

Peer Review on "Social inclusion, health and the equalisation of opportunities for young people with disabilities"

EUROPEAN COMMISSION

Directorate-General for Employment, Social Affairs and Inclusion

Unit C1

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Peer Review on "Social inclusion, health and the equalisation of opportunities for young people with disabilities"

DG Employment, Social Affairs and Inclusion

Directorate-General for Employment, Social Affairs and Inclusion

Peer Review on Social inclusion, health and the equalisation of opportunities for young people with disabilities'

Croatia, 13-14 September 2018

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This document has received financial support from the European Union Programme for Employment and Social Innovation "EaSI" (2014-2020). For further information please consult: http://ec.europa.eu/social/easi

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1 Introduction

The way modern societies look at disability have changed substantially in the last few decades. Since the emergence of the modern social movement of people with disabilities, disability advocates and their allies have influenced disability policies around the world (Barnes, Mercer, 2010). Today, disability is recognised much less as an individual medical problem, and more as a social and public policy as well as human rights issue.

Consequently, countries including EU Member States have long started to develop laws and policies aiming to tackle barriers people with disabilities face in modern societies. Such laws and policies, informed by the social model of disability (Barnes, 2012) include both sector-specific legislation such as education, employment, health or social laws and policies, and also more horizontal human rights laws that aim to combat discrimination in all areas of life to recognise people with disabilities as equal citizens.

Such horizontal, human rights-based disability laws and policies have spread across Europe in the last two decades, and today most European countries have relevant, often comprehensive disability human rights legislation in force (Vanhala, 2015). Moreover, since the approval of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) by the UN General Assembly (UN General Assembly, 2007), nearly all European states have ratified the CRPD which accelerated this trend, and most governments have started to develop policy frameworks to implement measures of the CRPD. Such policy frameworks include national and regional disability strategies and other types of government action plans relevant to disability policies.

This paper aims to map out national disability strategies and action plans, with a special focus on youth policies. Particular focus will be given to three main areas of laws, policies and services systems: education, health and employment. The paper also aims to aid policy and government experts in their strategic planning, by using the example of the recently approved Croatian National Strategy for Equalisation of Opportunities for Persons with Disabilities from 2017 to 2020. Other examples for national disability strategies and good practices will also be discussed.

What is disability?

Disability is a complex phenomenon that has various medical as well as social, political and legal definitions. As a result, the notion of disability has changed over history and it is likely to change in the future (Goodley, 2011).

Scholars as well as Disabled People's Organisations (DPOs) often distinguish between medical and social understandings of disability. Medical approaches see impairment as an individual problem that needs to be cured or rehabilitated by using methods informed mostly by medical sciences. On the other hand, the social model of disability asserts that an impairment (such as a sensory, physical or cognitive difference) becomes a disability when the society imposes barriers that hinder the social inclusion of citizens (Barnes, 2012). Article 1of the CRPD states that 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' – thereby using the definition of the social model of disability. On the other hand, the World Health Organisation's latest report uses a mixed, bio-psycho-social approach, framing disability as both a medical condition and a social issue (World Health Organization, 2011).

Domestic legal systems vary in how they define disability; thus, it is impossible to provide an all-inclusive definition employed in contemporary national disability strategies. In this paper, the term 'disability' will be used as inclusive of various types of disabilities / of various groups of people with disabilities, including for example people with visual impairments; hearing impairments; physical disabilities; intellectual disability and various learning difficulties; psychosocial disabilities; people on the autism spectrum; etc.

Given the fuzzy nature of contemporary disability definitions, it is encouraged that experts are aware of the differences between disability definitions enshrined in domestic laws.

Relevant international laws and policies, along with some basic data about young people with disabilities are presented in the first part of this paper. The second section draws upon the example provided by the Croatian national strategy and some other national action plans, and attempts to map out some of the common elements of disability strategies in contemporary Europe. Finally, the last section discusses how young people with disabilities can be supported by policy frameworks in specific policy areas including education, health and employment.

2 Setting the scene

2.1 Young people with disabilities in the EU – multiple disadvantages

Today, based on estimates by Eurostat, there are approximately 80 million EU citizens who live with a disability. Their lives, well-being and meaningful social inclusion are hindered by a number of systemic barriers including limited access to education, low levels of employment, poor health, poverty, lack of access to buildings, transport and public services, and lack of support to live in the community (European Disability Forum, 2016a).

These barriers are especially severe in the lives of many *young people* living with disabilities in the EU. For example, the number of young people with disabilities in education is generally lower than the number of their peers without disabilities, and they also usually leave education systems with lower qualifications (Eurostat, 2014). Reports also indicate that by the age of 26, young people with disabilities are four times more likely to be unemployed or be living on welfare benefits than people without disabilities of the same age (Burchardt, 2005). Studies on healthcare are even more concerning. For example, it was found that people with an intellectual disability in the UK are likely to die 16 years earlier than the average population, largely due to poor healthcare, lack of prevention and other systemic problems (Heslop et al., 2014) – and it is likely that similar trends can be found across Europe. Policy makers also warn that young people in general, and especially vulnerable sub-groups such as youth living with disability may have limited access to or interest in participating in public or political life (Denstad, 2009), and this is partially due to venues, meetings and public consultations being inaccessible to them.

