

Towards more independent lives for people with disabilities

Reflections from social services
across Europe

*Promoting
autonomy and
independence*





This publication has received financial support from the European Union Programme for Employment and Social Innovation 'EaSI' (2014-2020). For further information please consult: ec.europa.eu/social/easi. The information contained in this publication does not necessarily reflect the official position of the European Commission.



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About this publication

This publication is the result of the European Social Network's (ESN) work on disability between 2014 and 2016, mainly through its working group on disability, its cross thematic work on integrated social services, and research on the social services workforce in the framework of its 2014-2017 strategy.

About the European Social Network

ESN is the independent network for local public social services in Europe. It brings together the organisations that plan, finance, research, manage, regulate, deliver and inspect local public social services, including health, social welfare, employment, education and housing. We support the development of effective social policy and social care practice through the exchange of knowledge and expertise.

European funding

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For further information see: <http://ec.europa.eu/social/easi>

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For referencing, please use:

European Social Network (2017) Towards more independent lives for people with disabilities: Reflections from social services across Europe. Brighton: European Social Network.
ISBN: 978-0-9934556-3-6

Acknowledgements

This publication was drafted by ESN policy officers Valentina Guerra, Leyre Merchán Paúles and William Hayward, and edited by Alfonso Lara Montero (ESN chief executive) and Mary O'Hara (journalist).

ESN would like to thank the core members of ESN's working group on Disability, which ran between 2014 and 2016, for their valuable contributions and proactive participation: Marion Meany, Health Service Executive (IE); Jouni Nummi, Joint Municipal Authority for Social Services, ESKOO (FI); Carsten Wulff Hansen, City of Aarhus (DK); and Teije Dijk, Association of Local Governments for Social Welfare (NL). We would also like to thank the ESN members who contributed with practice examples at the working group meetings.

With thanks also to Sarah Carr, University of Birmingham (UK), who contributed to the analysis of the practices provided by ESN members, and Jake Gillam-Smith (communications assistant at ESN) for coordinating the production of this publication.

Country abbreviations

AT	Austria
BE	Belgium
BG	Bulgaria
CY	Cyprus
CZ	Czech Republic
DE	Germany
DK	Denmark
EE	Estonia
ES	Spain
FI	Finland
FR	France
GR	Greece
HR	Croatia
HU	Hungary
IE	Ireland
IT	Italy
LT	Lithuania
LUX	Luxembourg
LV	Latvia
NL	The Netherlands
NO	Norway
PL	Poland
PT	Portugal
RO	Romania
SE	Sweden
SK	Slovakia
SI	Slovenia
UK	United Kingdom

Executive summary

The purpose of this toolkit is to provide recommendations and examples of practice for senior social services professionals providing care for people with disabilities. The publication is based on desktop literature research, material from European projects in which ESN participates in an advisory role, ESN reports and the results of the disability working group meetings.

ESN's working group on disability met five times between 2014 and 2016. Professionals who plan, coordinate and manage social services for people with disabilities shared knowledge and best practice around different issues, such as ways to promote the autonomy of people with disabilities through employment, empowering them to actively participate in their care and support, and promoting their independence through the use of technology. Each chapter provides an overview of national policies and local practice, a detailed description of a relevant programme, and key challenges and opportunities for disability services planners and providers.

The first chapter focuses on active inclusion measures to improve the employment rate of people with disabilities. People with disabilities continue to experience lower employment rates and higher poverty rates compared to the wider population. Active inclusion policies are supported by a broad range of legal and policy instruments such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the European Disability Strategy. The chapter provides a review of strategies from several European countries that aim to increase the participation of people with disabilities in the labour market and a detailed local case study from the Netherlands.

The second chapter analyses different ways of involving service users to promote their choice and control over decisions affecting them on an individual or organisational basis. In the first case, service users are supported through person-centred planning, self-directed support and personal budgets. Service users may also be involved on an organisational basis through the design, evaluation and delivery of services. An overview of policy and practice in different European countries is presented and complemented with a detailed local practice in addition to useful insights and recommendations on the involvement of service users in service planning and delivery.

The third chapter examines the role of technology in promoting independent living across the life-cycle. Technology offers significant opportunities to promote greater independence by lowering barriers encountered by people with disabilities. Communication technology enables health monitoring and supervision to be undertaken remotely, whilst the collection and analysis of health data can enable early intervention. However, the introduction of technology raises questions on privacy and confidentiality, which require clear protocols to safeguard service users. In addition, there is recognition of the need to make technology user-friendly and attuned to the realities of the lives of people with disabilities and in a way that assists social workers to prevent a digital divide which could reinforce social exclusion.

The recommendations and examples of practice gathered in the field of disability from across Europe represent the introduction and the basis for our future work on social service co-design, co-planning, co-production and co-evaluation along the life-cycle that we will be implementing as part of our future 2018-2021 strategy.

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Contents	
Background	10
Chapter 1: Active inclusion	11
Chapter 2: Service user involvement	19
Chapter 3: Technology for independent living throughout the life-cycle	26
Checklist	32
Bibliography	34

Background

This toolkit is mainly based on desktop literature research, material from European projects in which ESN participates in an advisory role, ESN reports and the results of the disability working group meetings. In particular, all practice examples used in this toolkit to illustrate the challenges and opportunities within each topic come from the working group that ran between 2014 and 2016. The group's work aimed to increase the capacity of public authorities to plan and manage services for people with disabilities in a sustainable and person-centred manner, and to promote independent living and autonomy for service users.

