

EUROPEAN DYSLEXIA CHARTER 2018

Dyslexia Institute UK

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1 What is Dyslexia?

- a. Hereditary
- Chromosome cluster (missing/corrupted strands in DNA),
 The Dyslexia Research Trust website, 2017
- c. 4 main types: dyslexia, dyspraxia, dysgraphia, and dyscalculia.
- d. No link to IQ.
- e. Affects between 10% and 20% of the Global Population.
 Characteristics of Students with High Incidence Disabilities, Dr. Cecilia Batalo, June 7, 2014.
- f. No gender imbalance.
- g. Underlying issues: weak short term memory, poor organisation and concentration.
- h. Co-morbidity between the types of dyslexia.
- i. Often leads to low self esteem and self confidence; manifesting as behavioural issues and/or mental health problems.

2 Why is Dyslexia Still Not Properly Addressed?

- **A:** Because the channels of communication between observers/parents, researchers and education providers have not been opened up sufficiently to ensure understanding and the urgency of the need for action.
- **B:** Because 90% of the population with little to no personal experience of dyslexia remain unaware of the severe psychological damage dyslexia can cause: the loss of selfesteem and the drain on society and the economy.

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3 Why We Need a European Dyslexia Charter

- i. The 28 member states have high levels of disparity in both understanding and addressing dyslexia.
- ii. This costs: individual, family, and society.
- iii. Let's stop failing children from having misguided lives.
- iv. Regular appraisal of how effective these interventions are.
- v. Need for standardised approach to support: diagnosis, education, employment law, offender support, technological assistance, dyslexic families, teachers, the judiciary, and health care professionals.

A. HISTORIC CALLS FOR DYSLEXIA SUPPORT

UNESCO Salamanca Agreement 1994:

To give the 'highest policy and budgetary priority' to improve education services so that all children could be included, regardless of differences or difficulties.

Dyslexia in Europe – a Pan European Survey, by Anna Gyorfi and Dr Ian Smyth 29/01/2010: Called for systematic, national, uniform approach to supporting dyslexics of all ages and backgrounds.

DYSLANG 2012:

Dyslang (a project with funding from the European Commission), 2012, evidenced a lot of diversity is present across Europe with regard to issues related to dyslexia.

Different countries adopt different definitions; have different norms concerning diagnosis and different regulations regarding support measures for dyslexic pupils and students.

The EU and the Member States are parties to the United Nation Convention on the Rights of Persons with Disabilities, which recognises the right of people with disabilities to autonomy and independence.

The European Accessibility Act currently pending adoption by the co-legislators also proposes a common approach to accessibility as regards a number of products and services, for persons with disabilities, including dyslexia.

European disability policy / EPRS In-Depth Analysis, Marie Lecerf, June 2017.

"Alongside and in support of national policies, the EU made an undertaking to combat all forms of discrimination. In this context, and to improve the situation of disabled people, it has introduced a series of initiatives, programmes and strategies over a number of decades." An action programme to combat discrimination was adopted in 2001-2006, and 2003 was dedicated 'European Year of People with Disabilities'. In 2010, the EU published a new 'European Disability Strategy 2010-2020' enabling disabled people to exercise their rights in full and participate fully in the society and economy in which they live. A number of initiatives were set up on the back of that strategy, including the European Disabilities Forum, an EU disability card scheme and a directive on accessibility of goods and services.

B. NATIONAL VARIATIONS OF UNDERSTANDING AND SUPPORT: THE EU RESPONSE

I. AUSTRIA

"It is estimated that up to 10 % of all children are affected", ref 1.

II. BULGARIA

"There is no overall governmental policy concerning dyslexia, nor any legal acts which are binding", ref 2.

III. BELGIUM

"Children with disabilities from disadvantaged families are particularly vulnerable and have less access to mainstream education. Where families have financial resources, they have the opportunity to invest in support and assistance for the child and will generally take steps to get information and negotiate the registration of their child in schools of their

choice. Children from disadvantaged families do not have the possibility to do the same and often lack information about the available services. Education indicators showed an overrepresentation of disadvantaged children in the special needs education system.19".

(This is not unique to Belgium. The correlation between dyslexia and poverty is strong. This is further impounded as the parents of these POORER children are less able to negotiate the support for their children, ref 3.)

