EASPD

European Association of Service providers for Persons with Disabilities

**IMPROVING SERVICES
IMPROVING LIVES**

EASPD POSITION | **December 2019**

EASPD inputs on next European Disability Strategy

Contents

Introduction

Care and support services in the disability field are key to unlocking the rights of persons with disabilities by contributing to the implementation of the UNCRPD.

Care and support services are also the engine of the European project. They enable people to live better, longer and healthier lives. They help persons with disabilities to have full and active lives in society. They ensure that children can have decent lives and education, for active participation in society. They provide the right guidance and support for migrants to integrate fully into society. By doing so, they also help to provide choice and options to these people's families and friends in terms of informal care and support.

This report aims at giving EASPD's inputs in view of the discussions around the next European Disability Strategy post 2020.

Thanks to its members and its representation across Europe within 17.000 support services, EASPD has a direct communication channel with disability services on the ground and has up to date information on the use of various EU policy frameworks for millions of European citizens.

Who is EASPD

EASPD (European Association of Service providers for Persons with Disabilities) is a European NGO network representing 17.000 social and health support provider organisations across Europe and across disabilities, working towards the promotion of equal opportunities for persons with disabilities through effective and high-quality service systems.

EASPD is a unique organisation as it bases the development of social services on a human rights framework at European level. Since the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) came into force, it has become the core of EASPD's policy strategy. EASPD is accredited to the Conference of States Parties to the Convention on the Rights of Persons with Disabilities and our members are committed to facilitate human rights enjoyment within the framework of the Convention and to empower persons with disabilities through effective and high-quality service systems.

EASPD is registered at the Transparency Register under the following number: 120906010805-50.

Key facts

- More than 80 Million citizens in Europe have a disability
- Social services directly employ over 10 million professionals in Europe
- 1.75 million new jobs were created between 2008 and 2015
- The health and social services sector represents a 7th of EU's GDP[1]; a growing amount of that being the social services sector alone

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[1]European Commission – EU Employment and Social Situation – Quarterly Review – Supplement December 2014

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> The need for social services is estimated to grow in accordance with socio-demographic changes of the population and an increase of individuals who may require some form of support in the course of their life.

Who are social and health support services represented by EASPD

Social and health support services for persons with disabilities represented in EASPD's membership include a range of support services such as services providing support in the field of early childhood intervention, education, employment, housing, day care and respite facilities, prevention, community-based living, arts, culture, sport, leisure activities, etc. These services are essential to persons with disabilities to participate in society, enjoy their human rights and be empowered to live as independent as possible.

According to the European Commission, as well as to EASPD, "these services are a vital means of meeting basic EU objectives such as social, economic and territorial cohesion, high employment, social inclusion and economic growth".

The key role of support services is to be understood under the lens of promoting social and active inclusion, lifting people from poverty, preventing and combating discrimination and promoting overall a more equal and just society.

1. Support services in the UN CRPD and its explanatory documents

Both the **United Nations Convention on the Rights of Persons with Disabilities**, as well as the **United Nations Sustainable Development Goals** recognise the essential function of support services to facilitate the enjoyment of human rights.

In particular, when it comes to the UN CRPD, **support is a cross-cutting obligation under the Convention**. It is firmly grounded in an equality model, starting with its general obligation:

> *The Convention underlines the importance of adopting all appropriate measures to support the full and effective participation of persons with disabilities in society on an equal basis with others (Art. 4 (1) (a)).*
>
> *States must also undertake or promote research and development, and promote the availability and use, of devices and assistive technologies (art. 4 (1) (g)).*
>
> *[States must] provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, and other forms of **assistance, support services and facilities** (art. 4 (1) (h)).*

The Report (2017) of the Special Rapporteur on the rights of persons with disabilities (*theme: access to rights-based support for persons with disabilities*) [2], goes deeper into the importance of **support services**:

