

**Why you should read this article:**

- To be aware that social inclusion for people with intellectual and developmental disabilities (IDD) is a focus of welfare policies and legislation in many countries
- To recognise that the implementation of policy and legislation for people with IDD is the shared responsibility of governments, and health, education and social care professionals
- To identify shared learning among students in health, education and social care programmes as one means of achieving social inclusion for people with IDD

# Social inclusion for people with intellectual disabilities in seven European countries

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**Abstract**

Policies for people with disabilities, and specifically those with intellectual and developmental disabilities (IDD), have undergone significant changes during the past three decades. Many people with IDD experience social exclusion, which has significant implications for the individual, their family and wider society.

Today the focus is on accessing universal services, care and support in the community to facilitate social inclusion. Professions and professionals in health, education and social services implement social inclusion policy in the field of IDD. However, there is a lack of coherence between the policy intentions of social inclusion and the realities of professional practice. Educational collaborations involving academics, students and practitioners from the professions working with people who have IDD provide an opportunity for shared learning. These collaborations support the development of knowledge and understanding, and the barriers that need to be addressed to achieve social inclusion for people with IDD.

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accessible information, diversity, education, equality, inclusion, interprofessional learning, learning disability, professional

**Introduction**

Over the past three decades there has been a significant policy and legislative shift away from treating people with intellectual and developmental disabilities (IDD) as passive recipients of welfare services,

to recognising them as individuals with rights, responsibilities and capacities to control their own lives (United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) 2006). However, challenges remain in ensuring

these proposed policy and legislative changes become a reality (Bartolo et al 2016). Social inclusion is an area where there can be a lack of coherence between the policy vision, professional values and practice realities (Bartolo et al 2016). This is a paradox given that social inclusion and exclusion are important determinants of health and well-being and people with disabilities often experience exclusion and discrimination (Wilkinson and Marmot 2003).

Bigby (2012) criticised the research on social inclusion and argued that the concept has been inadequately agreed and measured. However, a definition that fits with a professional understanding of social inclusion relates to social participation between vulnerable people and those in the wider society that is frequent and meaningful, such as social interactions and relationships between people with IDD and their peers without disabilities.

In terms of the contemporary understanding of the professional role, which is described as delivering services according to a politically agreed mandate (Grimen 2008), professionals in IDD health, social care and educational services are the main providers of welfare policies in the area, including social inclusion for all people with disabilities (Grung 2016).

Social exclusion is understood as the opposite to social inclusion and can be short or long term. Long-term social exclusion, or ostracism, has widespread negative effects and may contribute to further marginalisation of already vulnerable and marginalised people (Riva et al 2017).

The absence of social inclusion may lead to risky behaviour, increase the risk of physical, psychological and sexual abuse and have a negative effect on health and well-being (Bernstein 2016). Social exclusion may also have a negative effect on the health and well-being of families and carers. Social exclusion may have significant financial consequences for society.

People with IDD are at risk of social exclusion for several reasons. Behaviour that challenges is more common in people with IDD than those without and is an important risk factor for social exclusion (Holden and Gitlesen 2006, Bigby 2012). Other risk factors include speech impairment, physical disabilities, complex medical conditions, mental disorders and need for assistance services (Social Exclusion Unit 2001).

This article provides an overview of the main national policies and legislation on the social inclusion of people with IDD in seven European countries: Norway, Romania, Poland, Sweden, England, Scotland and Northern Ireland.

The social inclusion of people with IDD is not only the responsibility of governments, however, but also the professions and professionals involved in delivering services to people with IDD. The article also identifies how the European Union's (EU) Erasmus+ programme, which enables universities to collaborate on EU priorities such as social inclusion, was used to bring together academics, students and practitioners from different professions working with people who have IDD across the seven European countries explored in this article. Seven universities in these countries deliver bachelor's degree programmes in health, education and social services for people with IDD (Table 1).

## Key points

- Professionals working with clients with intellectual and developmental disabilities (IDD) in health, social care and education are the main providers of welfare policies in the area and social inclusion is central in European welfare policy
- In Norway, Romania, Poland, Sweden, England, Scotland and Northern Ireland there is a gap between goals and visions of social inclusion and the realities on practice
- Social exclusion has widespread negative effects on the individual, the people close to them and for society in general
- Education programmes preparing professionals to work in services for people with IDD should develop a curriculum that includes theory and principles related to achieving social inclusion

**Table 1. Erasmus+ programme participants and education programmes**

University and country	Bachelor's degree programme
Oslo Metropolitan University, Norway	Social educator
University of Oradea, Romania	Psycho pedagogue
The Maria Grzegorzewska University, Poland	Special pedagogue
Stockholm University, Sweden	Special education
University of Hertfordshire, England	Learning disability nursing
Edinburgh Napier University, Scotland	Learning disability nursing
Queen's University Belfast, Northern Ireland	Learning disability nursing

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Developing opportunities for shared learning among students from these different programmes may contribute to the policy goal of social inclusion for people with IDD. Although the focus of these programmes is children and young adults, social inclusion is a goal for all people with IDD. Therefore, the term ‘people with IDD’ is used throughout except where the context is specific.