Several of these problems are also identified in the Croatian National Strategy for Equalization of Opportunities for Persons with Disabilities. For instance, the strategy states that children and young people with disabilities have limited access to primary, secondary and tertiary education in Croatia. The Croatian national strategy also sets out measures to improve the participation of young people with disabilities in public and political activities, for example by supporting their participation in public debates, recognising that people with disabilities need to be included in all decisions that concerns them.

2.2 International policy frameworks and young people with disabilities

Recognising the multiple problems people with disabilities face in modern societies, national governments have started to develop disability-specific laws and strategies, for example to improve policies and practices in healthcare, social services or education. Such sectoral laws and policies have been strongly influenced by human rights laws since the 1990s. Non-discrimination laws, equality laws, and even more specific 'disability human rights' laws have been developed in nearly all EU member states since

the first such European law, the UK's Disability Discrimination Act of 1995 (Vanhala, 2015). In the 'diffusion' of disability rights legislation in the EU, there are two major international laws that influence how EU Member States develop laws and policies to improve the lives of people with disabilities.

First, the most important disability-specific international law today is the CRPD which itself is referenced as the inspiration and guiding principle for both the European Disability Strategy and a number of national disability action plans. The CRPD, ratified by 177 countries by August 2018, was developed with the active involvement of DPOs who shaped its content significantly (Sabatello, Schulze, 2014). There is a strong consensus among DPOs and other civil society actors as well as academics that the CRPD is not only the most seminal international law in the field, but also the major driver for progressive laws and policies around the world. Indeed, although only 11 years have passed since its entering into force, the CRPD has already been found to influence laws, policies and services internationally. For example, since 2010 several European governments have started developing new legal capacity laws and also launched programmes to step away from institutionalised to community-based care and thus comply with principles set out in the CRPD (Turnpenny et al., 2018).

Second, the European Disability Strategy 2010-2020 sets out plans and actions to improve the social inclusion of people with disabilities in the EU, by proposing measures in eight priority areas, including accessibility, participation (in public life), equality, employment, education and training, social protection, health and (EU) external action. The Strategy builds strongly on EU Member States' voluntary commitments and also includes a reporting mechanism to follow progress made in the implementation on EU and Member State levels. Importantly, the EU Disability Strategy itself builds on the principles of the CRPD.

The Croatian national disability strategy makes references to both documents, among other international laws and policies. In fact, the CRPD is mentioned as one of the guiding principles of the Croatian strategy, whilst the paper also acknowledges the progress made around the world due to enhanced human rights advocacy and measures inspired by the CPRD itself.

The European Disability Strategy is not the only EU-level common framework that is relevant to disability laws and policies in Member States. The 'Europe 2020 strategy' is the European Union's agenda for economic growth, employment and other policies, including education and social inclusion (European Commission, n.d.). The strategy has set out ambitious targets, including lifting 20 million people out of poverty/social exclusion, the reduction of the number of early school-leavers and more EU citizens in employment. The framework builds on Member States' own targets, implementation and reporting.¹ Reports on the implementation of the EU 2020 strategy may contain important information about Member States' achievements in reducing the social exclusion of people with disabilities.

Of course, national strategies relevant to young people living with disabilities can be found in other policy areas and other action plans as well. For example, national *youth strategies* may contain measures aiming at young people with disabilities or may cover policy areas relevant to disability policies, such as the mental health care of young people. (People with mental health problems may be recognised as 'people with psychosocial disabilities' by governments, partly due to the provisions of the CRPD.)

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¹ Eurostat regularly updates its website on the targets achieved under the EU 2020 strategy. For more information about EU and national indicators visit: http://ec.europa.eu/eurostat/web/europe-2020-indicators/europe-2020-strategy/headline-indicators-scoreboard.

In fact, youth policy experts recommend that local and national youth strategies cover vulnerable groups such as young people with disabilities (Denstad, 2009). In national youth strategies, such as the Polish State Strategy for Youth 2003-2012, the Serbian National Youth Strategy (2015-2025) and the current Hungarian National Youth Strategy (2009-2024) young people with disabilities are recognised as a vulnerable group. The European Union's Youth Strategy 2010-2018 also provides a framework for cooperation between EU Member States in policy areas relevant to people with disabilities, including employment, social inclusion, health, education, and culture (European Commission, 2018a). Current national youth policy strategies consist of specific measures aimed at improving young people's participation in society by, for example, supporting their access to youth services or democratic procedures (European Commission, 2018b). Other national strategies such as childcare strategies or social policy frameworks may also contain measures aiming at young people with disabilities.

3 National strategies – what are the necessary elements of a 'good' disability strategy?

Government action plans and strategies can cover very different policy areas and they can be developed with various aims. So it is advised that policy experts are aware other national action plans and explore possible synergies. Government strategies can be developed in many ways:

- For example, strategies can be designed to tackle problems of a certain population group (e.g. Roma strategies or childcare strategies), such as the UK Autism Strategy that aims to improve the lives of people on the autism spectrum in Britain (Department of Health and Social Care, 2018) or the Hungarian Youth Strategy (Hungarian Government, 2014) that covers young people living in Hungary;
- Strategies may cover a specific policy area (such as mental health strategies, social policy strategies or housing strategies), for example the Estonian Social Welfare Plan 2016-2023 or the Scottish mental health strategy adopted in 2015 (Turnpenny et al., 2018);
- Sometimes, strategies set out actions in order to reach a desired state for example by including capital investments as well as policy changes. In the disability field, deinstitutionalisation strategies aim to replace residential institutions for various groups (e.g. children, people with disabilities, elderly people) with community-based services such as the Belgian deinstitutionalisation strategy adopted by the Belgian government in 2011 (Turnpenny et al., 2018).
- Sometimes, some form of strategic plan may exist in countries but they are not necessarily approved by the Parliament and have a lower legal status than laws such as acts or bills. For example, the UK Government published their *Improving Lives: the Future of Work, Health and Disability* (2017) document which is still in a 'white paper' form (i.e. legislative proposal) and has not been approved by the Parliament. Disability strategies in such a legal status may signal what a government plans to do in a policy area, but their implementation is not mandatory for public bodies.

