthood, which is associated with a marked change in access to existing services and suddenly leaves young people to make this transition on their own (regarding, for example, medical issues, bailiffs, housing, and official documents). According to the Polish report, this was associated with experiencing a period of confusion, uncertainty, and loneliness, all while receiving signals that they now had to cope on their own.

...a neurologist, there in the neurological ward, ... he said, 'Well, now you're 18, you have to cope on your own' (Polish participant).

The effect of this problematic transition is also obvious in the above-mentioned quote from the Danish young man who had to move away from home. In Poland and Austria this transition was highlighted as significant to the young participants' experiences of responsiveness, as it was when they experienced changes in responsiveness that are linked to an institutional gap in transitional social services. In Poland the young people's statements showed a tension between treating them like children, which they understood as dismissing their needs and not taking their opinions seriously, and burdening them with responsibility for tasks for which they were not prepared. The following quote from an Austrian participant illustrates such an experience:

And back then, after I got out of [social service] when I was 18, I was in such a predicament that I was homeless for half a year because the youth welfare office said that they weren't responsible for me and the social services said, 'We aren't responsible for you, because you're in the evening school-leaving certificate programme and you're in your final high school year, but the evening school-leaving certificate programme is theoretically for working people, so you have to work 40 hours or at least be willing to work so that you can get social welfare.' ... I actually always call it a legal gap.

This is an issue that various organisations (e.g. the National Care Leaver Association in Austria) are trying to raise awareness about on the legal level. Indeed, this gap in social services demands attention – both legally and in practice across countries.

### Responsiveness and participation at the organisational and group levels

When informants were asked about their experiences of (not) being listened to and (not) having influence, they responded with both examples of *individual cases (micro)* and *organisational-institutional (meso)* examples. The former have been discussed above and focused on interactions with social service staff and instances of (not) being given a choice between individual support offers and activities. The meso-level examples focused on taking part in group activities, such as house meetings, and participation in community projects and activities (generally daily), as well as more formal participation as mediators and members of Children and Young People Boards (Portugal).

In most of the countries, some, though not all, of the young participants had experienced collective consultative spaces, such as group or 'house' meetings, where professionals and users met together to discuss issues, make suggestions, and draw attention to any problems. The young participants in residential social services also reported participation in various routines, such as cleaning, cooking, serving meals, and completing homework (Romania and Denmark).

Thus, there seemed to be a variety of activities in which the young service users were participating, including activities led by organisations that support youth in participation and voicing themselves and daily activities at local levels, such as at residential services and schools. The Romanian report notes that The Residential Centre for Young People at Risk has implemented a system to assess the satisfaction of its residents regarding the provided services. The residents are asked to complete a satisfaction questionnaire in writing, which includes questions about the services received, the interaction with specialists, and whether they would recommend the services at the centre to other young people at risk. The youth are given questionnaires to complete each month, in which they can make recommendations to staff and for activities. Examples of such recommended activities include trips, outdoor activities, and cooking. This kind of participation provides feedback to the social services at a very local level.

Reported participation in different types of group activities was quite diverse. In France participation did not appear to be a priority, at first glance, for some of the interviewees. As one young man explained, the centre where he had lived for a year or two had been a temporary solution, after which he had returned to live with a parent. From the outset, it had been clear to him that the social service was not a place where he would build his future, and hence, he had not felt particularly motivated to spend time and resources trying to change things. In contrast, eight interviewees in Austria provided information on their attendance at regular participatory meetings in the social service. Such meetings were held in three of the investigated social services: the rehabilitation centre for young people with mental health problems, a night shelter for young homeless people, and a service that takes over custody of youths and supplies them with individual apartments and social workers. The informants reported on three different types of meetings: a monthly or weekly house meeting with staff and service users in which important topics, problems, and wishes can be discussed; a monthly meeting between the service users where they can discuss proposals, conflicts, or complaints that are then forwarded to the personnel; and a weekly meeting between staff and service users where they reflect on the previous week and discuss important topics.

The house meetings were generally rather well received – by those participants who had participated – across countries (especially Denmark, Romania, and Austria). Respondents reported a strong perception of an open and relaxed atmosphere and a committed reaction to and implementation of the aspects and wishes that were discussed:

It's not like at school, where you have to sit and listen and then point things out. ... Instead, for example, I say something now, then he says something, then he says something, and everyone has their point, and you can ... it's actually very relaxed and comfortable. ... And if we have ideas the staff writes them down and tries to implement them. Maybe not at the moment, but as soon as they have the means and the necessary resources, it will be implemented (Austrian participant).

The topics at the house meetings were mostly related to travels and trips, daily or weekly routines (e.g. cooking and gardening), and household or interior decoration.

Some participants – also across countries but especially in Denmark and Poland – emphasised participation in group activities with peers, such as Narcotics Anonymous and social activities arranged for kids/young people with specific social problems. A couple of participants mentioned the positive effects of, when they were kids, having a mentor to support them and participate in activities with, and some of the residents noted their participation in online networks (e.g. Facebook groups with peers). The interviewees in Poland provided several examples of responsive peer support activities. One such example involved a meeting that was organised by a group from an orphanage to educate their peers about what it was like to grow up in that living situation:

We gathered as a group from this orphanage and decided that we would rent a room and use the allowance from the orphanage to rent a room. We rented it, and we were just like you are now, they listened to us, asked us questions, and we told them what it was like (Polish participant).

Both the peer support groups and the house meetings created a sense of community and the potential for group empowerment. The purpose of the house meetings was, among other goals, to ensure that everyday life ran smoothly and to make the house a nice place to stay. During the joint ownership, the young residents learned about responsibility and how to prepare for a life on their own, as touched upon by a Portuguese participant in the following quote:

The essential thing, I think, is to deconstruct the idea that young people have nothing to add or have nothing to offer. ... and the proof of that is what we're doing right now, which is ... we're being heard. Very interesting and different points were presented. Even we young people learn other things from other young people. If we can teach others something, why shouldn't we give other people ideas?