The various meetings of the working group brought together around 30 ESN members from 20 different countries working in public social services within local authorities, national bodies, quality inspection services, as well as universities. A strong focus was placed on the practical implementation of services through the systematic collection and analysis of practices related to each meeting topic. These practices are available in ESN's [practice library](#). With this publication, ESN contributes to the local implementation of the UNCRPD and the European Disability Strategy.

The [first meeting](#) (Brighton, 4-5 December 2014) looked at initiatives and policy frameworks promoting independent living at local and European levels. A number of practices highlighted issues such as the role of local authorities in implementing services, and presented the state of play in the field of disability services across Europe.

The [second meeting](#) (Brighton, 12-13 March 2015) focused on the integration of services for people with disabilities, and how social and health services can better collaborate to meet users' needs in the best possible way. After the meeting, ESN produced a short [video](#) on integrated services featuring members from Denmark, the UK, Ireland and Spain.

The [third meeting](#) (Vilnius, 19 November 2015) addressed how social services and the public sector can help people with disabilities to enter and remain in the labour market by offering tailored, coordinated and gradual support, thus contributing to their full inclusion in society. The meeting was an opportunity to explore legislative background and practice in 12 EU countries.

The [fourth meeting](#) (Sofia, 5 April 2016) saw service users and ESN members come together to discuss service user involvement in the design, evaluation and delivery of social services. The meeting focused on latest policy and practice developments, such as peer support and co-production.

The [fifth and final meeting](#) (Brighton, 11-12 October 2016) focused on the quality and evaluation of disability services. In a joint session with ESN's ageing and care working group, participants discussed how services for people growing older with learning disabilities should be provided.

Chapter 1: Active inclusion

Inclusive labour
markets



Supporting
employment



Combating
stereotypes and
prejudices

1.1. Legal and policy background

The concept of 'active inclusion' was introduced as a social policy objective by the European Commission in 2008 in its Recommendation on the active inclusion of people excluded from the labour market (European Commission, 2008). Although not mentioned explicitly, people with disabilities fall under this category, as they continue to experience lower employment rates and higher poverty rates compared to the wider population. The employment of people with disabilities poses a significant challenge for Member States. Employment rates for persons without disabilities in the EU Member States are above 70% whereas, in the majority, the employment rate for disabled persons is under 50% (European Parliament, 2015).

In 2011, the World Health Organisation and the World Bank jointly published the World Report on Disability. Part of this holistic report focused on work and employment of people with disabilities. One of the report's main messages was the need for more research on factors that influence labour market outcomes for persons with disabilities and to understand which measures improve labour market opportunities and are also cost-effective and sustainable.

At present, it is widely recognised that people with disabilities in the EU are likely to face significant social and economic challenges. To provide a legal basis for the fight against any type of discrimination, Article 10 of the Treaty on the Functioning of the European Union (TFEU) refers to "the Union's aim of combating discrimination based on [...] disability". Moreover, The Charter on Fundamental Rights of the European Union prohibits discrimination on the basis of a number of grounds, including disability (Article 21).

At international level, the Convention on the Rights of Persons with Disabilities (UNCRPD) is the key legal framework. The purpose of the Convention is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (United Nations, 2006). Articles 8 and 27 of the Convention recognise the need for state parties to adopt immediate measures to improve the access to the labour market of people with disabilities.



Awareness-raising

States Parties undertake to adopt immediate, effective and appropriate measures: [...] To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market.



Work and employment

States Parties recognise the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is **open, inclusive and accessible** to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

- (a) Prohibit discrimination on the basis of disability (...);
- (b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions (...);
- (c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;
- (d) Enable persons with disabilities to have **effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;**
- (e) Promote employment opportunities and career advancement for persons with disabilities in the labour market (...);
- (f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;
- (g) Employ persons with disabilities **in the public sector;**
- (h) Promote the employment of persons with disabilities **in the private sector** through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;
- (i) Ensure that **reasonable accommodation** is provided to persons with disabilities in the workplace;
- (j) Promote the acquisition by persons with disabilities of **work experience in the open labour market;**
- (k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

In this chapter, we address employment as paid employment in the open, non-sheltered labour market following the 'social model' of disability. The social model is supported by the UNCRPD according to which disability is "a socially created concept", as opposed to the 'medical model' where disability is "a feature of the person" that needs to be "corrected" (World Health Organisation, 2002).

According to the European Commission, active inclusion is based on "three key and equally important social policy pillars" (European Commission, 2013). These are adequate income support, inclusive labour markets, and access to quality services. In November 2010, the European Commission released the 2010-2020 European Disability Strategy, which included employment among the key areas earmarked for increased action. More specifically, one of the objectives of the Strategy is to "enable many more people with disabilities to earn their living on the open labour market" (European Commission, 2010).

Although employment does not always fall within the remit of local authorities, many provide support in this area. The variety of practice examples gathered by ESN's disability working group has shown a great variety of arrangements and types of employment led or supported by local authorities. Partnerships with employment agencies, public and private companies signal a change in social care and welfare practice. From strategies based on deficit and dependency models, approaches at local level are now aimed at promoting people's choice, inclusion and independent living.

The employment situation of people with disabilities needs to be improved through quality jobs in open, inclusive and accessible work environments. Local authorities and public social services can support the successful transition of persons with disabilities into open employment, especially through integrated plans and better coordinated services. These have been unanimously recognised as a key feature of any successful employment initiative by the members of ESN's disability working group (European Social Network, 2015).

As outlined by the European Union of Supported Employment in 2005, supported employment is "a method of working with disabled people and other disadvantaged groups to access and maintain paid employment in the open labour market". This method of working is a proactive policy in accordance with the United Nations Convention on the Rights of People with Disabilities. Therefore, the concept of supported employment is based on the premise that successful job attainment is achieved when adequate support is given to both the employer and the employee.

