Monitoring of the Rights of Blind and Partially-Sighted Children in Europe: An Analysis of the European Blind Union CRPD Database

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September 2017
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1. Purpose of the Report

This report provides an overview and comparative analysis of the situation of blind and partially sighted children in European countries, as reported by country authors in the EBU database. The EBU database aims to provide information on progress towards implementation of Articles of the Convention on the Rights of Persons with Disabilities (CRPD) to support the membership of EBU, campaigners and policy makers.

The main section of this report presents and compares the information from the participating countries. To introduce this, there is a description of how Article 7 of the CRPD relates to other United Nations legal instruments, European Union polices and strategies as well as those of the Council of Europe and Fundamental Rights Agency.

2. Article 7 of the CRPD

The text of Article 7 of the Convention states that:

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 7 requires that children’s rights in all areas are met in terms of outcomes, acting as an overall statement on children’s rights in the Convention. It also draws attention to the need for processes that ensure equality between all children and their right to free expression of their views. The best interests of the child are given weight and there is
3. Related CRPD Articles

The rights of disabled children are also mentioned in the CRPD Preamble and in Article 3: General Principles, which requires “respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities”. Article 4: General Obligations, requires States Parties to “closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations”.

As well as this, disabled children have specific rights under:

- Article 16 - Freedom from exploitation, violence and abuse,
- Article 18 - Liberty of movement and nationality,
- Article 23 - Respect for home and the family,
- Article 24 – Education,
- Article 25 – Health, and
- Article 30 - Participation in cultural life, recreation, leisure and sport

Taken together, these articles provide wide – ranging requirements of States Parties in respect of both outcomes and processes.

Concluding observations of the CRPD Committee, which are developed following national reporting on progress, point out the issues that most need addressing for each country. In preparing this report, documents from the past three years on European and EBU countries were reviewed (2014 – 2017). Although only some countries reported in this time period, the observations are indicative of the types of problems faced by disabled children. The following issues were raised as being of major importance:

Institutionalisation of disabled children: Belgium, Denmark, European Union, Moldova, Serbia, Slovakia, Ukraine.

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Lack of involvement of disabled children in decision making / lack of respect for their views: Belgium, Cyprus, European Union, Moldova, Sweden.

Insufficient early intervention and support for disabled children and their families: Cyprus, Slovakia.

Exposure to violence: Sweden, Ukraine, United Kingdom.

Effects of poverty and austerity measures: Cyprus, United Kingdom.

Insufficient support for inclusive education: Cyprus, European Union.

Failure to incorporate a human rights perspective in legislation and policy: United Kingdom.

As the Committee of the CRPD is concerned with all disabled children, the situation of blind and partially sighted children is not specified separately. The most pressing issue for disabled children in Europe overall is continued incarceration in institutions and children with intellectual disabilities are most affected by this. However, blind and partially sighted children are also represented in this group and especially in countries where support to families is lacking, this is often the default option. The second most frequently mentioned issue is lack of involvement and respect for the views of children. Although in the list above just a small number of countries are mentioned, the problems also apply more widely in Europe and worldwide; these are long – standing and entrenched problems.


The Convention on the Rights of the Child (CRC)\(^2\) takes children’s rights as its central focus. All EU member states and EBU member countries have signed and ratified the CRC.

Disabled children and parents are mentioned in Article 2 as one of the groups to whom the rights in the Treaty specifically apply. Article 23 specifically addresses the situation of disabled children and sets out

\(^2\) Convention on the Rights of the Child
http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx
important rights. These include that disabled children should enjoy ‘a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community’. The CRC acknowledges disabled children’s need for appropriate support and, recognising the frequent problem of poverty, indicates that this should be free of charge wherever possible. Access to ‘education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities’ should be provided ‘in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development’. Finally, Article 23 sets out that States Parties shall exchange information so that their capabilities and skills regarding rehabilitation, education and vocational services are developed.

As an older Treaty, which came into force in 1990, well before the CRPD, the CRC is less clear about some important issues that affect disabled children. For example, the CRC is not explicit about the undesirability of institutions and the promotion of family life and independent living. Nevertheless, the conclusive evidence of the damage perpetuated by placing children in institutions is now recognised by the European Union, and is reflected in specific policy measures on disabled children’s rights as a whole.

