Analysis of DI situation process changes in Romania

a) How is DI conceptualised in the country (how it is, how is DI understood, what is wrong with the current state of affairs, why changes are taking place, what they are aimed at - the purpose of DI). It is also possible to draw on descriptions and analyses that have already been prepared in the country by other actors/participants).

In Romania, DI is not generally understood. Institutionalisation is perceived as a good solution for adults with disabilities, especially intellectual and psycho-social disability (65% of the ones in institutions). There is no sense of what is wrong with institutionalisation, the authorities, when confronting with the human rights based approach on disability, politely explain that yes, they understand this, but what can we do, if Romania does not have alternative community based services? As if those community based services would have to be developed out of nowhere, by who knows who.

Based on FAS's experience in supporting persons with (intellectual and psychosocial disabilities) transitioning out of institutions, we summarize a very subjective analysis below:

1. Institutionalization is in most cases decided by others:
    a. either public system employees for those raised in the protection system for children – placement centres, foster families,
    b. either family members: parents or grandparents – tired and aged after a lifetime of caring for the disabled child who became an adult; or distant relatives, after the death of the person's close family, who see the institution as a way to solve a problem.
    c. either legal representatives (we still have in place the legal guardianship system, which is currently reformed).

4 out of 10 persons living in public Romanian residential centers for persons with disabilities are former institutionalized children.[1] They faced all their life segregation and social isolation, deprivation of interaction and communication, and lack of personal autonomy and privacy, with long-term effects on a person's physical, intellectual, and mental development. (Wold Bank, guide for DI process in Romania).

Once in institution, it is very rare (and usually NGOs driven) for a person to leave the institution (67% remain in institutions for life; 14% are moved form one institution to another). 14% move in the community. The others – die in institutions (1200 pers / year) (data from the Centre for Legal Resources).

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[1] World Bank 2022c, 44.

The person cannot choose other support services in the community, because, unfortunately, they do not exist. Initiatives like UnLoc in Timisoara or ProActSupport in Bucharest are rare. And these services are not developed, because the public money is used to maintain the institutional system (there is no political will nor understanding about DI) and the residents of those places are not informed about their right to ask for support in the community. Romania has ratified the UN Convention on the Rights of Persons with Disabilities in 2010 and continues to violate almost all its provisions.

2. Institutions are a fertile field for human rights abuses, exposure to violence and trauma, negligence, the inability to exercise even the most basic civil rights (including the right to vote. And even more, in some institutions, staff members vote on the behalf of the residents, using their IDs, without them being aware that this is happening – *not proved / documented statement! Based on verbal sharing from former residents*). People lose their meaning, they have no control over any aspect of their lives (what they eat, how they dress, how they spend their day).

3. National public funds (at least 250 million euro per year) are spent on the functioning of the segregated system, in a non-transparent way and without any impact assessment. When project team member monitored in October 2021 such an institution, it looked terribly wrong: there was nothing individualized, no access to work or other activities. Just an example of the waste of money and the jobs created there: 50 staff members for 47 residents. Of the 50 employees, 20 administrative staff. Of the 20 administrative staff: stokers (people who guard and maintain the heating system of the facility, while residents had access to bathing once a week, within a schedule per pavilions), 4 guards, 2 laundresses (for two washing machines), 1 storekeeper. At the same time, for the 47 residents, there was only one psychologist. And we pay there 1400 euro / resident / month.

4. European public money still used for investments in institutions and the restructuring of large ones in smaller centres, for "only" 50 people, but where the institutional culture and approach prevail. All this, despite specific guidance from the European Commission to stop such practices. The Legal Resources Centre, a human rights watch dog organization, made a strong analysis of the latest European programs funds available to our authorities - the link is here. It is outrageous that out of the 38 million euros contracted by Romania, we proposed the deinstitutionalization of 608 people. And we managed to spend to date 4 million in 4 years and deinstitutionalize 0 (zero) persons… With the 34 million unspent, at least 3,100 people could be supported in the community through small, person-cantered services.

5. We have public institutions to defend the rights of people with disabilities, but they do exactly the opposite: keep the system closed and do not use their prerogatives for the benefit of people with disabilities. The Monitoring Council, a national entity under the control of the senate (the human rights commission), is politically hijacked. The County Directorates for social work could contract private social services providers or could develop, by themselves, small, person-centred service, but choose to spend the money from the state budget in institutions.

6. We have the so called ”Disability tax” – related to the quota in employment (every employer with more than 50 staff has to employ 4% persons with disabilities, if not, they pay a tax). The amount collected per annum: 450 million Euro. We do not have visibility on how this money is spent. If might be even used to support institutions! While, in other countries, is used to invest in community based services, accessibility, etc.

