**Questionnaire – Collecting promising practice in independent living / deinstitutionalisation processes**

1. **Context**

The [Strategy for the Rights of Persons with Disabilities 2021-2030](file:///C:\Users\martiob\Downloads\Union_of_Equality__European_Commission_presents_Strategy_for_the_Rights_of_Persons_with_Disabilities_2021-2030.pdf) (Strategy) aims to ensure the full participation in society of persons with disabilities, on an equal basis with others, in line with the Treaty on the Functioning of the European Union and the Charter of Fundamental Rights of the European Union, which establish equality and non-discrimination as cornerstones of EU policies. The Strategy supports the implementation of the [United Nations Convention on the Rights of Persons with Disabilities](https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd) (UNCRPD), to which the EU and all 27 Member States are individual parties.

As a flagship action of the Strategy, **the European Commission is preparing guidance recommending to Member States improvements on independent living and inclusion in the community,** in order to enable persons with disabilities to live in accessible, supported housing in the community, or to continue living at home (including personal assistance schemes). With this guidance, the Commission seeks to support the joint commitment of the EU and its Member States towards implementing the right to independent living and inclusion in the community, in line with article 19 of the UNCRPD.

Taking a practical approach, the guidance will seek to illustrate examples of Member States’ experiences in developing the conditions for independent living and carrying out deinstitutionalisation processes, with a particular focus on how EU funds can be used to accelerate progress in these areas. **This questionnaire is addressed to public authorities and bodies, at the relevant level of governance (national, regional or local), and to stakeholders in Member States (e.g. private and public service providers, civil society organisations, organisations representing persons with disabilities) involved in projects, investments, or the implementation of measures for advancing deinstitutionalisation processes and developing community support for persons with disabilities**. While the focus is on the use of EU funds, examples of relevant measures with support from other funding sources are also welcome.

**Objective**:

* To collect promising/positive practices and measures, or promising elements of a practice, underway in EU Member States that implement the principles for independent living for persons with disabilities and/or advance with deinstitutionalisation processes, in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),[[1]](#footnote-2) with a particular focus on how EU funds can be used to support investments that support these processes.
* To identify funding sources, transferability aspects and sustainability of promising projects/interventions, and to understand how positive practice is assessed.
* To collect promising practice from non-EU countries addressing similar challenges than EU Member States and with transferable elements that can inspire similar interventions in EU Member States.

Acknowledging that all EU Member States are on a pathway towards making independent living a reality for all persons with disabilities, some of the examples of practices may illustrate intermediate steps in a transition. it will be important to see them in the context of the national/regional/local plans and strategies to finalise the transition to independent living in line with UNCRPD. In addition, the perspective of diverse target groups of persons with disabilities (e.g. children with disabilities, older persons with disabilities, persons with intellectual disabilities, women/girls with disabilities, etc.) is important and examples of interventions or services targeting their specific needs are welcome.

It is important to note that other persons without disabilities, such as children deprived of parental care, might also live in institutions (e.g. orphanages). While these groups are not the focus of this guidance on independent living, and not a target group of this exercise, they may benefit from establishing synergies.

**Use of results:**

The examples collected will contribute to deliver the Guidance on independent living, a flagship of the Strategy for the Rights of Persons with Disabilities 2021-2030,[[2]](#footnote-3) and will help to share experience from national contexts in tackling the challenges and in advancing community living and deinstitutionalisation processes, notably through the use of EU funds. An important aspect in this exercise is thus to identify transferable elements to inspire similar measures in other Member States. We aim also to identify upscalable pilot projects showing objective evidence of positive results.

**Target group - who will use the results?**

Policy makers, managing authorities, public and private service providers, and organisations representing persons with a disability.

**Level/scale of intervention**:

National, regional or municipal level, from pilot project to large-scale intervention within broader reforms.

In practical terms, practices will be collected around the relevant areas of the forthcoming guidance, listed below. Under each heading some examples of relevant types of interventions are provided.