Thus, empowerment processes were taking place in the group activity. Here, empowerment can be understood as a multi-dimensional social process that helps people gain control over their own lives. It is a process that fosters power in people for use in their own lives, in their communities, and in their society by acting on issues they define as important. This situation facilitates the growth of horizontal empowerment processes that emphasise the development of powerful inward and downward networks between actors at the same level (e.g. between residents). Few of the participants seemed to focus on the macro level or vertical empowerment, which revolves around strengthening the voices of marginalised citizens upwards, towards the economic/political power centres at higher levels in society, by, for example, utilising advocacy organisations to strengthen youth policies (Bilfeldt, Jensen, and Andersen, 2014).

In Portugal some of the children's and young people's experiences of participation indicate provision of input at the macro level. There are, for example, references to participation in sessions with political representatives and decision-makers at specific events, namely at the local level (the mayor) and the national level (the president). At the local level (meeting with the mayor of the city), the interviewees felt that participation induced changes with relevant effects on the well-being of the community. At the national level (meeting the President of the Republic), it gave children and young people the feeling that the work they were doing at the community level or as board members had intrinsic value – their involvement and participation promoted a sense of empowerment. Although there are general difficulties for children and young people in participating (e.g. related to discrimination and social inequalities), they felt that everyone can participate if they commit to the process, whatever their social condition may be. One participant stated, *'My voice can reach further. I can actually show people my ideas'*.

### Recommendations for the future from young people who use social services

As a part of the individual and focus group interviews and of the future workshops, research participants were asked how social services can improve responsiveness. The following section presents suggestions to improve responsiveness in social services that work with youth at risk of social exclusion.

- Involvement of youth in decision-making
- More attention paid to the 'young' and what they want and need at that time of their life
- More transparency about decisions and what is written in the case record
- Shorter waiting time; waiting time worsens young people's situations and creates uncertainty
- More continuity in the casework, as changing case workers creates uncertainty – the relationship is important and must be rebuilt every time a shift occurs
- Accept the young people's limits concerning how quickly changes must be carried out (e.g. new residents or 'startups' in education); time to get their lives and mental health under control is a must
- More attention and coherent initiatives regarding the transition from youth to adult (the fact that someone is 18 years old does not necessarily mean that they can take care of themselves)
- More peer-to-peer support in social work – it is relatable and builds relationships

### Part 3. General findings of experiences of responsiveness

The following section is an outline of the different reports made for this work package, *Citizen experiences of taking part in co-creation processes*. It outlines the kinds of experiences citizens from the six countries and within the four different social services provided when asked how they experience and/or have experienced responsiveness within social services and what experiential knowledge of responsiveness they have regarding developing social services (see the research questions in Part One).

The findings and analyses presented as general findings are framed by an understanding of responsiveness on three levels: micro, meso, and macro. The analyses of the experiences were conducted on each of and across these three levels. This section concludes by identifying the drivers and barriers to citizen experiences of responsiveness.

Responsiveness can be experienced on multiple levels: the individual (micro) level, the group or community (meso) level, and the political or national (macro) level. This understanding of the three levels is mainly inspired by Bronfenbrenner and his ecological systems theory (1977). Bronfenbrenner employs five ecological systems in his theory: the microsystem, mesosystem, exosystem, macrosystem, and chronosystem. Although Bronfenbrenner approaches the systems from a psychological perspective, the understanding of connected systems is also helpful in a more sociological perspective, as the division of experiences and actions into different systems helps to highlight both barriers and drivers of responsive processes more clearly during analysis of the data. In this report we have taken the liberty of simplifying the number of systems into three (micro, meso, and macro). To more fully focus on how responsiveness is experienced and what kinds of drivers and barriers the analyses show, as well as to view these elements from the perspective of the citizens, we have also taken the liberty of using the notion of levels instead of systems. The *micro level* includes processes related to the actions of and collaboration between the citizen and a social worker or other persons representing social services. The *meso level* is characterised as the institutional, organisational, or community level where citizens participate in institutional meetings, are involved as members of boards or councils, or adopt an active role in initiatives in local communities. The *macro level* is characterised as the overall organisational and/or political level where citizens participate in national events and processes.

The following sections present the data and analyses. All sections deliver parts of the answer to the two overarching research questions: *how do citizens experience and/or have experienced responsiveness within social services? What experiential knowledge of responsiveness do citizens have regarding the development of social services?*

However, it would simplify the data and analyses too much to focus only on findings directly connected to the two research questions. Instead, data and analyses are presented in a form inspired by the coding processes in a grounded theory approach (Glaser and Strauss, 1967; Strauss

and Corbin, 1994), in which categories – in this report, sections – are allowed to emerge from the qualitative data to better understand and present research participants' experiences.

### 3.1 The experiences of responsiveness are diverse

The findings and analyses of the data show a huge diversity in experiences. Naturally, some are based on national contexts and the diversity among the chosen services, but the outcome is much more diverse than this: there are large differences within each of the countries and within each of the services. Furthermore, there are differences in time – if the experience is some years old or more recent. The diversity between being listened to and included and the opposite (that is, neither listened to nor included) is evident across all services and countries. The same citizen often meets different kinds of responsiveness or a lack of responsiveness from different social services at the same time. Hence, some citizens are dissatisfied with the collaboration with social services and experience little to no involvement or interest in their levels of understanding, life experiences, or suggestions. Other citizens – a smaller proportion – are satisfied with the support, involvement, and possibilities of being heard. There is no service or country with only positive or negative experiences. The findings are especially balanced in France, where approximately half of the informants are satisfied and the other half are dissatisfied, and in Portugal, where the majority is simultaneously satisfied with some community organisations and dissatisfied with other social services.

#### Specific focus on individual cases

A pivotal cross-country finding from the interviews with citizens is that research participants in general focused on their individual cases and challenges when talking about their experiences with responsiveness. Likewise, they noted when specific professionals included them and saw the person behind, for instance, their mental illness, highlighting the importance of working with professionals who care about them as people. A reasonable explanation for this focus is that the research participants value impact on their own lives. Several are facing severe challenges in life, often several challenges at the same time, and in families these challenges often affect more than one person.