1.2. Policy and practice at national and local level

There are numerous benefits associated with having people with disabilities included in the labour market for individuals, employers and social services. It improves the life chances, income and quality of life of people with disabilities. For employers, not least in the private sector, disabled employees represent “an untapped resource of skills and talent” (International Labour Organisation, undated). Participation of people with disabilities in the open labour market has also been associated with improved teamwork, morale, and good, stable performance on the job. For local authorities and public services, employing people with disabilities can reduce welfare and social services costs, and improve the quality of life and inclusion for people with disabilities.

Several European countries have established strategies at national level to increase the number of people with disabilities who participate in the labour market. In Austria, in order to implement the UNCRPD, the Ministry of Social Affairs has drawn up the National Action Plan on Disability 2012-2020 (NAP on Disability) in cooperation with all other federal ministries. The NAP on Disability is intended to represent the guiding principles of Austrian disability policy until 2020. In Austria, disability affairs have strong federalist components, that is to say, they are the responsibility of the Länder (regional authorities). Therefore, coordination between the national and regional levels is key to ensure the success of the strategy.

In Ireland, the Government published a ten-year comprehensive employment strategy for people with disabilities in October 2015. The employment strategy is a cross-government approach that brings together actions by different departments and state agencies in a concerted effort to address the barriers and challenges that impact on the employment of people with disabilities. The strategy seeks to ensure joined-up services as well as funding at local level to support individuals into employment. The strategy has six strategic priorities:

- Build skills, capacity and independence
- Provide bridges and supports into work
- Make work pay
- Promote job retention and re-entry to work
- Provide co-ordinated and seamless support
- Engage employers

In Denmark, national legislation supports the inclusion of people with disabilities into the labour market. The Consolidation Act on Social Services (2007) provides the legislative framework for disabled people to access education and training to prepare them for entry into mainstream employment, including work-based learning. In addition, the Social Pensions Act (2010) ensures that disabled people’s income is supplemented to meet a minimum level for those who cannot secure a full-time salary. The funding compensates employers for wages and the disabled worker receives an adjusted hourly wage. Income support is complemented by flexible working arrangements through ‘flexjobs’, where a person with a disability can work any time from one hour per week up to full-time, depending on their situation.

In several countries, employers and companies are subject to national and local policy initiatives, such as support and incentives to employ disabled people or nationally determined quotas and targets, an approach that is operational in Austria and is being considered in The Netherlands.

In Belgium, the federal 'Participation Ladder' defines six levels of participation and inclusion of people into society, from reliance on home care to regular employment. These six steps, depending on how far the individual is from regular employment, are split between the Ministry of Welfare (steps 1,2,3) and the Ministry of Labour (steps 4,5,6). At regional level, in Flanders, since April 2015 sheltered economy and social economy have been covered by a new regulation creating *maatwerkbedrijven* ('tailor-made businesses'), whose core mission is the labour market integration of people who have been excluded from the traditional mainstream labour market.

Figure 1: Framework for Supported Employment



Source: European Union of Supported Employment Toolkit, 2005

Table 1: Opportunities and challenges in supporting access to mainstream employment for people with disabilities.

 <p>Opportunities</p>	 <p>Challenges</p>
<p>Local authorities can support the employment of persons with disabilities by making sure that social workers and support workers are also involved in the process.</p>	<p>While encouraging cultural change and promoting diversity to guarantee access to employment for people with disabilities is crucial, the lack of adaptation within workplaces continues to be a major barrier to the participation in the labour market.</p>
<p>Targeted awareness-raising campaigns can be an effective instrument for drawing attention to the lack of participation of people with disabilities in the labour market.</p>	<p>Obstacles remain in the way of new approaches to promoting employment opportunities, but local authorities could develop more and better partnerships with private companies to support good quality job opportunities. This could improve the employment rate of people with disabilities.</p>
<p>A public procurement policy that incentivises employers to hire persons with disabilities could stimulate recruitment in some sectors.</p>	<p>Measures to improve workplace accessibility, such as physical changes like ramps for wheelchairs or other considerations for people with disabilities have not been implemented or acknowledged by all employers.</p>
<p>Strategic and service partnership agreements between employers and social services can help people with disabilities integrate into the labour market by fostering more accessible workplaces and raising awareness of the potential benefits of employing people with disabilities.</p>	<p>There remains a lack of data regarding the situation of people with disabilities in the labour market.</p>
<p>Improving the employment rate of people with disabilities could have a broad impact including lowering poverty and reducing the cost of disability benefits and allowances.</p>	
<p>Improving integration into mainstream training and education is key to ensuring people with disabilities gain vocational qualifications, which in turn can support them in accessing employment.</p>	<p>People with disabilities continue to face unequal access to education and training.</p>

Implementation in practice

The Locus Network in The Netherlands

Fresh, innovative approaches to expanding job opportunities for people with disabilities are very much a driver of change in the Netherlands.

As a result of mutual agreements between employers, municipalities, public social services, and private service providers through a partnership known as the Locus Network, launched by ESN member the Dutch Association of Directors of Social Services (Divosa), progress is being made on improving mainstream job opportunities for people with disabilities.

Alongside the Locus Network which reinforces connections between employers and public social services, a methodological approach has been developed for creating jobs which match the needs of both employers and people with disabilities. This approach is called 'Diswork'. It places emphasis on understanding the perspective of the employer and the abilities of people with disabilities. Unlike job carving, which consists of tailoring a job so that it is suitable for a particular worker, Diswork supports the creation of entirely new job positions, which can widen the opportunities for people with disabilities in the labour market and represents a more sustainable approach to the employment of people with disabilities.