5. European Context

5.1 European Union

EU policy, as with the UN, is concerned with both disabled people and children and there are separate strands of policy development. The EU aims to support Member States in ensuring respect for rights of the child and policies on children’s rights are set out in several key documents administered by DG Justice. The measures that need to be taken by Member States for EU membership are also specified, together with the actions being taken by the EU itself to promote children’s rights.

The European Forum on the Rights of the Child was established in 2006 as a mechanism to promote children’s rights in EU policy and to

support the efforts of Member States. Forum participants include Ombudspersons, Representatives of EU institutions, the Council of Europe and international organisation such as UNICEF.

In terms of priorities, the EU Disability Strategy 2016 – 2020\(^6\) includes a commitment to promote deinstitutionalisation through the redirection of structural funds in favour of independent living and the promotion of education for disabled children.

5.2 Council of Europe (CoE)

The Council of Europe Disability Strategy 2017 - 2023\(^7\) takes a mainstreaming approach to policy development for disabled children. Education is considered a priority, as is protection from violence perpetrated through social networking and in institutions.

The Council of Europe Strategy for the Rights of the Child 2016-2021\(^8\) sets out five overall areas as priorities: equal opportunities, participation, freedom from violence, child – friendly justice and the rights of the child in a digital environment. Deinstitutionalisation is again a priority for disabled children, especially for children under 3 years.

5.3 Monitoring: the EU Agency for Fundamental Rights (FRA)

The 2017 annual report from the FRA raises several issues in respect of children and of disabled people, although it does not address the situation of disabled children directly. Concern is expressed about child poverty and social exclusion and the situation of child migrants in Europe, especially unaccompanied children. A report from 2015 also raises the issue of violence against disabled children. The FRA has not addressed the situation of blind and partially sighted children specifically in any depth, however the organisation is a key participant in ensuring

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the rights of disabled people at EU level and recognises current challenges in respect of children’s rights.

6. Analysis of the Database

6.1 Overview of Questions

The EBU’s online database on the CRPD was initiated in 2008 and continues to be developed. Its focus is to collect and present data from a total of 42 participating countries on specific aspects of national law and policy. There is a particular emphasis on the collection of data relevant to blind and partially sighted people.

The database as a whole is organised into sections that correspond with the various UNCRPD articles. This report summarises the data presented by national authors in the section on Article 7: Children with Disabilities. Following the development of a questionnaire and its distribution to member countries, thirteen countries replied. Abbreviations are given for the countries mentioned in the summaries below and these are:

Austria – AT; Bulgaria – BG; Denmark – DK; Estonia – EE; Hungary – HU; Iceland – IS; Poland – PL; Romania – RO; Slovenia – SI; Sweden – SE; Switzerland – CH; The Netherlands – NL; United Kingdom – UK

The questionnaire for Article 7 has an introduction and three sections, which are:

Preliminary Issues, which asks whether countries register visually impaired children, the legal basis for registers and about the numbers registered

Section A: National Disability Strategies. This section is concerned with whether national strategies exist, whether organisations take part in their development, the inclusion of children and young people in this and conferences to raise awareness.

Section B: The extent and type of support that is organised locally for families with visually impaired children.

Section C: Whether and how children and young people with a visual impairment are consulted on issues that concern them.
Each part of the questionnaire contains a number of subsidiary questions and these are presented below with the results of the survey.

In this synthesis report, basic information is given. Several authors provided more information on the situation in their countries and readers should consult the relevant country questionnaires on the EBU web site for this.

6.2 Preliminary Issues

Question 1 asks⁹:

In your country, is there a register of children that has been developed as a legal requirement? If yes, what are the criteria for being admitted to the register? Yes/ No / Not aware

Five countries (DK, IS, PL, RO, SI, UK) reported the existence of a legally established register. For most, this register was established in education (IS, PL, SI, UK) and referred to the number of pupils with visual impairments. It was also in some instances used to identify children who were entitled to benefits. In Poland and Romania children with a disability certificate were placed on a register. Denmark did not report any specific purpose other than the existence of an impairment (sight loss equal to or less than 3/18). A level of 30% visual impairment was necessary for Iceland, Poland and Slovakia, while in Iceland 30 – 40% sight loss was classified as low vision. An age range of 0-18 was given for Denmark, while children up to age 16 were recorded in Poland. In the UK pupils were entered on the register where visual impairment is recorded as a primary or secondary Special Educational Need.

