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Support for Children with Special Educational Needs (SEN)

Sam Drabble



EUROPE

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The research described in this report was prepared for the European Commission, Directorate-General for Employment, Social Affairs and Inclusion.

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Preface

This policy brief was developed by RAND Europe, which in 2011 was appointed by the European Commission's Directorate-General for Employment, Social Affairs and Inclusion to provide content and technical support for the European Alliance for Families platform.

The European Alliance for Families (EAF) was set up to explore demographic and economic challenges in the EU from a family perspective. Its purpose is to share the best of policymaking for families and to foster cooperation and mutual learning in the field. This is achieved through information provided on the EAF website, which enables policymakers from the Member States to search evidence-based family practices from around the EU and to share knowledge about practices that are being developed, and also by bringing together government, civil society and European Union representatives for seminars and workshops to exchange ideas and learn from each other.

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The document is designed to provide insights into issues of interest to policymakers. It has been reviewed by one of the EAF's external experts in family policy, and internally, following RAND's quality assurance processes.

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Core Messages

- A strong political consensus has emerged in Europe on the importance of inclusive education, and ensuring children with special educational needs (SEN) are included within mainstream education. This is broadly, although not comprehensively, supported by the evidence base.
- There is a general trend towards placement of children with SEN in mainstream education, and away from special schooling. However, there remains substantial variance in placement patterns.
- Provision of support for children with SEN is a matter for individual EU Member States. Coordination at a European level through mutual learning and the sharing of best practice is lacking.
- There is a marked absence of pan-European data on the prevalence of SEN. This can be partly attributed to varying definitions of SEN across Europe and divergent methods of SEN identification. There is a need for a harmonised classification framework of SEN in Europe.
- Experts call for official assessment protocols and computerised screening to be further developed as diagnostic tools for some disabilities, notably dyslexia, and their use encouraged across Member States.
- Many Member States have made good progress in developing coherent, localised and inclusive early intervention strategies, which provide for consultation with affected families.
- Inclusive education can be facilitated by inclusive education plans (IEPs), the devolution of provision to a local level, funding regimes with the correct incentives, and the provision of specialist support to teachers.
- Information on the support mechanisms available to parents of children with SEN is incomplete, but examples of good practice do exist and can be replicated.

Summary

Mutual learning and the sharing of best practice on the provision of support for children with SEN are lacking at the European level. This is complicated by a marked absence of pan-European data on the prevalence of SEN, attributable to varying definitions of SEN between countries and divergent methods of SEN identification. Correspondingly, there is a case to be made for a harmonised classification framework of SEN in Europe. A political consensus has emerged on the importance of inclusive education, reflected by a general trend towards placement of children with SEN in mainstream education, and away from special schooling. Many Member States have made good progress in developing coherent, localised and inclusive early intervention strategies, which provide for consultation with affected families. Information on the support mechanisms available to parents of children with SEN is incomplete, although examples of good practice exist for replication.

1. Introduction

Approximately 800 million young children worldwide are affected by biological, environmental and psychosocial conditions that can limit their cognitive development. In Europe, recent estimates place the number of children with special educational needs (SEN) at 15 million. Conservative estimates state that dyslexia, a learning disability that impedes a person's ability to read, affects approximately 6 percent of Europe's population, whilst the prevalence of autistic spectrum disorders (ASDs) is also estimated to be higher than previously thought. Children with SEN frequently leave school with few qualifications and are much more likely to become unemployed or economically inactive. In addition to these concerns, the parents of children with SEN experience high levels of stress. If they are not adequately supported, not only will the development of the child suffer, but the family unit as a whole can be placed under considerable strain.

Efforts to support children with SEN are underlined at a European level by the *Education and Training 2020 Strategic Framework* (2009),¹ and the May 2010 *Council conclusions on the social dimension of education and training*.² Both documents emphasise the imperative that education systems in Europe provide for the successful inclusion of all learners. They were preceded by the UNESCO Salamanca Statement (1994),³ which called on the international community to endorse the approach of inclusive schooling, and by the UN Convention on the Rights of People with Disabilities (2006),⁴ with 144 signatories. The aims of European policymakers in this area are chiefly supported at an institutional level by the European Agency for Development in Special Needs Education (EADSNE), established in 1996, whose remit is to improve the quality of special needs provision across Europe by encouraging cross-country collaboration and knowledge exchange. In the *Disability Strategy 2010–2020*, the European Commission notes 'the strong mandate on the EU and Member States to improve the social and economic situation of people with disabilities', and further underlines 'the aspiration of creating a barrier-free Europe'.⁵

¹ European Commission (2009), Main policy initiatives and outputs in education and training since the year 2000: Strategic framework for European cooperation in education and training ('ET 2020'). As of 30 March 2013:http://ec.europa.eu/education/lifelong-learning-policy/policy-framework_en.htm

² Council of the European Union, *Council conclusions on the social dimension of education and training*. As of 30 March 2013:
http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/educ/114374.pdf

³ UNESCO, *The Salamanca Statement on Principles, Policy and Practice in Special Needs Education*. As of November 2012:
http://www.unesco.org/education/pdf/SALAMA_E.PDF

⁴ United Nations, *Convention on the Rights of Persons with Disabilities and Optional Protocol*. As of 30 March 2013:
<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

⁵ European Commission (2010), *The European Disability Strategy 2010–2020*. Brussels: European Commission.

Although the concept of inclusive education has secured a prominent position in the political agenda of many Member States, progress towards this goal remains fragmentary. Efforts to support children with SEN at a European level, through the open method of coordination (OMC), the exchange of best practices and mutual learning, are undermined by the absence of pan-European data and comparable country data on the prevalence of SEN. This is coupled with a relative lack of formal evaluations of policy initiatives in this area, and of comprehensive information on the nature of support mechanisms available to children with SEN and their families. In this context, a better overview of the variations in national laws supporting SEN provision would be helpful. Dyslexia non-discrimination and provision of support is one such example where little substantial pan-European research has taken place.⁶

The purpose of this policy brief is to inform decisionmakers on policy trends and practices in relation to children with SEN across Europe. It first provides an overview of existing evidence on effective diagnosis and early intervention for these children, before outlining progress towards greater inclusion of children with SEN in mainstream education, and efforts to support their parents and wider family unit.