The model consists of a training programme for employers, who can learn the theories of job differentiation, lean management and organisational change. This helps to create a positive business case for the employment of people with disabilities, as before there was a focus on placing people with disabilities with an employer regardless of whether this would match the requirements of the employer, who must prioritise making a profit.

The 'Diswork' approach has led to the creation of hundreds of new sustainable jobs for people with disabilities in the regular labour market and has helped raise awareness among employers of the contribution people with disabilities can play within their organisation. It has proven to be particularly successful at creating opportunities for those more likely to be excluded from mainstream employment. Most service users who found a job through this approach for example were either working in sheltered workshops or unemployed. As far as the costs of the training and guidance programme are concerned, this depends on the needs of the organisation and range between EUR 5,000–10,000.

Thanks to Brigitte van Lierop from the Locus Network for her contribution to this practice.



The full practice example is available in ESN's practice library:
<http://www.esn-eu.org/raw.php?page=files&id=2515>

Chapter 2: Service user involvement



Self-advocacy



Co-production

Personalisation
of services

2.1. Legal and policy background

Service user involvement is set out in international and European legislation and guidance, notably the United Nations Convention on the Rights of People with Disabilities (UNCRPD), adopted in 2006. In its preamble, the UNCRPD states that: “persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes directly concerning them”. Furthermore, Article 4 establishes that “States Parties shall closely consult with and actively involve persons with disabilities”.

At European level, the European Disability Strategy supports, with EU funds, actions promoting the transition from institutional to community-based care (European Commission, 2010). EU funds can be used for training staff and adapting social infrastructure, developing personal assistance funding schemes, and promoting sound working conditions for formal and informal carers. In 2014, the European Social Network (ESN) led a joint action with other European level networks that saw the organisation of national workshops to train civil servants on the use of EU funds for the implementation of community care services in their countries.

In its 2014 report on the implementation of the UNCRPD by the European Union, the European Commission stressed the importance of respecting service users’ rights and involving them in decision-making, preventing institutionalisation and creating community-based services (European Commission, 2014). Moreover, the report highlighted that users should be fully informed and actively involved in all decision-making processes to prevent their institutionalisation.

For social service managers and service commissioners, involving users means personalising services, that is to say ensuring that people have access to information and advice to make good decisions about the care and support they need (SCIE, 2009). This is particularly important when it comes to the transition from institutional to community-based care, as this process requires new living arrangements, notably housing. Implementation can be facilitated by cooperation between service users, social workers, local and regional authorities, third sector organisations and public and private service providers.

Involving service users and their families also means including them in the design, delivery and evaluation of services to ensure that ‘experts by experience’ have a say in how services are designed and delivered. Harnessing users’ experience, skills and expertise at all stages helps to ensure that services respond effectively to their needs. Their involvement allows people with disabilities to make their own life choices, be included in the community and enjoy independent living. Moreover, involving and listening to users helps to reduce the risk of violence and abuse, and it increases people’s safety and wellbeing (European Social Network, 2010).

User involvement is sometimes referred to as co-production. Co-production understands users as ‘co-producers of services’ in a process where “professionals and citizens make better use of each other’s assets, resources and contributions to achieve better outcomes and/or improved efficiency” (Institute of Local Government Studies, 2012).

Think Local Act Personal, a British national partnership of 50 organisations committed to transforming health and care through personalisation and community-based support, also stresses the importance of the “equal relationship between people who use services and the people responsible for services. They work together, from design to delivery, sharing strategic decision-making about policies as well as decisions about the best way to deliver services” (Think Local Act Personal, 2016).

Co-production also recognises the contribution made by service users in service delivery. Therefore, it goes beyond the concept of simple participation or co-creation of services. Co-production implies that users and social services professionals are equal partners and that users can take over some of the work done by practitioners.

The Social Care Institute for Excellence (SCIE, in the UK) identified four different elements of co-production: co-design, co-decision, co-delivery and co-evaluation (SCIE website). In order to ensure that the process of co-production is successful, the social services workforce needs to be trained to 'create spaces' that support service users' engagement. Furthermore, it is crucial to enhance the solidarity of communities and the participation of volunteers in all four different elements of the co-production process.

Figure 2: Service user involvement – Individual and Collective



Source: ESN own creation with information provided for the meeting on user involvement of ESN's working group on Disability.

2.2. Policy and practice at national and local level

European countries implement different approaches to secure the participation of service users, at both individual and collective or organisational levels. There are also different ways of promoting the equal rights of people with disabilities to lead independent lives in the community. The majority of projects are strategically designed to improve the involvement of people with disabilities in decisions about their care and support. This includes having more choice and control over their individual support and being involved in strategic decision-making about service development, design, evaluation and delivery.

National policies focus broadly on continuing deinstitutionalisation in social care and mental health. This process is underpinned by the rights of people with disabilities to be supported to live independently in the community as per Article 19 of the UNCRPD. Some countries, such as Croatia, France and Denmark, are implementing specific social and welfare policy reforms and funding streams to promote independent living, social inclusion and peer support initiatives.

Members of ESN's working group provided examples of service users and carers involvement in the governance, commissioning and design of the services they use or in developing local policies and programmes that affect them. Disabled People's Organisations, run by and for people with disabilities, and peer support organisations are increasingly funded to provide services.

For instance, in the Danish municipality of Aarhus, people with learning disabilities, their families and staff who use or provide services develop new initiatives together, using a common framework for the development of services for adults with learning disabilities. This initiative is part of Aarhus' disability policy on active citizens' involvement and on the development of workable solutions and strategies to improve the lives of people with disabilities. A series of meetings have been organised and 1,000 ideas were proposed for improving and innovating in the municipality's social services for people with learning disabilities.