Two countries (BG, HU) were ‘Not Aware’ of any register

Four countries (AT, NL, CH and SE) answered ‘No’

The second part of Question 1 asks

If there is a register, but not based on legislative measures, what is the basis for the establishment and running of such a register?

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⁹ These questions are written slightly differently from the way they were framed in the questionnaire. More guidance was given in the original questionnaire.
Five countries identified a register that had not been mandated by law and that identified children with visual impairments. In Hungary, the national census allowed the self-identification of children. Two national organisations of blind and partially sighted people (CH, SI)\textsuperscript{10} collected information on their membership that included the identification of children. In Sweden one eye clinic collected data on children who were blind or had low vision.

**Question 2 asks:**

What are the numbers of children with a visual impairment aged between 0 and 18 years in your country? The figures are presented below:

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of children with VI</th>
<th>% compared with non-disabled</th>
<th>% of total population</th>
<th>% who have additional impairments</th>
</tr>
</thead>
<tbody>
<tr>
<td>AT</td>
<td>35,000\textsuperscript{11}</td>
<td>2</td>
<td>0.4</td>
<td>2.2\textsuperscript{12}</td>
</tr>
<tr>
<td>BG</td>
<td>Not available</td>
<td>Not available</td>
<td>Not available</td>
<td>Not available</td>
</tr>
<tr>
<td>CH</td>
<td>6,000\textsuperscript{13}</td>
<td>No answer</td>
<td>No answer</td>
<td>Not available</td>
</tr>
<tr>
<td>DK</td>
<td>2,000\textsuperscript{14}</td>
<td>0.16</td>
<td>0.03</td>
<td>1,200</td>
</tr>
<tr>
<td>EE</td>
<td>437\textsuperscript{15}</td>
<td>0.17</td>
<td>0.03</td>
<td>286</td>
</tr>
<tr>
<td>HU</td>
<td>4,679\textsuperscript{16}</td>
<td>0.23</td>
<td>0.047</td>
<td>185\textsuperscript{17}</td>
</tr>
<tr>
<td>IS</td>
<td>165</td>
<td>0.02</td>
<td>0.048</td>
<td>1,200</td>
</tr>
<tr>
<td>NL</td>
<td>Between 2,000 and 3,000</td>
<td>Not available</td>
<td>Not available</td>
<td>Not available</td>
</tr>
</tbody>
</table>

\textsuperscript{10} The Swiss National Organisation for and of the Blind (SNAB) has an overview of children with visual impairment who receive special education and the Union of the Blind and Partially Sighted of Slovenia has a register of its members.

\textsuperscript{11} 2009 figures. Recent numbers not available

\textsuperscript{12} In 2009 there were 1.6 million people living with a disability. 19.9% of this number were visually impaired and 2.2% were visually impaired children.

\textsuperscript{13} Estimate by authors.

\textsuperscript{14} All figures for Denmark are approximate.

\textsuperscript{15} Figures from the Estonian Social Insurance Board

\textsuperscript{16} From Census 2011

\textsuperscript{17} Refers to the number who are Deafblind. Other figures are not available.
<table>
<thead>
<tr>
<th>Country</th>
<th>Age 0-16</th>
<th>Age 15-19</th>
<th>Not available</th>
<th>Not available</th>
<th>Some data from Polish Association(^{18})</th>
</tr>
</thead>
<tbody>
<tr>
<td>PL</td>
<td>262,100</td>
<td>25,000</td>
<td>Not available</td>
<td>Not available</td>
<td>Some data from Polish Association(^{18})</td>
</tr>
<tr>
<td>RO</td>
<td>2,891(^{19})</td>
<td>0.08</td>
<td>0.015</td>
<td>Not available</td>
<td>58 of the 210</td>
</tr>
<tr>
<td>SI</td>
<td>210</td>
<td>0.06</td>
<td>0.01</td>
<td>58 of the 210</td>
<td>1,800 approx.</td>
</tr>
<tr>
<td>SE</td>
<td>3,000 approx.</td>
<td>0.15</td>
<td>0.03</td>
<td>1,800 approx.</td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td>21,343(^{20})</td>
<td>0.2(^{21})</td>
<td>Not available</td>
<td>29,000</td>
<td></td>
</tr>
</tbody>
</table>