⁶ Gyorfi and Smythe (2010).

2. Defining Special Educational Needs

Despite the universally accepted importance of supporting children with SEN, there is no common agreement in Europe of what constitutes special needs in education. The construction of any such definition is hindered by the absence of a harmonised system of classification for individual learning difficulties. There are significant differences across Europe in the labels used to categorise children with SEN, and the social understandings which underpin particular labels.

The Network of Experts in Social Sciences of Education and training (NESSE) distinguishes between normative and non-normative difficulties. Physical and sensory difficulties fall into the normative category, where there is broad agreement on what constitutes normal functioning, and as a result, relatively objective assessment measures are available. This policy brief is primarily concerned with what NESSE terms ‘non-normative’ difficulties. These refer to types of difficulty where there is less agreement about normal functioning and where professional judgement plays a larger part in identification; examples include social, emotional and behavioural difficulties such as ASDs, and learning difficulties including dyslexia. Normative categories tend to be low-incidence, whereas non-normative categories tend to be high-incidence, accounting for the majority of children identified as having SEN in many countries.⁷

⁷ NESSE (2012), *Education and disability/special needs: policies and practices in education, training and employment for students with disabilities and special educational needs in the EU, An independent report prepared for the European Commission by the NESSE network of experts*. As of 30 March 2013: <http://www.nesse.fr/nesse/activities/reports/activities/reports/disability-special-needs-1>

3. Identifying Children with Special Educational Needs

Ensuring that children with SEN receive adequate support begins with the correct identification of their needs, which may in turn lead to a diagnosis. Research emphasises the need for effective screening and diagnostic systems to identify developmental disorders at the earliest possible stage, clearly indicating that the chances of overcoming difficulties are significantly enhanced by early identification.⁸ Although research has shown that neuroplasticity continues to exist into adult life, the first years of childhood remain vital for future cognitive development. Screening for SEN is therefore recommended during infancy and preschool years.⁹ However, owing to limitations in the sensitivity and specificity of screening instruments, universal screening is not possible for a number of neurodevelopmental disorders. Accordingly, there is a scarcity of commonly employed screening instruments to identify developmental disorders in the EU. The M-CHAT instrument, used to screen children at risk of autism, is one example that has been found to be effective.¹⁰ The diagnosis is, however, thought to be reliable only at three years of age. In cases of mild developmental difficulties, symptoms may go unnoticed initially, becoming evident at a later age. Identifying and assessing children's needs is therefore an iterative process, and screening needs to be repeated at a later stage to identify problems not yet emergent at nursery level.¹¹ Experienced clinical judgement, taking into account a variety of sources, remains the most reliable tool for diagnosis.

Although parents may observe developmental problems at an early age, a lag commonly exists between first observation and the child being correctly diagnosed. For example, the median age for the earliest diagnosis of ASDs is between 4.5 and 5.5 years, despite the majority of these children exhibiting signs by the age of three.¹² The fact that diagnosis of ASDs is based on behavioural characteristics presents challenges for the construction of appropriate diagnostic tools, and leaves these vulnerable to socio-economic and cultural differences. For example, language delays linked to specific disorders can be overlooked in socially deprived areas, where language skills for children of a certain age may be less developed as a whole. An inability to engage in eye contact, symptomatic of some ASDs, might also be interpreted as reflecting cultural difference. One challenge for the provision of SEN support in Europe is

⁸ Mendez, K., et al. (2011), 'Cross Cultural Variation in the Neurodevelopmental Assessment of Children – The Cultural and Neurological to 2nd Language Acquisition and Children with Autism', in Mohammadi, M-R (ed.), *A Comprehensive Book on Autism Spectrum Disorders*, InTech.

⁹ Baird, G., et al. (2001), 'Screening and surveillance for autism and pervasive developmental disorders', *Archives of Disease in Childhood* 84.6: pp.468–475.

¹⁰ Mendez et al. (2011).

¹¹ Taylor, H.G., et al. (2000), 'Utility of kindergarten teacher judgments in identifying early learning problems', *Journal of Learning Disabilities* 33.2: pp.200–210.

¹² Baird et al. (2001).

therefore to develop screening mechanisms that reflect the cultural variations and diversity of socio-economic background of families served.

The difficulties of identifying children with SEN are reflected in the scarcity of reliable data on the prevalence of certain disorders, which in turn hinders the development of effective support policies. In the case of ASDs, limitations in diagnosis methods mean the reported high prevalence rates in the EU cannot be used to derive absolute conclusions.¹³ The European Autism Information Service (EAIS) was created to improve knowledge of ASD prevalence and services in the EU, and commissioned a survey to understand the problems associated with determining prevalence and accessibility to services in 11 participant countries.¹⁴ The resulting EAIS report highlights the variation in ascertainment methods across the participant countries. It stresses the need for a common framework in order to understand prevalence in the EU, and for the introduction of more complex monitoring systems. The report reveals that some Member States have no established protocol for the early detection of ASDs. The 2010 EMBED (Embedding Dyslexia-Responsive Practices in Lifelong Learning) project, which assessed activities in the field of supporting dyslexia provision for children in six partner countries across Europe,¹⁵ mirrors the findings of EAIS. It emphasised the need for an official assessment protocol to be introduced as an aid in diagnosing dyslexia, and advocated the introduction of computerised mass screening.

Where universal screening is not implemented and developmental disorders are not identified at the pre-school stage, it may be incumbent on teachers to identify difficulties, and then refer the child to a trained expert or diagnostician. The evidence is unclear on the extent to which teachers should be relied upon to identify special educational needs, and implies that early detection requires specialised competencies. A review commissioned by the UK Government argues that all teachers should have a working knowledge of warning signs and advocates that the acquisition of this knowledge should be a normal constituent of Initial Teacher Training (ITT), together with training to enable teachers to develop the required expertise. The report also details the need for better access to specialist dyslexia teachers, and teacher involvement in dyslexia assessment and intervention.¹⁶

The literature on specific learning disorders again stresses the importance of ensuring teachers are properly trained in assisting and helping to identify developmentally challenged children. For example, research has highlighted the importance of teacher input in understanding behavioural events, and their knowledge of developmentally appropriate behaviour, in successfully identifying children with Attention Deficit Hyperactivity Disorder (ADHD).¹⁷ However, in the identification of developmental difficulties related to poor reading, standardised tests are a more effective tool for diagnosis than teacher judgement.¹⁸ Whilst the latter correlates significantly with standardized achievement test scores, recent studies highlight that teachers tend to overestimate the reading ability of low-achieving students and the progress of low-

¹³ Mendez et al. (2011).