### National policies and legislation on social inclusion

#### Norway

Until the beginning of the 1990s, services for people with IDD, such as special needs education, care and housing, were the responsibility of 19 (now 11) county municipalities or administrative regions. Helsevernet for psykisk utviklingshemmede (Health Service for the Mentally Handicapped or HVPU) was a public care scheme for people with IDD organised by the county municipalities.

The increased focus on values such as normalisation and integration, combined with criticism of the living conditions in the HVPU and coercive practices (Norges offentlige utredninger (NOU) 1985: 34 (1985)), saw responsibility for these services transferred in 1991 to 450 (now 356) local municipalities. However, as set out in the Salamanca Statement on Special Needs Education (UN 1994), the concept of integration was replaced with inclusion. Other services for people with disabilities in Norway soon followed (NOU 2001: 22 (2001)).

Today, inclusion is central in Norwegian policy and decision-making in welfare services and education. The processes facilitating social inclusion are based on a relational perspective of the individual’s reduced functional ability. This relational perspective is called the gap model (NOU 2001: 22 (2001)): the individual has their way of life significantly limited because of the ‘gap’ between their reduced ability to function and the demands of the environment and society.

In the same vein, the gap model refers to the concepts of accessibility, anti-discrimination, equality and universal design, concepts that are recognised and accepted in Norway as central in community planning in general and services for people with disabilities specifically. Although the UN General Assembly adopted the UN CRPD on 13 December 2006, Norway ratified the convention on 3 June 2013, with work ongoing since then to meet its requirements.

While inclusion is central in policy and decision-making, recent evaluations of kindergarten, school and after-school care have found that many children with IDD are separated from their peers, with low expectations of achievement (Norwegian Ministry of Education 2019). In healthcare services for people with IDD, evaluations, from ministries and directorates, have identified lack of self-determination, reduced legal security, lack of coordination of welfare services, lack of goal management, coordination and implementation, and a lack of statistics and documentation (NOU 2016: 17 (2016)). Norway still has some way to go to ensure that social inclusion for people with IDD is a reality.

#### Romania

The issue of social inclusion in Romania can be understood from a historical perspective. During the communist period (1948-1989), there was a desire to impose a model of the ‘new socialist man’, a utopian representation of a selfless life dedicated to the development of society. Although significant investment was made in education and mass literacy, educational projects were strongly ideologised and the emphasis was on general development (Kiss 2013).

After the fall of the communist regime in 1989, services for people with disabilities had to be reconstructed from scratch with the support of the UN Children’s Fund (UNICEF), US Agency for International Development, the EU and western non-government organisations (NGOs). Romania ratified the UN (1989)

Convention on the Rights of the Child in 1990, established the National Authority for Persons with Disabilities in 1990 and the Departments for Social Assistance and Child Protection in 1997. In 2003 Article 50 was added to the Romanian Constitution of 1991 regarding the protection of people with disabilities (Chamber of Deputies 2020). Finally, the national inclusion strategy for children with disabilities was initiated in 2005 (Gherguț 2005).

In 2018 in Romania there were more than 700,000 beneficiaries of special social protection (4% of the Romanian population) (Autoritatea Națională pentru Persoane cu Dizabilități [National Authority for Persons with Disabilities] 2018).

In terms of social inclusion, there are family placement strategies (familial custody of abandoned children until the age of 18) and residential institutions, either state-financed or private, following a family pattern for abandoned children and adoptions. In education there are inclusive schools, special schools for children with severe disabilities and schools for pupils with sensory disabilities. For adults with IDD, work inclusion services include fiscal facilities for hiring companies and adapted work conditions (sheltered workshops).

Most of the policies in Romania focus on avoiding institutionalisation. However, there is a lack of resources to implement adequate inclusive strategies in schools. The private sector and NGOs compensate the state-financed services. The focus is mainly on children and adolescents up to the age of 18 and there is a lack of services for adults.

