

Report of the Member Survey of the EDA

2020-2021



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Executive Summary

The European Dyslexia Association (EDA) has 41 member organisations in 25 European countries. The EDA Board decided to conduct a member survey in late 2020 to get a current picture of our member organisations, their interests and priorities to identify common development goals for the EDA. The questionnaire was set up online and filled out by representatives of the member organizations. The answers were evaluated descriptively and with the help of the qualitative content analysis. The goals of the member associations show similarities of the EDA goals at national level. The main aspects of the importance for the member associations of being a member of EDA is to share the latest information, good practice and activities and EDA is the place of the associations in Europe and at the international level. Campaigns at that level are seen as important from the perspective of the members.

From these results, it is evident that EDA's actions and activities are in line with the member's needs. EDA's events provide a space for sharing information and good practices. They also provide a networking space for EDA's member organisations and others interested in dyslexia. EDA's lobbying efforts at the European level also seek to reinforce and support the national lobbying efforts of the members.

Background

The European Dyslexia Association (EDA) was founded in Brussels on October 18, 1987. In the beginning, twenty-five representatives from Dyslexia Associations in eight European countries set the course for the future of the Association. Currently, the EDA has 27 regional and national Effective Members in 21 EU countries plus Switzerland and Norway and 14 Adherent member organizations; in all 41 member organizations in 25 countries: Austria, Belgium, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Israel, Italy, Lithuania, Luxembourg, Malta, the Netherlands, Norway, Poland, Romania, San Marino, Slovenia, Spain, Sweden, Switzerland, Turkey and the United Kingdom.

In 2019, Rosie Bissett became the organization's president. Due to the new wind that was sparked by the members of the EDA Board, the idea arose to actively involve the member organizations in the further development process of EDA and to gather current data on the profile of members and their organisation's activities and objectives.

As a first step, an online survey of EDA's member associations was carried out. This survey was announced during the 2020 General Assembly. As well as gaining an up to date profile of the EDA members, the survey also sought was to identify commonalities and differences regarding the experience of people with dyslexia across Europe.

This report provides information about the results of that survey.

Methodology

Since such a survey was being carried out for the first time, various questions that were in the interests of the EDA were formulated. Questions were asked about the names of the associations and their goals, the number and type of members, cooperation partners, terminology, funding and questions about EDA. The questions about EDA ranged from points of contact, knowledge about EDA, most important activities, and the importance for the organizations of being members of the EDA. At the end of the survey, there were questions asked about the main challenges faced by people with dyslexia in the own countries and about the impact of Covid-19.

Here is an overview of the formulated questions.

Questions about the member association:

- What is the name of the association (in the language of the country and translated in English)?
- Please confirm the email address that EDA should use to contact your organisation with feedback on this survey, and on other EDA activities of interest?
- What is the name (web address) of the website of your organization?
- What kind of social media do you use?
- What are the goals of the association set out in the statutes/governing document?
- How many members does the association have?
- Do you have different memberships? (Individuals, families, therapy facilities, organisations)
- How many members do each type of membership have?
- Who does the association work with? (e.g. doctors, teachers, speech therapists, schools, ...)
- Which terms are used in your country for dyslexia (in the language of the country and translated in English)?
- Does the association work on a voluntary basis or how is it financed?
- What was the annual income and expenditure of your association in 2019? This will help us to understand the scale of organisations across different countries.

Questions about EDA:

- How did you find out about the EDA?
- What do you know about the activities of the EDA?
- What do you think are the most important activities of the EDA?
- What is the importance for your organization of being a member of the EDA?
- What kind of help would you like from the EDA for your work?

Questions about main challenges:

- Please list the main challenges faced by people with dyslexia in your country which your organisation is trying to address?
- How has the Covid-19 pandemic and lockdown impacted people with dyslexia in your country?

Any other comments/ideas you would like to share with the EDA.