The Municipality of Sofia in Bulgaria involves users through consultative bodies on local social policies implementation. NGO representatives are included in the Public Council for Social Policy, which also consists of representatives of the local administration, councillors, state and regional government representatives, and social services.

Personal assistants also support service users to live independently in the community and participate in daily life activities. In Croatia, the Ministry of Social Policy and Youth provides personal assistance services to people with disabilities through service users organisations contracted by the government. The service user chooses what the personal assistant helps them with and how. Meanwhile in Finland, the Centre for Disability Empowerment Eskoo implemented a programme to help people with disabilities to source and directly employ their own personal assistants. The service users together with Eskoo project workers decide what support they need. In both examples, service users receive support to recruit personal assistants. Personal assistants are also trained and supported, for example on dispute resolutions with service users.

User led organisations are increasingly contributing to the provision of quality assurance and service evaluation alongside service providers and municipal authorities. In the UK, the Gloucestershire Learning Disability Joint Commissioning Team, a partnership between Gloucestershire County Council and the Clinical Commissioning Group responsible for the planning and commissioning of care services, started a programme in 2013 involving Gloucester Voices, a service user organisation of 'experts by experience', to provide social care service quality checks. The Joint Commissioning Team and Gloucester Voices have regular information and planning meetings on quality assessments of a wide range of commissioned private and public services. These may include residential care homes, supported living schemes, home care agencies, treatment units and day care services.

People with learning disabilities are also trained to carry out service quality checks themselves. The results of the quality checks inform care commissioning practice in Gloucestershire County Council.

Funding for service user involvement programmes may come from a variety of sources including central government funding, regional and municipal funding. Central government funding is associated with policy implementation and the establishment of services and approaches to promote choice and autonomy, independent living and peer support. Mixed-funding sources are also used, for example through the European Social Fund. Or, more globally, the World Bank invests in long-term national deinstitutionalisation reforms and models on the transition to community care.

On regional and municipal levels, funding streams are associated with local social service reform, improvement programmes and participation initiatives, as well as investment in disability organisations as providers of consultation, support and advice.

Most initiatives at national, regional and local levels have a strategic aim of rights-based culture change, living in the community, and a gradual but radical reorientation of social services to support people with disabilities to live independent lives and have full social inclusion. This implies having the choice and control over the services they use both as direct users and as citizens to whom services are accountable.

The policy goal of achieving independent living, social inclusion and citizenship through service user involvement is gradually being realised in a variety of ways. Approaches to service user participation fall broadly into two categories of individual, and collective or organisational. Many of the involvement opportunities and service user organisational activities described in this chapter require on-going investment to ensure their sustainability and strong underpinning values based on human rights that retain their focus on equality.

Table 2: Opportunities and challenges for social services in involving service users

Opportunities	Challenges
	
<p>Service users, as 'experts by experience' can provide a wealth of information on how to design services.</p>	<p>Information about services aimed at people with disabilities is not always adapted in a way that ensures it is widely accessible.</p>
<p>Harnessing users' experience, skills and expertise at all stages helps to ensure that services respond effectively to people's needs.</p>	<p>Social workers and personal assistants do not always receive the appropriate training needed to work with people with disabilities while service users would benefit from training on how to become employers themselves.</p>
<p>Service user led organisations can play a key role in social service development, quality assurance and delivery of services.</p>	<p>There are still barriers to creating the conditions for co-production, especially concerning co-delivery of services. Co-delivery cannot be misunderstood as a mere downsizing of services. All providers involved need to guarantee the quality of services in the best interest of service users.</p>
<p>Recruitment of personal assistants by service users increases the chance that they will have services better suited to their needs.</p>	<p>There are often insufficient resources specifically designed for service users' involvement in the long-term.</p>
<p>Peer support can generate opportunities to improve the quality of life of people with disabilities and to reach higher levels of independent living.</p>	<p>Peer support groups might encounter organisational difficulties in recruiting peers and staff. They should be able to access professional advice on human resources and finance.</p>
<p>Personalisation of services can have a range of positive outcomes including helping social care markets to diversify the service offer and to improve the quality of services through competition between different providers.</p>	<p>Competition may have a negative impact on care, promote profit-making over care or penalise the worse-off.</p>

Implementation in practice

Mutual Support Groups promoting recovery in France

Peer support has become an important strand of user involvement in social services, and in France Mutual Support Groups (*Groupes d'Entraide Mutuelle*) have been developed with this in mind.

These groups aim to support service users through the involvement of people who experience similar problems, such as mental health issues or brain injuries. Such groups were officially recognised by the French Disability law, Loi n° 2005-102, approved in 2005. This law created a new category of social services called 'mutual support group' financed by public funding. ESN member, the National Solidarity Fund for Autonomy (CNSA), allocates funding to regional health agencies that distribute funding to the various associations responsible for these groups.

Mutual Support Groups rely on peer support and self-organisation. They are organised as non-profit organisations, created and run by people with disabilities. Public funds allocated to the groups can be managed directly by service users, who can also hire social workers to support them in the process. In terms of structure, more than 80% of the groups have two employees or more while around 70% of the groups also employ volunteers. Mutual support groups also involve a non-profit organisation for additional help and advice regarding organisational challenges.

Mutual support groups are mainly funded and supervised by public authorities and can also involve several sectors. Health, culture, housing and employment services often provide help and services required by members of the mutual support groups.

