INCLUDE

Inclusive Leadership and Democratic Engagement for Persons with Disabilities

REPORT ON FOCUS GROUPS

Focus groups with people with disabilities: First-hand insights on experiences, challenges and ideas for promotion leadership and representation

Work Package 2 · Task T2.2 · Focus Groups with Persons with Disabilities

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Report on Focus Groups with Persons with Disabilities

From Participation to Influence: The Voice of Persons with Disabilities in Public and Political Life

Date held	**26 October 2026 (in-person)** **27 October 2026 (online)**
Participants	9 persons: 5 women and 4 men
Age	18–37 years
Scope	Experiences, barriers, representation, leadership and recommendations for inclusive participation

Purpose and Approach

As part of the INCLUDE – Inclusive Leadership and Democratic Engagement for Persons with Disabilities project, in-person and online focus groups were held with persons with disabilities to explore their personal experiences of civic and political participation, barriers to assuming leadership roles, and opportunities to improve institutional practices. The discussions also aimed to jointly identify content for the Inclusive Representation Handbook.

This report presents an integrated thematic synthesis of the views and experiences shared. Individual opinions are presented anonymously, without distinguishing between modes of participation. The examples cited reflect participants' experiences and assessments, rather than independently verified institutional facts.

Brief Summary of Key Findings

Participants associate meaningful participation with being able to express their needs independently, propose solutions, and influence final decisions. Attendance at an event, formal consultation, or representation through others is not considered sufficient without a tangible outcome. While individual positive experiences were identified, participants also highlighted inaccessible infrastructure, inadequate communication, prejudice, inconsistent institutional responses, and unequal opportunities across different settings and groups.

1. Thematic Findings

1.1. The Meaning of Participation and the Right to Speak for Oneself

For participants, participation means being present in public and cultural life, engaging in youth councils, public discussions and civic initiatives, and, where possible, making decisions directly. Particular emphasis was placed on the principle "Nothing About Us Without Us": persons with disabilities should express their own experiences, and where representation is indirect, the representative should have a sound understanding of the community's needs.

Participants called for involvement throughout the entire process, from planning and consultation to monitoring the implementation of solutions.

1.2. Experiences of Being Heard or Overlooked

One specific positive example concerned the acceptance of an accessibility proposal during the construction of a new municipal building. An experience was also shared of university lecturers providing accessible electronic materials to a student with a visual impairment. Some participants recognised a willingness among local government representatives to listen to and address certain needs.

By contrast, participants described institutional meetings where officials addressed an accompanying person rather than the person with a disability directly. They also mentioned poorly publicised public hearings, a lack of inspection of completed accessibility measures, and experiences of empty promises or proposals not being taken seriously enough. Such experiences undermine trust and willingness to participate in the future.

1.3. Leadership Aspirations, Activism and Trust

There is interest in rights advocacy and taking a more active role, but not always trust in political or organisational mechanisms. Some participants believe their efforts do not lead to change, that decisions lack transparency, or that activists remain mere attendees without genuine opportunities to exert influence. Others would become more actively involved if they could see concrete results and if citizens not directly affected by disability also offered support.

Internal relationships within some organisations were also identified as a challenge: favouritism towards certain members, unequal access to information and opportunities, and insufficient support for new initiatives. At the same time, participants emphasised young people’s leadership potential when working alongside more experienced activists.

1.4. Physical Accessibility, Transport and Personal Assistance

Accessibility was identified as a fundamental prerequisite for participation, rather than merely a technical adjustment. Participants mentioned streets and buildings with obstacles, ramps that are not used or fail to meet needs, inadequately adapted public transport, and healthcare facilities that cannot be accessed independently. One participant described undergoing a medical examination outside the consulting room because a lift was inaccessible or out of service.

Participants also identified the need for better training for drivers and institutional staff, consistent use of bus ramps, and longer or more flexible personal assistance, including at weekends. One personal account described an extended period without access to a personal assistant, which, combined with inaccessible transport, severely restricted opportunities for independent mobility and participation.

1.5. Prejudice, Discrimination and Institutional Culture

Participants believe assumptions about the lower capabilities of persons with disabilities remain prevalent. As a result, some constantly feel compelled to prove their abilities and, due to exhaustion, sometimes choose not to participate in unfamiliar settings. Beyond physical accessibility, they called for respect, direct communication, staff training, regular external evaluation, and greater accountability within public administration.