The questionnaire was introduced at the EDA's General Assembly in 2020 and it was forwarded to the member organizations by email. Reminders were also issued a few weeks later to encourage participation. It was up to the people, who completed the questionnaire, whether all questions were answered or not. This means that not all questions from all participants who took part in the questionnaire were completed.

The answers were evaluated descriptively and with the help of the qualitative content analysis according to Mayring (2015). Summary and structuring were chosen as the basic form of content analysis. This means that frequency analysis, and inductive category formation was carried out.

The results are summarized based on the questions.

RESULTS

General Results

67% of the member organizations completed the questionnaire.

The first question gives an overview of the members and their names. Then questions were asked about contact information (email address and website), which are used for the EDA to contact the member organizations.

Social Media

Figure 1 shows the most frequently used social media channels. All participants who answered the question indicated Facebook, followed by Twitter. This means that the social media channel Facebook, which is also used by the EDA, makes sense as a platform. EDA also maintains a Twitter account.

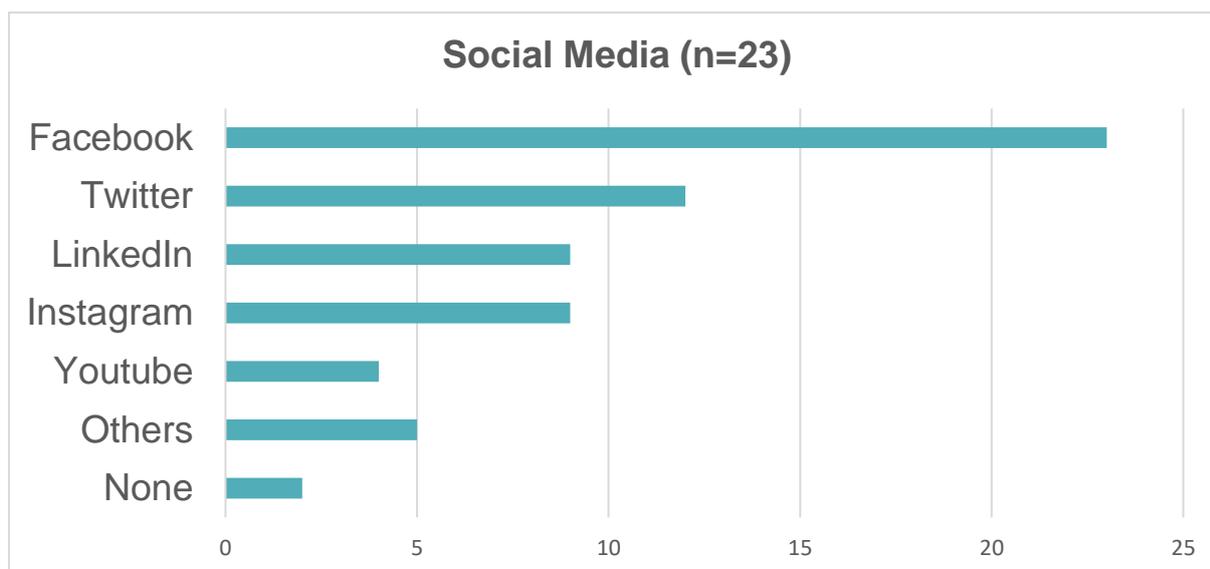


Figure 1: Overview of the social media channels used

Goals for the Associations



Figure 2: Goals for the Associations

Question 5 dealt with the goals of the associations that were related to their statutes/governing documents. 16 member organizations stated their primary objective was supporting various actors, like families, parents, teachers and counsellors, to enable optimal conditions for people with dyslexia. 14 participants reported that they provide information to the public and society to create a dyslexia friendly society. The third most popular answer was providing direct supports to people with dyslexia from children up to adults. Another common goal was to offer training for trainers, and also training for teachers, parents and others. Sharing knowledge was also reported. Further goals are shown in Figure 3.