For some countries (IS, PL, SI), the same definitions of visual impairment were used, at 30%. Although the figures give interesting data on the numbers of children and the extent to which statistics are available, the numbers are not comparable with one another for several reasons. In all cases they were compiled from national statistics which frequently did not use the same criteria and definitions as one another. Further, many were compiled from records used for other specific purposes, mostly education. It is not clear whether children not in education (for example some children living in institutions) were included in the statistics. Also in several instances, the question was interpreted differently by the country authors, giving different results. The figures are included here with these caveats.

Most notable is the higher rate of visual impairment recorded for Austria, which is also evident in other Austrian statistics. Another difference concerns the extent to which there is inclusion of people with low vision in the figures. Some countries are purposeful in only including people with greater impairments (for example SI) while others (for example IS) include people with low vision.  

### 6.3 National Disability Strategies

This section asked four questions about various aspects of planning and policy.

\(^{18}\) The Polish Association of the Blind has approximately 50,000 members, about a third of whom have additional impairments. The author states that “we assume that the number of visually impaired children with additional disabilities may rise to half of the number of them registered in our organisation”.

\(^{19}\) Data from 2015

\(^{20}\) Figures from 2014

\(^{21}\) Using the World Health Organisation definition.
**Question 1 Asks:**

Is there in your country according to legislative provisions an adopted national disability strategy? Please indicate if there is a strategy that is not based on formal rules or legislation.

Most countries indicated that a formal strategy was in place and that this was formally based on law (AT, BG, EE, HU, IS, PL, RO, SE, UK)

Switzerland (CH) indicated that a strategy was under development but not in place at the time of compiling the report.

Denmark noted that there was a strategy but it was not based on law. Established in 2013, the strategy included the establishment of a body to monitor discrimination, a measure that was removed in 2015 by a subsequent government. The authors note that the strategy has been criticised by disabled people as being ineffective. In Estonia the strategy was very old and had not been updated since 1995.

The Netherlands reported that there was no strategy in place.

**Question 2 asks:**

Does your organisation participate in preparing national disability strategies?

Almost all countries clearly answered ‘Yes’ to this question (AT, BG, DK, EE, HU, IS, NL, PL, RO, SI and SE). Some emphasised that they were consulted in matters to do with the CRPD (NL, PL) which is not exactly the same as being consulted on a national strategy. The Estonian Chamber of Disabled People and the Estonian Federation of the Blind as a member organisation, had participated in 1995. Clearly there are degrees of participation and authors were not asked to go into detail about how they were consulted. Two countries seemed to hint that consultation could be better organised. In Switzerland, the authors note that:

“We promote a national disability strategy with a concrete action plan. Also existing disability laws must be completed and well-coordinated in future.”

In the UK, the representative organisation participated in consultation exercises before and after legislation was developed.
Question 3 asks:
Are children and young persons included in such existing national disability strategies?

Most countries answered ‘Yes’ to this question (DK, EE, HU, IS, NL, PL RO, SI, SE) and two answered ‘Not aware’ (AT, BG).

Four countries gave a few more details. In Switzerland (CH) it was pointed out that disability strategies are a regional rather than national responsibility. Each canon is required to develop a concept of disability and of a special-needs school based on self-determination and integration. In Sweden, it was considered that improved protection was needed in relation to violence in the family. In the UK children were thought to be consulted to the extent that they participated in responses to consultations.

No authors identified any steps that were being actively taken by organisations to increase participation of children with visual impairments.