¹⁴ Bulgaria, the Czech Republic, Denmark, England, France, Italy, Malta, Poland, Portugal, Scotland (Highland Region) and Spain.

¹⁵ Bulgaria, Hungary, Italy, Poland, Spain and the UK.

¹⁶ Rose, R. (2009), *Identifying and Teaching Children and Young People with Dyslexia and Literacy Difficulties: An independent report from Sir Jim Rose to the Secretary of State for Children, Schools and Families*. Cited in Györfi, A., and Smythe, I. (2010).

¹⁷ Brock, S., Jimerson, S., and Hansen, R. (2009), *Identifying, Assessing, and Treating ADHD at School*. New York: Springer.

¹⁸ Ise, E., et al (2011), 'Support Systems for Poor Readers: Empirical Data From Six EU Member States', *Journal of Learning Disabilities* 44.3: pp.228–245.

performing students.¹⁹ These findings suggest that standardised tests yield more objective and accurate measures of reading ability and are better suited for the identification of poor readers. Effective support systems typically identify poor reading skills first by a standardised test, followed by a thorough diagnosis by a trained expert.²⁰

As outlined in a recent report by the NESSE network of experts, statistics on the proportion of children with SEN reflect different identification practices that often depend on local decisionmaking.²¹ All Member States have their own system of categorising children with SEN, and this is one of the factors that make it difficult to run international comparisons on SEN policies and practices. In some countries, SEN identification is mainly used to trigger special school placement, and in countries with a larger number of special schools (Belgium, the Czech Republic, Lithuania, Finland, Germany) there are relatively high rates of SEN identification. In countries where SEN identification is linked to additional resource allocation (for example, Norway and Scotland), a relatively large group of children may also be identified.²² EADSNE has illustrated this diversity but has not tried to propose a harmonised system of classification. The OECD went further in inviting the 22 countries participating in its ongoing studies of SEN to reclassify their national categories into a three-category framework (see Box 1).

Box 1. Framework for classification of children with SEN

Category A: disabilities with organic origins where there is substantial normative agreement about the categories (for example, sensory, motor, severe and profound intellectual disabilities).

Category B: difficulties that do not appear to have organic origins or be directly linked to socioeconomic, cultural or linguistic factors (for example, behavioural difficulties, mild learning difficulties, specific learning difficulties and dyslexia).

Category C: difficulties that arise from socio-economic, cultural and/or linguistic factors; some disadvantaged or atypical background that education seeks to compensate for.

SOURCE: OECD (2000).

The framework devised by the OECD has been used for cross-country comparisons in the identification of SEN. In 9 out of the 11 countries for which incidence data were available, there is a lower proportion of pupils in category A (organic disabilities) than category B (non-normative difficulties). There are also large differences in the placement of pupils in category A. For example, the United States reported 5.6 percent of pupils in category A, 70 percent of whom were in mainstream classrooms, compared with 1.8 percent in the Netherlands, 87 percent of whom were in special schools. Figure 1 illustrates the considerable variation across Europe in the percentage of the school population identified as having special needs, ranging from 1.5 percent in Sweden to 24 percent in Iceland. Such a pronounced

¹⁹ Ise et al. (2011).

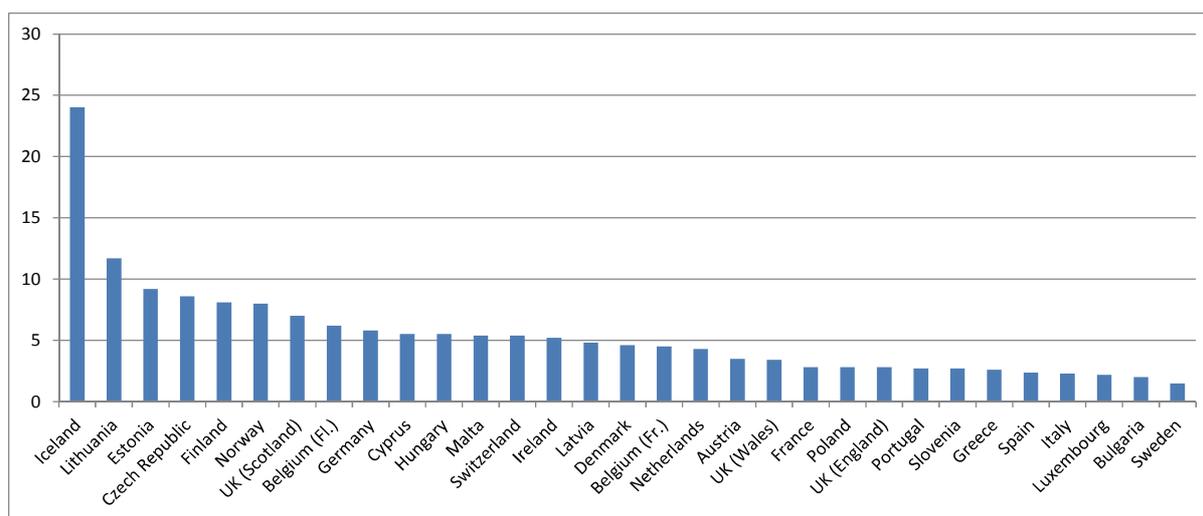
²⁰ Ise et al. (2011).

²¹ NESSE (2012).

²² NESSE (2012).

discrepancy between countries is testament to the distorting effect of different counting practices. Accordingly, any efforts at the European level to assist children with SEN must first be clear about the types of needs being referred to, and propose a system of classification that addresses the widely divergent identification practices currently in place across Europe.

Figure 1: Pupils identified as having SEN as a percentage of the total school population in selected European countries



Source: EADSNE Country Data 2010 (cited in NESSE, 2012). Note: The statistics for Bulgaria and Italy are drawn from EADSNE Country Data 2008, since they are not included in the 2010 publication.