### Poland

Since the transition from communism in 1989, Poland's approach to people with IDD has been influenced by western policy, for example the UN (1989) Convention on the Rights of the Child and, since the country became a member state of the EU in 2004, the EU policy on equal treatment in employment, social affairs and inclusion

(European Commission (EC) 2020). The UN (2006) CRPD (Polish Forum of People with Disabilities 2020) has had the greatest effect on policy implementation. It emphasises the right to an independent, autonomous and active life, with no form of discrimination. It includes the rights to:

- » A barrier-free environment, including access to public buildings, transport, information and means of communication.
- » Education.
- » Work in the open labour market in adapted conditions.
- » Participate in public, social and cultural life.

The Polish Constitution of 1997 (Sejm 1997) prohibits discrimination on any grounds and requires public authorities to ensure special healthcare for children and people with disabilities (Article 68) and provide aid to people with disabilities to ensure their subsistence, adaptation to work and social communication (Article 69).

Article 72 of the Constitution protects the rights of the child against violence, cruelty, exploitation and actions that undermine their moral sense (Sejm 1997). It also requires the appointment of a Commissioner for Children's Rights, a government minister responsible for providing special care and assistance to children with disabilities and their families.

The Act on the Education System 2004 entitles children with disabilities to (Pogodzińska 2013):

- » Early childhood development support (section 71b).
- » Education in all types of schools according to their individual developmental and educational needs and predispositions (sections 1-5).
- » Adaptation of the content, methods and organisation of the education to the intellectual and physical capabilities of students, as well as the possibility of using psychological and pedagogical aids and special forms of teaching (sections 1-4).

- » Realisation of personalised learning process, forms and curricula and rehabilitation activities (sections 1a-5a).
  - » Prolongation of every stage of education, assessment of their knowledge and qualifications in adapted forms and conditions, free accommodation in a special educational-pedagogical centre, free transport and assistance to school or special centre (sections 14a and 17).
- In practice, since 1989, institutional care has been on the decline and carers have gained more choice. However, ongoing challenges include: the majority of carers for children and adults with disabilities are female; lack of respite; a limited number of specialists available through the national health service; insufficient focus on mental health; low income; inadequate financial support, and disproportionate access to services between large cities and more remote locations. These challenges were reflected in the protests by people with disabilities and their carers inside and outside the Polish parliament building in 2014 and 2018 (Kubicki et al 2019).

### Sweden

Social inclusion of people with disabilities in Sweden is influenced by the Swedish welfare state regime, which emphasises an open and egalitarian society. The main policy on social inclusion for people with disabilities is From Patient to Citizen: A National Action Plan for Disability Policy, passed by the Swedish Government in 2000.

A core aspect of the policy is the ideological shift from considering people with disabilities as ‘patients’ requiring specific and special measures to be part of society, to seeing them as citizens with the same rights and opportunities as others (Danermark and Bolling 2008, de Chenu et al 2016). The policy underpins an inclusive citizenship based on the principles of a diverse society, and equal opportunities and full participation in the community for people with disabilities of all ages.

Strategic policies for social inclusion of people with disabilities include the Strategy for Implementing the Disability Policy 2011-2016, which focuses on accessibility and participation in everyday life for people with disabilities. It identifies nine priority areas including education, public health, social, labour market and transport (Swedish Government 2011). The National Reform Programme 2018 (Government Offices of Sweden 2018) articulates social inclusion for people with disabilities, including those with IDD. It states:

*‘The objective of disability policy is, proceeding on the basis of the UN Convention on the Rights of Persons with Disabilities, to attain equal standards of living and full inclusion in society for people with disabilities, in a society based on diversity.’*

In the same vein, the Swedish Government’s Action Plan Agenda 2030 stipulates (Gustafsson 2018):

*‘The differences that exist in living conditions between individuals and groups should be levelled. Sweden should be a vivid and sustainable democracy, which is characterised by participation and where the opportunities for influence are equal.’*

It is important to note that Sweden ratified the UN (2006) CRPD in 2008. In addition, Sweden adheres to the UN (1993) Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, which commit governments to take action to attain equal opportunities for people with disabilities.

Sweden has made great strides in fostering the social inclusion of people with IDD, but much remains to be done. There is a gap between policy goals and intentions and the practical realities facing people with IDD (Tøssebro et al 2012). Regional inequalities in access to services for people with IDD have increased because of decentralisation and marketisation. More still needs to be done in terms of access to employment, healthcare and inclusive education. There is also evidence of increasing institution-

like arrangements in community care for persons with IDD (Blomberg et al 2011, Socialstyrelsen 2011).