And all these issues are still unknown to the public - very, very few people outside the system care about those within institutions. They do not (anymore) have family members, they do not have friends, they themselves do not know their rights and, therefore, they cannot claim them. They need allies!

We must carefully investigate and document the use of public money, we must communicate massively and wisely on the subject, we must implement, starting from the vision of the UN convention, a human rights-based approach and develop community social services.

b) *If these data are available in the country, a description of how many people live in institutional services, in what conditions, what adverse situation in particular and how it is addressed, the structure of support provision for people - the support network (not only social services, also informal support - relatives, community...).*

In 2022, Romania had a population of 875,594 persons with disabilities (3.99% of the general population of the country): 53.42% women; 18-64 years old: 46.94%; over 65 years old: 44.46%; profound disabilities: 42.21%; severe disabilities: 46.67%; light disabilities: 11.12%.

Out of the total of the persons with disabilities, 16,418 (1.88%) are institutionalized in 496 residential centres (263 centres – 20-50 people – 6068 persons in total; 59 centres – more than 50 residents each, 9106 persons in total; 13 centres – up to 20 persons, 157 protected houses – up to 10 persons each, 1079 persons in total). Out of them, approx. 4000 are deprived of legal capacity.

There are also 59 day services (at home support, day care, mobile teams, respite centres, crisis centres, decision making support, professional personal assistance). (National Authority for Persons with Disabilities, data as of Dec 21, 2022).

The residential system is overcrowded, with large institutions, uneven national distribution (from 3 in one county, to 35 in other), with some counties having a larger concentration of centers. The number of persons admitted each year is higher than the number of residents who leave the system to return to the community. Most institutionalized persons have intellectual or mental disabilities, are poor, have a low level of education, and lack family support and social networks. The resident population consists of young people from public care, the elderly in the community, as well as some middle-aged residents. (World Bank analysis).

A recent assessment of Romanian residential centers for adults with disabilities[2] highlighted multiple situations where institutional practices violate human rights: limited autonomy and control over day-to-day decisions (schedule, food, clothing, leaving the center) and the lack of accessible buildings and communication, poor access to means of communication (phone, computer), limited access to medical services, combined with a high number of chronic diseases and deaths, the lack of access to other mainstream services (employment, education), as well as the lack of social networks and contacts with the community. Institutions are generally places where residents' everyday life is closely surveilled, and institutional care can encourage conformism and uniformity, including staff who use punishment to induce residents' compliance, sometimes without their consent (e.g., containment, isolation, or psychotropic medication). (World Bank analysis).

There if no support network, only a handful of NGOs, one self advocacy organization and one human right watch dog organization. People are locked in, without access to information and support with regards to community living.

c) *Who is involved in providing support to people and their responsibilities - the system, management and funding of support to people.*

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[2] *Complex Diagnosis Report on the Situation of Public Social Care Residential Centers for Adult Persons with Disabilities* (World Bank).

Public funding is used to maintain the current institutional system. The funds come from county level (out of VAT), while the methodological guidance comes from national level (the National Authority for the Protection of the Rights of Disabled Persons). Some institutions have their own legal entity, while others – no, they function as units within the county directorates for social work and child protection.

Funds are allocated per social service provider, not per the needs of a person. There are minimum costs established for each type of social service, the institutional ones being the most expensive (from 17.000 euros / year / person in a big centre to 8.100 euros / year / person in a minimum protected house).It seems like the state financially "rewards" institutionalisation. If a person decides to leave an institution, (s)he is left without any support, unless there is an NGO covering for the gap (unstable funding, project based).

It is possible for the public authorities to contact private service providers, usually at the minimum cost. This is a random practice, there is no long/medium term planning, providers do not know what and when to expect, so they can create new services and license them: public money can be allocated only to **accredited** social service providers – Ministry of Labor, who implement **licensed** social services – National Authority for Persons with Disabilities (if the services are provided in small apartments / studios, each living unit must go through the licensing process as a separate social service).