4. Early Childhood Intervention

It is widely accepted that effective support for children with SEN should begin as early as possible, epitomised by the phrase ‘early intervention’. As noted by the British Institute of Learning Disabilities, ‘research and practice have proven that Early Intervention produces immediate and long-term benefits for children with disabilities, their family and society’.²³ Early intervention is defined by EADSNE as ‘a range of all necessary interventions – social, medical, psychological and educational – targeted towards children and their families, to meet the special needs of children who show or risk some degree of delay in development’.²⁴

Early intervention is targeted at children from birth to three years of age, and has four primary goals: 1) to support families in supporting their children’s development; 2) to promote children’s development in vital domains; 3) to promote children’s coping confidence; and 4) to prevent the emergence of future problems.²⁵

Successful early intervention strategies recognise the holistic nature of support for families. The literature cites the importance of multi-disciplinarity, and the construction of linkages between policy development for early intervention and policy on childcare, employment and housing.²⁶ Healthcare services must take into account the importance of the child’s first year in detecting delays and difficulties, with an emphasis on regular medical surveillance and immunisation during the first year of a child’s life.²⁷ EADSNE notes that the decentralisation of early intervention services and provisions may be necessary, in order to ensure the same quality of services in different geographical areas, and to avoid overlaps and irrelevant pathways.²⁸

The organisation and structure of early childhood intervention (ECI) services varies across Europe, in line with the centralised or decentralised administrative approaches of European countries. In Austria, Belgium, the Czech Republic, Denmark, Finland, Germany, Iceland, the Netherlands, Norway, Spain, Sweden, Switzerland and the United Kingdom (England), ECI services are to a large extent built upon a regional or local decentralised model. Although the tendency in policy measures is to ensure equal access to ECI services for all citizens, in practice there are differences between regions and between urban and

²³ National Children’s Bureau (2004), *The Early Support Pilot Programme: Phase 1 – Evaluation Report*, p.5. As of 30 March 2013: <https://www.education.gov.uk/publications/eOrderingDownload/RBX06-04MIG2517.pdf>

²⁴ EADSNE (2003), *Special Needs Education in Europe: Thematic Publication*, p.49.

²⁵ National Children’s Bureau (2004), p.5.

²⁶ EADSNE (2010), *Early Childhood Intervention – Progress and Developments, 2005–2010*.

²⁷ EADSNE (2010).

²⁸ EADSNE (2010).

rural areas. Notable examples of ensuring widespread access to services include Switzerland, where ECI services, including home therapy, provide the same quality of provision to citizens in cities as well as rural areas. In Finland, services are offered as close to home as possible. Where distances are considerable, the national insurance system compensates for travel and medical costs.²⁹

The majority of ECI services in Europe are publicly funded, and normally families are not required to pay. Some NGOs and independent centres with an interest in particular conditions may offer services, for example to support children with Down syndrome, autism, deafness, speech, or language and communication difficulties. These are often voluntary organisations that raise funds to enable families to use their services free of charge.

4.1. Identification and early intervention practices

The following examples illustrate identification and early intervention practices for children with SEN:

Priority access to pre-primary education: One important mode of facilitating early intervention is to give children with learning disabilities priority access to educational centres for pre-primary education. This is the case in England, Germany, Iceland, Norway, Spain, Sweden and the Netherlands. Support can be provided at home, in outpatient or day care clinics, in early intervention services or in pre-primary settings.

Sure Start, UK: Sure Start children's centres act as local hubs for community services for children of all ages. The centres offer support in the early identification of children with special needs, and offer portage home teaching programmes for young children with SEN. Ongoing evaluations of Sure Start have found a number of positive outcomes, including that mothers report providing a more cognitively stimulating home environment.³⁰ Coverage is targeted at compensating for social disadvantage by concentrating on geographical areas considered to be highly socially disadvantaged.

ECEC, Finland: In Finland, every child from the age of 10 months to 7 years can join the day care system (called ECEC). Day care includes both education and care (so called EduCare). Most children with special needs or at risk (85 percent) are included in this provision.³¹

Early Intervention Centre, Hungary: The Early Intervention Centre (EIC) provides a package of services for children with delayed or impaired development aged 0–6 in Budapest. Services are delivered by a group of specialists who focus on the development of the child as well as the needs and circumstances of the family. With a team of paediatricians, special teachers, physiotherapists, psychologists, social workers and integration specialists, the Centre aims to provide a complete approach to care. The main goal of their activities is to ensure the health and well-being of the child, to enhance families' abilities in caring for

²⁹ EADSNE (2010).

³⁰ National Evaluation of Sure Start (NESS) Team (2010), *The impact of Sure Start Local Programmes on five year olds and their families*. As of 30 March 2013: <http://www.ness.bbk.ac.uk/impact/documents/RR067.pdf>

³¹ EADSNE (2006), Euronews on Special Needs Education, Issue No.15. As of 30 March 2013: http://www.european-agency.org/news/euronews/euronews-15/euronews15_entext.pdf/view

their children and to minimise developmental delays. The centre specialises in helping premature babies and children with autism and severe and multiple disabilities.³²

Networking as a model for language learning, Norway: Networking as a highly specialised model for language learning was introduced in the Sorlandet Resource Centre (SRC), Norway, in 1999. In the SRC, networking groups work together with professionals, families and other individuals in order to support children's speech and language development. A child's language development is promoted by interacting with people who have different roles on a daily basis: the network's function is to create such opportunities.³³

Pre-school language support, Schleswig-Holstein, Germany: In order to address speech difficulties before children begin school, teachers in Schleswig-Holstein specialising in speech and language impairments deliver training to nursery school teachers. As a result of this provision, nursery school teachers develop the knowledge to identify children requiring speech therapies or language support.³⁴

³² European Union Early Intervention Centre. As of 30 March 2013: http://europa.eu/epic/practices-that-work/practice-user-registry/practices/early-intervention-centre_en.htm

³³ EADSNE (2006).

³⁴ EADSNE (2006).