This practice has received encouraging positive feedback from users, who report increased levels of self-confidence, social integration, autonomy and empowerment. The groups have also had an impact on social workers who report that their relationship with users has become more balanced through the recognition of the users' expertise and seeing them as peers, rather than simply the subject of care policies. Mutual Support Groups mean people with disabilities are actively involved in their own care and many families have reported an increase in the ability of people with disabilities to manage daily tasks.

Thanks to Daphné Borel from the National Solidarity Fund for Autonomy (CNSA), for her contribution to this practice.



The full practice example is available in our practice library:
<http://www.esn-eu.org/raw.php?page=files&id=2200>

Chapter 3: Technology for independent living throughout the life-cycle



Overcoming
barriers

Connecting
people



Improving
efficiency

3.1. Legal and policy background

Technology is revolutionising how people go about their daily lives, with the Internet, smartphones and other digital tools playing a vital part in society today. This transformation includes social services which are also taking advantage of the opportunities that technology offers to improve lives and promote the independence of those they design services for, including people with disabilities.

For social services, the adoption of technology enables the possibility for more efficient and effective ways to organise people and ideas, better access to knowledge and education, and improved efficiency and collaborative ways of working. It has been particularly important in the context of ensuring the financial sustainability of social services following the economic crisis.

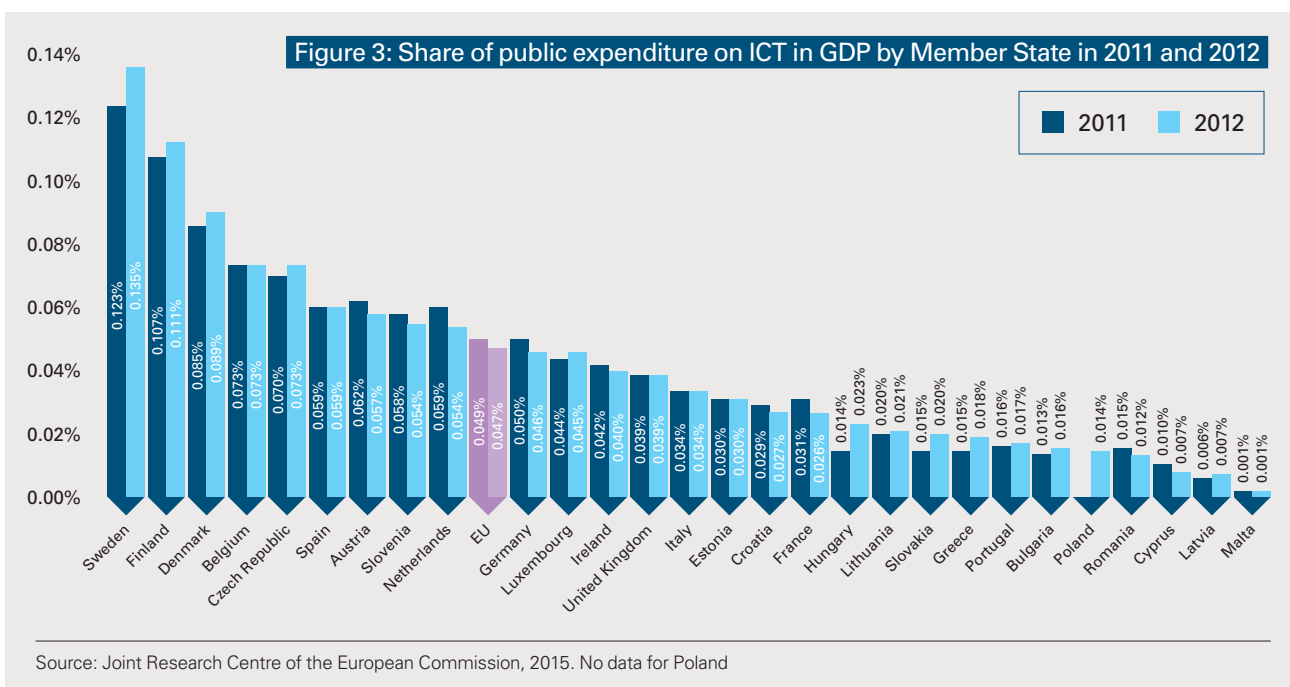
However, the possibilities are not limited to the planning and management of social services. Technology can play a crucial role in lowering the barriers that people with disabilities encounter. It is also important that in an increasingly digital society, people with disabilities can access the same information and services as the wider population and can enjoy the benefits a digital society presents.

Technology can also contribute to the objectives of international legislation applicable to people with disabilities. This applies for example to Article 19 of the UNCRPD on promoting independent living and inclusion in the community, and Article 21 on enabling equal access to services and goods. Technology is also relevant for meeting some of the priorities of the European Disability Strategy 2010-2020. These include:

- Accessibility to goods and services
- Participation in society
- Equal opportunities
- Access to health services

The future European Accessibility Act provides important impetus for making services and goods accessible for people with disabilities as part of the European Disability Strategy 2010-2020 (European Commission, 2015). This is particularly relevant for digital services. The Act aims to reduce barriers for people with disabilities, by emphasising that services and goods such as computers, smartphones and audio-visual services must be accessible for all.

Figure 3 outlines public expenditure on ICT as a share of GDP for each EU Member State. It demonstrates a significant gap, with Nordic countries in particular investing the most. This suggests that some countries are exploiting the potential of technology much more than others.



3.2. Policy and practice at national and local level

A wide variety of technologies can be utilised by social services for people with disabilities. For example, integrated information systems can enable the collection and sharing of information between different professionals on children at risk of developing a developmental disorder (European Social Network, 2017a). Systems like this can include information on disability assessments and general socio-economic data, allowing different professionals involved with the child to keep track of developments. This can encourage early intervention and a more coordinated approach, improving the planning and personalisation of care.