The narratives presented in the research show that most informants have to focus on their own problems to meet their challenges and overcome their circumstances. As explained by some Danish families in the child protection sector, 'there is no energy left to take part in more general [meso or macro] activities' – if they do not focus on their own problems, the family will, according to the by family members, break down. Several research participants had never been invited to participate in boards or collective discussions about responsiveness, their own experiences of being involved, etc., and few social services are structured to include citizens on the meso and macro levels. Consequently, informants were often not accustomed to micro-level participation and responsiveness and were even less familiar with the meso and macro levels. This has made the micro level of responsiveness the most dominant in the findings, which has implications for

understanding democracy. Participation – as a central aspect of democratic processes – is not based in abstract concepts but in people’s own lives and well-being.

The following sections present data and analyses based on interviews, observations, and future workshops carried out in the six countries. The presentation is, as mentioned above, framed by the micro, meso, and macro approaches and divided into beneficial and adverse citizen experiences. The final part of the presentation is a collection of drivers and barriers to citizen experiences of responsiveness.

### 3.2. Responsiveness at the micro level

This section focuses on micro-level experiences – processes involved in the actions of and collaboration between the citizen and a social worker or other persons representing social services.

#### Beneficial experiences of responsiveness

The first part of this section discusses beneficial or more positive experiences, as seen from the perspective of the research participants.

#### *Truly heard and taken seriously*

Satisfactory support from social services is often directly connected to satisfactory responsiveness or being listened to. Support is valued when it is clear, conscious, and deliberate and has altered research participants’ lives positively (e.g. examples from France’s child protection sector). Research participants in Austria emphasised the beneficial consequences when:

- they have treatment options,
- they can make decisions in their own case (e.g. select personal assistants),
- they are believed and their symptoms are taken seriously,
- they are valued, and
- the professionals dialogue with them and adopt a holistic approach towards their problems.

Austrian research participants also emphasised trust, comfort, and closeness – *‘distance has no place in this job’*, as one of the Austrian citizens said. In Poland positive experiences are in many cases connected with closer relations with the service providers and if there is enough time to listen to the citizens.



### *Receiving support based on citizens' needs*

A positive experience of responsiveness is in general combined closely with receiving the correct support. The findings show that receiving meaningful support based on personal needs was stressed more than involvement in the process. This does not mean that people using social services do not care about being involved at the meso level. The potential to receive meaningful support is based on citizens being able to describe their situation and needs the way they experience them. Based on the interviews it seems that 'being listened to' is ranked higher than 'involvement' by the research participants. Seen from the perspective of levels, micro-level responsiveness, for a large number of research participants, is as a rule more important than macro-level responsiveness. Or to put it differently: responsiveness for citizens challenged by several different social problems is responsiveness on the micro level; similar to the pyramid of needs, it is the basis for responsiveness on the meso and macro levels. However, it is important to stress that most of the research participants have never experienced 'involvement' on meso or macro levels. The data below show that citizens involved at the meso and macro levels are pleased to be involved and active within institutional settings and local/national organisations.

Therefore, not being involved on meso and macro levels is generally indicative of not being invited to participate on those levels, not of a lack of interest or, as seen in Polish data, a perception that involvement, especially at the macro level, does not make sense. This may be due to a lack of confidence in the system as such. Danish parents within child protection generally felt that they were being listened to by family case workers, that their suggestions and comments were considered, and that they could say no to offerings from the social service – all elements that they considered highly satisfying. Their experiences were, however, closely connected to the time when the department started using the relational welfare approach – the point of departure is how citizens name and understand their own problems and how to eventually act towards them – an approach that is very closely connected to what is also understood as empowerment (see below). Thus, inviting citizens to meso or macro levels of responsiveness demands the implementation of both new structures and/or models and a new culture that considers citizen voices and participation critical to solving individual problems and implementing more democratic procedures. This was even more apparent when the same families at the same time had the experience of not being listened to or involved in other departments (Danish municipality departments that did not use the relational welfare approach).

### *Responsiveness is supporting empowerment processes*

When focusing on responsiveness towards people who use social services, it seems that democratic perspectives are connected closely to empowerment processes. Involvement and participation do not 'only' support involvement and participation in themselves. They also support empowerment processes – which can be understood as multi-dimensional social processes that help people gain control over their own lives (Bilfeldt, Jensen, and Andersen, 2014). Several citizens expressed that being respected, being involved in their own case, participating in group

activities, and being involved in political actions is empowering for their self-esteem and for solving their individual issues; therefore, empowerment processes can also be considered small steps towards gaining more control in one's life. The analyses thus suggest that micro-level responsiveness with a specific focus on individual challenges and needs can serve as a foundation for expanding responsiveness to meso and macro levels, as well as a facilitator of empowerment processes.

#### *Adverse experiences of limited responsiveness*

The second part of this section focuses on adverse or more negative micro-level experiences.

#### *Misguidance, lack of transparency, frequent changes, and frustration*

Although several research participants have positive experiences of responsiveness, the major experience by citizens is that they seldom experience being listened to and that the support given by social services – as described by French parents – is often intrusive, inappropriate, and misguided. Likewise, research participants within the disability and mental health sectors experience a lack of information and transparency regarding their rights. This is exemplified by the experiences of the citizens from Austria, where some informants expressed that social services do not reflect citizen rights but emphasise the rules that citizens must follow. The lack of openness and an explanation of rights seem to become a barrier to establishing a close relationship and, through this, also a barrier to responsiveness and exercising rights. Informants expressed that they often miss information about decisions made by social services and the process of their case. This is described as highly emotional and frustrating by Austrian citizens. Misinformation, frustrations, emotional challenges, and inappropriate support make it difficult to summon the spirit or energy to use their voices or participate in the handling of their cases – or even to believe in participation. Furthermore, citizens within the disability sector in Poland, Austria, and Portugal often feel discriminated against and infantilised by paternalistic attitudes and practices and, hence, a dis-responsive culture. In general, the research participants' experiences indicate a lack of or low level of responsiveness from the social services towards the citizens they collaborate with. Disabled citizens in Denmark generally do not feel listened to or responded to by social services in the municipalities. They are experiencing being given one or two offers of service(s) that most often do not meet their needs, including potential mental health issues. None of the disabled citizens involved in the Danish municipality job clarification programme experienced readiness on the part of services to comply with their stated wishes. In Austria research participants underlined the experience of being 'reduced' to the role of service users.