Importantly, DPOs also publish statements and voice demands about how national disability strategies or other strategies impacting the lives of people with disabilities should look like. One such statement is that of the European Network on Independent Living (ENIL) which provides guidelines about how disability strategies should be

developed and implemented (Parker, Anguelova-Mladenova & Bulic, 2013).² According to ENIL, as part of their recommendations to the Government of Romania's national disability strategy in 2013, developing a disability action plan should have five core elements: the assessment of the current situation; setting targets and objectives; developing action points; monitoring and evaluation; and revision (Figure 1.). The process is cyclical, implying that disability strategies need to be regularly reviewed (a requirement in line with provisions of the CRPD, which require regular reporting mechanisms of States Parties to the Convention). The cyclical process should be built around principles such as participation (of a broad range of stakeholders including DPOs); coordination (by state bodies); and adequate resources necessary for the success of the strategy.



Figure 1. Developing an action plan (adapted from Parker et al. 2013)

Although such recommendation may influence how governments develop their disability strategies, a closer look at current disability strategies shows that EU Member States employ different approaches when designing their frameworks – and probably there is not a single 'best way' to do it. However, certain common features of existing strategies may indicate crucial elements needed for success.

Notably, many countries develop national disability strategies that provide a broad policy framework and timeline for actions to be taken to improve social inclusion of people with disabilities. However, this is not an approach that all countries follow. Some countries – like Sweden or Spain – decide to mainstream disability policy reforms in other national action plans.

In this section, national disability strategies are reviewed and common features of current strategies are presented, with the aim to point out what elements may be

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² Another such recommendation is the so-called 'Common European Guidelines on the Transition from Institutional to Community-based Care' (Deinstitutionalisation Guidelines) published by a broad coalition of DPOs, NGOs and international organisations in 2012, and endorsed by both the United Nations Office of the High Commissioner for Human Rights, UNICEF and the European Commission. The 'Deinstitutionalisation Guidelines' consist of several recommendations and good practices about how to develop and implement national action plans aiming to move away from large residential institutions to community-based services. The guidelines is available in 12 languages at https://deinstitutionalisation.com/eeg-publications/.

necessary in order to develop a sound strategy that has a real impact on the lives of people with disabilities.

3.1 National Disability Strategies³ in the EU

Currently, the large majority of EU Member States have a government-approved national disability strategy in force, with some of them – typically in federal states such as Germany and Austria – featuring both national and regional strategies (see Annex 1). All national laws/policies listed in the Annex provide a general legal framework specific to disability, with a timeframe and specific objectives to be met. In other words, what differentiates a generic law from a national strategy is that a strategy / action plan usually contains a timeframe, responsible bodies and specific targets to be met before the end of that timeframe.

In the case of national disability strategies, civil society actors and particularly DPOs, have been issuing recommendations -and often criticism- about government proposals. For example, Inclusion Ireland, the national umbrella organisation representing people with intellectual disabilities and their families in Ireland, issued a comprehensive position paper about the Irish National Disability Strategy in 2013 (Inclusion Ireland, 2013). Furthermore, on the EU-level the European Disability Forum, the leading European DPO, has been voicing criticism about the European Disability Strategy, because it is seen to be too vague, lacking ambition and an effective monitoring mechanism (European Disability Forum, 2016b).

The overview of current national disability strategies allows for some comparisons between Member States' approaches. A handful of EU Member States such as France, Portugal and the UK do not have a current national disability strategy in place (although local or regional action plans may be in force). Notably, some countries feature disability-specific policy measures in other national action plans: for instance, Estonia's Social Welfare Plan for 2016-2023 was designed to include several provisions and targets in disability policies.

All current national disability strategies make explicit links to international frameworks. For example, all of the reviewed national disability strategies make references to the CRPD as their guiding principle. In fact, several strategies claim that their objectives are in line with the CRDP and some strategies even claim to be the actual implementation framework of the CRPD, for example in the case of Austria, Latvia and Luxembourg. With regard to compliance with the CRPD, caution is necessary because evidence indicates that not all national implementation mechanisms comply with the CRPD or other international human rights laws (Phillips, 2012).

While the CRPD seems to be a fundamental international law in the context of national disability action plans, several strategies also make references to other international frameworks. The European Disability Strategy 2010-2020, which relies strongly on voluntary commitments of EU Member States, is linked to nearly all current strategies.

By using recent core literature relevant to both national and international disability policy frameworks (Lawson, Priestley, 2013, Parker, Anguelova-Mladenova & Bulic, 2013) and to international and national youth policy (Denstad, 2009), the following common elements of national disability strategies are discussed: timeframe, policy areas, coordination and cooperation, monitoring, and budget.