- *For most persons with disabilities, access to quality support is a necessary precondition for living and fully participating in the community on the basis of choices equal to others.*
- *The provision of appropriate support is necessary to the realization of the full spectrum of human rights and enables persons with disabilities to achieve their full potential, thus contributing to the overall well-being and diversity of the communities in which they live.*
- *Evidence indicates that in most developed and developing countries, **the majority of persons with disabilities have limited access to support services**. Especially:*
  - *Deaf and deafblind persons frequently face difficulties in accessing trained interpreters, particularly in rural or isolated communities.*
  - *Persons with psychosocial and intellectual disabilities are overrepresented among the homeless because of the lack of support for living in the community and for decision-making.*
  - *Furthermore, general public services in such areas as education and employment do not envision support measures to ensure the full participation of persons with disabilities.*
  - *While all persons with disabilities face challenges in accessing support, those with high support needs are disproportionately affected by the lack of appropriate **services***

- *States should therefore adopt and implement policies and programmes that enable persons with disabilities to obtain the support they need to participate in decisions affecting their lives and in the life of their communities.*

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[2] Report of the Special Rapporteur on the rights of persons with disabilities (theme: access to rights-based support for persons with disabilities)

- *States have an obligation to take immediate steps to the maximum of their available resources, including those made available through international assistance and cooperation, to ensure support for persons with disabilities, including the adoption of legislative and policy frameworks and budgetary measures.*
- *States must ensure that the support made available is of good quality. This requires, inter alia, the implementation of person-centred approaches and the adoption of guidelines and criteria to regulate the delivery of assistance and support services, including standards for training and certification.*

The Convention not only incorporates support services in its general obligation (*Article 4*), but also throughout the specific obligations, which are further explained in the general comments, thematic studies, and reports.

2. The relevance of the European Union for disability support services

Service provision in the disability field has been undergoing substantial changes over the past years, and many services that were set up according to the medical-based approach to disability, are currently moving away from this model towards the human rights approach introduced by the UN CRPD in 2006, whereby needs and preferences of the individual are at the core of the attitude towards disability. These fundamental changes in the design and delivery of services are clearly yet to be fully accomplished, both in the legal frameworks and in the practice, and they represent the challenge for the service provision of tomorrow as well as for policy makers at EU and national level.

The need to initiate profound reforms in the social care systems is at the same time also urged by the changes in the demography: more and more people will be in need of a range of services, whose demand is currently not sufficiently met.

Social and health support services have since the very beginning relied on **European Structural and Investment Funds (ESIF)**, which are key for the development of innovation in service provision through training of staff and set up of new facilities. These include the funding of employment support for groups at risk of exclusion, inclusive education measures, inclusion projects and quality social care and support among many others.
It is also relevant to acknowledge that following years of tightened public investment towards the social sector, the ESIF funds have often replaced State investment, becoming therefore fundamental to fund the regular running of the activities.

Support services are therefore among the key players for an effective implementation of the **European Pillar of Social Rights**, as well as for the **Sustainable Development Goals**.

Many of the support services in the disability field are in a transition phase as service provision is being structured more and more around the needs and the preferences of the individual, becoming more person-centred and individualised. These changes are requested by the United Nations Convention on the Rights of Persons with disabilities, which was ratified by all EU Member States and by the European Union as well. Although yet to be fully accomplished, at policy and at practical level, they represent the challenge for the service provision of tomorrow. By bringing about its human rights model, the UN

CRPD has legitimised this change of vision about disability and has become the lead model for the development of support services for persons with disabilities.

In this regard, **the guiding role of the European Union has made it possible to complement national shortcomings and bring forward the needed changes in social care systems across the Europe**, however, many challenges are still ahead and reforms in service delivery are to take place in the coming years.

3. The role of disability support structures in the services ecosystem

Social services provide the necessary support that enable millions of people to enjoy fundamental rights such as:

- to participate actively in life from the very early stages,
- to be educated
- to be in employment,
- to receive support at home,
- to relax and enjoy leisurely activities.

Support services not only impact the lives of persons with support needs themselves, **they are often equally important for their families and friends**, being as well a reference for safety and protection, even when family is no longer available, along the entire life cycle of individuals.

In a nutshell, support services play the essential function of bringing children, adults, elderly and their families in society, making them active contributors as members of a community. In the past years the way services are being organised and delivered has changed enormously, and yet a lot remains to be done. Together with the persons they support services are now revising their vision and scope as they are providing models of support co-produced and they are now striving to **support individuals to take choices and have full control over their lives**.