In general, citizens experience a lack of suitable information (especially in Portugal, Poland, and France, particularly regarding information about rights). Likewise, there are frequent changes of staff and little stability within services, which makes it difficult to establish a responsive relationship. Such a relationship is based on knowledge about each other and accumulated trust and confidence, which takes time to build up. However, disengaged staff with few competencies in responsiveness and wrong or no suitable support also influence the experience of responsiveness

and the relationship (Poland). Likewise, the children in Romania and Austria often experience rules as rigid and non-negotiable; they also experience a lack of flexibility and openness to their suggestions. The children and young people interviewed in Romania expressed that their opinions have not always been taken into account. They have observed providers expressing intentions to follow up on the feedback without any concrete or visible actions or changes. In general, the children and young people in Romania do not feel that they have had any influence on their relationships with adults in social services. A main topic in the Romanian interviews was participation in and the outcome of the Children's Council – an activity that could be regarded as a group or meso initiative. On one hand, membership seems to have supported their self-confidence – a feeling that they have a special responsibility – and the assumption of a mentor-like role. On the other hand, the children were not prepared for the role in any way, and based on research participants' experiences, it seems like the Council has become a formality rather than a responsive supporting action.

### *Transition*

The data show that there is a general need for responsiveness, especially being listened to, when citizens are in transition (e.g. from not having support to applying for it, from being a child to becoming an adult, or from one supportive activity to another). For example, some of the Portuguese children and young people who participated in this study were in the transition from being in residential care to being on their own. Often citizens are enmeshed in a confusing and 'breaking up' period of life when they are in transition – and sometimes they do not even know why they are in transition. In these situations, research participants express that they more than ever need explanations, understanding, and involvement. If they are not heard and understood, if social services do not respond to their frustrations and despair, it is easy to lose confidence in the social services and the possibility of having a say.

### *Challenges in collaboration with different services*

An ongoing issue mentioned by some of the research participants is the challenging collaboration with schools. It is difficult to make schools understand the extent of the challenges they are facing and the consequences of the challenges for the families or to make them act upon the problems (Denmark and Portugal). Although school is often where problems are discovered and where children and young people spend much of their childhood and adolescence, neither children/young people nor parents feel that schools have the requisite skills to understand and assist with the issues in their lives. Schools are, however, dealing with problems that go far beyond their main task of teaching and hence need skills and support to be able to support families. According to Danish citizens, schools do not have the skills necessary to communicate with and support children and their parents in solving problems. This lack of knowledge in the school system is underlined by one of the Danish mothers claiming that the 'odd' kids are too challenging for the school and that they would rather get rid of those children than attempt to understand and support them. The 'school example' emphasises that responsiveness demands services and actors

within those services who are skilled in communication and involving citizens, and that responsiveness in traditional social services also includes other supporting systems.

### 3.3 Responsiveness on meso and macro levels

This section focuses on meso- and macro-level experiences expressed by the research participants.

#### *Few invitations to participate on the meso level*

When it comes to the meso and macro levels, the estimation of responsiveness is more general than it is in individual cases and problems. While responsiveness on the micro level is often connected to critical issues that individuals are dealing with in their everyday lives – the foundation of the pyramid mentioned earlier – meso and macro responsiveness often deal with issues that are levels higher in the pyramid and hence a little more abstract. The reflections about responsiveness on these two levels are closely connected to participation in, for example, local or national actions, service user organisations, and community-based NGOs. Several citizens within child protection and in some countries also youth at risk had never been invited to participate in any social services participatory processes beyond collaboration with the social/case workers. In Poland none of the informants had been asked or invited to take part in any consultations, evaluations, or other meso-level activities related to social services; this also applies to the parents in child protection in Denmark, despite the relational welfare approach (please see page 68). In France some informants described social services avoiding bringing service users together in collective spaces, sometimes even explicitly refusing a request to do so from youth participants. At the same time, more than half of the research participants in France had experienced macro participation or advocacy (i.e. contributing to a group, forum, or discussion aiming to improve child protection above the service level). These experiences, which included partaking in research projects and representing youth in political fora, were generally perceived as positive.

The majority of the research participants had very little or no experience with responsiveness on the meso level. Citizens in Romania had little or no experience in organised participation. Within mental health and disability, none of the Romanian participants could mention any form of organised participation to provide feedback, beyond group discussions and decisions about practical activities. Youth at risk spoke about participating in decisions about activities, but primarily on an individual micro level. In child protection, citizens reflected on experiences related to being members of the Children's Council (in Romania), which can be categorised as a meso-level activity, but their experiences of participating in the Council were closely connected to their experiences of being listened to and involved in their own cases. This underlines the connection between the different levels and that the micro level must be part of any consideration of meso- and macro-based initiatives. Danish citizens' experiences with meso- and macro-level participatory initiatives are very mixed. Some citizens have been involved in 'house meetings' and the like in institutional settings (within the disability and youth at risk sectors), some have voiced their challenges themselves (within the mental health sector), and some (within child protection) had

never been invited to or participated in joint meetings, boards, or similar. Citizens in various institutional settings in multiple countries had often automatically participated in ‘house meetings’, ‘planning meetings’, or ‘resident meetings’ – these everyday activities tend to connect to meso-level participation. The development from the micro to the meso level becomes even stronger if house meetings or other kinds of incorporated participatory activities are supplemented with supportive approaches that help young people learn democratic competencies related to speaking, debating, and arguing in public spheres, as noticed by the Austrian and Portuguese teams.