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³ The term 'strategy' will be used as synonymous with 'action plan', especially because several current national disability strategies (e.g. in Cyprus, Denmark and Spain) are titled 'action plans'.

3.2 Timeframe

Current national disability strategies in the EU set up timeframes between three to ten years. Most action plans cover shorter periods, for example the national strategies of Cyprus, Belgium, Bulgaria, Germany and Romania all span over three or four years. Longer disability strategies include Austria with eight years and Cyprus and Hungary with ten years, respectively. Although timeframes vary between countries, several EU Member States have developed national strategies ending in 2020 which may indicate that EU Member States are harmonising their national policy frameworks with that of the European Union. The current EU Multiannual Financial Framework 2014-2020 (the EU 'budget') will be renewed after 2020 and there are also proposals to follow-up on the European Disability Strategy after 2020.

Timeframes of national strategies allow for stringent planning by setting deadlines for certain deliverables. This approach is particularly important to sequence correctly interdependent activities managed by different actors. For instance, if an action plan sets out to train doctors and nurses in hospitals about the special needs of people with severe and multiple disabilities, first the trainings needs to be developed and piloted (milestone 1), and then once the training curriculum is finalised the trainings can commence reaching a number of professionals (milestone 2). Timeframes in some cases are also broken up into shorter periods: for example, in the case of Latvia, where the national strategy that spans seven years (2014-2020) is divided into two shorter action plans (2014-17 and 2018-20). Similarly, in the case of Hungary, the 10-year long national disability action plan (2015-2025) is divided into 3-year long terms (2015-2018, 2019-2022, etc.). Such arrangements of intermediate plans and milestones also allow for regular reviews, and help closer monitoring, enabling adjustments that may be necessary due to external factors such as socio-economic trends.

3.3 Policy areas

Current disability action plans – as stated before – strongly build on the provisions of both the CRPD and the EU Disability Strategy. Consequently, some policy areas are found in nearly all national strategies, for example anti-discrimination measures, accessibility, education, employment, health and social inclusion are included in the large majority of existing domestic action plans. Other areas are mentioned in several strategies: cultural or sports activities (Bulgaria, Croatia, Germany, Hungary, Lithuania, Slovakia, Slovenia); political participation (Croatia, Czech Republic, Romania, Luxembourg); and (accessibility of) public transport and personal mobility (Bulgaria Croatia, Denmark, Ireland, Germany). Notably, recognising the need for combatting stigma and to inform society about rights of people with disabilities, several strategies include measures about public awareness-raising (Austria, the Czech Republic, Latvia, and Slovenia). Some countries also set out plans for data collection and research.

Disability action plans vary in how comprehensive they are. Based on available information, some national strategies are much more wide-ranging than others, for example, the Austrian, Croatian, Czech, German, Hungarian and Romanian action plans consist of various policy areas, while others like the national strategies of Spain, Denmark or Belgium have a somehow narrower focus. For example, the current Belgian framework is mostly focussed on supporting community living by re-designing personal welfare payments and by eliminating segregated settings.

3.4 Coordination and cooperation

Both coordination and transparency are necessary elements of an effective national strategy (Denstad, 2009, Parker, Anguelova-Mladenova & Bulic, 2013), and nearly all disability action plans include provisions with regards to coordinating government bodies and – regular or one-time – reviews (further discussed in 3.5).

Coordination is usually assigned to one or more ministries within a government structure. These are typically ministries responsible for social affairs or human rights. Other human rights bodies may also be involved in the monitoring of implementation. Such focal points ensure that a government – as the responsible authority for the implementation – 'owns' a national strategy (Denstad, 2009) and can be easily contacted by all relevant stakeholders about inquiries regarding the implementation. This is not to say that others, such as municipalities, regional authorities or DPOs and other civil society actors cannot and should not claim 'ownership' over a strategy and its implementation. On the contrary: government ownership and clear responsibilities, transparent coordination and close monitoring can ensure that a strategy is implemented with the fullest possible involvement of DPOs as well as other stakeholders where necessary (Lawson, Priestley, 2013, Denstad, 2009).

Current national disability action plans – where information is available – feature very different types of coordination mechanisms. In some cases, one ministry is clearly mentioned as the focal point for implementation, for example in Latvia and Slovakia. In other cases, several ministries are responsible for managing and reporting on the implementation, like in the case of Denmark and Germany. In the case of federal states like Germany and Austria, responsibilities may also be delegated to regional governments and shared between different levels of public administration.

Importantly, coordination and the clear division of responsibilities may also aid the better cooperation between different sectors and state bodies. In fact, disability policies often make it necessary for different sectors such as social and health sectors to cooperate, for example when developing community-based services for people with disabilities (Parker, Anguelova-Mladenova & Bulic, 2013, European Expert Group, 2012).

Cooperation can be both horizontal, when authorities of the same level, such as different ministries are consulting over issues – or vertical, when state bodies of different levels are meeting regularly, for example when ministries are consulting with local and regional authorities. Coordination between sectors (ministries, authorities, services systems) may be a potential weak point in all comprehensive national strategies, not only in the disability but also in the youth field (Denstad, 2009). Inter-ministerial working groups may be an effective way of ensuring such cross-sectoral cooperation, where different ministries can regularly discuss the progress made and the adjustments necessary during the implementation. Such inter-ministerial groups are found to be helpful and necessary when implementing not only disability but also youth action plans (Denstad, 2009). The establishment of a secretariat at the focal point, and thematic working groups can also aid both the successful coordination and cooperation between different sectors and bodies.