### **England, Scotland and Northern Ireland**

Devolution across the four countries comprising the UK means that some policy issues including health, education and social welfare are under the control of the constituent nation governments: the Scottish Government, Senedd Cymru in Wales and the Northern Ireland assembly. England also has a specific policy that aims to close the health gap and reduce inequalities for children and adults with IDD, mental health and autism (Department of Health (DH) 2010). The project group producing this article did not have a representative from Wales and so it is not discussed further here.

While there are some differences in the implementation of health, education and social welfare policies, the underlying principles are similar across the four nations (Alcock 2012). For example, the transition from child to adult services for young people across health, education and social care is a policy priority in preparing young adults with IDD for adulthood. This commitment is demonstrated through the Equality Act 2010, implemented across all the component nations of the UK. This legislation makes it illegal for any public body, such as health, education, employment, housing and leisure facilities to directly or indirectly discriminate against any person with a disability, including people with IDD. All public bodies therefore have a legal duty to make 'reasonable adjustments' to ensure that people with disabilities, including those with IDD, are not unfairly disadvantaged or discriminated against.

An overview of the main legislation and policies relevant to people with IDD in England, Scotland and Northern Ireland is presented in Table 2.

The legislation and policies on discrimination and social inclusion across the four UK countries reflect the aspiration

that people with IDD are included fully in their communities as equal citizens, with control over their lives and life aspirations. However, progress has been impeded by financial restraints and funding cuts which are managed by health and social services departments (Emerson and Baines 2011). Despite the UK's positive history of reforms promoting social inclusion and equality for people with IDD, they remain a significantly disadvantaged group. Many people with IDD continue to experience education, health and social disadvantages (Heslop et al 2013, Heslop and Marriott 2015). They are more likely to be unemployed and rely on social welfare benefits for income, are less likely to own their own homes, are at greater risk of physical and mental ill-health and more likely to die prematurely from preventable health conditions.

### **Discussion**

This article has presented an overview of the main national policies and legislation relating to the social inclusion of people with IDD in seven European countries. Policies and legislation are two sides of the same coin, where legislation is a tool for implementing policy. It is evident that important declarations, such as the CRPD (UN 2006), have been influential and adopted widely, forming the basis of national policies related to the social inclusion of people with disabilities, including those with IDD. This is welcome and necessary if the policy intentions about social inclusion are to be a reality. However, for Norway, Romania, Poland, Sweden, England, Scotland and Northern Ireland there is a gap between goals and visions and the realities of matching service provision to increasing demand. Each of these countries is struggling to achieve the goal of social inclusion for people with IDD.

The starting point for social inclusion differs in the seven countries, as all have different historical contexts that affect the journey towards this goal. The policy shift

in Western European countries regarding social inclusion and people with IDD has been ongoing since the 1970s. Eastern European countries, such as Romania and Poland, have had a sustained focus on

social inclusion since the 1990s. However, while policies can provide clearer direction and drive welcome change such as the move to care and support in the community and the closure of institutions, on their

**Table 2. Overview of social inclusion, health and education legislation and policies in England, Scotland and Northern Ireland**