For adults with disabilities, assistive technologies, new communication methods and monitoring technology allow them to go about their daily lives with less supervision, less need for direct assistance with tasks, and reduced need to travel to meet with carers or other health staff. One example of this type of technology for adults with a disability is the development of more accessible smartphones.

The Project Ray Smartphone (Debating Europe, 2017) for example is designed for people who are blind, and is controlled through touch, voice and sound controls. Similarly, the Sesame Phone is touch-free and can be used by people with limited use of their hands (Debating Europe, 2017). These examples will be crucial for allowing people with disabilities to connect with others and access online services through their portable devices, something which is now seen as an intrinsic part of our digital society.

For those who are more vulnerable, a number of technologies are being implemented to simplify the provision of care. Portable GPS alarm watches can allow a person with a disability to go about their life without the need for direct supervision, thanks to the ability to send an alarm which allows emergency services and their family to pinpoint their exact location (European Social Network, 2017b).

Other technologies can reduce the need for home visits by care staff. Home cameras have been developed which can inform carers if a person with a disability is in their bed at night, and automatically send an alarm if not (European Social Network, 2017b). Furthermore, health data on weight or blood pressure can be recorded by the user at home (made even easier by Internet-ready bodyweight scales) and then uploaded to online platforms accessed by care and health staff, reducing the need for regular in-person check-ups (European Social Network, 2017b).

Assistive technology such as robotics can play an important role in making daily tasks easier for people with disabilities. In the Swedish municipality of Örebro, a collaboration between the local authority, the University and research organisations has helped to foster the development of technologies which can support independent living. This includes Bestic, a robotic arm which can be used by people with mobility impairments to eat their food (Camanio, 2017).

These examples highlight that the nature and types of technology being utilised by social services for people with disabilities are diverse. They also demonstrate the important contribution that new technology is making towards removing barriers in ensuring that people with disabilities can participate in society to the same extent as others.

However, it should be acknowledged that whilst technology is enabling people to connect in new and faster ways, there is the risk of isolating people whose human contact is replaced by digital devices. Therefore, it is important that the value of relationships and human contact between service users and professionals is taken into account when implementing digital initiatives, especially where there is the risk of loneliness.

The emergence of new technologies that alter how social work with people with disabilities is undertaken, has ethical implications. Social workers and carers must make considerations for client privacy, confidentiality, relationship boundaries and informed consent related to new forms of communications and information recording. There is evidence that service users are unsure about how their personal information is used, and who it is accessed by (Reamer, 2013), which highlights the need for clear protocols on these issues that ensure that service users are aware of how their information is managed.

Another issue regarding the introduction of technology is the fact that technological tools or systems introduced in social services are often implemented in a top-down manner. Policy decisions on introducing technology may be made at national level and translated into practice by corporate ICT developers, far removed from the daily work of social workers and the lives of people with disabilities (Garrett, 2005). This can lead to frustration among social workers who may find a new ICT system or digital tool to be confusing and time-consuming to use.

To overcome this, some have called for a more practice-led approach where social workers and service users play a key role alongside technical specialists in developing new technologies (Baker et al, 2014). This can help ensure that technology used by social services and people with disabilities is more user-friendly and better attuned to their needs.

Table 3: Opportunities and challenges for social services in using technology to support the autonomy of people with disabilities

 <p>Opportunities</p>	 <p>Challenges</p>
<p>Communication technology can allow service users and professionals to connect remotely, reducing the need to meet in person to discuss social and health concerns.</p>	<p>Communication technology risks isolating people who may lose out on human contact, potentially leading to loneliness or isolation.</p>
<p>New ICT systems can reduce the administrative burden on social workers by making recording procedures more efficient.</p>	<p>Technology introduced without consultation of the end-user may not be tailored to their abilities, which would reduce its effectiveness.</p>
<p>The sharing of data in a single platform can enable professionals to have a better common understanding of the user, enabling more coordinated support.</p>	<p>The privacy and confidentiality of service users is at risk of being compromised if procedures are not in place to protect their data and privacy.</p>
<p>Technology can overcome barriers to services and goods, by making devices suitable for people with sensory impairments for example.</p>	<p>There is a risk that if digital services and goods are not made accessible to all, a digital divide could lead to the social exclusion of people with disabilities.</p>
<p>Assistive technologies can make daily tasks, such as eating or cleaning, easier through robotics and simplified processes.</p>	<p>Some technological tools and devices can be expensive for users or public social services to purchase or hire.</p>
<p>Technology can enable the recording of health and social data, analysis of which can enable early detection of possible problems.</p>	<p>There is a risk that if professionals are not trained to record data accurately, the effectiveness of care undertaken over digital platforms may be reduced.</p>

Implementation in practice

Alborada: Early Warning System for Children with Developmental Disorders in Andalucía, Spain

Early intervention can make a huge difference to the overall quality of services provided for young children with developmental difficulties.

In Andalucía, Spain, an early intervention initiative utilising technology has proven noteworthy. The Early Warning Information System for children with developmental problems aged 0 to 6 was introduced by ESN member, the regional government of Andalucía, in 2011. Its introduction followed the emergence of various reports that recommended the creation of an information system that covered all the services provided for children under six with developmental disorders, and for their families.

The number of children included in the early warning system reached 19,998 in 2016. The system has been a success, by being able to identify the number and coverage of care services for young children with developmental difficulties and disabilities in Andalucía as well as risk factors, causes and types of disability for children in the region. Furthermore, it has been able to act as a mechanism for ensuring the continuity of care between social services, health services, and early intervention centres.