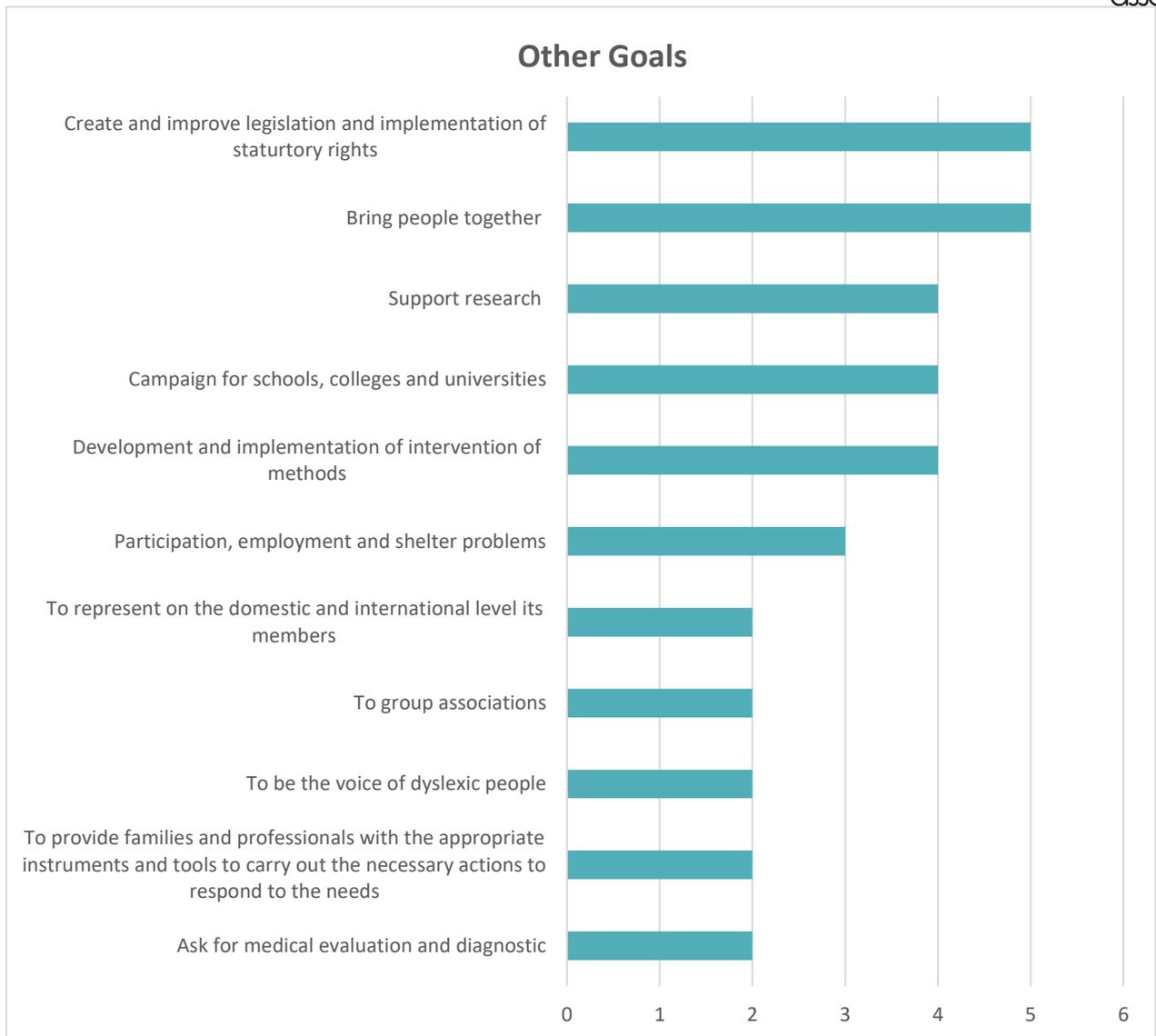


Figure 3: Further Goals for the Associations

Members of the associations

The range of the number of members of the associations ranges from 30 up to 10,000+. This different information can be traced back to the information behind it. In this context, different information, such as the number of members, pupils, families, schools and Facebook members, was provided by the survey participants.