#### *Little and frustrating experience in macro-level participation*

Few of the involved citizens had experienced responsiveness on the macro level. As mentioned above more than half of the citizens in France had experienced macro participation or advocacy elements via contributing to a group, forum, or discussion that sought to improve, for example, child protection above the service level. Few of the informants within the disability and mental health sectors had experienced delegation of power, participation in decision-making, or formal spaces for voicing their views, either on the micro or on the meso and macro levels. Some research participants within the disability sector in Austria had experienced participation at the policy level, but the outcome was described as frustrating and disappointing. The reason for the frustration and disappointment was identified as failure to adopt the results of participatory consultations or incorporate critical feedback from users into the final versions of policy documents – an experience of pseudo-participation.

#### *The meso level contains several layers*

Meso-level experiences are different in different social services and when facing different social challenges, as described by the Austrian team. Meso-level experiences can include taking part in house meetings and institutional-based citizen boards as well as writing inquiries and complaints. There is, of course, a big difference between house meetings, incorporated as a part of everyday life in an institutional setting, that focus on practical issues and writing inquiries or complaints, which are outside of daily activities and much more confronting than house meetings. Likewise, the meso-level activities on the organisational level, through which young people are trained to voice themselves and to participate in local – and sometimes national – discussions (Portugal) or within which citizens act as members of organisations and/or representatives on boards (France and Austria), are very different from writing inquiries and complaints. One could say that the meso level contains several layers, including one that is similar to the ‘individual-like level’ (house meetings and inquiries/complaints) and another that correspond more closely to the group level (organisational training).

### 3.4 Drivers and barriers to responsiveness

This section presents a number of drivers – to support and develop responsiveness – and barriers – obstacles to establishing responsiveness – that are based on citizens’ experiences of

responsiveness, as well as further analyses. The drivers and barriers are not connected specifically to the micro, meso, or macro levels. Rather, they appear to be cross-cutting or basic at all three levels. Although drivers are placed at the beginning of the section and barriers at the end, they are mixed in the subsections. A driver can be based on positive examples experienced by research participants, or it can represent issues and elements they wish were present. Likewise, elements described as barriers can also be viewed as reminders of what could be done differently.

## Barriers

### *From luck of the draw to well-functioning organisations and skilled professionals*

Although they shared experiences of being listened to, some of the research participants found that participatory processes are a matter of chance rather than a commonly encountered experience. French citizens within the disability and mental health sectors expressed that the possibility of social workers being responsive and involved is often the ‘luck of the draw’. The following compilation based on the experiences of Portuguese citizens primarily covers two areas that were emphasised by several interviewees in different countries, professional competencies/skills and poorly functioning services/organisations.

Concerning professionals, a lack of responsiveness is often connected to being poorly prepared, possessing a lack of care, attention, and sensitivity, stigmatising people, and treating users unequally based on prejudices. On the other hand, professionals often appear overloaded, time-constrained, and stressed. The informants also characterised poorly functioning services as those with laborious bureaucratic processes, strict rules for scheduling and attendance, and a lack of resources/time. A change in ‘mindsets’ and ‘attitudes’ among professionals and organisations towards people in vulnerable positions is needed, as emphasised by citizens from the disability sector in Portugal. When observed in different services, among different professionals, and in different countries, it is presumed that the reason could be defined as a missing responsive culture, as mentioned above. A missing or opaque structure for participation and responsiveness (for both citizens and professionals) and a non-existent culture for responsiveness to citizen voices make it difficult to understand responsiveness and even more difficult for professionals to implement it. The consequences could easily be coincidental practices and involvement procedures based on a single professional – and professionals who are, as described above, overloaded, poorly prepared, and scarcely trained to be responsive.

## Fear

Fear stands out as a major barrier to responsiveness. Some citizens expressed fear of potential negative consequences from social services if they voice dissatisfaction or try to interfere in the work of their case. Fear was mentioned by citizens in France, Poland, Romania, and Portugal when considering whether to act or how to act to avoid negative consequences or even sanctions from social workers. In France this took the form of a fear of speaking and being seen as a ‘bad kid’; in

Poland a reluctance to make complaints, a fear of being accused of being overdemanding, a fear of making social workers uncomfortable, and a fear of losing a nice social worker; in Romania a fear of sharing their opinion; and in Portugal a fear of retaliation. Fear of losing support and a dependency on social services was perceived by some informants as hindering their freedom of expression and their full involvement in formal and informal spaces of participation. Therefore, fear (and dependency) influence responsiveness on micro, meso, and macro levels.

Another side of the same phenomenon is the feeling of having to please the social worker – remembering to write ‘thank you for a good meeting’ or ‘yes, it was nice that you listened’. Similarly, respondents noted wanting to avoid appearing to be a grumbler, to behave properly, to act co-operatively, and to highlight their good qualities (Denmark). The data collected in Poland suggest that, in general, foster care leavers and biological parents were reluctant to make complaints, even when they felt their rights were being violated. Other citizens mentioned that they did not want to voice their opinions, as they were afraid of being seen as troublemakers. On top of the stigmatisation of citizens as service users, the fear of annoying or disturbing the professionals and the services seems to entail forms of self-stigmatisation, as explained by Polish research participants.

## Drivers

### *The importance of relationships*

The individual relationship between professionals and citizens appears to be a crucial channel for participation and for being listened to because the professionals are the main contact persons within the services. For many of the participants, a close, warm, and enduring relationship was regarded as decisive for improving their situation and encouraging them to take part not only in the collaboration with social services but also in social life in general. The relationship between the citizen and the professional is, hence, a key phenomenon when developing and processing responsiveness. According to the findings, it seems that there can be no responsiveness without a strong and respectful relationship between citizens and social workers (or other people within social services). Research participants primarily associate (good experiences of) responsiveness with the quality of the relationship between the citizen/service user and the professional(s). Responsiveness should be, according to the research participants, dialogical, trustful, and cooperative, and social workers should meet users’ individual needs. The positive experiences of responsiveness were often connected to institutional settings and, for example, involvement in decisions concerning cooking, cleaning, budget planning, and selecting activities – elements that could also be related to some of the meso-level activities.