1. **Themes and examples of types of intervention (examples of interventions provided are** **not exhaustive):**
2. Developing support and services in the community (including prevention of institutionalisation, inclusive mainstream services and accessible housing and environments) and transitions to independent living in the community - perspective of different groups:
   * **Prevention:** early childhood intervention services to prevent the institutionalisation of children with disabilities; crisis interventions to avoid institutionalisation of persons with disabilities, including e.g. women/girls with disabilities, persons with intellectual and psychosocial disabilities. Support for older person who acquire disabilities to remain living in their homes receiving the services they need.
   * **Support systems and networks:** support systems and informal community support structures are composed of peers, family members, friends, neighbours or other trusted persons, like volunteers, who provide the support that a person with disabilities requires for decision-making or daily activities, in order that the person can exercise the right to live independently and to be included in the community. Support systems are key for some persons with disabilities, in particular for persons with intellectual disabilities and persons requiring intensive support, in navigating and determining the support services that they may require.[[3]](#footnote-4) (e.g. users’ cooperatives).
   * **Supported decision making**: support that enables persons with disabilities to exercise their legal capacity in choosing, managing, initiating and terminating the provision of community-based support, and including financial decisions. Support in exercising legal capacity can be provided as a service funded by the State or through the individual’s support systems and networks.
   * **Individualised community services**: personal assistance, home support and care services, including mobile units that support persons with disabilities in their own homes.
   * **Living arrangements**: accessible (social) housing; adapted housing (smart homes adapted to respond to needs of people with disabilities, remote monitoring or alert systems etc.), foster care.
   * **Accessible and inclusive mainstream services in the community**: inclusive early childhood education and care services for children, other education, employment, social and health care services, ensuring accessibility of infrastructures and services in the community.
   * **New models of governance** and organisation of services around the user (integrated, person-centered models), including taking into account the family.
   * Use of **assistive technology** and technological aids to support independent living (e.g. digital services).
3. Alternative funding models and budgets:
   * **Personal budgets.**
   * **Financial support** to persons with disabilities and their families, including for housing.
4. Development and capacity building of care, support and services workforce and of responsible administrative levels:
   * **Recruitment and capacity building** for case handlers, personal assistants, care providers, staff involved in deinstitutionalisation processes, or staff delivering community-based services from public authorities, public social services staff, private and third sector service providers.
   * **Capacity building** for support systems (training/coaching of families, informal carers, peers, volunteers, advocacy organisations, friends, etc.).
   * Building **capacity on the responsible administrative levels** for assessment of needs and selection of providers.
5. Support for **self-sufficiency** and empowerment of persons with disabilities.
6. **Partnership** and consultation: Co-production or **participation** of persons with disabilities and/or organisations that represent them in the design, implementation and/or monitoring of interventions, including in the development of the new service offer as expert by experience. Consultation with peers and family.
7. **Innovative elements** in national strategies and action plans to operationalize the principles of independent living:
   * Implementing the principle of choice and control over one’s life.
   * Models for individual needs assessment.
   * Improving data (e.g. on persons with disabilities living in institutions and the situation in which they live, on use of personal assistance schemes, etc.) and monitoring systems.
8. **Outreach to service users**: how persons with disabilities and their families are informed about and offered the new service or change of practice.
9. **Public awareness campaigns**, changing mindsets for inclusion in the community.
10. **Process for selecting practices to be included in the guidelines:**

1. Identification and selection. Questionnaires will be processed on a rolling basis as received by the European Commission. Based on the relevance and completeness of the answer, the practices will be shortlisted for possible inclusion in the guidance. The contact point may be contacted to gather further information about the practice by telephone or e-mail.

2. Consultation. The draft guidance with examples will be shared with the Disability Platform[[4]](#footnote-5) for consultation.

3. Publication. After consultation, the European Commission will publish the guidelines.

1. **Questions**

**Introductory remarks:**

Building on your expertise, we are kindly asking you to complete the questionnaire with the requested information for each practice or project example. Please feel free to send more than one example per country/organisation – in this case, **please complete a separate questionnaire for each practice or project example**. Please also share the questionnaire with relevant organisations or bodies owning inspiring practice/projects.

The questionnaire collects detailed information about interventions/measures to understand their implementation, how they are assessed and to be able to identify transferable elements. In some cases, a follow up exchange, either through phone or email, might be required during the review process to delve deeper into the points highlighted in examples provided. See detailed steps of the process for collecting promising practice under section 3.