Even though this is not their intrinsic aim, social services are also one of Europe's biggest job creators; providing 10 million people – and growing - with meaningful professions. Social Services also benefit from the inspiring support and commitment provided by millions of volunteers.

Every individual has or will benefit(et) from social services at some point in their life; be it through childcare, support for persons with disabilities, support for mental health, elderly care or another form of social service. This is a simple truth. Still, social services are too often seen as someone else's problem, as a minor issue or simply in terms of their monetary cost; especially -but not only- by our political leaders. This leads to the wrong policy choices being made.

Over the last decade, the social services sector has been one of the sector's hit hardest by the financial crisis, with the austerity measures having disproportionately affected the funding of social care and support. The argument that in some countries funding in social services has never been higher rings hollow given that demand for social services is growing much faster. In short, social service providers – and their staff and volunteers – are asked to do more, with less money. This may sound normal to some; but the consequences on-the-ground are proving to be dire: the reform of social services has been too slow with persons with support needs continuing to have little choice and control over the services they need, staff shortages are high and increasing, social innovation has been hindered and

many of the smaller more localised providers have gone bankrupt or are at risk. This all negatively impacts the effectiveness of social services and therefore making the most of each tax-payers contribution.

The UN Convention on the Rights of Persons with Disabilities (UN CRPD) is a game-changer for social service providers and all those involved and Europe's new social compass, the European Pillar of Social Rights, both call for enabling forms of services, for more homecare and community-based services and much more. There is now little doubt as to why and how social services should be developed.

Yet, alongside the cuts to public spending, this necessary transition also comes with many challenges for social service providers: how to train and re-train professionals, how to provide more choice, control and flexibility for persons with support needs whilst developing a more sustainable business model, how to build, adapt or modernise the social infrastructure and how to reach out and engage with other stakeholders to achieve more inclusive communities.

Support services are part the economy of wellbeing and, as such, their role needs to be dutifully recognised and enabled so that they can contribute meaningfully to quality of life outcomes.

EASPD believes it is essential to support the development of an ecosystem for social services, cooperating with EU and international networks and mainstream partners. Only this way can inclusive service provision in early childhood intervention, education, employment, migration, culture, leisure, social housing sector, health and long-term care be accelerated and enacted.

4. Challenges of disability support providers

Shared values of dignity, equality and non-discrimination, included in all major international human rights conventions, have been embraced by European legislation and are guiding current and future policy developments. As a consequence, social welfare structures are increasingly called upon to adapt and set up new and innovative systems to support individuals, families and children. Persons with disabilities and the related services are the heart of major reforms needed in the social welfare sector across Europe. The following are among the main areas of service provision in need for reforms and/or support.

Delivery of inclusive and community-based support systems

- **Deinstitutionalisation and the set-up of community-based care systems**.
  The concept of deinstitutionalisation embodies the transition away from isolating institutional care towards community-based care, as well as **the development of a range of support and other services in the community** which enable participation and inclusion, such as prevention, family support, health, education, employment and housing. This implies a fundamental reshaping of how society can provide the necessary tools to individuals to participate on an equal basis
- Deliver effective support systems to allow persons with disabilities and support needs to **access mainstream labour markets**.
- Support the inclusion of persons with disabilities and support needs in **mainstream education systems**.

- Provide support to individuals with various needs aimed at e.g. **supporting their participation to society** by removing barriers to people making their own decisions and assisting them in taking decisions about their lives.
- Delivering services aimed at **facilitating access to justice**.
- Supporting inclusion of persons with disabilities through **arts, culture, sport and leisure activities**.

Training and retraining of staff

- Disability services face a constant need to adapt the ways they deliver their support to **meet individual needs**. This requires an understanding of human rights and how staff can support individuals requiring support to enjoy them to their full extent.
- Work in social care and support requires resources and investment. The underinvestment of the past decade has created staff shortages in most if not all countries; moreover poor resources also undermine career opportunities. The lack of social dialogue is not facilitating the promotion of good conditions for a qualified workforce which should be at the heart of quality support service delivery.