Positive experiences of being listened to and involved were, however, mostly connected to current circumstances. Individuals with a history of institutionalisation in ‘old-type residential centres’ in, for example, Romania have experienced dehumanisation and emphasise the distinctions between the past and the present. In Portugal children and young people recounted being listened to,



respected, valued, ‘truly heard’, and involved in activities, projects, and decisions within the social services they have been connected to. Nevertheless, they identified quite different adverse experiences outside the relationship with these specific community-based social services (in the context of family, employment, or other social services). The experiences in Portugal were closely connected to a more structured approach to participation and supporting children and young people to voice themselves, ‘leaning’ towards a meso or even macro level. It is, however, important to remember that the relationship between the citizen/service user and the professional(s) is crucial, whether activities take place on the micro, meso, or macro level.

According to the French analyses, especially the experiences contributed by young participants, a close relationship can also be seen as a professional ability to act horizontally (instead of acting vertically – a top-down collaboration between professionals and service users). The horizontal relationship is described by young research participants in France as a collaboration where they meet engaged and friendly professionals who provide consistent and solid support; no fear should be included in the collaboration. Although a friendly relationship with, for example, one’s social worker was seen as crucial, it was also apparent that staff had to be professional and experienced – meaning that the horizontal relationship still included different roles. The horizontal relationship connects the focus on a more equal relationship with the (friendly) professional role described in the next section.

#### *Being listened to and understood from the start*

Several parents in child protection, young people in youth at risk services, and citizens within the disability sector emphasised that it is difficult to make services listen to and understand their challenges at the beginning of the collaboration. This experience of not being listened to and not being understood is a major barrier to the experience of responsiveness and has an impact on citizens for a long time – even after their problems were ‘accepted’ by social services. It is said that the gate-keepers citizens meet in the social services are keeping the doors closed rather than helping citizens to open them. Instead of gatekeepers, participants asked for ‘gate-openers’, especially when citizens are new to the social services or have less life experience.

#### *Availability, attentiveness, adaptability, and accompany*

Based on the data and cross-analyses of the experiences of (or a lack of) responsiveness, four points of attention and, accordingly, social service/social worker reaction/interaction suggestions can be provided:

- *availability or accessibility of social services* – acknowledging receipt of messages and responding to them
- *attentiveness of social services* – the ability and willingness of social services to pay attention to and respond to calls for help
- *adaptability* – the capacity of a social service to modify its support of the service user to take into account the person’s evolving situation and sensitivity



- *accompany* – the capacity of social service staff to ‘walk with’ users towards autonomy and ensure continuity, avoiding abrupt ruptures and a loss of support

Although these four reactions or interactions, at first sight, might look like ‘tools’ to establish the relationship, mainly on the micro and very individual level, it is recommended that services be aware of these on all three levels. Some of the research participants will probably need support for many years – maybe for the rest of their lives. Responsiveness will not suddenly change their disability, mental illness, risk group position, or challenges during childhood – although responsiveness will presumably support empowerment processes and improve life conditions (as described by informants participating in meso- and macro-level activities). Therefore, these interactions are needed as ongoing focus points or checkpoints at all levels – professionals must be competent in all four. Seen from this perspective these elements can generally be considered central to qualifying professional actions in responsive processes.

#### *The organisational structure and professional culture are important*

The asymmetric collaboration between vulnerable citizens and powerful organisations, according to French informants, triggers a feeling of ‘we need them [social services], but they don’t need us [citizens]’, emphasising that social services do not have a responsive culture in which citizen knowledge is seen as critical to the outcome and quality of social support. On the micro level, the culture in the organisation – including knowledge about involvement, communication, and responsiveness processes among professionals, the way the collaboration is organised, and the relationships between professionals and citizens – seems to be important for establishing, expanding, and maintaining responsiveness. Having a structure to support responsiveness processes is crucial (see Work Package 1). A responsive culture within the organisation and among the professionals is foundational for both basic micro-level co-creation that focuses on the single citizen and their challenges and meso- or macro-level institutional, community, and/or national activities. A culture that prioritises citizen input, knowledge, and advice is the only appropriate way to solve challenging issues in citizens’ lives and involve citizens in the development of local communities and national policies.

#### *Distinct democratic aims*

The experience of responsiveness is much clearer if the institutional setting is aimed specifically at democratic processes. The participants from Portugal were especially satisfied with the way they are listened to and supported in voicing themselves and overcoming the challenges they are facing. This is likely because they are involved in community-based organisations with clear democratic aims of having boards and making it possible for young people to participate in sessions with political representatives and decision-makers on both local and national levels. This outcome of responsiveness is also seen in the disability and youth at risk sectors, especially in Danish and Austrian institutions where research participants automatically become members of boards, have house meetings, and experience open door access to the management.

### *Being trained in actions and voicing one's own situation*

The findings from Portugal and Austria are different from those of other countries, as a majority of the research participants talked primarily about responsiveness on the meso level and secondarily about responsiveness on the macro level. Children and young people in Portugal have experienced being listened to and being involved in activities and decision-making. They felt 'truly heard' – they were valued and respected, their ideas were taken into consideration, and the professionals were not only pretending to hear them. Their ideas and opinions were taken into consideration and put into practice when possible. Besides being truly heard and involved, the young people are trained to voice their own situation and discuss it with local and even national politicians; hence, they recounted experiences of participating in general and public discussions and dialogues. Their positive experiences and training are closely connected to their present involvement in local organisations. In other social services, however, the young people in Portugal felt that their participation is little valued. Likewise, several research participants in Austria had significant experience taking part in policy-level participatory processes at the regional or national level, although they had also experienced disappointments and frustrations when suggestions and responses were not adopted by services/politicians.