Question 4 asks:
Has there been any type of national conference or similar coordinated gathering focusing on children and young persons with disabilities and specifically on children and young persons with a visual impairment within the last five years?

National conferences are important for raising awareness, increasing knowledge and stimulating action on specific issues.

Two countries stated that there had not been any conferences relevant to visually impaired children (RO, SI) and two that they were not aware of conferences (BG, NL). At the same time, smaller events had sometimes been organised, such as seminars and meetings, in two instances by organisations representing blind and visually impaired people.

The most evident theme was inclusive education and / or support in education (AT, CH, DK, IS, PL). Hungary had hosted a European conference on Psychology and visual impairment. These kinds of events were more likely to have official support from government ministries or national organisations. The second most frequent theme was vocational training and employment for young people (BG, EE). Organisations representing blind and visually impaired people were more likely to focus
on a wider agenda, such as the general issues facing young people (EE) or rights and opportunities (BG).

6.4 Local Support for Families with Children with Visual Impairment

This is the main section of the questionnaire and it asks about support to families of children with visual impairments. There are ten questions that taken together provide a picture of processes and outcomes experienced by families.

**Question 1 asks:**

Is there in your country legislation or other requirements that ensures collaboration amongst social, health and educational authorities with a purpose of coordinating information and proper measures?

Answers given were as follows:

<table>
<thead>
<tr>
<th>Yes</th>
<th>To some extent</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>CH, IS, NL, RO</td>
<td>BG, SE, UK</td>
<td>AT, DK, EE, HU, PL, SI</td>
</tr>
</tbody>
</table>

Some authors reported that there was legislation to co-ordinate some aspects of service provision (for example, health care in Sweden and education in the UK) but not others. However, co-ordination on a wider basis, such as between different departments was often lacking. Three countries (DK, EE, SI) pointed to the desirability of co-ordination from the point of view of families because making arrangements was considered onerous. Different types of co-ordination were also noted. For example, in Switzerland co-ordination was required by law at the regional level, and in Bulgaria there were different requirements at national and institutional levels. Co-ordination is a complex question, in that it can also impact on issues of choice and control and it would be worth looking into this issue in more detail at another time.

**Question 2 asks:**

Is there specific legislation in your country that guarantees that families with children or young persons with disabilities / a visual impairment receive support from the national or local authorities?
Answers were given as follows:

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>AT, BG, DK, HU, IS, RO, SI, SE, PL, UK</td>
<td>NL, CH</td>
</tr>
</tbody>
</table>

**Question 3 asks:**

What kind of support is offered in your country on a central and/or local level?

There was a lack of clarity in answering this question. Some countries interpreted it as asking about the kinds of services that were made available to families. Others identified the mechanisms in place to deliver services (such as the law, or organisations involved in delivery), while others still identified problems experienced by children and families. It is evident that answers were also not comprehensive, given the scale of the question: involving potentially all services at all administrative levels. In summarising the responses, the types of services mentioned are shown below and readers are referred to the individual reports for further details about key aspects identified by the authors.

<table>
<thead>
<tr>
<th>Types of Support</th>
<th>Countries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finance</td>
<td>AT, BG, HU, EE, SE</td>
</tr>
<tr>
<td>Education</td>
<td>AT, EE, CH, IS, SE</td>
</tr>
<tr>
<td>Transport</td>
<td>EE, HU, SE</td>
</tr>
<tr>
<td>Technical Devices</td>
<td>DK, HU, SE</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>EE</td>
</tr>
<tr>
<td>Counselling</td>
<td>DK, EE, PL, SI</td>
</tr>
<tr>
<td>Financial support for assistants, child care</td>
<td>BG, EE, SE</td>
</tr>
</tbody>
</table>

It is important to note that identification of these sorts of support does not mean that other sources of help are not available in any country.

**Question 4 asks:**

Are there coordinated private initiatives, where parents with children and young persons with disabilities / visual disabilities may obtain consultation and support (for example, advice, counselling, and assistive devices for pedagogical / educational purposes)?
Most countries appeared to interpret ‘private’ to mean organisations composed of family members and/or people with visual impairments, rather than companies that are for profit, although not all did (for example Estonia).