5. Inclusive Education

Much of the research into supporting children with SEN in Europe centres on the concept of inclusive education – defined by Booth (2000) as ‘the process of increasing participation and decreasing exclusion from the culture, curriculum and community of mainstream schools.’³⁵ Inclusive education is supported by European Commission funding and promoted jointly by EADSNE and UNESCO. Implementing inclusive education is high on the agenda of many Member States, though the policy is approached from differing historical and structural perspectives. The core underlying assumption of this policy for children with SEN is that these children would benefit most from education alongside neurotypical children in mainstream schools, as opposed to special schools catering specifically for those with special needs. There are marked discrepancies among EU countries with regard to their use of special schools (see Figure 2), which reflect the broader education systems in place. European countries with selective rather than comprehensive school systems (including the Netherlands, Germany, and both the French and Flemish communities of Belgium), where pupils are divided along ability lines, correspondingly have a relatively high number of special schools per head of population. In contrast, Spain and the UK, with comprehensive school systems, have less special provision, and countries such as Italy and Greece, in the absence of any historical tradition of special schooling, educate almost all children in mainstream schools.

Whilst in most Member States the preference is still to maintain some form of special provision, the general trend is towards a gradual reduction in the number of special schools and an increase in the number of children with SEN in mainstream schooling.³⁶ In accordance with this trend special schools are increasingly being transformed into resource centres for mainstream schools. The relevance of inclusive education in public debate is illustrated by the popularity of the Index for Inclusion.³⁷ Originally developed in the UK, the Index provides a list of indicators and questions to assist schools in engaging in a process of self-review, with a view to developing inclusive ethos and practices. The Index has been translated into more than 32 languages.³⁸

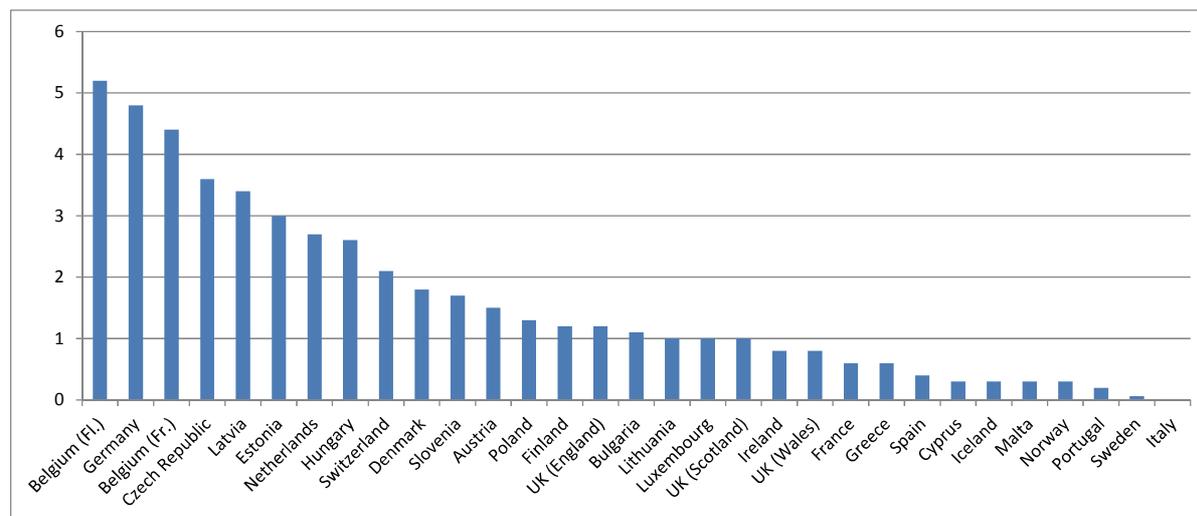
³⁵ Booth, T. (2000), ‘Controlling the agenda: policies on inclusion and exclusion in England’, in Armstrong, D., Armstrong, F. and Barton, L. (eds.), *Policy, Contexts and Comparative Perspectives*, London: Fulton. Cited in NESSE (2012), p.9.

³⁶ NESSE (2012).

³⁷ Booth, T. et al. (2002), *Index for Inclusion*, Centre for Studies on Inclusive Education.

³⁸ NESSE (2012).

Figure 2: Number of pupils in segregated special schools as a percentage of total pupil population in selected European countries



Source: EADSNE Country Data 2010. Note: The statistics for Bulgaria are drawn from EADSNE Country Data 2008, since they are not included in the 2010 publication.

The evidence suggests that any differences in outcomes for children with SEN between special and mainstream schools are small, but tend to favour mainstream schools in terms of educational attainments and social integration.³⁹ The most prominent beneficiaries of inclusion policies tend to be higher-achieving children with physical or sensory impairments, who might once have been taught in special schools but are now routinely educated in mainstream classes. An OECD study found that other pupils may also benefit from the inclusion of Children with SEN in their schools: their inclusion necessitates that teachers devote more energy to the curriculum to ensure it is appropriate for the learning needs of all pupils, which increases teachers' overall teaching skills.⁴⁰ Contact with children with a disability in an inclusive setting is also said to increase familiarity and reduce prejudice over the long term.⁴¹ However where children with SEN are integrated into mainstream classes, neurotypical pupils should be informed of the implications of various syndromes and disorders. For instance in ASDs, for instance, inflexible behaviour or acute reactions to change of routine might be perceived as defiant by teachers and peers, if not properly understood as symptomatic of the child's condition.

It should be noted that empirical research into the merits of mainstream and special schooling for children with SEN is now fairly dated, and there have been very few quasi-experimental studies conducted owing to ethical considerations. The emphasis on inclusion can therefore be said to be motivated by political and human rights concerns, rather than scientific analysis of what works best for particular children.⁴² Children with SEN can struggle to be accepted in mainstream schools, and inclusion does not preclude the possibility of marginalisation. Pupils with special needs in mainstream schools are often less popular,

³⁹ Topping, K., and Maloney, S. (2005), 'Introduction', in Topping, K., and Maloney, S. (eds.), *The RoutledgeFalmer Reader in Inclusive Education*, London: RoutledgeFalmer.

⁴⁰ Peters, S.J. (2003), *Inclusive education: achieving education for all by including those with disabilities and special education needs*, Prepared for the Disability Group, The World Bank.

⁴¹ NESSE (2012).