### *Supporting persons is important*

A way to support activities on both the micro and meso levels, besides the above-mentioned options, is by involving family members, friends, or lay representatives from organisations, who can help give citizens a voice. Citizens' personal crises or physical or mental issues can make it difficult for them to know and understand the rules and regulations and to remember what has been said; they often need support to be able to participate. A very specific and perhaps exemplary option, self-advocates, was mentioned by the participants in Poland. Self-advocates are people with intellectual disabilities who advocate for other people with intellectual disabilities. These supporting groups of people are both helping citizens to fulfil their rights on the micro level and supporting them in voicing themselves on a meso level. As stated by citizens in the Polish mental health sector, you need to have family and friends in order to effectively undergo treatment.

### *The development and maintenance of responsiveness must include citizens*

The data make clear that participation is challenging. As emphasised in the analyses of citizen experiences within the Portuguese disability sector, the data provide evidence for three different challenges that may hinder participation at the meso and macro levels:

- *participation fatigue* – it is difficult to find the time needed to participate on meso and macro levels – especially if participants do not feel that their suggestions are included in, for example, policy papers

- *discredited participation* – when participation is not credited by other participants, either during the process or when final decisions are made
- *fragmented/divisive participation* – when the participation process is not coherent, when the results are controversial, or if the process divides the opinions of the participants

This underlines that the development of more responsive social services that consistently listen to and involve citizens must include citizens in the development and planning processes. Responsive and participatory structures and processes should not be planned and implemented without involving citizen representatives. The development and implementation of participatory and responsive processes must also include ongoing evaluation of and reflection on those processes – not just by the services alone but in close collaboration with the participating citizens. Their knowledge and experiences are necessary to build citizen-friendly responsiveness and identify drivers and barriers in the processes, which will strengthen responsiveness, assist with the creation of a new participatory culture, and help to alleviate the participatory fatigue that leads citizens to withdraw from meso and macro processes.

## Part 4 Conclusion and recommendations

### 4.1 Conclusion

The data and analyses emphasize that responsiveness seen from the perspective of users from the four services is far from being practiced in social services. There are elements of responsiveness in individual practice of social services staff and in some institutional settings and community-based organizations, but it is very random and seldom built on strong cultures and structures.

Citizens' experiences of responsiveness in social services show that they are focused on:

- their individual challenges and cases – making their situation central in their understanding of responsiveness
- the relationship between themselves and the social service professionals – being seen, listened to, being acknowledged as a whole person, being truly heard and taken seriously – is the basis for having and giving a voice, being listened to and being supported.

When expressing their experiences of responsiveness, the majority of citizens in this research talked about experiences connected to their own cases and the collaboration with social workers or other authorities. Likewise, the impact on social services was considered in relation to their own challenges and required support rather than the general operations of social services.

For the majority of the citizens giving voices to experiences of responsiveness, the focus is to receive as high-quality and relevant support as possible. Not that a possible impact on the development of social services is not interesting for citizens, but data underlines that citizens in need of support 'have to' focus on their own lives and that they are not in a position to influence or support to voice their suggestions in social services. Based on the experiences and voices of citizens, it is possible to propose the following definition of responsiveness:

<b>Responsiveness in social services is the process of learning from and reacting to the voices and actions of citizens facing diverse social challenges. It aims for citizens' voices and lived realities to have an impact on their individual situations and influence on social services.</b>
---

The impact on social services and ways of suggesting developments of responsiveness within social services are particularly visible when citizens are in institutional settings and/or working with organizations that have a clear participatory approach. Citizens' experiences and suggestions for organizational changes on group and more general levels are hence connected to the case-based individual level. A pivotal and important starting point for responsiveness and participation is, according to the findings of this work package, citizens' individual challenges and aims, which constitute a basis for democratic governance processes.

## 4.2 Recommendations

This section presents recommendations either directly suggested by research participants or coming out of the analyses of the data. The recommendations are pointing at social services, but categorized in the policy, the managerial/organizational and the professional levels. A 'keep in mind' category has also been made covering all three levels.

### Policy level

- Set specific democratic aims for citizen involvement in social services through legislation and policy reforms on national, regional and municipality levels
- Involve citizens in the development of national policies both concerning development within the four sectors and beyond and the development of responsiveness
- Initiate anti-stigma campaigns to reduce stigma and labelling around use of services
- Provide information about rights to support

### Managerial/organizational level

- A democratic mindset and values in organizational policy
- An organizational and professional culture prioritizing citizen participation, knowledge, advice, descriptions and co-creation
- An organizational and professional structure facilitating participation and co-creation processes with clear democratic aims including establishing spaces for participation and the development of methods and approaches to facilitate democratic processes (boards, house meetings, suggesting boxes, 'open door' access to the management etc.)
- Ongoing training of professionals' competences and skills in dialogical participation and in democratic and co-creative processes
- Training professionals in being attentive, available, adaptable and accompanying towards citizens
- Training citizens to act in participation and in voicing their needs, ideas and suggestions
- Greater transparency about rights, decisions and processes
- Open discussions including debate with and giving feedback to citizens – because openness makes citizens less alert and reduces the fear experienced by several citizens
- Include citizens as peer-workers
- Avoid responsiveness and participation to be a luck of the draw and coincidental
- Include citizens when developing, planning and evaluating responsiveness and participation
- Support empowerment processes as a part of responsive and co-creative processes
- Back citizens to bring families, friends or lay representatives to support and give voice
- Establish feedback and responding processes
- Including citizens in key-decision making meetings

- Strengthen participatory processes and integrated collaboration between different services and sectors working with citizens (social, health, education) and between public and non-governmental sectors

#### Professional level

- Establish a close, trustful, and respectful relationship between themselves and citizen
- Include citizens own views, needs and suggestions before, during and after decisions making
- Work creatively, dialogically and inclusively
- Act as gate-openers instead of gatekeepers, working together with and not against citizens
- Work with holistic approaches towards citizens and their problems
- Be transparent about problems, analyses and decisions

#### Keep in mind

- That there will be no possibility of responsiveness without a dialogical, trustful and respectful relationship and without meeting citizens' personal needs
- Lack of information about rights is a barrier to establishing a close relationship
- Participation in own case is a basis for participation in boards, voicing oneself etc.
- People in vulnerable situations have a legitimate voice
- To be welcoming, listening and sensitive to citizens problems from the very start
- To respond and communicate quickly
- Responsiveness will support empowerment and improve life conditions
- Citizens often fear to make suggestions, speak out and to be regarded as annoying, demanding and disturbing.
- Participation and responsiveness although requested is also challenging for citizens.