3.5 Monitoring

Monitoring the implementation of strategies is closely linked to the involvement of civil society organisations, most importantly DPOs. The CRPD itself recommends that DPOs should be meaningfully involved in the planning, development, implementation and monitoring of policies and programmes aiming at people with disabilities – in the spirit of the slogan 'Nothing about us without us'. Of course, this principle is not always easy to respect, for example because existing consultative bodies lack the mandate to access information or to influence the coordination of action plans, or because DPOs themselves lack the – human or financial – resources necessary for their meaningful involvement. Therefore, when setting up monitoring procedures it needs to be ensured that organisations involved have access to information, and also have the necessary resources to carry out actual evaluation, to travel to venues, to employ experts or to publish reports on findings of the monitoring.

Monitoring provisions should be included in action plans because implementation needs to be followed, outcomes need to be measured and reported, and actual results need to be compared with the original plans (Parker, Anguelova-Mladenova & Bulic, 2013).

Indicators may be a useful tool to assess outcomes and to aid monitoring. Monitoring can be carried out by various different partners including non-governmental organisations such as DPOs, academic institutions, human rights bodies, and others. Monitoring and evaluation may include both quantitative and qualitative data (Lawson, Priestley, 2013). For example, quantitative data can include statistics, the number of participants reached by a programme or the number of service users accessing new or adapted services. Qualitative evaluation, on the other hand, can focus on subjective variables, for example whether participants of a training actually found the training useful or not, or how users feel about newly established services.

Importantly, DPOs as well as academic studies emphasise that monitoring and evaluation of disability policies or services should look at personal outcomes, for instance how personal needs and preferences of the individual (and, where relevant, their families) are met (European Expert Group, 2012). In terms of measuring personal outcomes, the 'Quality of Life' framework developed by Robert Schalock and his colleagues (Schalock et al., 2002) is broadly accepted and recommended by both service providers and DPOs. as it offers flexibility and includes various human rights principles. As a result, monitoring and evaluation may need to step beyond looking at data already present in state databases such as statistical data on people with disabilities, data on special aids handed out per year or the number of recipients of welfare provisions. Monitoring can include (UNICEF & World Bank, 2003) the analysis of data about (a) regulatory mechanisms such as licensing, accreditation; (b) inspection that looks at good practices as well as areas where improvements are needed - reports should be public; (c) performance measurements that relies on predefined indicators; (d) complaints systems that offers protection to those making complaints under an independent system for processing complaints; (e) ombudsmen and other independent advocates that look at the fulfilment of rights.

Current national disability strategies employ very different monitoring provisions. For example, the Austrian monitoring mechanism was established in close cooperation with the national disability council and it includes a supervisory body that is responsible for regular reviews and reports on the implementation of the strategy. On the other hand, in several countries such clear responsibilities were not found or information was not available indicating that some national strategies may see monitoring less crucial in their framework.

Caution about expected and actual outcomes of national strategies is necessary. For example, recent reports on government deinstitutionalisation strategies found a lack of data about the actual progress made even in currently running deinstitutionalisation programmes (Turnpenny et al., 2018). Reports from youth policy strategies also indicate that seemingly ambitious government youth strategies often lack effective monitoring mechanisms (Denstad, 2009).

3.6 Budget and resources

Both academic and civil society reports recommend that government strategies include detailed plans for the necessary resources needed for meeting the desired targets (Denstad, 2009, Parker, Anguelova-Mladenova & Bulic, 2013, European Disability Forum, 2016b). Budget constraints and limited resources can impose serious limitations on the impact of an otherwise ambitious strategy. In other words: actions need resources and funding which should be allocated by the government and other responsible authorities. Such resources may include the costs of human resources (e.g.

recruitment of new personnel or training of existing workforce), capital investments (such as new buildings, accessibility), costs of monitoring and capacity building of DPOs.

Of course, state budgets are always limited and prioritisation is needed to prevent unrealistic planning. Shorter periods of implementation may prevent unrealistic planning and allow for adjustments, including the allocation of extra funding (for example, budget-planning may allow for transfers between budget lines during the implementation). For several EU Member States, possible sources of funding include not only domestic budget but also EU Structural Funds. Not surprisingly, several current national disability strategies allocate both domestic and EU funds for the implementation of actions; this is the case in several East European countries such as Bulgaria, Hungary, Lithuania and Romania. Countries may also rely on both national and local funds, for example contributions by municipalities or in federal states by regional governments, like in Germany where regional strategies are co-funded by regional authorities.

4 Policy areas: education, health and employment

In this section three core policy areas, education, health and employment are presented with a focus on how current government disability strategies address problems in these sectors. Particular attention is given to core problems mentioned before, namely:

- Cooperation between stakeholders and different sectors in the implementation of actions;
- Accessibility of mainstream services;
- Effective monitoring and evaluation.

4.1 Education

Education, including access to education has been at the core of disability rights policies around the world and it is also covered by the CRPD. Yet, children and young people living with disabilities still have significantly lower access to education around the world, including in countries of the European Union (World Health Organization, 2011). Currently, EU Member States have diverse systems in place, with some countries providing more inclusive education for children with disabilities, and other states still relying strongly on special (segregated) school systems (ANED, 2017). Since education is outside the European Union's competences, Member States regulate their policies independently.