Types of Membership

58% of the members have different kinds of memberships. Figure 4 gives an overview of the types of memberships.

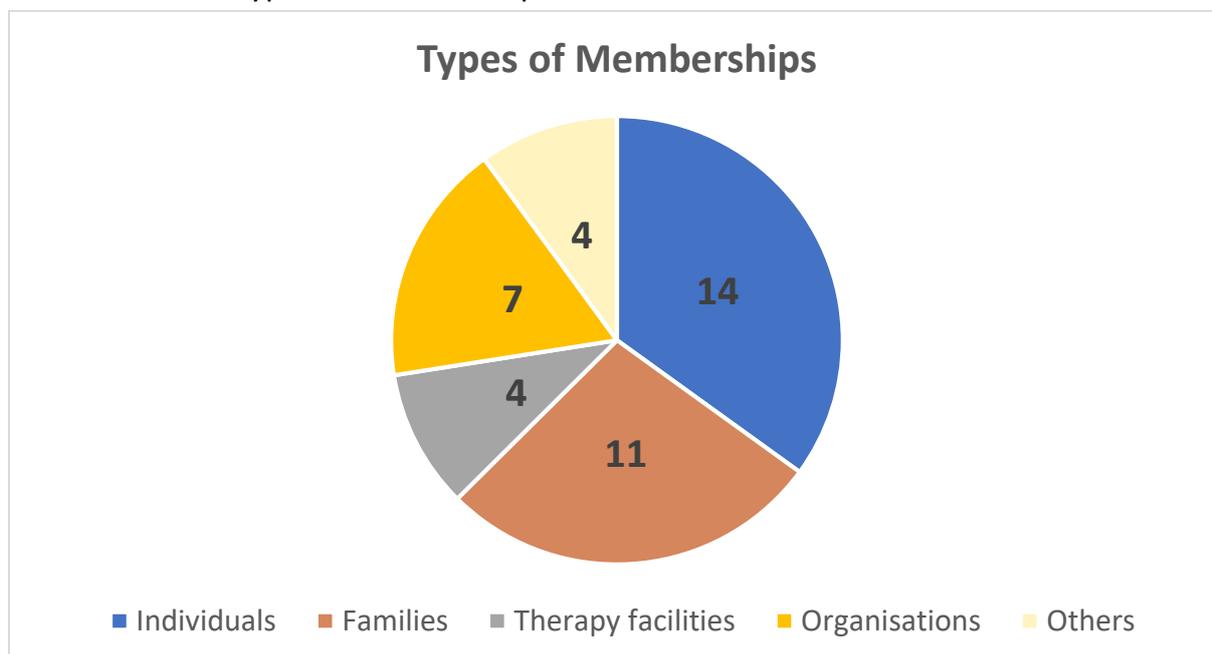


Figure 4: Types of Memberships of the member associations

Cooperation Partners

Question 9 was in a multiple-choice format, where the following items were formulated. Therefore, the results give the number of answers of each of the items.