Please note that not all boxes may be relevant to all practices, please indicate “non-applicable” where needed.

While the geographical focus of the exercise is on EU Member States and implementation of EU-funded programmes, examples from other national contexts with transferable elements to EU countries are also welcome.

In case of questions, please contact: [EMPL-D3-CONSULTATION@ec.europa.eu](mailto:EMPL-D3-CONSULTATION@ec.europa.eu)

**Please submit the questionnaire by 15th of September 2023 to:**

**EMPL-D3-CONSULTATION@ec.europa.eu**

1. **Contact Information**

**Organisation**

* 1. Name**:** Ministry of Social Affairs, Republic of Estonia
  2. Department (if applicable): Department of Social Welfare
  3. City: Tallinn
  4. Country: Estonia
  5. E-mail: info@sm.ee
  6. Telephone: 626 9301

**Individual contact details**

* 1. Name: Preimann
  2. First Name: Elen
  3. Job Title: counselor
  4. Email: elen.preimann@sm.ee
  5. Telephone: -
  6. Type of organisation:

National/federal government

Regional government

Local/Municipal government

National EU funds managing authority

Regional EU funds managing authority

Monitoring body of EU funds

Implementing body of EU funds

Public social service

Not-for-profit social service

Private service provider

Disabled Persons Organisation / Advocacy

Other, please describe:

* 1. Could the person listed as contact point be contacted by a contractor of DG EMPL for a follow-up interview?

YES

NO

1. **Description of the action**
   1. **Name** of the intervention in English and in original language

Service model of person-centered special care in local government

Isikukeskse erihoolekande teenusmudel kohalikus omavalitsuses

* 1. **Classification**: To which theme and type of intervention does your example of practice belong?
* **Themes**: you may select up to three answers, please rank the themes according to relevance, from 1 – most relevant, to 3 – least relevant.

\_\_1\_\_ Innovative elements in national strategies and action plans to operationalize the principles of independent living

\_2\_\_ Developing support and services in the community (including prevention of institutionalisation and inclusive mainstream services and housing) and transitions to independent living in the community

\_3\_\_ Alternative funding models and budgets

\_\_\_\_ Development and capacity building of care, support and services workforce

\_\_\_\_ Support for self-sufficiency of persons with disabilities

\_\_\_\_ Partnership and consultation

\_\_\_\_ Outreach to service users

\_\_\_\_ Public awareness (changing mindsets and fighting discrimination)

\_\_\_\_ Other:

Reply

* **Types of intervention**: multiple answers are possible, please rank in order of relevance, with 1 – most relevant. If your example of practice is not in the list below, please add under “other”.

\_\_\_\_ Implementing the principle of choice and control over one’s life

\_\_3\_ Models for individual needs assessment

\_\_\_\_ Improving data collection/monitoring systems

\_\_1\_ Prevention of institutionalisation

\_\_6\_ Personal assistance

\_\_7\_ Home support, including mobile units

\_\_\_\_ Supported decision making

\_\_\_\_ Centres for Independent Living, users’ cooperatives

\_\_\_\_ Developing support systems and networks (e.g. peer support)

\_\_\_\_ Living arrangements

\_4\_\_ Inclusive mainstream services in the community

\_2\_\_ New models of governance and organisation of services around the user

\_\_\_\_ Use of assistive technology and technological aids to support independent living

\_5\_\_ Personal budgets

\_\_\_\_ Financial support to persons with disabilities and their families

\_\_\_\_ Recruitment and capacity building of workforce for services

\_8\_\_ Coaching and training of support systems and networks

\_\_\_\_ Coaching and training for self-sufficiency of persons with disabilities

\_\_\_\_ Organising the consultation and participation of persons with disabilities and/or organisations that represent them

\_\_\_\_Reaching out and accessible information for service users, including digital solutions

\_\_\_\_ Awareness-raising activities targeting the public, persons with disabilities, family members, policymakers and service providers, changing mindsets for inclusion in the community.