The following answers were given:

<table>
<thead>
<tr>
<th>Yes</th>
<th>Not aware</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>AT, CH(^{22}), DK, EE(^{23}), IS, NL(^{24}), PL(^{25}), RO(^{26}), SE(^{27})</td>
<td>BG, SI, UK</td>
<td></td>
</tr>
</tbody>
</table>

**Question 5 asks:**

Are there any magazines, newsletters or publications financed by public resources or private funding specifically for:

- Employees/personnel that work with children and/or young persons with a disability / with a visual impairment;
- Children and young persons with a disability / visual impairment
- Parents of children and young persons with a disability / visual impairment?

\(^{22}\) Referring to the national parent association Insieme

\(^{23}\) Assistive devices are all offered by private companies, partly paid for by state. Other advice and counselling is offered by public institutions and NGOs.

\(^{24}\) Referring to Facebook groups for children and family members

\(^{25}\) Referring to five organisations of parents of blind children in Poland.

\(^{26}\) Referring to the Romanian Association of the Blind.

\(^{27}\) Referring to Facebook groups for children and family members
The following table summarises answers given by the countries.

<table>
<thead>
<tr>
<th>Publications</th>
<th>Yes</th>
<th>Not aware</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employees</td>
<td>AT&lt;sup&gt;28&lt;/sup&gt;, EE&lt;sup&gt;29&lt;/sup&gt;, NL&lt;sup&gt;30&lt;/sup&gt;, PL, SE, UK</td>
<td>BG, HU, RO, SI&lt;sup&gt;31&lt;/sup&gt;</td>
<td>DK, IS</td>
</tr>
<tr>
<td>Children and young persons</td>
<td>AT, NL&lt;sup&gt;32&lt;/sup&gt;, PL&lt;sup&gt;33&lt;/sup&gt;, SE, UK</td>
<td>BG, HU, SI</td>
<td>DK, EE, IS, RO&lt;sup&gt;34&lt;/sup&gt;</td>
</tr>
<tr>
<td>Parents</td>
<td>AT, NL&lt;sup&gt;35&lt;/sup&gt;, PL, SE, UK</td>
<td>BG, HU, SI</td>
<td>DK, EE, IS, RO</td>
</tr>
</tbody>
</table>

Some countries mentioned organisations of blind and visually impaired people that produced information in large print or Braille (PL, SE) and several countries pointed to the importance of web based material (AT, CH, EE, PL, SE, UK). However, six countries were either not aware of any information for any of the three groups or stated that it did not exist (BG, DK, HU, IS, RO, SI). In some countries information is only partial. In Estonia there was none for children and young people or parents and in Switzerland there was none for children.

**Question 6 asks:**

Are there any leisure activities available that are especially developed and adapted for children and/or young persons with visual disabilities?

All countries answered ‘Yes’ to this question, except Bulgaria where authors were not aware of the situation and suggested that an organisation of parents of visually impaired children was more likely to know about this.  

**Question 6.1 asks:**

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<sup>28</sup> Publications include German ones.

<sup>29</sup> Twice yearly publication by the Estonian Federation of the Blind.

<sup>30</sup> Newsletter produced by Oogvereniging

<sup>31</sup> However, the Union of the Blind and Partially Sighted of Slovenia and Institute of Blind and Partially Sighted Ljubljana publish various leaflets to raise awareness about VI and to promote their services.

<sup>32</sup> Referring to Facebook groups

<sup>33</sup> Talking books were also mentioned by Poland.

<sup>34</sup> The Romanian Association of the Blind intends to publish a magazine for children in Braille.

<sup>35</sup> Referring to Facebook groups

<sup>36</sup> Association of the Parents of Visually Impaired Children (APVICh)
If yes: who is responsible for maintenance and the management?