IV. CROATIA

"There is no official government definition of dyslexia in Croatia." ref 4.

VI. FINLAND

"Between 5 and 15% of people are dyslexic. They have problems reading, writing and spelling." ref 6.

VII. FRANCE

"In France, 8% of children in school age have a learning disability. That is dyslexia, dyscalculia, dysorthography and Dysgraphia", ref 7.

VIII. GERMANY

"Illiteracy in Germany: more than seven million adults are barely able to read and write. Germany has a population of over 80 million. Of these, about 7.5 million adults between the ages of 18 and 64 are 'functionally illiterate' and can barely read and write. But help is available for those affected," ref 8.

IX. GREECE

"It is only quite recently that dyslexia or specific learning difficulties have been widely acknowledged and researched."

X. HUNGARY

"Children with specific learning difficulties An estimated 10 % of students suffer from specific learning difficulties (dyslexia, dysgraphia, dyscalculia) in Hungary, but the number of these students is gradually increasing." ref 9.

XI. IRELAND

"There was a time in Ireland when dyslexia was the disorder that dare not speak its name."

i. "One in 10 people is affected by the condition, and although general teacher training doesn't include enough about how to teach children who have it," ref 10.

XII. ITALY

"This means that in the Italian population there may be hidden cases of dyslexia," Frith says, because the relative ease of written Italian language means dyslexia may not be diagnosed as often." ref 11.

1. "This study shows that dyslexia is largely underestimated in Italy and underlines he need for reliable information on prevalence, in order to better allocate resources both to Health Services and Schools." ref 12.

XIII. LUXEMBURG

"It is estimated that around 5 percent of children, or 4,500 young people, in Luxembourg have dyslexia, it has emerged from a parliamentary question.

1. In a joint response, Luxembourg Health Minister Lydia Mutsch and Romain Schneider explained there is currently no official body supporting people with the dyslexic disorder in Luxembourg and therefore no exhaustive inventory of cases exists." ref 13.

XIV. NETHERLANDS

Minister Jet Bussemaker and State Secretary
Sander Dekker of Education are concerned
about the number of children in the country
registered as dyslexic. With a dyslexia
statement school students can get a number of
advantages, including longer time to complete

an exam and having the questions read to them, NOS reports.

1. A study by the Ministry revealed that at 30 percent of primary schools between 10 and 19 percent of the students have a dyslexia statement. At 8 percent of primary schools this percentage is even higher. At 40 percent of pre-vocational schools, 20 percent of final exam students had such a statement, ref 14.

XV. SPAIN

"In Spain, the ratio of individuals with dyslexia is estimated at around 8-10%, but there have been no real measurements on the Spanish population, ref 15."

XVI. SWEDEN

"according to the definitions typically used in research studies and clinical contexts, 5-15% of the population has some kind of reading and writing difficulty." ref 16.

XVII. UK

It's a "specific learning difficulty", which means it causes problems with certain abilities used for learning, such as reading and writing. Unlike a learning disability, intelligence isn't affected. It's estimated that up to 1 in every 10 to 20 people in the UK has some degree of dyslexia. ref 17.

1. "Dyslexia is the most common cause of childhood loss of self-confidence. It can lead to misery, depression and even suicide. Sometimes the frustration leads to vandalism, violence and criminal behaviour. Dyslexia accounts for a majority of school children with special educational needs and is by far the commonest cause of disability among University undergraduates", ref 18.

EU RESPONSE SUMMARY

- It is clear that there is a significant lack of consistency across Europe.
- There is a need for clear guidelines to be given to help support every nation to better serve their people.
- Even in countries that were thought to have an advanced understanding, and lifelong provision, clearly could do better.
- Too many dyslexics are not fulfilling their potential in their school or work life.
- The EU could be having a massive positive impact on those struggling with this condition (50 – 100 million).

C. OPAQUE VS TRANSPARENT LANGUAGES

Some European languages are more difficult, Opaque – French, Danish, English, (Slavic) Bulgarian, Polish, etc. Therefore, problematic for dyslexic learners.

Other EU languages are easier to learn for dyslexics, Transparent – German, Italian,

Spanish, etc.

These languages have complicated language rules, e.g. gender, silent letters, lack of uniformity, complex grammar rules, etc.

These languages have simpler grammatical structures, smaller lexicons, etc.