1.6. Local and National Levels; Territorial Disparities

Some participants find municipalities easier to approach for direct communication but believe that changes at national level can have a wider reach. Others see no significant difference between the two levels. The disparity between Skopje, larger cities, and smaller or rural communities is far more pronounced in the experiences shared: less accessible infrastructure, fewer activities, and fewer opportunities to participate in smaller communities.

Some participants reported relocating because of a lack of accessibility, opportunities to study, or independent living options in their previous communities. They called on local authorities to plan for the long term and monitor implementation of adopted measures, rather than limiting their action to isolated interventions.

1.7. Diverse Needs and Unequal Opportunities

Participants highlighted barriers faced by persons with visual or hearing impairments, persons with intellectual and psychosocial disabilities, persons with rare conditions, and those living in rural areas or with limited financial resources. They pointed to a lack of accessible content, communication accommodations, and appropriate institutional support. Concern was also raised that certain individuals cannot access specific benefits because of how eligibility categories are defined. This is a personal account requiring further verification by the relevant institutions.

For persons who need support to express their views, the solution is not to exclude them or automatically replace their voice with that of their family, but to provide adapted forms of communication and participation.

1.8. Good Practices and Their Sustainability

Alongside individual positive experiences with local authorities, education and civic initiatives, some participants mentioned urban and cultural organisations as environments offering opportunities for involvement. At the same time, others could not identify a stable systemic model, only isolated steps without clear sustainability. Positive examples should therefore also be assessed in terms of continuity, accessibility, and actual influence on decisions.

1.9. Support Needed for Activism and Leadership

Needs identified include practical training in communicating with institutions, expressing and substantiating requests, public speaking, advocacy, and following procedures through to a final resolution. Participants called for mentoring by people with direct experience in civic and democratic life, rather than training courses with no practical application. Participation is also affected by accessible materials, personal assistance, transport, financial support, and the support of the wider community.

2. Guidance for the Inclusive Representation Handbook

The views expressed indicate that the Handbook should be a practical tool for both persons with disabilities and institutions. Printed and accessible digital versions, clear and simple language, visual explanations and examples, and, where necessary, alternative formats with appropriate communication support were proposed.

- Step-by-step guidance on requesting a meeting with a municipality or institution, formulating a request, following up on a response, and verifying implementation.
- Templates for invitations, meeting requests, proposals, minutes, and checklists for accessible public consultations.
- Rules for timely, personal invitations; accessible venues and materials; communication accommodations; and active involvement rather than symbolic attendance.
- Guidance for staff on communicating directly and respectfully with persons with disabilities, rather than automatically addressing accompanying persons.
- Real, verified good practices, including examples showing how a specific proposal led to change.
- Simplified language and avoidance of stigmatising terms such as “disease”, “invalid” and “handicapped”; use of respectful terminology and recognition of individual self-identification.
- Piloting with persons with different types of disabilities and with municipalities, ministries, educational and other public institutions, and civil society organisations.

3. Priority Recommendations

1. From consultation to influence: Establish procedures that involve persons with disabilities at every stage of decision-making and provide feedback on accepted and rejected proposals.

2. Accessibility as a condition for participation: Assess venues, public transport, information, digital content, and communication support in advance; inspect implemented solutions on site.

3. Institutional capacity and accountability: Provide continuous training for officials and consultation facilitators, with public accountability and periodic evaluation of measures.

4. Support for youth leadership: Provide practical training, mentoring, communication skills, and genuine opportunities to lead initiatives, together with support from experienced activists.

5. Equitable representation: Ensure open access to information, transparent selection of participants, and adapted mechanisms for persons with diverse needs, including those outside larger cities.

6. Monitoring results: Measure tangible changes: proposals implemented, improved services and spaces, more persons with disabilities in advisory and decision-making roles, and greater independence.

4. Conclusion

The combined views show that participants seek not merely to be consulted, but to have an equal, accessible, and influential role in public and democratic life. Challenges arise simultaneously from inaccessible environments, institutional culture, insufficient support, and limited leadership opportunities. There are individual positive experiences, but a transition is needed towards regular, clear, and sustainable mechanisms that can be assessed through concrete results.

For INCLUDE, these findings provide direct guidance for developing a Handbook that connects individual empowerment, institutional procedures, and practical monitoring of change. The desired long-term outcome is greater visibility and independence for persons with disabilities, more young people actively advocating for their rights, and participation that genuinely influences decisions.

Methodological note: This thematic report is based on experiences and assessments shared by 9 participants. No statistical generalisations are made, and individual claims concerning institutions or officeholders have not been independently verified.