Many of the organisations mentioned that they were involved in sports activities of one kind or another. A summary of the information given is as follows:

<table>
<thead>
<tr>
<th>Type of organisation</th>
<th>Countries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local organisation run by volunteers</td>
<td>DK, EE</td>
</tr>
<tr>
<td>Schools</td>
<td>HU</td>
</tr>
<tr>
<td>Sports organisations</td>
<td>IS(^{37}), SE(^{38}), UK(^{39})</td>
</tr>
<tr>
<td>Youth clubs</td>
<td>SE</td>
</tr>
<tr>
<td>Private organisation</td>
<td>CH(^{40})</td>
</tr>
<tr>
<td>Cinemas and theatres</td>
<td>UK(^{41})</td>
</tr>
<tr>
<td>Regional low vision centres</td>
<td>SE</td>
</tr>
<tr>
<td>Organisation of visually impaired persons</td>
<td>RO, SI, SE</td>
</tr>
<tr>
<td>Not aware / Don’t know</td>
<td>AT, BG, PL</td>
</tr>
</tbody>
</table>

It is difficult to draw conclusions about access to leisure activities because the question only asks about special groups for visually impaired children rather than integrated activities. While some countries (e.g. IS) limit their answers to special activities, others (e.g. UK) mention integrated activities such as going to the cinema and theatre performances. Finally, it is notable that several organisation responding to the questionnaire are themselves providers of special activities (e.g. RO, SI).

**Question 7 asks:**

In your country, is there an arrangement either constituted by legal requirements or established on a voluntary basis, through which children and young persons with a disability / visual disability may have the right to:

- Sighted guides / company
- Financial support
- Transportation to leisure activities

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\(^{37}\) Paralympic Committee of Iceland and Special Olympics
\(^{38}\) Parasport Sweden
\(^{39}\) Sport camps
\(^{40}\) National organisation Blindspot, that runs leisure and sport activities.
\(^{41}\) Provision of audio description.
The answers are summarised in the table below.

<table>
<thead>
<tr>
<th>Right</th>
<th>Yes</th>
<th>Not aware</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sighted guides</td>
<td>AT, CH(^{42}), DK, EE(^{43}), IS, PL(^{44}), RO, SE</td>
<td>UK</td>
<td>BG, CH(^{45}), HU, NL, SI</td>
</tr>
<tr>
<td>Financial Support</td>
<td>AT, BG, DK, EE(^{46}), IS, PL, RO, SI, SE, UK(^{47})</td>
<td>HU, NL</td>
<td></td>
</tr>
<tr>
<td>Transport to leisure activities</td>
<td>AT, CH(^{48}), DK(^{49}), EE(^{50}), IS, NL(^{51}), RO, SE, UK(^{52})</td>
<td>PL</td>
<td>BG, HU, SI</td>
</tr>
</tbody>
</table>

It is noticeable overall that, the availability of support tends to follow a pattern of either being provided or not, across all three categories. The lack of support in some countries is of concern, especially given the persistence of institutional living arrangements in the countries where support to families is lacking.

**Question 8 asks:**

Are there formal or informal opportunities by which children and/or young persons with a visual impairment may meet / spend time together with their peers (children facing the same challenges) and meet mentors

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\(^{42}\) In Switzerland an assistance contribution is part of disability insurance benefits. Children of school age can benefit, but they have to organise their guide themselves.

\(^{43}\) The author points out that it is complicated to get this.

\(^{44}\) The programme “Assistant of a person with disability” is for example conducted in Warsaw.

\(^{45}\) However, some financial support, for example additional expenditure in education, is provided.

\(^{46}\) Under the Benefits for Disabled Persons Act and the Social Welfare Act

\(^{47}\) Through child benefits and the Disability Living Allowance.

\(^{48}\) There are price reductions for public transport and leisure activities but none for private transport services.

\(^{49}\) Only for children over 12 years old.

\(^{50}\) Public transport is free for all disabled children up to 16 years. Local authorities may support special transport.

\(^{51}\) There are voluntary initiatives (such as the Lions club) that transport visually impaired children and adults to leisure activities.

\(^{52}\) This may be paid for through financial allowances.
All countries answered ‘Yes’ to this question, except for Hungary, which answered ‘Not Aware’. Most counties gave examples of specific organisations that arranged for young people to meet, the majority of which were organisations of visually impaired people. Other examples included local parent groups (UK), special schools (CH).