⁴² NESSE (2012).

have fewer friendships and participate less often as members of a subgroup.⁴³ Children with ASDs may have sensory problems that require special equipment or adaptations in the schooling environment, and are particularly likely to become victims of teasing and bullying linked to aspects of their behaviour (including thinking out loud, pacing, fixation on objects and echolalia). However, additional support provided to children with behavioural, social and emotional difficulties in mainstream schools should be carefully balanced, since overtly special treatment may lead to stigmatisation and hinder possible progress.⁴⁴ Notwithstanding these difficulties, the prevailing view, as expressed at a European level, is that mainstream education lessens the chances for most children with SEN of leaving school with few or no qualifications, and equally of moving into specialist training, which can, in some cases, impair rather than increase their job prospects.⁴⁵

A competing 'discourse of difference' continues to have some support in Europe, whereby, in opposition to the ethos of inclusive education, disabled children are regarded as requiring special placement and pedagogy. This particularly applies to provision for children diagnosed with ADHD, the diagnosis of which has increased considerably.⁴⁶ A prominent example of this trend is Sweden, where about 10 percent of children are officially diagnosed as having the condition. These children are taught in separate classes within mainstream schools using teaching techniques based on behaviour modification, and may receive pharmacological treatment to control their behaviour.⁴⁷ There are also strong advocates of specialist pedagogies in the field of autism, with many independent schools across Europe promoting particular regimes.⁴⁸

Despite the aforementioned widespread political endorsement of inclusive education, there is still wide variation across Europe in the identification of children with SEN, and in whether they are placed in mainstream or special schools. Greater efforts are needed to harmonise definitions, and to improve data gathering that will enable cross-national comparisons. It has also been noted that less transparent forms of segregation are on the rise. For example, the majority of children in Pupil Referral Units (PRUs) in England have some sort of special educational needs, but these children are not counted as being in the special sector. Behaviour support units, nurture groups and alternative schools are becoming increasingly common in countries such as Norway and the UK. These alternative forms of provision attempt to develop pupils' social and life skills, and may provide temporary respite for children who are experiencing instability within their families. However, they risk the child leaving school with few qualifications.⁴⁹

A barrier to inclusive education remains the clear tendency in all Member States for deprived children from ethnic minority and socio-economically disadvantaged backgrounds to be over-represented in special schools. Children living in areas of social deprivation are more likely to be identified as needing special

⁴³ Pijl, S.J., Frostad, P., and Flem, A. (2008), 'The Social Position of Pupils with Special Needs in Regular Schools,' *Scandinavian Journal of Educational Research* 52.8: pp.387–405.

⁴⁴ Keslair, F., and McNally, S. (2009), *Special Educational Needs in England: Final Report for the National Equality Panel*, London: Centre for Economic Performance, London School of Economics.

⁴⁵ European Commission (2012).

⁴⁶ NESSE (2012).

⁴⁷ NESSE (2012).

⁴⁸ NESSE (2012).

⁴⁹ NESSE (2012).

needs support from the outset, and this trend continues once in school. In addition, an OECD report found that boys are universally more likely to be identified as having special needs, constituting over half the children identified as such in every country in the study.⁵⁰ There are a number of theories presented in the literature as to why this is the case, with no consensus. The gender discrepancy is highest in the non-normative categories of special needs, such as learning difficulties. Immigrant children are also more likely to be placed in special needs classes, and Roma children face particularly high segregation rates.

5.1. Inclusive education practices

The following examples illustrate inclusive education practices:

Inclusive Education Plans (IEPs): In many Member States extensive use is made of IEPs (known as ‘targeted action programmes’ in Scandinavia). These documents set out short- and long-term learning targets for pupils with SEN, enabling teachers to consider how the mainstream curriculum might be adapted and personalised. The IEPs specify the pupils’ needs and goals, and detail the degree and type of adaptations to be made to the curriculum in order to evaluate their progress. An IEP can also serve as a contract between parents, teachers and other professionals. Positive strength-based approaches and needs-based assessments are generally used to determine appropriate curriculum accommodations and adaptations.⁵¹

Decentralisation: Although in most countries the ministries of education have the sole responsibility for special needs education, there is a clear and widespread trend towards decentralisation of responsibilities. As local forces can more easily facilitate a responsive provision of special needs education, the devolution of responsibilities (and corresponding funding) to a local level may enhance inclusive practices. EADSNE outlines that over the past decade, decentralisation has been a central theme in the debate on SEN provision in the UK, the Czech Republic and the Netherlands. In England there is an increasing shift of resources and decisionmaking to those nearest the child, reflecting evidence that this brings the greatest benefits to the largest numbers of pupils needing such support.⁵² In the 1990s in Finland, the number of special schools decreased following reforms of school administration towards decentralisation of decisionmaking power to municipalities. In other Scandinavian countries (Sweden, Denmark and Norway) special needs education is also strongly related to decentralisation, and municipalities are legally responsible for providing all resident pupils with education regardless of their abilities. A similar evolution towards decentralisation of provision is also visible in France.⁵³

Effective funding regimes: Funding regimes have also been found to play an important role in incentivising inclusive provision. In a study of 17 European countries, Meijer (1999) found that funding regimes that channelled resources to special schools tended to increase the use of the special sector, since available places were always filled. The study also suggests that allocating individual budgets to pupils with SEN tends to encourage schools and parents to seek such funds, escalating the number of pupils identified as

⁵⁰ OECD (2007), *Students with Disabilities, Learning Difficulties and Disadvantages: statistics and indicators*, Paris: OECD/CERI.

⁵¹ Peters (2003).

⁵² EADSNE (2010).