KEY POINT: This does not mean that dyslexia does not exist in similar numbers in countries with "easier" Transparent languages. Merely that these dyslexics are more easily hidden. They still struggle with: organisation, concentration, short term memory, under performance, self esteem, etc.

D. COSTS/CONSEQUENCES OF MAINTAINING THE STATUS QUO: HEALTH, FINANCIAL, POVERTY, JUDICIARY, EMPLOYMENT, AND TECHNOLOGY

HEALTH CONSEQUENCES

Less than 1% of dyslexics are diagnosed.

The LACK OF AWARENESS, understanding, assessment, and support has clear links to poorer mental (and physical) health of dyslexics, ref 18.

A total of 1267 articles were reviewed, and 215 met inclusion and exclusion criteria. At least 1 in 3 adolescents and young adults had low health literacy; most child health information was written above the tenth-grade level. Adjusted for socioeconomic status, adults with low literacy are 1.2 to 4 times more likely to exhibit negative health behaviours that affect child health, adolescents with low literacy are at least twice as likely to exhibit aggressive or antisocial behaviour, and chronically ill children who have caregivers with low literacy are twice as likely to use more health services.

Several health services researchers have suggested that literacy may be an important mediator of the relationship between socioeconomic inequality and health disparities. After controlling for educational attainment and income, adults with limited health literacy are much more likely to be hospitalized, use urgent health services, and have poor control of chronic illness. Medicare and Medicaid enrollees with limited literacy skills have significantly higher health costs, particularly for emergency services, than enrollees with adequate literacy. It is estimated that health literacy-related disparities cost the US health care system more than \$50 billion per year. ref 19

Among community-dwelling older adults, inadequate health literacy was independently associated with poorer physical and mental health. During the past decade, the magnitude and consequences of low health literacy on the health of individuals have received considerable attention, contributing a new perspective on the broader and more complicated relationship between education and health. Limited health literacy has been linked to problems with the use of preventive services, delayed diagnoses, understanding of one's medical condition, adherence to medical instructions, and self-management skills. Although estimates vary, low health literacy has been attributed to higher health care costs. ref 20.

We discuss major aspects of the diagnosis, treatment, and prevention of dyslexia on the basis of a selective literature review and the guidelines of the German Society of Child and Adolescent Psychiatry, Psychosomatics and Psychotherapy. 40% to 60% of dyslexic children have psychological manifestations, including anxiety, depression, and attention deficit.

The Prevention, Diagnosis, and Treatment of Dyslexia / Gerd Schulte-Körne, Dtsch Arztebl Int. 2010 October; 107(41): 718–727.

The family members, managers and colleagues of an un-diagnosed dyslexic are also presented with genuine difficulties. They may feel baffled and annoyed at the inefficiency of the person, resentful that they have to constantly recheck or redo work and find the person's social manner offensive with no obvious explanation. Somebody who is observably disabled, for example a blind person, is readily accepted as having genuine difficulties. A person with hidden difficulties, such as dyslexia, can be regarded as being, at best, difficult and workshy, and, at worst, a fraud (Sylvia Moody, 2010).

Personal: 40% Drug/Alcohol addicts are dyslexic, Dyslexia Foundation, 2007:

"Problem boozing is costing Greater Manchester a staggering £1.2bn per year, police and council chiefs have revealed". By Jennifer Williams, *Manchester Evening News*, 22 AUG, 2014.

Family: Dyslexic parents do not achieve at work, or expect their children to achieve at school, high levels of relationship issues: *Dyslexia and Mental Health*, Neil Alexander-Passe (2015).

FINANCIAL COST

In the United Kingdom, **KPMG** reports, 2004, "the total resulting costs to the public purse arising from failure to master basic literacy skills in the primary school years are estimated at between £5,000 and £43,000 per individual to the age of 37, and between £5,000 and £64,000 over a lifetime. This works out at a total of £198 million to £2.5 billion every year.", ref 21.

"Without identification and effective intervention, the impact of dyslexia can be significant and long-lasting not only for the individual, but for society at large. Social costs, unemployment, consequent mental health problems and remedial programs as well as costs incurred due to antisocial behaviour, such as drug abuse, suicide, early pregnancy and most significantly of all, criminal justice involvement", Dyslexia International

Societal: Cost of keeping someone in prison, it costs £65,000 to imprison a person in this country once police, court costs and all the other steps are taken into account. After that it costs a further £40,000 for each year they spend incarcerated. Well over 70,000 people are being held, £4,550,000,000. (Focus Prisoner Education website, 2017).