Innovation

- **There is a need for support services to find new ways to provide support**, keeping up with developments of society and with changing needs of individuals. Concretely this means that traditional systems to support individuals such as via one-size-fits-all approaches or "block treatments" cannot constitute anymore acceptable and qualitative solutions. There is a need to think of how support can accommodate individual needs, contexts and resources.
  At the same time, support services have created many innovative support schemes that have contributed to increase the quality of life while making individuals less dependent on benefit schemes.

Investment needs

Over the past few years, the cuts to public funding for social services in most, if not all countries in Europe, have significantly hindered the development and sustainability on more enabling forms of support and care. This has led to 2 major consequences for social services:

1) to be compelled to adapt their support schemes in order to welcome more users with lower budgets, thus placing additional pressure on the quality of the service.
2) to set aside the innovations developed in the past 20 years and reinstall outdated models of support at the expense of quality and individualisation of support.

The financial contribution of the EU to the development of support services has always been crucial to the following aspects:

- unlock potential of more disadvantaged regions
- support the much-needed development of innovation in service delivery

develop skills and competencies of individuals, as well as to financially support different types of services.

Digitalisation

- **Technologies** will fundamentally change the way in which we live, work and relate to one another. It will also change the ways we provide and receive social care and support. It will affect the day-to-day job of staff working in the sector by potentially improving working conditions and the service itself. ICT is becoming thus an important factor in service provision. ICT within broader assistive-person-centred technologies can sensibly improve quality of life, but, at the same time, there is a need for both staff and users to be knowledgeable on digital numeracy.

Rural and remote areas

- While the importance of high-quality social care and support services is hard to undermine, it is important to note that access to these services is not equal for all. In particular, people in remote rural have relatively poor access to welfare services, education, employment, income and life chances. Obstacles to using and providing social care and support services in rural areas include:
    - increased costs in time and transport taken to provide and access services
    - lack of alternative provision from the independent and voluntary sector
    - lack of anonymity
    - poverty and homelessness, which make the possibility of accessing or receiving information about such services more difficult.

Ageing persons with disabilities

- The share of older persons in the total population is rising significantly in Europe; almost half of Europe's population.
- on is over 65 and with the improvement of the health care, persons with disabilities are living longer as well. At the same time, more than 46% of persons aged 60 years and above have disabilities worldwide.
- The support provided to older persons and/or persons with disabilities who are ageing is quite fragmented and many issues need to be addressed. Legal, social and administrative barriers are hindering social inclusion and prevent full enjoyment of human rights.

Health

- There is a need to reorient health services, putting individuals, families, carers and communities at their centre, supported by responsive services that better meet their needs, and that are coordinated both within and beyond the health sector. These reforms should also incorporate a human rights approach, enshrining access to health care as a basic right.

5. Key proposals for next European Disability Strategy

5.1 Early childhood intervention and education

Context

Research and our experience show that - in general - the earlier a young child with disabilities is excluded from mainstream childcare and education services, the more excluded that person will be throughout their lifetime and as a consequence, the higher the societal cost.

Whilst young persons with disabilities often need the right type of support to enable them to participate in mainstream services, they also have the right to grow-up alongside all other children. This is of course beneficial for all children involved; both in terms of childcare and in Education.

Many positive developments are taking place across Europe to support these developments; yet such improvements continue to be too limited and frail, even within the same Member State. Whilst the main policies for these areas are at national level, there is a role for the European Union in supporting the upward convergence of all policies towards these more **#InclusiveEducation** & **#EarlyIntervention** models.

Recommendations on the role the EU could take

➢ *By being focused on [Early Childhood Education and Care](), the focus of the European Union often fails to take into account the informal learning and early years of the child and his family, which are both crucial to develop inclusive quality services for children with disabilities. The European Disability Strategy should recognise this gap and propose a strategy to address participation and inclusion for children with disabilities from the very early stages of their lives. The framework of operation of the **Child Guarantee** should be linked to the future Disability Strategy ensuring complementarity and alignment.*

➢ *The EU should look to increase funding opportunities for inclusive education, both for the promotion of inclusive education's impact on children with or without disabilities and for the funding of research and publications on inclusive education.*

➢ *Additional funding opportunities to support inclusive education outside of the Erasmus+ programme should be sought. **Erasmus+** has been and is currently being the main source of funding in the area of (inclusive) education. But given the characteristics of the programme, its scope is limited to few actions, whilst the development of inclusive education systems requires a comprehensive framework of action.*