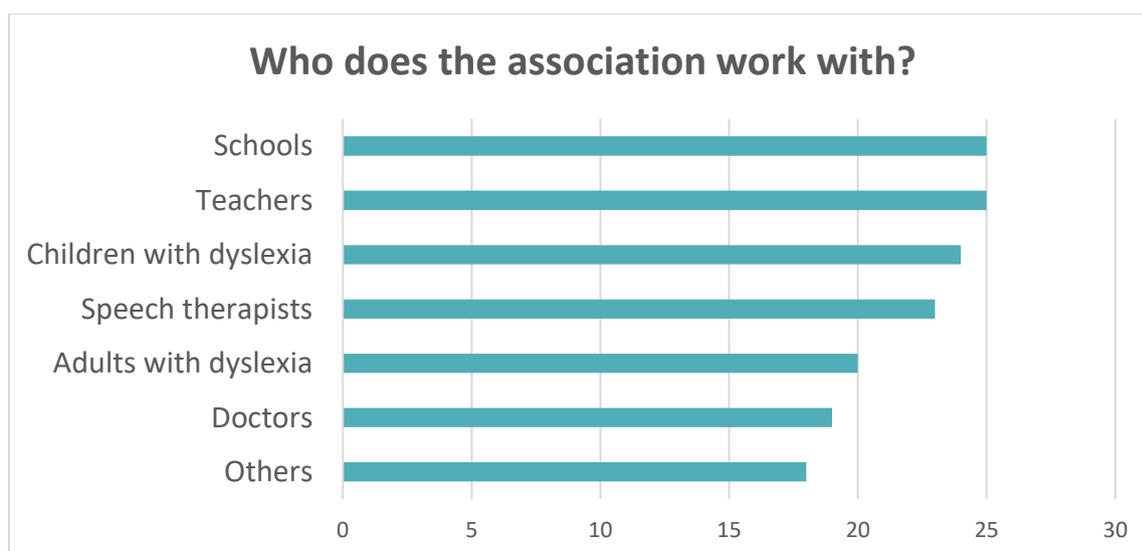


Figure 5: Cooperation Partners

Terms of Dyslexia

21 of the 26 answers were similar to the term Dyslexia in English. The answers were also given in the language of the country.

Funding of the Associations

21 of the associations are working on a voluntary basis. This, combined with the different numbers of members, means that the annual income and expenditure levels are very different between EDA member associations.

Questions about EDA

These questions mainly serve to define possible fields of development for the EDA. The first question in this section is “How did you find out about EDA?” which give a good overview of the visibility of the EDA. As figure 6 shows, most of the members had contact persons, who introduced them to the EDA.

