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CONCLUSIONS ON THE RESULTS OF THE CONFERENCE

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The conference focused on advancing discussions to accelerate transition from institution-based services to community-based services in the EU Member States. The aim of the conference was also to propose new approaches to the development of concept and financing of DI and promotion of human rights respectively, and to support the development of the EU-wide framework of participatory social welfare policies.

A little bit more than two hundred participants took part from across Europe, among them governmental experts and representatives of both users` and service providers` organisations.

The following conclusions contain suggestions and concerns voiced by participants at the conference, from plenary speakers and panellists through to members of the thematic working groups.

Rationale

The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) is a field of shared obligation of EU and Member States as duty bearers, and as such calls for synergies between the EU and its Member States in the implementation. Article 19, Independent Living and Inclusion in the Community, is key for the enjoyment of a number of other rights enshrined in the Convention. It embodies the Convention’s innovative spirit – the paradigm shift from treating persons with disabilities as passive objects of care to recognizing them as active subjects, as rights-holders who have an equal right to live in the community as everyone else. The recent General Comment on Article 19 CRPD (2017) by the Convention’s Committee is of particular importance in terms of policy guidance.

Beyond disability-specific policies, there is a need for life course policies. After all, Article 19 CRPD – independent living and inclusion in the community – is not a new right only for persons with disabilities, it is spelling out of a right that everyone has and that has long been denied to persons with disabilities. As such, it can serve as guidance for policies applicable across categories of rights-holders, from children to older persons. The move away from institutional care to services that support inclusion in the community is the same vector, same challenge. For children, the United Nations Guidelines on the Alternative Care of Children (2009), which interpret the UN Convention on the Rights of the Child, also provide relevant guidance (i.e., that poverty should not be a reason for separating children from their families and that when separation is necessary, family-based or family-type services should be preferred over institutional ones).



The **economic argument** for a move towards inclusion in the community (de-institutionalization) exists, but it is not the right argument. It has to be seen as secondary to the primary argument, which is the **ethical and legal one**. Independent living and inclusion in the community is an obligation under Article 19 CRPD. Ethically speaking, it is wrong to remove persons with disabilities – as well as older persons or disadvantaged children – from the community to care institutions. It is right that they should be in the community – right for them and right for the community itself. It is a sign of a normal community. To argue in favor of removing these people from the community is to perpetuate stigmatization, even if it is shrouded in terms like “needs” and “care”.

Therefore, on a policy level, it is important to re-formulate the issue – it is not primarily about cost-effectiveness, but about ensuring effective equality. It is not about ensuring mere survival of human beings at the lowest possible cost, but about allowing them to thrive, to flourish as best they can, as self-determining individuals and as social beings.

Risks

There are several risks involved in de-institutionalization processes.

The **risk of the first type** is that of failing to develop services of sufficient quality and capacity to replace the institutions which are being closed. This risk is particularly high where policy-makers are driven above all by the desire to reduce costs. There are lessons to be learned from several countries, in Europe and beyond, where this actually happened, leading to abandonment, homelessness and, in case of persons with psychosocial disabilities, imprisonment.

It has to be emphasized that the aim of reforms is not to return care responsibilities to families. Today’s societies cannot return to a pre-modern situation where care would be provided only by families – or, more precisely, by women. This would be neither feasible (due to the changed demographic profile of contemporary families) nor desirable (from the perspective of gender equality). The objective must be to create modern 21st century services which follow the user in the community (including, but not restricted to, personal assistance) while at the same time increasing support to family carers.

The **second risk**, even more prevalent in the current situation where ESIF are used, is that of investing heavily in the replacement of large and clearly dehumanizing institutions by new, smaller and prettier ones. This is often the result of the appropriation of the “de-institutionalization discourse” by the technocratic leadership of the existing institutional system – particularly where this leadership is traditionally close to the Government. The risk may be increased where the management authorities of the ESIF are under pressure to spend these resources.

While the replacement of large outdated institutions by smaller and nicer ones can superficially appear as an improvement, its impact is highly questionable. Research from the USA shows that if the facility houses more than 6 people (in other words, if it is larger than family-sized), its character is likely to remain institutional, i.e., driven by the organizational needs of the service provider rather than by the choice of the users. Replacement of large institutions by small ones does not challenge the top-down institutional model of care, does not lead to real inclusion in the community and does not necessarily empower the users. Large sums of money risk being spent on “bricks and mortar” instead of on





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services that actually have an impact on the users' quality of life. Moreover, if massive resources are invested in the construction of the new facilities, it may become very difficult to advocate for more profound change for decades to come.