➢ *The future European Disability Strategy should provide actions for the empowerment of families with members with disabilities. Prevention measures along with a focus on development, availability and accessibility of early intervention measures as they represent essential measures to prevent poverty, discrimination and exclusion from society.*

5.2 Employment

Context

Persons with disabilities continue to have far higher levels of unemployment than persons without disabilities; with the employment rate situated at around 50%, or around 25% if including those considered as unable to work. This reality is made even worst if taking into account that these statistics have not particularly evolved over the past 20 years; despite the techniques, expertise and research pointing to far more effective ways in which to build more inclusive labour markets. This is partly due to the fact that employment policies have not always evolved in line with this developing know-how.

Besides the terrible human element to this context, there is also an important economic cost; especially as a time when Europe needs to maximise its workforce due to the ageing population. Research conducted by EASPD demonstrates that investing in creating more inclusive labour markets is better for taxpayers and the economy too; due to the higher costs of persons who are permanently disenfranchised. Businesses are also more and more keen to have a more diverse workforce, yet often lack the support, knowhow and policies which can enable them to act.

With the European Union having ratified the UN Convention on the Rights of Persons with Disabilities, the European Union should do more to make **#Employment4All** a reality, by bridging the gap between persons with disabilities, the labour market and employment support providers. Social economy enterprises also have an important role to play having demonstrated their potential in helping persons with disabilities onto the labour market.

Recommendations to the European Union

> *The EU should better support the Member States to follow the principles of Article 27 of the UNCRPD, promoting the development of services with expertise in supporting people in accessing the labour market.*

> *The EU should take better into consideration the specificities of unemployment for various segments of the population and be mindful of this gap in the **collection of data** to draw statistics.*

> *The EU should continue supporting the Member States in their reforms of the social care system focusing on the active inclusion of persons with disabilities. The crucial role of support services should be better incorporated in the spectrum of services if the EU is to develop a healthy labour market which is inclusive for all population.*

> *The positive results in the fields of education, labour mediation as well as promising practices on the employment of persons with disabilities on the open labour market should be further enhanced, so as the role of social economy enterprises and their potential to employ persons with disabilities.*

5.3 Inclusive Living

Context

The needed changes in disability service provision towards the human rights model and an individualised and inclusive model of support require investment in infrastructures and in human capital ensuring a qualified and skilled workforce.

In several EU Member States, the provision of care and support for persons with disabilities is not part of comprehensive strategies with clear goals and benchmarks. The lack of long-term planning of support services development as well as the lack of clear roles and responsibilities in the deinstitutionalisation process puts at risk the viability of support.

Recommendations to the European Union

> *There is a need for strong leadership, mutual support and exchange of best practices to develop inclusive support systems where these are missing and to adapt those that do not respond to the human rights model of the CRPD. The EU should keep as a matter of priority on its disability agenda the development of community-based services.*

> *The EU should promote dialogue with national and local service providers organisation in order to facilitate the access to the support that persons with disabilities might need.*

> *Many persons with disabilities are still under a guardianship regime which does not allow to have full control over their lives. The EU should promote the development of **support models enabling individuals to make decisions** and enhance their self-determination.*

5.4 Staffing issues and disability workforce

Context

The disability sector has been suffering from staff shortages, recruitment and retention issues since many years and yet, while these issues don't seem to have a solution in the short-term, they represent a real challenge for the future.

Moreover, poor working conditions and increasing atomisation of the workforce (reducing number of secure labour contracts) has added to a detrimental situation where budget constraints are faced with increasing demand due to changing societal structures and socio-demographic situation.

The development of skills and competencies of individuals, as well as the financial burden to fulfil these requirements is yet to be fully recognised by European legislative frameworks.

Recommendations to the European Union

> *To ensure that the sector and its workforce can meet the increasing demand of individualisation it is crucial that social care and support services have access to sufficient resources that can enable them to meet the needs of both users and staff.*

> *The provision of individualised services that can address specific needs of individuals requires financial support that takes into consideration quality elements in the delivery of the support. Tailored investment, targeting innovation in service provision, should*

promote and incentivise active cooperation with users through e.g. co-production methodologies.