## References

- Andersen, M. L. et al. (2020). Engaging service users in practice research. In L. Joubert & M. Webber (Eds.), *Routledge Handbook on Practice Research*. Routledge.
- Beresford, P., & Croft, S. (2001). Service users' knowledges and the social construction of social work. *Journal of Social Work*, Volume 1, Issue 3 (pp. 295–316).
- Bilfeldt, A., Jensen, I., & Andersen, J. (eds.) (2014). *Rettigheder, empowerment og læring* [Rights, empowerment and learning]. Aalborg Universitetsforlag.
- Brinkmann, S., & Kvale, S. (2018). *Doing interviews*. SAGE Publications Ltd.
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513.
- Brzozowska, M. (2017). Ryba, która ma głos. Prawo dziecka do partycypacji. Dziecko krzywdzone. Teoria, badania, praktyka, 16(2), 45-64.
- Farr, M. (2013). Citizens and the co-creation of public service innovations. In S. P. Osborne & L. Brown (Eds.), *Handbook of innovation in public services* (pp. 445–458). Edward Elgar.
- Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative research*. Mill Valley, CA: Sociology Press.
- Hammersley, M., & Atkinson, P. (2007). *Ethnography – Principles in practice* (1st ed.). Taylor and Francis.
- Jæger, B. (2013). User involvement in public services innovation. In S. P. Osborne & L. Brown (Eds.), *Handbook of innovation in public services* (pp. 432–444). Edward Elgar.
- Jungk, R., & Müllert, N. R. (1987). *Future workshops. How to create desirable futures*. Institute for Social Inventions.
- Kettunen, P. & Petersen, K. (2011). *Beyond welfare states models: Transnational perspectives in social policy, Globalization and Welfare*. Edward Elgar Publishing Limited.
- Ostrom, E. (1996). Crossing the great divide: Co-production, synergy, and development. *World Development*, 24(6), 1073–1087.
- Parker, C., Scott, S., & Geddes, A., (2019). Snowball sampling. In P. Atkinson, S. Delamont, A.

Cernat, J. W. Sakshaug, & R. A. Williams (Eds.), *SAGE research methods foundations*.

Pestoff, V. (2012). Co-production and third sector social services in Europe: Some concepts and evidence. *Voluntas: International Journal of Voluntary & Nonprofit Organizations*, 23(4), 1102–1118.

Rasell. M., Furtschegger, D., Ohnmacht, F. et al. (2023) *Normative, policy, legal and organisational contexts shaping the responsiveness of social services to citizen participation*. Research Report 1, Horizon Europe project 'Increasing responsiveness to citizen voice in social services across Europe' (RESPONSIVE). Available at: <http://www.responsive-europe.eu/>

Strauss, A., & Corbin, J. (1994). *Grounded Theory Methodology: An Overview*. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (Chapter 17, pp. 273-285). Thousand Oaks, CA: SAGE

Uggerhøj, L. (2011). What is practice research in social work – Definitions, barriers and possibilities. *Social Work & Society*, 9, 45–59.

United Nations Convention on the Rights of Persons with Disabilities. (2006). <https://www.ohchr.org/en/hrbodies/crpd/pages/conventionrightspersonswithdisabilities.aspx>

Voorberg, W. H., Bekkers, V. J. J. M., & Tummers, L. G. (2014). A systematic review of co-creation and co-production: Embarking on the social innovation journey. *Public Management Review*, 17(9), 1333–1357.



## APPENDIX: Country tables showing the numbers of citizen boards and research activities

### Austria

**Table 1: Citizen boards and research activities – Austria**

	Citizen boards	Interviews	Focus group interviews	Observations	Future workshops
Disability	1	11	0	0	1
Mental health	1	12	0	0	2
Child protection	1	12	0	0	1
Youth at risk					
<b>Total</b>	3	35	0	0	4

### Denmark

**Table 2: Citizen boards and research activities – Denmark**

	Citizen boards	Interviews	Focus group interviews	Observations	Future workshops
Disability	0	7	0	1	1
Mental health	0	5	0	0	0
Child protection	0	10	0	0	0
Youth at risk	1	6	1	1	1
<b>Total</b>	1	28	1	2	2

### France

**Table 3: Citizen boards and research activities – France**

	Citizen boards	Interviews	Focus group Interviews	Observations	Future workshops
Disability	1	6	2	0	0
Mental health				0	0
Child protection	1	10	0	0	0
Youth at risk		9	2	0	0
<b>Total</b>	2	25	4	0	0

## Poland

**Table 4: Citizen boards and research activities – Poland**

	Citizen boards	Interviews	Focus group Interviews	Observations	Future workshops
Disability	1	10	1	0	0
Mental health	0	10	1	0	1
Child protection	1	10	1	1	0
Youth at risk	1	8	1	0	1
<b>Total</b>	<b>3</b>	<b>38</b>	<b>4</b>	<b>0</b>	<b>2</b>

## Portugal

**Table 5: Citizen boards and research activities – Portugal**

	Citizen boards	Interviews	Focus group Interviews	Observations	Future workshops
Disability	1	4	1	1	0
Mental health	1	4	1	2	2
Child protection	1	13	2	1	0
Youth at risk					
<b>Total</b>	<b>3</b>	<b>21</b>	<b>4</b>	<b>4</b>	<b>2</b>

## Romania

**Table 6: Citizen boards and research activities – Romania**

	Citizen boards	Interviews	Focus group Interviews	Observations	Future workshops
Disability	1	2	2	0	0
Mental health	0	7	1	0	0
Child protection	0	2	1	0	1
Youth at risk	0	6	2	0	0
<b>Total</b>	<b>1</b>	<b>17</b>	<b>6</b>	<b>0</b>	<b>1</b>