Education is featured in most current national disability strategies of EU Member States, including in Austria, Bulgaria, Czech Republic, Germany, Hungary, Ireland, Lithuania, Romania etc. In some countries, for example in Ireland, education is also included in other national strategies. Provisions about education in national action plans usually include two common elements:

- making educational services and facilities (primary, secondary and tertiary education) accessible;
- the importance of multi-stakeholder planning, for example in the transition from secondary to tertiary education or from education to the labour market⁴.

Accessibility in education includes both improved physical accessibility and various other factors that ensure young people with disabilities are able to join secondary schools and universities. For example, the Czech national disability strategy includes provisions to improve access to education for children and young people with disabilities, including

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⁴ Measures enhancing inclusive education (i.e. the inclusion of children with disabilities, most often children with intellectual or multiple disabilities in mainstream school systems and the provision of appropriate support) are also part of several national disability strategy, but measures are not part of the present analysis.

specific know-how increasing teachers and university staff, adapting curricula, and more flexible teaching. In order to monitor progress, the Czech action plan also includes data collection and monitoring, for example about the number of university students with special needs. Other provisions like awareness-raising and anti-stigma campaigns may also target schools and young people, because pupils with disabilities and students are often stigmatised by their peers without disabilities (World Health Organization, 2011).

Another core problem in education policies is the transition from education to employment or the transition between secondary to tertiary education. Academic studies found that although there are comprehensive, multi-stakeholder models that aim to aid successful transition for youth with disabilities, these models have been scarcely evaluated. In the absence of such evidence, writers of a systematic review still found evidence that person-centred planning involving both the student, their family and schools are the most effective (Cobb, Alwell, 2009). Studies also suggest that among young people with disabilities those with a learning disability and acquired brain injury receive even less support (Cobb, Alwell, 2009).

Notably, studies also found that for the successful transition from education to employment for young people with disabilities, both funding, necessary equipment and facilities, and trained personnel are necessary (Burchardt, 2005) – which means that for successful transition programmes significant resources may need to be allocated. For example, the right to be taught in sign language and the use of Braille in schools may also be part of disability strategies (ANED, 2017). For young people on the autism spectrum, practitioners in a Scottish policy paper emphasised that planning for the transition to employment must start early and follow the young person up to their 25 years of age, in order to discover a wide range of (work) opportunities and related special support needs (Stewart, 2017).

4.2 Health

Healthcare and rehabilitation in general and equal access to health, in particular, have been recognised as a basic right for all citizens, including people with disabilities. Health policy is in EU Member States' competencies; therefore, EU countries regulate healthcare in diverse ways. Health is often mentioned together with rehabilitation, a term used for complex services aiming to restore someone's skills or health through various interventions, training and therapy. Such services, depending on a countries' traditions, can be found in the healthcare or in social services systems, or in both.

DPOs as well as a number of international human rights laws including the CRPD recommend that reasonable accommodation⁵ is provided for patients with disabilities, for example by giving them information in easy-to-read or plain language⁶, by providing them with accessible facilities, flexible treatment plans or adapted interventions (Parker, Anguelova-Mladenova & Bulic, 2013). Currently, equal access to healthcare is hindered by numerous factors, including inappropriate / inaccessible facilities, lack of information and stigma. Studies carried out in several EU countries show that people with disabilities often face discrimination, when receiving health services (Waddington, 2015).

Several national disability strategies recognise healthcare as a core area for developing new policies and better services. Health and rehabilitation are featured in the majority

⁵ Reasonable accommodation (also referred to as reasonable adjustment) is defined by the CRPD (Art 2.) as 'necessary and appropriate modifications and adjustments not imposing a disproportionate or undue burden [...] to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.'

⁶ Inclusion Europe has published European standards for making information easy to read and to understand in 16 languages available at http://easy-to-read.eu/wp-content/uploads/2014/12/EN_Information_for_all.pdf

of national action plans, including in Austria, Bulgaria, Germany, Hungary, Ireland, Lithuania, Romania, and Slovakia.

Accessibility in the context of healthcare is a complex issue. Access to healthcare can be ensured by various means: for example, by giving personal support to access health services (personal assistance), by organising adapted transport to facilities, by making buildings accessible (including inpatient and outpatient facilities) or by ensuring that sign language interpretation is freely available for deaf or hard of hearing patients (World Health Organization, 2011, Waddington, 2015). Informed consent by all people with disabilities is of particular concern, because it is found that many people with an intellectual disability or people with mental health problems, are not always consulted properly by medical staff (Waddington, 2015).

National strategies may recognise different areas for intervention to ensure better access to healthcare. For example, the Hungarian national strategy includes comprehensive measures such as training of health personnel (including doctors and nurses) on disabilities and about the special needs of people with disabilities; broad consultation among stakeholders to develop strategies for the better healthcare of people with psychosocial disabilities; improving participation of people with disabilities in screening programmes; carrying out research about the needs of people with mental health problems; reviewing access to special aids and devices for people with disabilities; and awareness-raising programmes to combat stigma. Furthermore, Hungarian authorities also commit to improve the physical accessibility of health facilities. A multi-stakeholder approach is ensured by consultation with various partners (e.g. patients' organisations, DPOs, health authorities, unions).