Recently (Jan 23), Romania adopted its first law for prevention of institutionalisation and acceleration of DI. There are some governance mechanisms put in place (for the moment, only on paper, as the process did not actually start):

- A National Coordinating Committee (NCC): coordinates the DI process (working groups); provides support at county levels; assesses and monitors the progress of DI; organizes debates / public meetings. It is lead by the National Authority and comprises representatives of:
    - CRPD focal points (Ministry of Education, Justice, Health, Communication and IT, EU Funds)
    - Other institutions, like:
        - Ministry of Labor and Social Affairs; of Family, Youth and Equal Opportunities; of Finance.
        - National Authority for Payments and Social Inspection (they license, on the ground, social services, and distribute financial benefits to persons with disabilities)
        - National Agency for Employment
        - Monitoring Council for the CRPD implementation
    - Self-advocates / representatives of DPOs
    - Other actors involved in community inclusion
- County Coordinating Committees (CCCs) for DI and inclusion in the community: responsible for DI process at local level (implementation of DI plans at the levels of the centers) and for mobilizing resources. They are coordinated by the County Directorates for Social Affairs and Child Protection and include representatives of:
    - County Council (owns budgets)
    - Prefecture
    - Civil society organisations and private service providers
    - Self-advocates
    - Town halls / local councils
    - Social work directorates (under municipality)

    - County Authority for Payments and Social Inspection
    - Representatives of all general interest services: culture, sports, public health, education, employment…
    - Other actors (like lawyers / judges – legal guardianship transition; community based psychiatric services; banks; etc) with impact in community inclusion and participation.
- Independent civil society Advisory Group (AG) – national level: it evaluates the DI plans for each center; it monitors the DI progress; it participates in awareness raising activities, debates…
    - Self-advocates
    - DPO representatives
    - Human rights watch dog organizations

Each center will have a DI plan, created by a DI management team appointed for each center, that works closely with the residents, the staff and assesses the resources of the center. The DI plan sums up the findings from the individual plans of every single resident in that respective center. The plan is to use a person centered planning methodology (MAPS or LIFE).

d) *Specific experience and practice in the country with the change process, DI:*
- What has been done and with what outcomes

A so-called restructuring or reorganisation process of residential centres of more than 50 residents started in 2018. We can not consider this DI, as it meant moving people in blocks into smaller scale (but still of 50 places!) institutions – without them choosing if and where and with whom to move. Basically, Romania started the process of downsizing its huge institutions, a step that could have been cut, based on the experience of other countries. In some cases, new institutions were built (some, even in the same courtyard as the current big institution); in other cases, big institutions were "artificially" divided into 2 ore 3 smaller institutions, so they comply with the on-paper requirements of having less than 50 residents (ie: divide the building into pavilions; declare 1st floor as one residential center, the 2nd floor – another one).

- What has been successful throughout the change process
Nothing much, except the DI that happened through public-private contracting with NGOs (private residential services providers), that benefitted less than 200 persons in the last decade…

The mindset is public residential centre centred, not person centred. And the decision makers – at national and county levels – do not endorse the CRPD human rights-based vision. If the one that would have to be the champions of the process do not get it and do not really want to implement it, we can not talk about successful change processes.

We have now in place promising strategic documents:

- National Strategy to prevent institutionalization and speed up deinstitutionalization, 2023–30
- "Equitable Romania" National Strategy on the Rights of Persons with Disabilities 2022–27
- Diagnosis of the Situation of Persons with Disabilities in Romania (World Bank 2021)
- Complex Diagnosis Report on the Situation of Public Social Care Residential Centers for Adult Persons with Disabilities (World Bank 2021, 2022)

2023-2030 is the time frame to implement these documents.
The strategy has six main lines of action:
I. DI process coordination
1. committees and coordination commissions (regional and local authorities, NGOs)

2. monitoring and evaluating progress on DI

II. Person Centered Planning (PCP)

1. framework assurance so that PCP can function (new quality standards for the case management service, monitoring of PCP application, training of case managers in PCP, training of disabled people as self-representatives).
2. Monitoring the way PCP is applied for those in institutions.
3. Prevention of institutionalization, with case managers from municipalities, or contracted, and service plans.

III. Providing services in the community

1. Inclusive housing (people will receive a transition benefit for the period of transition from the institution to the community and a housing benefit - for rent, utilities, repairs...)
2. Support services (focus on personal assistance, decision support and assistance, occupational counseling and mediation, household support, home care, mobile teams). There will be changes in quality standards for personal assistance, mobile teams, respite and crisis centers, assistance and support services, day centers, protected housing.
3. ensuring the quality of services (personal training, monitoring of respect for people's rights).

IV. Staff training

1. initial and ongoing training; mechanisms of professional supervision, evaluation.
2. increasing the attractiveness of the sector: events, trainings, opportunities + adequate funding.