About 14% of America's student population are dyslexic, to make matters worse, a majority of that percentage stem from high-poverty, low-income school districts. *BeginToRead*, a WriteExpress Corporation, released two startling statistics: that 85% of all juveniles that are incarcerated are illiterate, and 60% of inmates in our country's prisons are illiterate (BeginToRead, n.d.). Dwell on those statistics for a moment. 60% of 2.4 million people (US), who are incarcerated, are likely to be dyslexic.

DYSLEXIA AND POVERTY

"Education indicators show an overrepresentation of disadvantaged children in the special needs education system. A child living in a very poor district is four times more likely to be oriented to the special needs education system. This risk is increased to eight in cases of mild disability"; Belgium is not untypical of the rest of Europe, ref 22.

"System Failure – this occurs when inappropriate educational opportunities are given to dyslexics at school, resulting in 'academic or school failure'; leading to: low expectation, insensitive teaching, ignorance, no identification or misidentification of needs, and a weak curriculum" Neil Alexander-Passe, *Dyslexia and Mental Health* (2015).

Constructed Failure – in the UK there is no mandatory screening of dyslexia...thus a child is required to continuously fail educationally for many years before identification and interventions are considered (Poole, 2003).

State sanctioned public "humiliation and teasing" leads dyslexics to withdraw from education, 80% of truants are dyslexic, Dyslexia Foundation, (2014).

Deliberate corrosion of the dyslexic individual's **self esteem** by authority by causing dyslexics to "experience continued failure and a fear of learning and new or unknown situations" (Palomo, 2001).

"Empirical evidence suggests that dyslexia is similar to religious orientation or homosexuality, in that they are all invisible sources of potential stigma", Beatty and Kirby, 2006.

MERTON'S STRAIN THEORY

Dyslexics are unable to achieve the socially accepted goals of wealth/success through the socially constructed norms. This situation puts great pressure on people to achieve material success by illegitimate means (acquisitive crime) to avoid being branded a failure.

Strain Theories, Robert Agnew, Heather Scheuerman, 2014.

PATHWAYS INTO EMPLOYMENT AND RETENTION

"the annual average cost for each prisoner exceeds £40,000" The Guardian,28/07/2008, The real cost of prison Kevin Marsh. Because of associated reductions in re-offending rates, prisons which include educational and vocational programmes save society £50,000 for each inmate whilst prison with drug treatment saves £125,000.

Steve Killelea, the founder and chairman of the Institute of Economics and Peace said:

"According to the results of the UKPI, poverty and lack of employment are closely related to high levels of crime." "By focusing on creating high-levels of employment in deprived areas, it is possible to reduce the levels of crime."

BENEFITS OF TECHNOLOGY FOR DYSLEXICS

Technology can be hugely beneficial for dyslexics. However, this can often be out of reach of many poorer dyslexic individuals.

Software can support: organisation (electronic diaries, mind mapping tools, etc). It can also support reading and writing skills (voice to text, reading pens, and text to speech software).

Many apps can be a smart way of dyslexics achieving higher academic/workplace function, but again cost can be prohibitive.

4 European Dyslexia Charter

1. ASSESSMENT

"The treatment of dyslexia is based on two main strategies: specific assistance with the impaired learning areas (reading and spelling) and psychotherapy for any coexisting psychological disturbance that may be present. Evaluated preventive strategies are available for use in kindergarten and at home."

The Prevention, Diagnosis, and Treatment of Dyslexia, Gerd Schulte-Körne, Dtsch Arztebl Int. 2010 October; 107(41): 718–727.

Develop an international policy on dyslexia and inequity of access to assessment for dyslexia — we have many people who are undiagnosed due to the lack of a public assessment service.

2. TEACHER TRAINING

Teachers are not adequately trained on dyslexia and related learning difficulties – we are been calling for mandatory teacher training at all levels as this would have a long-term positive impact. To include all teacher training courses and existing staff.

While we have a large further and community education sector, including literacy supports, this sector also lacks sufficient knowledge and expertise to adequately include people with dyslexia.