Investments in healthcare, of course, often involve significant financial costs. Importantly, EU Member States do not have to rely solely on their domestic budgets, because EU Structural Funds have been available to initiate projects in healthcare, for example they can be allocated to projects that reduce inequalities in terms of health status (Parker, Anguelova-Mladenova & Bulic, 2013).

4.3 Employment

The field of employment is a shared competency between Member States and the European Union. The rate of employment is consistently lower for people with disabilities than people without in many countries around the world (World Health Organization, 2011) – therefore, one of the main objectives of existing international legislation like the CRPD and the European Disability Strategy is to ensure that more people with disabilities can earn their living in the open labour market. Since the employment of young people (with and without disabilities) is already low in several EU Member States (Eurostat, 2017), it can be assumed that young people with disabilities are hindered in the labour market not only by the lack of disability-specific laws and support services, but also by major labour market and economic trends.

Similar to the field of health, people with disabilities may be entitled to reasonable adjustments at the workplace. DPO statements emphasise that such reasonable adjustments are necessary for the successful employment of people with disabilities (Parker, Anguelova-Mladenova & Bulic, 2013). These adjustments can be various, including accessible buildings; special tools, hardware and software necessary to work; flexible working hours; training; special assistance; awareness-raising; etc. However, studies indicate that the reason why enterprises do not employ more people with disabilities is not only the lack of such provisions, but also the fear of extra costs, lack of awareness of disability (stigma), and fear of liability (Kaye, Jans & Jones, 2011).

Specialised programmes and tailored labour market services can be effective in supporting the employment of people with disabilities. For example, evidence shows that some alternative labour market services such as 'Supported Employment' or

'Individual Placement and Support (IPS)' can be effective in helping people with disabilities to find jobs and to stay in employment (Bond, 2004).

Unsurprisingly, employment is also one of the core policy areas in most current national disability strategies, for example in Austria, Bulgaria, Cyprus, Czech Republic, Germany, Hungary, Ireland, Latvia, Lithuania, Slovakia, and Spain. While some countries – for instance, Germany and Austria – use a more comprehensive approach by setting a number of measures in the field, other countries, such as Spain focus more on one particular area of policies (discrimination at work, particularly gender-based discrimination).

Monitoring employment and evaluating impact of labour market provisions in national strategies is usually carried out through regular EU-wide labour market surveys, national data collections and other statistical studies. However, DPOs also emphasise that organisations representing people with disabilities should be involved in evaluating the employment of persons with disabilities, for example because unemployment is closely related to other factors of social exclusion, such as the lack of support services in the community.

The issue of employment is also closely related to the availability of services in other sectors, most prominently social services. For example, according to the consensus of a broad coalition of policy experts and NGOs, including organisations representing children, people with disabilities, and service providers, the existence of community-based services is a precondition of successful employment (European Expert Group, 2012).

5 Conclusions

National action plans and strategies relevant to disability policies are a popular form of setting policy targets and implementing policy changes in EU Member States. By 2018, several countries have gathered significant experience in developing and implementing national disability strategies, while other countries prefer mainstreaming disability policies into other national frameworks. The human rights approach to disability and particularly the principles enshrined in the CRPD have informed most current national strategies. Most countries try to harmonise their national action plans with relevant EU policies such as the EU Disability Strategy or the EU 2020.

Currently, good practices are available in several countries. International exchange and 'lessons learned' can inform public officials before and during the development of national strategies.

Several core elements seem to be common factors for an impactful and realistic strategy. For example, carefully planned and transparent coordination and cooperation between public bodies, including between different service sectors are necessary for an effective implementation. Strong monitoring mechanisms are important to follow up on outcomes achieved. In the evaluation of outcomes, both quantitative and qualitative methods can be used to illuminate not only statistical data but also the actual impact achieved, for example through collecting the views of those covered by the strategy. Appropriate and realistic funding is of paramount importance to turn plans written on paper into actual actions – financial resources can be allocated from both domestic (national, regional, local) and EU-funds. Synergies between disability strategies and other national action plans e.g. youth strategies or welfare strategies can enhance impact.

DPOs, as representative organisations of people with disabilities must be consulted throughout the planning and implementation – and they must be provided with

appropriate funding to be able to participate in the monitoring and evaluation of the strategy.

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7 Annexes

ANNEX 1. National Disability Strategies in the European Union

Country	Title of strategy	Timefram e	Policy areas covered	Governance / coordination	Finance
Austria	National Action Plan on Disability 2012 – 2020: Strategy of the Austrian Government for the implementation of the CRPD.	2012-2020	Disability policy (definition etc.); protection against discrimination; accessibility; education; employment; living Independently; health and rehabilitation; awareness-raising.	A 'supervisory group' is established that oversees the implementation of the strategy. Interim assessments in 2015-2018. Final report in 2021.	n/a
Belgium	Perspective 2020	2016-2020	Main focus falls on the support to community living and the elimination of segregated settings.	n/a	Strategy aims to implement personal budgets for people with disabilities.
Bulgaria	National Strategy for Persons with Disabilities	2016-2020	Accessibility; freedom of expression & access to information; inclusive education and life-long learning; healthcare; employment; community living; cultural, tourist & sport activities	The Strategy is divided into Action Plans. The current Action Plan (2016-18) was adopted in 2016. Monitoring is the responsibility of the Ministry of Labour and Social Policy.	National, local and EU funds are possible sources of funding.
Cyprus	Second National Disability Action Plan	2018-2028	Actions include priority areas such as accessibility, social inclusion, and employment.	The first review is due after the period of 2018-2020. Eight ministries will take part in the implementation.	n/a
Croatia	National Strategy for the Equalisation of Opportunities for Persons with Disabilities 2017-2020	2017-2020	The strategy covers 16 areas including health, education, employment, community living, social care, culture, participation in political life, sports, international cooperation, families etc.	A complex monitoring mechanism includes local, regional and national authorities as well as NGOs and DPOs.	Both domestic and EU funds are allocated for the implementation.