	Social inclusion	Health	Education
England	Department of Health (2001, 2010)	Mental Capacity Act 2005	Children and Families Act 2014
	<p><b>Aim</b> The Valuing People strategy (DH 2001) advocated four main principles for people with learning disabilities:</p> <ol style="list-style-type: none"> <li>1. Recognising their legal and civil rights.</li> <li>2. Promoting their independence.</li> <li>3. Empowering them to make choices.</li> <li>4. Promoting inclusion in mainstream services and full inclusion in the local community</li> </ol>	<p><b>Aim</b> To protect and empower people aged 16 and over who may lack the mental capacity to make their own decisions about their care and treatment. The act also allows people to express their preferences for care and treatment, and to appoint a trusted person to plan on their behalf should they lack capacity in the future</p>	<p><b>Aim</b> To support major changes to the special educational needs system for identifying children and young people with intellectual and developmental disabilities in England, assessing their needs and making appropriate provisions for them. The act was guided by the special educational needs and disability code of practice: 0 to 25 years (Department for Education and DH 2015), which provided statutory guidance for organisations that work with and support children and young people who have special educational needs or disabilities</p>
	National Health Service (Direct Payments) Regulations (2013) (DH 2013)		
<p><b>Aim</b> To provide people with learning disabilities with greater control over their lives, by enabling better financial controls and broadening how packages of support might be designed to meet an individual's needs</p>			
Scotland	Fairer Scotland Action Plan (Scottish Government 2016)	Adults with Incapacity (Scotland) Act 2000	Education (Additional Support for Learning) (Scotland) Act 2004
	<p><b>Aim</b> To reduce the effect of social inequalities on all Scottish citizens including:</p> <ul style="list-style-type: none"> <li>» Child poverty</li> <li>» Access to education</li> <li>» Access to work</li> <li>» Duty to increase flexibility of working around care needs</li> </ul>	<p><b>Aim</b> To ensure autonomy and right to choose is embedded and protected by law for those with reduced capacity and decision-making abilities</p>	<p><b>Aim</b> To enshrine in law the duty to assess for additional support needs when requested and duty to ensure provision of services to meet these needs</p>
	Children and Young People (Scotland) Act 2014		
<ul style="list-style-type: none"> <li>» <b>Aim</b> To strengthen and enhance existing legislation to support the well-being of children and young people with consideration given to:</li> <li>» Education and early years</li> <li>» Care experienced by children</li> <li>» Transdisciplinary working and planning</li> <li>» Child protection</li> <li>» Increasing carers support</li> </ul>			
Northern Ireland	Priority Issues for People with a Learning Disability in Northern Ireland (All Party Group on Learning Disability 2018)	Bamford Review of Mental Health and Learning Disability (Northern Ireland) (2007)	Special Educational Needs and Disability Act (Northern Ireland) 2016
	<p><b>Aim</b> To promote a better understanding of the issues facing people with a learning disability and their families; and influence policy, legislation and service development to improve the lives of people with a learning disability and their families in Northern Ireland, and ensure their full participation in society</p>	<p><b>Aim</b> To identify and tackle factors which can contribute to social exclusion and to undertake positive initiatives to improve and enhance the life and circumstances of the most deprived and marginalised people in our community</p>	<p><b>Aim</b> To reform how children with special educational needs are identified and supported, consider the child's view and transition planning in preparation for adulthood</p>

own they will not result in social inclusion. There remain ongoing challenges, especially related to social inclusion, that need to be addressed. Professions and professionals in health, education and social services for people with IDD have a politically agreed mandate to effect social inclusion for people with IDD (Grimen 2008). Central to this mandate is the implementation of policies in their profession and area of practice. Therefore, the challenge of achieving the social inclusion of people with IDD is a collaboration between policy makers and the professions and professionals in health, education and social services.

There are also new issues and challenges to be considered and addressed. There is growing evidence of the increasing life expectancy of people with IDD, with many living into adulthood with a range of complex physical and mental health conditions, neurodevelopmental disabilities and behavioural challenges (Taheri et al 2016). The population changes and increasing complexity of needs have significant implications for the delivery of social inclusion policies for all the professions involved in the education and care of people with IDD now and in the future. A starting point is therefore for all education programmes preparing professionals to work with people with IDD to reflect the legislative and policy intentions regarding the rights of people with disabilities. The curriculum in IDD education programmes needs to include theories and principles related to achieving social inclusion, examples of what does and does not work and the solutions required to overcome the barriers. An example of how this can be achieved is through the EU's Erasmus+ programme to support education and training across Europe.

#### **Erasmus+ programme**

The Erasmus+ programme enables universities to collaborate in teaching, research, networking and policy initiatives on EU priorities, such as social inclusion. Erasmus+ is the largest programme for

student mobility ever developed in Europe. Since 1987 when it was first established, more than five million students have taken part in Erasmus+ (EC 2019).

The Erasmus + programme was used to bring together academics, students and practitioners from the different professions working with people with IDD across the seven countries. It enabled the development of a collaboration between seven universities in these countries (Table 1) focusing on social inclusion and people with IDD. The aim of the collaboration was to develop shared learning opportunities among professions that historically have not been educated together, to develop their knowledge and understanding of the policies that affect social inclusion. Participation also identified areas where collaboration across the professions will be required in the future to ensure that the complex needs of people with IDD are identified and addressed.

#### **Conclusion**

Norway, Romania, Poland, Sweden, England, Scotland and Northern Ireland all have social inclusion as a central goal of their welfare policies and legislation. However, it is evident that all these countries are struggling to achieve social inclusion for people with IDD. While policies and legislation on social inclusion are the responsibility of governments, their implementation relies on the professions and professionals educating and caring for people with IDD. Therefore, the challenge of achieving social inclusion for people with IDD is a shared objective between government and the professions and the professionals involved. One approach to achieve social inclusion is to develop opportunities for shared learning among students in health, education and social programmes. This will enable them to explore and develop their knowledge and understanding on the issue. It is an area that deserves further attention and development.



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