3. CLASSROOM INTERVENTIONS

The ability to read is one of the main skills of a human being. However, some of us have reading difficulties, regardless of social status, level of intelligence or education. This disorder is the main characteristic of dyslexia and is maintained throughout life, requiring early and specialized intervention. The implemented prototype focuses the Portuguese language and was tested with Portuguese students with ages between 10 and 12 years old.

Preliminary results show that the proposed gamified set of activities, allow dyslexics to improve multisensory perception, constituting an added value facilitator of adaptiveness and learning. Teaching assistants can be of huge

benefit; the sooner the support is put in place the better,

Assistive Mobile Applications for Dyslexia.

TAKING ADVANTAGE OF PLASTICITY

Can you change a brain that tends to fire differently or will it always remain the same? The exciting answer is that a lot of change is possible.

Dr. Sally Shaywitz and a team from the Yale Center for Dyslexia and Creativity studied the brain activation patterns of children who were struggling to read but then received a yearlong experimental reading program.

Brain images from the early part of the study showed only 'tentative use' of left side patterns used by strong readers as well as the right hemisphere 'secondary pathways' for reading

"the final set of images obtained one year after the intervention had ended was startling. Not only were the right-side auxiliary pathways less prominent, but more important, there was further development of the primary neural pathways on the left side of the brain... we had observed brain repair!", Sally Shaywitz, Overcoming Dyslexia, (Vintage Books. 2003).

4. HEALTHCARE

Develop an international policy on dyslexia and address the inequity of access to assessment for dyslexia – we have millions of people who are undiagnosed due to the lack of a public assessment service.

Health service to provide testing for patients and their staff. Thereafter, to support the diagnosed individual cope with their diagnosis (If a person was failing at school due to poor eye sight or a mental health problem, would they be tested by the school? No a health care professional).

5. PATHWAYS TO EMPLOYMENT

Create pathways to employment, and support dyslexic staff while working. Specialist staff in Jobs Centres to identify, diagnose, and support dyslexic job seekers into employment.

There are too many **dyslexics unemployed** (40% of the unemployed are dyslexic, Dyslexia Foundation).

Major employers need to understand the value of employing individuals who are neuro diverse. Highlight companies which employ positive support for dyslexics in their employ under their Corporate Social Responsibility framework.

Positive support to be given to dyslexics in the work place to ensure they achieve their potential, whereas, at the moment dyslexics are usually in positions below their natural competency. Support continuing professional development for dyslexic employees.

6. TECHNOLOGY

Even though technology has been a real boon for people with dyslexia, many cannot afford it or lack the basic literacy skills to be able to use it effectively. Therefore, a clear support strategy needs to be designed and implemented.

IT needs to be made available (software and hardware) to support dyslexics throughout education and in employment.

7. JUSTICE SYSTEM

To screen all offenders for dyslexia immediately on entering the criminal justice service, and teach literacy/maths skills for those diagnosed by specialist dyslexia teachers. Also, provide dyslexia education for all prison staff, probation workers, lawyers, judges, and prison educators.

To provide ongoing literacy/numeracy training after they have left prison.

Have counselling available for all inmates, in and outside the prison gates

Provide better quality services for those pupils most at risk of falling by the way side at school (provide intensive support for children most at risk).

Design apprenticeship schemes with employers that give ex-offenders a fresh start. These can begin in prison.

Give financial incentives to dyslexic exoffenders who stay out of trouble for 6/12 months.

Offer dyslexia support to offender families (50% probability that other family members are also dyslexic).

5 Conclusion

If dyslexic difficulties are fully recognised, understood, and confidently disclosed to other people, and if appropriate support in the way of skills training and counselling is provided, then the more likely it is that a dyslexic person will become less defensive and more able, in both professional and social life, to confront the world in an assertive and confident way rather than an aggressive and defensive one.

The ongoing abuse and neglect of the European Dyslexic Population (50 – 100 million people) cannot be allowed to continue. The benefits of taking the required actions will significantly improve the lives of many millions of people and the communities they inhabit.

If change is not brought about then the massive waste of money, resources, and lives will continue. This is an excellent opportunity for the EU Parliament to demonstrate what is inherently laudable about the collaboration of nations implementing positive change for their communities.

LET'S CHANGE THIS STATUS QUO AND IMPROVE LIVES TOGETHER!

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