Czech Republic	National Plan for the Promotion of Equal Opportunities for Persons with Disabilities	2015-2020	Areas include: discrimination, education, accessibility, equality before the law, awareness raising, personal mobility, independent living, family life, health, employment, political participation, social security, statistics etc.	Coordination lies with several ministries, including the Ministry of Human Rights. Central role to the Government Board for People with Disabilities (composed of ministry representatives, the DPOs and cooperatives).	Financial limitations are applied to all policy areas.
Denmark	National Disability Action Plan	2013-	Non-discrimination, access to IT and transport, 'compensation for barriers', prevention.	Ministry of Children, Gender Equality, Integration and Social Affairs and other bodies	n/a
Estonia	No national disability strategy. ⁷				
Finland	No current national disability strategy.8				
France	No national disability strategy.9				
Germany	National Action Plan 2.0	2017-2021	The strategy includes 13 areas such as education, employment, health and rehabilitation, children and youth, women, mobility, culture and sport, political participation, housing, awareness-raising	The strategy is amended by regional strategies in nearly all German administrative regions. Several ministries are responsible for the implementation.	Federal and regional budgets.

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 $^{^{7}}$ Although Estonia has no specific national disability strategy, but the 'Social Welfare Plan for 2016-2023' includes several actions relevant for disabled people.

A previous national disability strategy 'VAMPO' ran between 2010-2015.
 The French government has proposed to develop a national disability action plan, to be published in 2018.

Greece	No national disability strategy ¹⁰				
Hungary	National Disability Programme	2015-2025	Areas include healthcare, education, social services, employment, rehabilitation, and legal capacity, transport, sport, culture, accessibility etc.	The strategy is divided into action plans. The current action plan runs from 2015 to 2018, overseen by the Social Ministry. DPOs are consulted and take part in monitoring.	Costs of actions are specified in the action plan; both national and EU funds.
Ireland	Disability Inclusion Strategy	2017 - 2021	Equality and choice; policies and public services; education; employment; health and wellbeing; person-centred disability services; living in the community; transport and accessibility.	Annual reporting on implementation by a Steering Group.	n/a
Italy	n/a				
Latvia	Guidelines on the Implementation of the UN CRPD 2014-2020	2014-2020	Priority areas include education, labour and employment, social protection, and public awareness.	The strategy is divided into implementation plans, 2015-2017 and 2018-2020. The Ministry of Welfare is responsible for the coordination.	n/a
Lithuania	National Programme for Social Integration of the Disabled	2013-2019	Education & training, healthcare, rehabilitation & psychosocial rehabilitation, social services, education, social security, employment, culture, sport, recreation, family life.	n/a	Funding is allocated by using both domestic and EU funds.
Luxembourg	National Action Plan on the Implementation of the CRPD	2012-	The plan has a strong focus on legal capacity and political participation.	n/a	n/a
Malta	National Disability Strategy	n/a	n/a	n/a	n/a

¹⁰ Disability-related measures are part of the National Strategic Framework for Social Inclusion (2014-2020), e.g. deinstitutionalisation, employment, and education.

Netherland	ds No formal disability strategy.				
Poland	n/a				
Portugal	No current disability strategy. 11				
Romania	A society without barriers for people with disabilities, 2016 – 2020	2016-2020	Eight main areas are included: accessibility, participation, equality, employment, education and training, social protection, health, and statistics and data collection	n/a	Both national, local and EU funds are used for the implementation.
Slovakia	National Program on improving living conditions of persons with disabilities 2014-2020	2014-2020	education, rehabilitation, cultural life, political and civil participation.	The focal point for coordination is the Ministry of Labour, Social Affairs and Family. Monitoring reports are published regularly.	n/a
Slovenia	Action Plan for Disabled 2014- 2021	2014-2021		A multi-stakeholder body, the Commission for Monitoring was established. Focal	n/a
Spain	Strategy Action Plan on Disability 2014-2020 ¹²	2014-2020		n/a	n/a
Sweden	No national disability strategy ¹³				
UK	No current national strategy ¹⁴				

¹¹ Portugal had a national disability strategy for the period of 2011-2013.

¹² Spain has several national strategies that include policy measures targeting people with disabilities, such as the National Action Plan for Social Inclusion, the Action Plan 2014-2017 for Equality between men and women in the Information Society, and the National Strategic Plan for Children and Adolescents 2013-2016.

¹³ Although Sweden has no national strategy, but a government proposal in 2016 set out plans to improve policies and services for people with disabilities. Policy areas covered in this proposal include: labour, education, discrimination, communications, transport and IT.

¹⁴ In 2017, the UK government published the white paper *Improving Lives: the Future of Work, Health and Disability* with strategic objectives for disability policies. The white paper has a lower legal status than bills, and is still a subject to future approval by the Parliament.

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