\_\_\_\_ Other:

Reply

* 1. **Target group** of the action (it is possible to mark more than one target group)

Children with physical disabilities

Children with intellectual, psychosocial or developmental disabilities

Adults with physical disabilities

Adults with intellectual, psychosocial or developmental disabilities

Women/girls with disabilities

Persons with disabilities who are homeless

Older persons with disabilities

* Workforce:

Care providers

Case handlers

Social services providers

Personal assistants

Other (please specify)

Reply

Family / informal carers

Peer support networks

Other (please specify)

Reply

* 1. **Policy framework**: Is your example of intervention embedded in a broader national/regional/local policy or action plan? If so, please provide the title of the legal act, policy document, strategy or plan that the intervention implements.

YES

NO

If yes, title in English and in national language:

* Intention to develop a law amending the Social Welfare Act (updating the organization and funding of special welfare services)

Sotsiaalhoolekande seaduse muutmise seaduse väljatöötamise kavatsus (erihoolekandeteenuste korralduse ja rahastuse ajakohastamine)

* The implementation plan of the welfare development plan 2016–2023

Heaolu arengukava 2016–2023 rakendusplaan

* The welfare development plan 2023-2030

Heaolu arengukava 2023–2030

* Implementation program of cohesion policy funds for the period 2021-2027

Ühtekuuluvuspoliitika fondide rakenduskava perioodiks 2021-2027

* Strategy "Estonia 2035"

Strateegia "Eesti 2035"

* 1. **Timeframe**: what is the operational timeframe of the example provided – Please indicate the starting and finishing year for the intervention.

ESF funded pilot project from 2017 until the end of 2025, then we hope to implement the model in to national law and budget.

* 1. What is/was the **level of implementation** of your example of intervention? (it is possible to mark more than one answer)

Cross-EU

National

Regional

Local (municipality level)

Other (please specify – e.g. non-EU country)

Reply

* 1. **Funding:** Please indicate the financing source(s) for the intervention and related investments, several choices are allowed. Where possible, please indicate the name of the relevant fund/programme and what measures were funded (complementarity of funds).

EU funds

Name of programme/fund and measures financed: The project is financed from ESF funds: 2020-2027 ’’conditions for granting support “Access to social protection and long-term care” sub-activity “Testing of an integrated, person-centered and flexible system of special care services”

National/federal budget

Name of programme/fund and measures financed:

Regional programme

Name of programme/fund and measures financed:

Municipal/Local budget

Name of programme/fund and measures financed:

Private funding/foundation or other resources

Name of programme/fund and measures financed:

* 1. **Amount** of investment (in EUR): What is the overall budget of the intervention? Different options possible, depending on scale and timeframe (e.g. one-off investment, permanent intervention)

\_\_\_\_\_\_\_\_\_ per year

\_Years 2017-2022 cost was 7 million EUR, for the next EU period (2023-2025) we have allocated approximately 12 million EUR in total.

If applicable, amount or share from EU funds (amount in EUR/share in %):

Reply

* 1. **Problem description**: Please describe the main challenge(s) in your national/regional/local context, which the practice seeks to address. Use data where available. (100 words)

The current system of special care services is service-centric, not people-centric. The service system is fragmented for its users, it is difficult to understand their rights and opportunities. People in need of help are not noticed in time, intervention is carried out too late. Support offered to caretakers is not sufficient, families have a heavy burden of care.

Regardless of what services large service providers introduce in the community, if local governments do not participate, the services will not become part of the local support network. Local governments are ready and motivated to develop services for the people of the region, but they currently lack the money, knowledge and manpower to do so.

We aim to make the supporting system for adults with intellectual, psychosocial or developmental disabilities more person centered.

Also, in order to ensure equal access to services, a financing model for services provided to people with special mental needs in the community must be developed, which would work and be sustainable.

* 1. **Summary**: Please describe your practice. What elements are particularly promising to advance the right to independent living? In your specific national/regional/local context, what is the advantage of the practice compared to the previous situation? Please refer to the criteria for your assessment, including independent criteria (e.g. implementing recommendations from UN, national human rights bodies, or an external evaluation, implementing a recognised model, etc.), and to the principles for independent living.[[5]](#footnote-6) Use data where available, and please disaggregate by gender if possible. Please include data on number of persons with disabilities supported by the project and also number of persons who were included in the implementation (e.g. number of personal assistants, or number of persons providing support to persons with disabilities). (400 words)

In the model, the provision of assistance to a person is viewed as one comprehensive service necessary for a person to cope, where all necessary activities for a person are guaranteed, which have been provided so far as various municipal, rehabilitation or special care services. According to the model, the municipality assesses in which areas of life a person needs help (primary support for a person). After the assessment, permanent help and support for the person is organized by one service provider (basic support for the person). If necessary, the person is provided with other supportive or restorative activities necessary for coping (additional support is offered).