The **third risk** is that of the creation of new inclusive services alongside large old institutional ones, without de-institutionalizing these old services. In this scenario, the mainstream of care does not change because the ESIF resources are being used only for small-scale "pilot projects" while national resources remain invested largely in long-established institutional care. Thus, the innovative services remain the exception rather than the rule. Moreover, the innovative projects tend to be unsustainable and short-lived because they depend on EU funds which are usually temporary. Even where non-institutional alternatives are being successfully developed, the persons currently living in institutions should not be forgotten.

Solutions

Solutions need to be sought and found on all three levels – European Union, national and regional.

As for the **EU level**, it is essential to ensure that the *ex ante* conditionalities are maintained and indeed strengthened in the next programming period. They could be more explicit and apply also to external policies (EU investment in accession and neighborhood countries, in development programs). Within the EU, it is vital to strengthen monitoring of the existing conditionalities, ensure more transparency and strengthen the partnership principle. The meaningful participation of civil society organizations, which are usually the first to identify misuse of the ESIF resources, needs to be guaranteed. It should not be reduced to a formalistic box-ticking exercise.

The EU can also use other instruments than the ESIF. In the area of knowledge, the EU already has at its disposal the indicators for Article 19 CRPD (independent living and inclusion in the community), as developed by the EU Fundamental Rights Agency on the basis of structure-process-outcome methodology introduced by the Office of the UN High Commissioner for Human Rights. EU research funds can be used to develop further relevant knowledge.

In terms of policy guidance, two initiatives could be considered. In the short term, the European Commission should adopt a Communication on the Transition from Institutional to Community-based Services (Care), which would spell out more explicitly what is meant by a move to independent living, inclusion in the community, de-institutionalization and person-centered services. Such a Communication could provide much more clarity and guidance to Member States and help avoid wrong interpretations. Given that the EU itself has ratified the CRPD, the aforementioned General Comment of the CRPD Committee on Article 19 CRPD could be seen as a powerful argument for the adoption of such a forward-looking Communication. It would, however, be necessary to avoid the frequent use of ambiguous language that seeks to justify non-inclusive practices.

In the medium to long term, the adoption of a new Disability Strategy – long requested by many stakeholders – appears essential. The current Disability Strategy will have effectively run its course with the adoption of the European Accessibility Act. Moreover, it has to be noted that the current Disability Strategy had wasted an important opportunity to address the key issue of independent living and inclusion in the community, probably for the reason of political expediency (i.e., the lack of political





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will to open a theme which might constitute a challenge to the established practice of the Member States where institutional models of care dominate). The new Disability Strategy should be much more committed, modern and forward-looking in this regard, once again drawing on the recent General Comment on Article 19 CRPD.

Moreover, it is important to mainstream the inclusion agenda (de-institutionalization agenda) throughout the EU institutional machinery. For instance, it has to be avoided that other financial instruments undermine the achievements of the ESIF in the area of transition from institutional to community based services.

On the **national level**, there is a need for better data collection (e.g., to know what part of the resources are still going into institutional care). It is also of vital importance to remove perverse initiatives (such as the higher financial support for children with disabilities in institutional than in family settings, which still exists in some Member States). Finally, it needs to be ensured that resources “saved” by closing institutions are ring-fenced, i.e., that it can be guaranteed that they are indeed reinvested in new person-centered services and not transferred to other policy areas.

On the **national and regional levels**, meaningful involvement of the users (rights-holders) is a key factor for success. Policies cannot be just established in a top-down manner – they must be thought through with those whom they concern. On a broader policy level this concerns disabled persons’ organizations (DPOs). On the implementation level this is about consulting individual users and their families. The new paradigm requires a move from an excessively expert-driven perspective – one defined by needs assessment which is carried out by professionals – to a perspective with a strong element of choice on part of the users.

When it comes to independent living and inclusion in the **community**, not everything can be entrusted only to the area of public policy that is traditionally labelled as “social policy”, i.e., the domain of ministries of social affairs. For instance, we have to recognize the crucial importance of housing, transportation, urban development (accessibility of public spaces, creating of community space for interaction of persons across the life course) and employment for persons with disabilities (an emphasis on supported employment in the mainstream labor market, with skills matching and on-the-job training, rather than the traditional but wrong emphasis on “job preparedness” which leads to endless training, benefiting mainly the training agencies).

In the **area of technology**, including ICT, cooperation with and inspiration from the private sector could be of vital importance for furthering the agenda of independent living and inclusion in the community.

To sum up, it has to be remembered that the aim of the reforms is an ambitious one. The aim is not to cut costs or ensure simple survival of persons with disabilities and other vulnerable categories of people (children, old people, homeless people etc.). **In the 21st century, the aim must be to create personalized support services, empower the users, and to allow them to exercise their self-determination and their role as social beings.**