V. Support for families

1. Information and advice, regulation of the status of informal carers.

VI. Society awareness

1. Of the general public, public debates, national communication plan, financing of NGO projects.

> *- What is not going well - where are the biggest barriers in the change process, in which area (e.g. strategy - understanding the purpose of change; managing change, attitudes of service leadership; identifying people's needs and preparing people for change, guiding them through change; working with staff; funding for change, public insights and attitudes...anything where you see a barrier).*

Strategic:

- Lack of vision. Values not aligned with CRPD. Still a medical approach of disability.
- Missing the objective of the change.
- Assuming the persons with (severe / profound) disabilities would be better of in institutional settings.
- Lack of a strong, charismatic, genuine leader / team of leaders. We miss the “engine” of the DI process.
- Policy documents without funding sources to implement the changes.
- No coordination among different authorities.
- Needs to revise some legislation (funding of services, access to housing, etc).
- Poorly allocation of public funds: spent in institutions instead of being invested in community based services.

Operational:

- Inability to manage a change that is not desired.
- Project / short term based funding for private service providers
- Lack of properly trained staff

- Oppositional attitudes towards DI (from current institution staff, from family members / legal representatives)
- Lack of community based services – no interest in developing them (vicious circle: people from institutions do not ask for such services; but they do not ask because they do not know they would have the right to do it, not because they are happy in institutions).
- Lack of understanding DI ("the centre will close, people will end up on the streets")

Persons with disabilities:

- Lack of access to information and support for DI
- No community based services. No social / affordable housing.
- No support groups / enough self-advocacy know how and organisations.
- Poverty and loneliness / no circle of support.
- Inaccessible mainstream services.
- Discrimination and stigma.

> *- What tools are available in the country and how they are used, how functional they are (e.g. from the country's legislation supporting DI, other support strategies to other methodological tools). A preview of the results of their use (what works, what doesn't, what needs to be different).*

Tools are currently developed. The plan is to use a person-centred planning process and to start empowering the residents. We expect it to be a slow process – residents do not have the habits of making any choice, of deciding and the staff from institutions does not believe in the potential of the residents.

Currently, the instruments are piloted in five centres throughout the country. Fist conclusions are expected by mid-April. Two FAS psychologists are involved in the pilot phase.

> *- Identification of what partners would need - description of needs from the perspective of people with disabilities, from the perspectives of organisations, service providers. Which can then be targeted and addressed in the development of the Guide and training programme.*

People with disabilities in institutions:

- Access to information about their right to live in the community; coordinated visits in the community, to understand what it entails (many people never rode a tram nor shop for themselves, for instance). Tailored made transition processes. Preparation for community living.
- Access to support in making formal DI requests
- Access to justice (to make complaints, to get rid of the legal guardianship – often, the guardian is a staff member of the centre or the mayor of the town / village where the centre is located, as many people do not have relatives)
- Access to self-advocacy / support groups
- Access to community based / inclusive housing and support services.
- Financial benefits / aids for housing and accessing support services.

People currently living in the community, but at-risk of being institutionalised:

- Access to community based services
- Access to self-advocacy / support groups
- Access to **accessible** mainstream services

Social service providers:

- Funding as per the real cost of service
- Development of a variety of service providers, that would complement (and even compete) with each other.
- Staff training
- Monitoring & evaluation of the quality of services and of the quality of life of their clients.

- Transition process management.

Guardianship authority, the Courts:

- Technical assistance in transitioning from full guardianship to the new legal safeguarding mechanisms.

Mainstream services:

- Accessibility (physical, informational)
- Staff training.

Local / county authorities:

- Staff training and staff moving from institutions to community services: who? How? Why?
- Community based resources identification and mechanisms to allocate them to community services.
- Risks assessment (lack of political will; misunderstanding of DI; lack of coordination, etc) and mitigation strategies.
- Funds allocation mechanisms.
- Staffing needs assessment.
- Types of services needed and quality controls (new licensing processes).

Local community:

- Information and awareness
- Opportunities to interact, participate, get to know each other.

- What is the experience of active participation in change by people using the service, their relatives.

So far, minimal. Only few individual exceptions, people supported by NGOs.
The staff from the county authorities decides for the life of the residents.
Relatives – often, they are poor and disconnected from the residents.

- The output should also identify whether people who have been through the change - the carriers of the experience - are available/ready for involvement, transfer of experience to others in the country. From amongst former users of the inpatient service, from providers - management and staff, the person's surroundings - people close to the public, regional politicians supporting change etc.

Approx. 20 persons – former residents of institutions, experts by experience – willing and available and ready to get involved: share their story, talk about their experiences and difficulties in the transition from institution to community, the support needs

Management and staff from service providers: at least 20 persons.

Volunteers / mentors / employers / people from the community: at least 20.

Regional politicians supporting change: 5.