➢ *Support the EU Member States in the set-up of **social dialogue structures** to enable discussions around the way staff can contribute to deliver quality support.*

5.5 Person-centred technology

Context

(Assistive) Technology is an enabler that leads to inclusion and participation, rather than an aim itself, or a bolt on solution. When accessible, available and affordable for all, the development and deployment of technological solutions for persons with disabilities could help reducing the digital divide and embrace the numerous opportunities for inclusion.

Person centred approaches require the further integration and coordination between professionals and services belonging to different sectors, in particular health and social care, education, employment, housing. There is a need to breakthrough professional silos.

Recommendations to the European Union

➢ *A strong focus on the role of assistive and person-centred technology should drive the European disability agenda to inspire research, training and deployment of technological solutions with the potential to untap benefits for people at risk of exclusion such as persons with disabilities.*

5.6 Migration

Context

Many asylum seekers and migrants and their families are currently entering Europe under precarious situations. Many of them have disabilities and/or develop a disability while traveling to Europe, being therefore vulnerable, at risk of exclusion and segregation and with a variety of support needs due to poor mental, physical and intellectual health. These needs are currently unmet due to the lack of adequate support structures as those existing are primarily focused on treating emergency issues rather than long-term needs.

Recommendations to the European Union

➢ *There is a need to use Needs Assessment Tools for the identification of migrants and refugees' support needs. Needs Assessment Tools could also contribute to improve data collection and have a better understanding of the context. Only this way can an effective services spectrum responsive to individual needs be planned and delivered.*

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6. Conclusions

The European Association of Service providers for Persons with Disabilities (EASPD) believes the **European Union has helped to advance** the development of quality community-based care and support services across Europe. It must continue to do so.

There are many examples of the **EU's positive social impact**: the EU's ratification of the UN Convention on the Rights of Persons with Disabilities, the EU's funding programs supporting the transition to community-based care and support, as well as legislation such as the Public Procurement directive which promotes the use of quality criteria in the funding of social services; all useful instruments for social service providers. The **European Pillar of Social Rights also comes at the opportune time**; being able to act as a social compass during the transformative times.

As in other areas of society, the **social care and support sector is experiencing significant** change; in terms of expectations from beneficiaries, the way services are provided, diminishing investment levels yet increase in demand, growing staff shortages, limited innovation, et cetera. These challenges are cross-European issues and often have transnational consequences.

A new European Union Strategy on Disability should help to consolidate the good work done so far by setting clear objectives and concrete achievements for the coming years to make the European Union more disability friendly paving the way for further developments at national and international level.
In this regard a future Strategy should have clear links to other EU policies and funding programmes such as the European Semester, the European Structural and Investment Funds, Invest EU, Horizon Europe and the Child Guarantee.

In EASPD's views, instruments such as the **High Level Group on Disability** should also be revisited to become a platform to work on joint actions and exchange views through cooperation across stakeholders. As a unique set up, its potential should be further exploited to become a leading structure for the discussion and implementation of policy issues.

To conclude, next European Disability Strategy should play a role in supporting the future of care. Only by bringing together organisations providing support and organisations representing the interest of the beneficiaries, next to mainstream and relevant actors will the European Union become the pivot of an inclusive welfare systems that provides equal opportunities to all. We believe that support services are a precondition for all to be part of society. By working together - **in co-production** - in the delivery of disability policies and in **mainstreaming disability issues across EU policies**, we shall all make Europe more inclusive reaching out to society at all levels.

EASPD is ready to be partner in the implementation of a future European Disability Strategy in cooperation with all relevant actors.

Resources

2019, EASPD Report: European Semester Report: Disability Support Services In The EU: A Reality Check

2019, EASPD Report: How to fund quality care and support services: 7 key elements (Bucharest Conference 2019 Report)

2018, EASPD Report: The role of services in the implementation of the Convention on the Rights of Persons with Disabilities

2018, EASPD Report: Provision of social care and support services in remote rural areas

2018, EASPD Report: The State of Disability Workforce in Europe: needs in training, qualifications and skills

2018, EASPD and Social Services Europe Report: Improving work-life balance through enabling social services: From service provision to decent policies

2018, EASPD Report: Financing Needs in Social Services

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