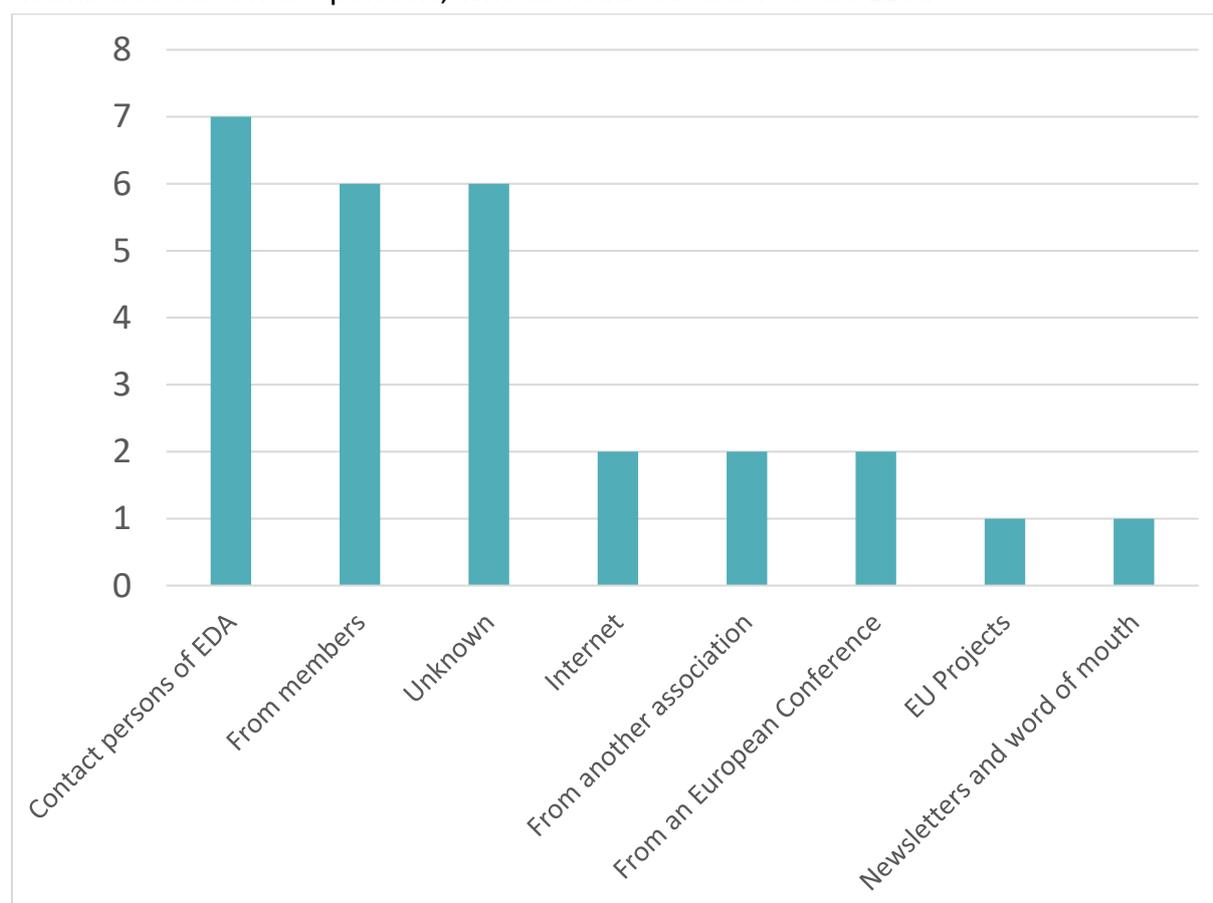


Figure 6: Contact to EDA

The next question gives the participants the possibility to indicate what they know about the activities of the EDA. The answers range from “not much really” to “since you are more active just lately” to “everything”.

Figure 7 shows the main aspects of the importance of being an EDA member for the member associations. The most common answer is to share the latest information, good practice and activities. Secondly, it is mentioned that EDA is the place of the associations in Europe and at the international level. Therefore, campaigns at that level are important from the perspective of the participants.