⁵³ EADSNE (2010).

having SEN. It is argued that allocating funds to local authorities and schools, rather than to individual pupils, might be a more effective means of promoting inclusion and curbing escalating special needs budgets.^{54,55}

Provision of specialist support to teachers: Classroom assistants play a vital role in making inclusion work well in practice. In Europe support is frequently given to the mainstream class teacher by a specialist teacher, who may be peripatetic or based in the school.⁵⁶ In Germany, special school teachers are increasingly spending part of their working hours in mainstream schools, undertaking consultancy work with class teachers or directly supporting children. A clear distinction is evident between countries where support is delivered by a specialist school staff member, and those where support is delivered by a specialist professional external to the school. It is argued that classroom assistants need to be sufficiently qualified if they are to improve the education of children with special needs – for this reason Italy has tended to use additional learning support teachers rather than classroom assistants.⁵⁷ However, the majority of moderately disabled children, for example moderately dyslexic students, are taught in mainstream classrooms by non-specialist teachers.⁵⁸ The authors of an international survey on support for dyslexic children recommend that each educational establishment should have at least one member of staff trained in the recognition of dyslexia, and that primary school teachers be trained in evidence-based dyslexia-preventive literacy teaching.⁵⁹

The importance of specialist support is illustrated by the success of Finland in reducing its number of poor readers. In a study of six European countries, the Finnish system was found to be the most effective at reducing the number of at-risk students. The achievement has been largely attributed to the significant proportion of teachers in Finland (60 percent) who consult a specialist contact person at their school on a regular basis. These frequent interactions were in turn facilitated by the high time resources of Finnish remedial teachers, who typically worked for a single school where they spent a mean of 18 hours per week, above that of other countries in the study.⁶⁰

⁵⁴ Meijer, C. (ed.) (1999), *Financing of Special Needs Education: a seventeen-country study of the relationship between financing of special needs education and inclusion*, Middlefart: European Agency for Special Needs Education.

⁵⁵ Bowers, T. and Parrish, P. (2000), 'Funding of special education in the United States and England and Wales', in McLaughlin, M.J. and Rouse, M. (eds.), *Special Education and School Reform in the United States and Britain*, London: RoutledgeFalmer.

⁵⁶ Winterman, K., and Sapon, R. (2002), 'Everyone's Included: supporting young children with autistic spectrum disorders in a responsive classroom learning environment', *Teaching Exceptional Children* 35.1: pp.30–35.

⁵⁷ NESSE (2012).

⁵⁸ Gyorfi and Smythe (2010).

⁵⁹ Gyorfi and Smythe (2010).

⁶⁰ Ise et al. (2011).

6. Supporting Parents of Children with Special Educational Needs

Numerous studies have documented the strain on parents raising a child with a disability. Parents of children with special needs often report feelings of isolation and high levels of stress, with several studies pointing to an increase in depression.⁶¹ The stress of having a child with SEN can challenge family functioning through exerting pressure on parental well-being, the well-being of siblings and other relatives, spousal relationships, extra-spousal support, and negative effects on parenting behaviour.⁶² Parental responsiveness and sensitivity are necessary for children with SEN to develop secure attachments, yet these are liable to be compromised by the stress exerted on some parents. The time-intensive nature of the care required by many children with SEN also presents an inherent risk of parental burn-out. Providing support to parents with SEN is therefore vital to both the flourishing of the child and of the family as a whole.

Involvement of parents of children with SEN is a vital factor in promoting inclusive schooling.⁶³ This is not easily done in practice, with parents often struggling for adequate resources to be procured for their child. Even in the formulation of IEPs, where schools and local authorities make an explicit commitment to engaging with parents, time constraints often make it impossible for teachers to truly involve parents.⁶⁴ There is variation between Member States with regards to parents being able to choose their child's school, and their legal right to challenge decisions concerning placement and resource allocation. In the UK, parents can legally challenge school placement in court, with around 3,000 cases each year. This contrasts with around 100 per year in the Netherlands, where parental right of appeal is much weaker.⁶⁵

Enabling parents to challenge school and local authority decisions has raised the profile of special needs education in the UK, and increased the funding allocated to disabled pupils. It is equally clear, however, that such options need to be accompanied by support for socially disadvantaged parents, who may otherwise be unable to access the judicial routes available to them due to lack of knowledge and resources. Some parents do not recognise their child as having a disability or SEN,⁶⁶ and those who do often express

⁶¹ Barnett, D., Clements, M., Kaplan-Estrin, M. and Fialka, J. (2003), 'Building New Dreams: Supporting Parents' Adaptation to Their Child With Special Needs', *Infants and Young Children* 16.3: pp.184–200.

⁶² Barnett et al. (2003).

⁶³ NESSE (2012).

⁶⁴ Kane, J., Riddell, S., Banks, P., Baynes, A., Dyson, A., Millward, A. and Wilson, A. (2003), 'Special educational needs and individualised educational programmes: issues of parent and pupil participation', *Scottish Educational Review* 35.1: pp.38–48.

⁶⁵ NESSE (2012).

⁶⁶ Parsons, S., et al. (2009), 'Satisfaction with educational provision for children with SEN or disabilities: a national postal survey of the views of parents in Great Britain', *Educational Review* 61.1: pp.19–47.

uncertainty about the formal mechanisms available to them. Parents should therefore be able to access clear information in everyday settings, such as libraries, supermarkets and doctors' surgeries.⁶⁷ Many parents will also need assistance in identifying the information most relevant to the specific needs of their child.

Information on the range of support systems available to the parents of children with SEN across the EU is incomplete, though evidence suggests there is a sizable variation between Member States. In one study, EAIS surveyed the support services available to parents in 11 countries after their child had received an ASD diagnosis.⁶⁸ Mothers of children with autism have been found to experience more stress than mothers of children with mental retardation, cystic fibrosis or fatal physical illness,⁶⁹ and professional support systems have been found to make a measurable difference to their perceptions of stress. Most of the countries surveyed had early intervention services and speech therapy, and systems whereby families can receive economic support and family counselling; a majority also declared to have respite programmes and social work services available in case of poverty. However, in less than a third of the countries surveyed did the supply of these services match demand. The accessibility of services often depended on fulfilling specific requirements, notably income, residency and severity of disorder. The average waiting time for receiving services was again highly variable, typically between one and six months. Encouragingly, all participant countries had at least one national parent support group or patients' organisations for ASD. In Spain, Poland, England and Scotland, these organizations provided diagnosis and intervention services. In three countries they only provided intervention services (Bulgaria, France and Portugal), whereas in three countries (Malta, Czech Republic and Italy) these organisations did not provide either diagnosis or intervention services in their area.