The purpose of the model is to make comprehensive help available to a person and their caretakers easily and quickly, close to their own home and with the support of the community. We proceed from the principles of deinstitutionalization. While special welfare services and social rehabilitation services are currently organized by the state, according to the new model, it is done by the local government. Ensuring the availability of services and managing pooled resources remains the responsibility of the local government. The task of the municipality is to identify the service needs of its region and develop services and/or create a favorable environment for service providers that would ensure the availability of services.

According to the new model, the service is formed from the activities that are now part of the special care and social rehabilitation services necessary to support a specific person, i.e. the (additional support) service components. The model has 26 service components covering seven areas of life. In addition, there are activities to support the family and basic support: consistent personal case management, which includes the creation of an action plan and monitoring of its implementation. The case manager who prepares the comprehensive assistance package is an employee of the local government.

The maximum amount of the budget per person in need of assistance depends on the level of the support need of the person in need of assistance. As with piloting, so also with implementation, we consider it necessary for local discretion to cover the case management fee.

In total, number of persons with disabilities supported by the project, is 1955.

* 1. **Stakeholders**: which of these stakeholders were involved in the development and implementation of the action (it is possible to mark more than one group of stakeholders)

International organisation

National/federal government

Regional government

Local/Municipal government

National EU funds managing authority

Regional EU funds managing authority

Monitoring body of EU funds

Implementing body of EU funds

Public social service

Not-for-profit social service

Private service provider

Disabled Persons Organisation

Other, please specify:

In 2017, a prototype of the person- centered model was completed in cooperation between Ministry of Social Affairs and private joint adventure Trinidad Wiseman. The prototype was developed together with people with special care needs, their relatives, service providers, representative organizations and The Social Insurance Board.

* 1. **Partnership and consultation**: if relevant to the action, please describe how were persons with disabilities/organisations representing them involved or consulted in the design, implementation and/or monitoring/supervision of the intervention. (200 words)

Reply

* 1. **Evaluation:** was the practice evaluated?

YES, internally

YES, by a body/organisation not affiliated with its implementation

NO, it was not evaluated

* 1. **Outreach**: How was the target group informed about, and/or offered, the new service or new practice? (it is possible to mark more than one reach out channel)

Referrals through public social services

Referrals through NGOs

Referrals through private service providers

Broadcast media (television or radio)

Printed media (newspapers and magazines)

Social media (Twitter, Facebook, Linked-in, Instagram, Snapchat, WhatsApp)

Website or E-mail

Conferences with stakeholders

Other (please add)

Reply

* 1. **Awareness raising campaigns:** which channels were used to raise awareness and communicate on the new service/practice to the general public and relevant public authorities?

Television

Radio

Newspapers and magazines

Billboards o Brochures/leaflets/items

Social media (Twitter, Facebook, Linked-in, Instagram, Snapchat, WhatsApp)

Website o E-mail

Meetings/conferences with experts/colleagues/stakeholders

Guidelines from authorities to local social services

Scientific publications

Other (please add)

Reply

* 1. What **quality standards** and monitoring/control mechanisms are put in place, if any?

Monthly participant monitoring reports;

Twice a year interim report on project implementation.

1. <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd> [↑](#footnote-ref-2)
2. <https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8376&furtherPubs=yes> [↑](#footnote-ref-3)
3. As described by UN Committee on the Rights of Persons with disabilities: [CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies (2022) | OHCHR](https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including) [↑](#footnote-ref-4)
4. <https://ec.europa.eu/transparency/expert-groups-register/screen/expert-groups/consult?lang=en&groupID=3820> [↑](#footnote-ref-5)
5. In line with article 19 of UNCRDP and its General Comment 5. [↑](#footnote-ref-6)