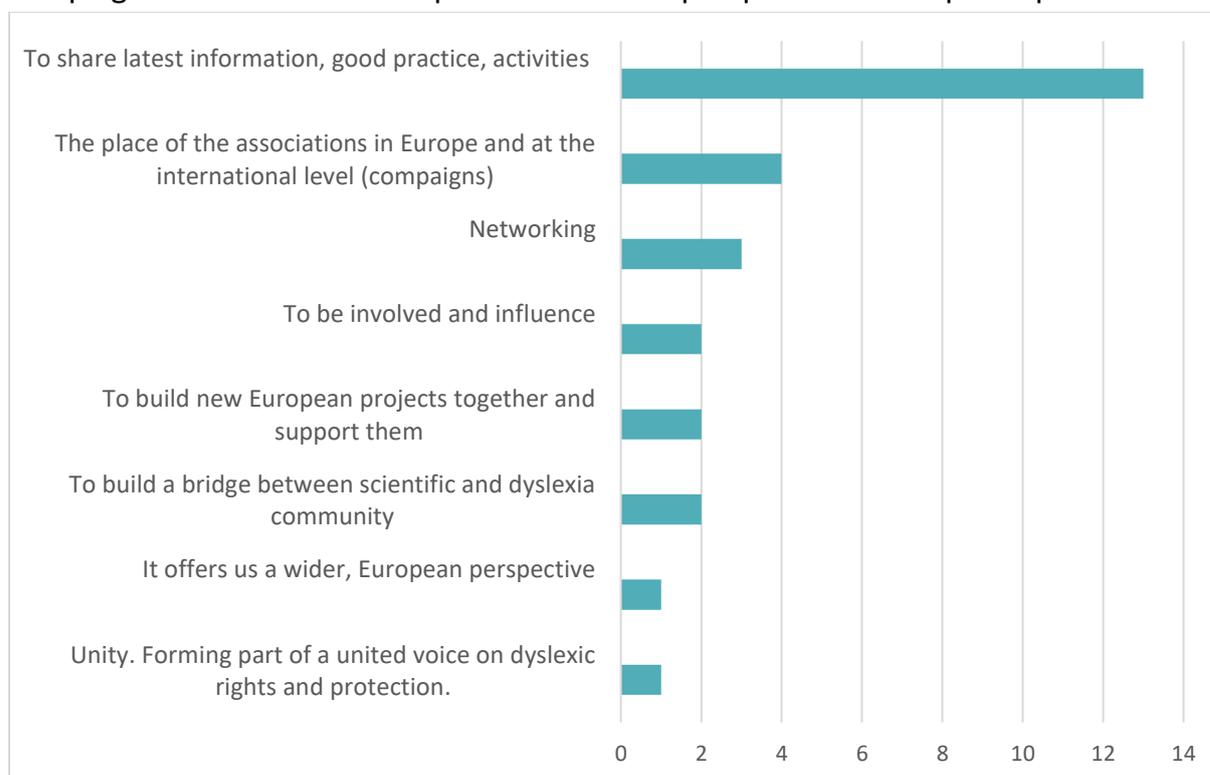


Figure 7: Main aspects of the importance for the associations of being a member of the EDA

With support from the EDA, most of the participants wish to mutualize experiences and practice, but also to share information through the different countries. Another point is to be the connection between Europe and the national level and to create awareness and commonality of European legislation, especially about accessibility and inclusion policy in Europe. Another point is the promotion of unity and the consistency of dyslexic rights and protections across Europe. Some participants also noted moral, financial and international support.



Figure 8: Aspects of support of the EDA

Challenges faced by people with Dyslexia

The last questions relate to the challenges facing people with dyslexia in their own countries, which the associations are trying to address. According to the qualitative analysis, it can be summarized that primary commonalities regarding the experience of people with dyslexia are the need for awareness and attention, diagnosis and identification, lack of access to appropriate support within schools, universities, professions and employment, and appropriate training for teachers.