Evidence supports early intervention strategies that place the family in a central role. Correspondingly, EADSNE has identified several areas for improvement in order to support families with SEN children⁷⁰: these include the availability of information; proximity of services through decentralisation; affordable services; interdisciplinary working and cooperation with families; and coordination across and within sectors. Efforts are also required to promote a stable home learning environment by supporting parents through systems of informal care, such as the care that grandparents can provide. Research has found that the home environment within which children with special needs spend much of their early years will again be instrumental in their learning, with the quality of the home learning environment said to be more important for intellectual and social development than parental occupation, education or income.⁷¹

⁶⁷ Parsons et al. (2009).

⁶⁸ Posada et al. (2007). The 11 participating countries were Bulgaria, the Czech Republic, Denmark, England, France, Italy, Malta, Poland, Portugal, Scotland (Highland Region) and Spain.

⁶⁹ Weiss (2002).

⁷⁰ EADSNE (2010).

⁷¹ Sylva, K., et al. (2004), *The Effective Provision of Pre-School Education (EPPE) Project (Final Report)*. Nottingham: DFES.

6.1. Parental support practices

The following examples illustrate practices supporting parents of SEN children at the early intervention stage:

Involving parents in early intervention: A number of Member States effectively integrate parents in the early intervention process. In addition to the examples below, legislation in Ireland and Greece promotes close cooperation between professionals and families, which is also notably encouraged in France and the Czech Republic.

UK: In the UK, a national implementation programme ('Early Support') encourages the development of Early Childhood Intervention services. The programme actively promotes partnership working through regular 'team around the child (TAC)' meetings with families, designed to keep parents at the centre of decisionmaking. National programmes such as the National Service Framework for Children, Young People and Maternity Services and Aiming High for Disabled Children promote partnership working with parents via a system of regular meetings, joint writing of Family Service Plans, shared information, shared training and, where appropriate, regular support from a lead professional or key worker. 'Sure Start' programmes cooperate closely with families to ensure that services reflect family involvement and participation. Parents are represented in the management committees and mechanisms are in place to ensure their regular evaluation of Sure Start services.⁷²

Estonia: In Estonia, pre-school teachers assess children's development in collaboration with their families, conduct interviews and, if necessary, prepare individual development plans for children. A study by the Ministry of Education and Research into institutional collaboration with parents indicated that nearly half of all parents participate actively in preparing and implementing their children's individual development plans, and that 93 percent of parents were very satisfied with the monitoring of children's development at childcare institutions.⁷³

Also in Estonia, *Vaimupuudega Laste Vanemate Ühing*⁷⁴ is a parents' association that promotes motivational programmes for parents of children with intellectual disabilities. The organisation cooperates with physicians and maternity hospitals and provides support for the mothers of new born babies with mental disabilities and Down syndrome.

Germany (Bavaria): In Bavaria there is a long-standing tradition of taking a family-centred approach to early childhood intervention. Parents are actively involved in all decisions concerning their child, and in addition may receive parental training and counselling and take part in child-focused sessions.⁷⁵

Denmark and Sweden: All provision in Denmark and Sweden has a holistic approach to the child and family, with close cooperation between professionals and the family a priority. Families are involved in suggestions for action and intervention, and are offered guidance and counselling.⁷⁶

⁷² EADSNE (2010).

⁷³ EADSNE (2010).

⁷⁴ Association of Parents of Children with Intellectual Disabilities.

⁷⁵ EADSNE (2010).

⁷⁶ EADSNE (2010).

The following examples illustrate practices of support for parents that may continue beyond the early intervention stage:

Relief families: Relief families offer respite for parents of children with special needs by taking care of the child for a certain amount of time, usually ranging from one day to one week. This allows the parents to rest, be alone together, or concentrate on other brothers and sisters. The service is in high demand for families with disabled children, and is common practice in Denmark, the Netherlands, Norway and Sweden. It also appears in specific situations in France, Germany, Iceland, Italy and Luxembourg, and can be found in England and Wales. Similar schemes may entail having various organisations taking care of the child during holidays and offering a variety of activities. In Ireland, respite care with a family is funded by the Respite Care Grant, an annual cash payment made by the Department of Social and Family Affairs to certain carers to use as they wish.⁷⁷

Parent Know How', online, UK: Launched in May 2008 by the UK government's Department for Children, Schools and Families (DCSF), this €65 million programme offers a variety of free online and offline services designed to provide support and advice to parents in England. From 2008, 15 independent service providers were funded by the DCSF to deliver expert advice to parents through telephone helplines and digital services, including social networking and instant messaging to reach new audiences, especially young parents and parents of children with disabilities. Other services included syndicated online and print content in newspapers and magazines, and expert advice on specialist issues, such as mental health and disability.

Neath Port Talbot Family Action Support Team (FAST), Wales: The FAST service combines a range of preventative family support services for children, young people and families on behalf of the local authority. The structure of FAST means that packages of support can be tailored to match a family's individual needs and a flexible and timely response to urgent situations can be organised. The range of community-based services includes early preventative support, including work with parents with learning difficulties.

Side by Side, EU: The European project 'Side by Side' is led by APPDA, the Portuguese association for development disorders and autism, with the support of the European Commission's Directorate-General for Education, under the 2003–2005 Socrates Grundtvig programme. The project also involves partners from the Czech Republic, Hungary and Spain. Side by Side offers a training course to families using an interactive webpage. Autism-Europe disseminates the results of the project among its members across European Union Member States.⁷⁸

Early Bird Programme, UK: Established by the National Autistic Society, the 'Early Bird' programme aims to support parents in the period between diagnosis and school placement, empowering and helping them facilitate their child's social communication and appropriate behaviour in their natural environment. It also helps parents to establish good practice in handling their child from an early age, pre-empting the

⁷⁷ World Health Organization (WHO) (2010), *Better health, better lives: children and young people with intellectual disabilities and their families*. As of 30 March 2013: http://www.euro.who.int/_data/assets/pdf_file/0003/126408/e94421.pdf

⁷⁸ World Health Organization (2010).

development of inappropriate behaviours. Many regions of the UK now run the programme for local families.⁷⁹ The programme also offers group training sessions to help parents work with their child.

⁷⁹ National Autistic Society, *Early Interventions training: Early Bird*. As of 30 March 2013: <http://www.autism.org.uk/our-services/residential-community-and-social-support/parent-and-family-training-and-support/early-intervention-training/earlybird.aspx>

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