The system structure includes three main types of information: general information about the family, data about the child's problem or health condition, and information about the child's school and socio-economic circumstances. The data about the family and the child includes the date and reasons for referral, the diagnosis and associated pathology and the tests that have been carried out.

In terms of information about the child's condition, the system includes a disability assessment and the degree of disability, information about the types of interventions provided and their intensity, and the professionals and resources involved. Each child's file also includes information about the school or pre-school that they attend, the type of support and social benefits they receive, whether the child is in care and information about the child's legal representative. Each file is assigned to a case manager and all professionals who can access the system may be able to see who the case manager is and where they work.

Thanks to Antonio Sagués Amado and Antonio Pons from the Regional Government of Andalucía for their contributions to this practice.



The full practice example is available in our practice library:
<http://www.esn-eu.org/raw.php?page=files&id=2675>

Implementation in practice

Digital solutions to support independent living in Östersund, Sweden

ESN member, the social services department of the municipality of Östersund in Sweden, recognised that the use of digital technology could promote the health and independence of people with disabilities and other vulnerable groups by ensuring their safety and security.

To instigate its plan, a dedicated team of ten people, including specialised technicians was set-up to organise and manage the delivery of digital solutions. A range of technologies have been developed on this basis.

These include a portable GPS alarm watch, a device with an alarm button that can be activated to send a signal to emergency services and the person's family who can then pinpoint their location. There are 150 in use in Östersund, and it has been successful in providing a sense of safety for people with disabilities and their families.

Another is a digital key. Designed to minimise time spent preparing for a home visit, digital keys allow for carers to unlock the front door of a user's property using an application on their phone. There are 1,400 of these in Östersund, and an evaluation report has found that the initiative has saved the amount of time that carers spent preparing and carrying out home visits.

Remote home cameras are another example. These cameras are installed in the bedrooms of service users and are able to check if they are in bed at night. They can send an alert to health services if the camera detects that the person is not in bed over a certain length of time. Ten have been set-up so far and have been able to replace or complement night visits by care staff.

Next is an Internet of things. Professionals caring for a person with disabilities or any other service user can access an online platform to check their data which can be uploaded automatically onto the 'Internet of things' by service users using digital-ready bodyweight scales and sleep sensors. By accessing this information, staff can verify basic information about the person, reducing the need for regular in person check-ups. Measures are in place to protect the confidentiality of users' data on this platform with each user represented by a code known only by staff responsible for them, ensuring their anonymity.

Overall, the combination of these different technologies has enabled staff to focus more of their time on caring for users instead of administrative tasks or travelling. Another benefit is also cost-savings for the municipality resulting from more efficient use of staff's time. Ultimately, the most important achievement is the promotion of the health and independence of service users.

Thanks to Lars Liljedahl, Tommy Ceder, and Åsa Trolle from the municipality of Östersund for their contributions to this practice.



The full practice example is available in ESN's practice library:
<http://www.esn-eu.org/raw.php?page=files&id=2676>

Checklist

This checklist has been designed to provide recommendations for directors and professionals working in social services providing care for people with disabilities. It is intended to assist them in the development and implementation of services to promote independent living and autonomy for people with disabilities.

I: Active inclusion

- ✓ Compile data on the employment of people with disabilities to assess the outcomes of active inclusion policies.
- ✓ Improve the flexibility of education and training systems to help people with disabilities acquire the qualifications and skills required to compete effectively in the open labour market.
- ✓ Design and implement disability benefits to prevent them becoming a barrier to employment for people with disabilities or a fiscal burden to public authorities.
- ✓ Design measures to overcome barriers to services accessibility, such as health services and transport, to promote the active inclusion of people with disabilities.
- ✓ Separate systems like education and training, or health and income, must not only collaborate, but be designed in such a way that their combined efforts lead to the implementation of an active inclusion approach.
- ✓ Improve the accessibility of workplaces to facilitate the integration of people with disabilities into the labour market. This could include physical adaptations such as ramps or disabled toilets, specialised equipment like audio visual fire alarms for deaf people, and flexible recruitment processes which make considerations for people with disabilities.

II: Service user involvement

- ✓ Improve service information so that it is fully accessible and corresponds with service users' needs. This can help ensure that informed choices are made about how the care received supports independent living.
- ✓ Seek the involvement of service user led organisations for their direct input and advice on services development and quality assurance.
- ✓ Work with service user led organisations to develop public procurement procedures attuned to the reality of people with disabilities.
- ✓ Provide training for social workers and personal assistants on how to work with people with disabilities being their direct employer.
- ✓ Provide training for service users on how to become employers.
- ✓ Support service users in the process of recruiting personal assistants to help them choose according to their specific needs.

III: Technology for independent living throughout the life-cycle

- ✓ Ensure that technology utilised by social services and service users is user-friendly and tailored to their needs.
- ✓ Create clear protocols regulating issues such as privacy, confidentiality and use of data to ensure service users understand how their information is managed.
- ✓ Introduce assistive technologies, new communication methods and monitoring technology that can promote greater independence for people with disabilities.
- ✓ Make sure staff and users are able to effectively use technology (through training and ensuring that technology is user-friendly) to prevent a digital divide that excludes people with disabilities from accessing digital goods and services.
- ✓ Introduce new ICT systems that can reduce the administrative burden on social workers and help them analyse data to promote early detection of possible problems.

Towards more independent lives for people with disabilities

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Notes:

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ESN is the independent network for local public social services in Europe. It brings together the organisations that plan, finance, research, manage, regulate, deliver and inspect local public social services, including health, social welfare, employment, education and housing. We support the development of effective social policy and social care practice through the exchange of knowledge and expertise.