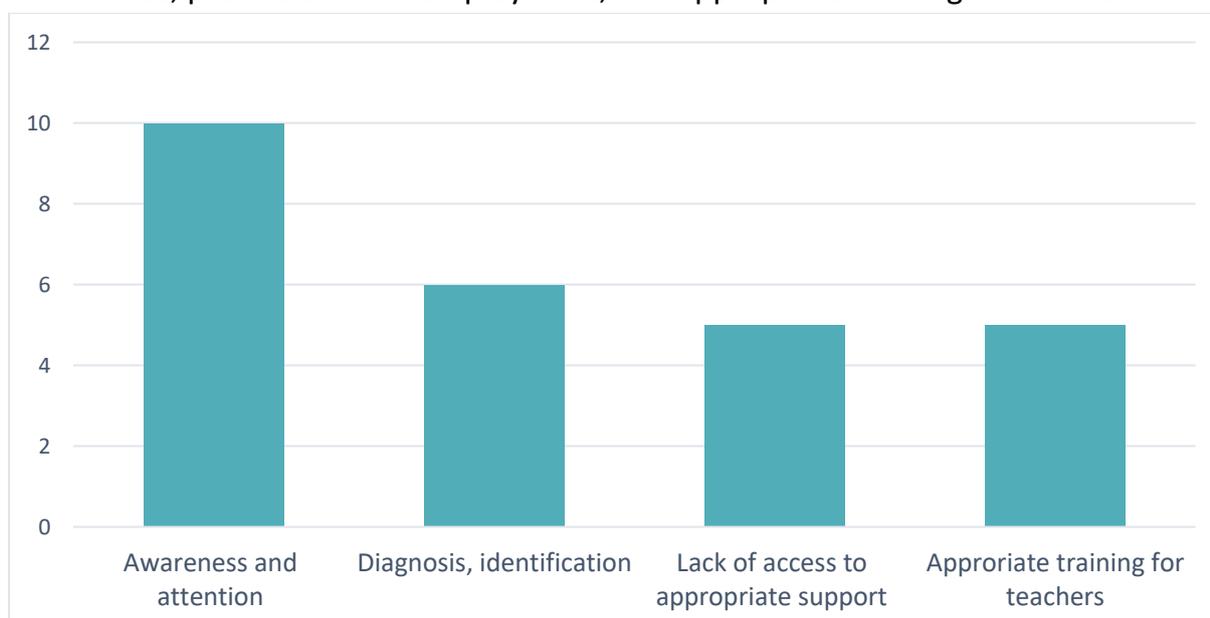


Figure 9: Commonalities of challenges of people with dyslexia

In connection with the Covid-19 pandemic, challenges and opportunities were discussed. As challenges, the following aspects are mentioned:

- (Social) isolation (most common answer).
- Schoolchildren were left behind (challenges with support, psychological aspects) (most common answer).
- Students facing studying alone.
- Diagnostic assessments were cancelled.
- Adults not having reasonable adjustments when working from home, or losing jobs is working in sectors such as hospitality, creative arts.
- Special education has been interrupted.
- Online education/distance learning was chaotic, and adaptations have not been applied in online classes, leading to difficulties to maintain attention.

Opportunities are noted in the following aspects:

- Digital learning platforms help in education.
- Respect for different ways to participate in the lessons and at the evaluation.
- Reduction of pressure.
- Access to help.

The situation of parents was also mentioned in both a positive and negative way.

Ideas to share with EDA

The last field allows the participants to share ideas. The following aspects are interesting for further developments of EDA:

- To develop key lobbying actions each year.
- Creation of a European rights framework including obligations for states to improve the life conditions of people with dyslexia.
- A Europe wide visibility campaign for dyslexia (e.g. a unified dyslexia awareness week theme).
- Discussion about a common European definition of dyslexia.

Conclusions and Recommendations

From the results, it can be concluded that the broad goals and actions of the EDA are in line with the members' needs and expectations. The EDA has developed the following recommendations based on the survey results and the identified needs of our member associations.

Events

- EDA's events provide spaces for sharing information, on research, good practice and activities. This sharing and networking is seen as important for the member associations and should continue.
- EDA will develop the number of events organized each year, to provide members with more opportunities for networking and sharing. As the first step in this regard, the General Assembly and Members Forum will be held separately from the Seminars.
- EDA events should continue with the theme of bridging the gap between research, policy and practice, and provide opportunities for sharing of experiences from different countries.
- EDA should incorporate the impact of Covid on people with dyslexia in its Autumn Seminars.

Communications

- EDA to continue to use Facebook and Twitter as its primary social media communication platforms.
- EDA to continue the development of its website with regular blog posts on topics of interest.

Finance/Supports

- EDA to review its membership fee structure, considering the wide size differential of its member associations, so that the membership fee is proportional and affordable.
- EDA to continue to offer one free place at its Seminars and Conferences to member organisations, to support their participation.

Lobbying

- EDA to continue its work advocating at the European level, for better inclusion policy.
- EDA to promote common rights for people with dyslexia across Europe.

- EDA to develop European campaigns on key themes linked with future conferences and awareness weeks.

Projects

- EDA to continue participating in relevant projects at the European level on dyslexia, such as the Dyslexia@Work project, and the Reading Disability Document Access (RDDA) project, as EDA is uniquely placed in offering a pan-European perspective and knowledge base to such projects.
- EDA to support teacher training on dyslexia. EDA took over the Basic Training Course for Teachers from Dyslexia and Literacy International. This course should be reviewed and updated, and then the potential for translating it into other European languages should be investigated.
- Potential future projects should be chosen based on areas of need faced by people with dyslexia and dyscalculia, and EDA's member associations.

Appendices

Mayring, P. (2015). *Qualitative Inhaltsanalyse. Grundlagen und Techniken [Qualitative content analysis. Basics and Techniques]*. 12. Auflage. Weinheim: Beltz Verlag.