**Question 9 asks:**

Are there any formal or informal opportunities for children and young persons with a visual impairment to meet adults with a visual impairment in order to meet role models / mentors? And if so, who is responsible for running such meeting opportunities?

This question is essentially the same as the previous one, except that it involves opportunities for contact with adults who can act as mentors. Again, all countries answered ‘Yes’ and gave examples of organisations that are led by visually impaired people. Two countries (HU and UK) answered ‘Not Aware’ and one country (AT) did not answer the question.

### 6.5 Consulting Children

There are four questions in this section of the questionnaire, focussing on aspects of participation and the possibility of influencing law and society.

**Question 1 asks:**

Is there any existing legislation in your country generally, or within the specific social, educational or the health area that ensures that children and young persons with a disability / a visual impairment have the opportunity / right to express their points of view pertaining to their specific situation or to general issues pertaining to disability policies?

Countries are also asked to indicate the provisions made, and details are given in the footnotes.

This question invites comments on both national and local law and policies in several areas (social, education and health). It also asks whether children have an opportunity to express their views on both their own individual situations and wider general issues of disability policy. All
authors gave a single answer, with some providing more details by way of example.

Below is a summary of the responses:

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Not Aware</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legal right of express views</td>
<td>DK&lt;sup&gt;53&lt;/sup&gt;, EE&lt;sup&gt;54&lt;/sup&gt;, NL&lt;sup&gt;55&lt;/sup&gt;, SE&lt;sup&gt;56&lt;/sup&gt;</td>
<td>BG&lt;sup&gt;57&lt;/sup&gt;, HU, IS, SI, UK</td>
<td>AT, PL, RO&lt;sup&gt;58&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Although all children are entitled to express their views under the provisions of the Convention on the Rights of the Child, whether this right is promoted in practice shows some national variation. For disabled children, restrictions on legal capacity may apply and views may be discounted in practice even if not in formal law. As is evident in many of the answers given, the right may only be realised in limited circumstances. Two replies (NL, RO) were not very clear in terms of a straightforward ‘Yes’ or ‘No’ answer. They have been allocated to a category but it is not clear whether these are the most accurate ones.

There is clearly variation between countries; however the right to express views exists for all CRPD signatories and should be implemented with appropriate support depending on the child’s age and situation.

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<sup>53</sup> In divorce cases the Law on Parental Responsibility says that the child has a right to express his or her opinion. If a forced adoption order is made, the Consolidation Act on Social Services gives the child a right to express his or her opinion.

<sup>54</sup> The Child Protection Act.

<sup>55</sup> The author states there is only a right to express views on social media.

<sup>56</sup> The following examples are given: Health and Care Act (planning for habilitation), Patient law (children’s health and care), Social Service Act (support from municipality) and the School law (planning for support in education).

Law on the support and service for some people with disabilities, LSS – support from municipality.

Law on parental support – child is to be heard when parents cannot agree on custody matters.

<sup>57</sup> There is no specific right to expression for disabled people in Bulgarian legislation.

<sup>58</sup> Although the author answered ‘Yes’ to this question, I have placed it in the No group. This is because there is not an indication of a legal right to express views and be heard directly. The author states: ‘Children under 18 years old are represented by their parents in such consultations. Mostly, Romanian Association of the Blind lobbies their needs and advocates their concerns in the area of visual impairment’.
**Question 2 asks:**

Do the national organisations of blind and partially sighted persons in your country have a functioning subdivision, wing or independent representative organisation with specific focus on issues relating to children and young persons?

The answers given were:

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Not aware</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Section for young people</td>
<td>DK, IS, NL, PL, SI, SE, UK</td>
<td>AT</td>
<td>BG, CH, EE, HU, RO</td>
</tr>
</tbody>
</table>

Countries with sections of the organisation for children and young people did not specify the activities involved.

**Question 3 asks:**

Is there any formalised network or organization(s) of parents and relatives of children and young persons with a disability / visual impairment?

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Not aware</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Network of family members</td>
<td>BG, DK, EE, IS, NL, PL, SI(^{59}), SE, UK</td>
<td>AT, HU, RO(^{60})</td>
<td></td>
</tr>
</tbody>
</table>

Countries also answered further questions about aspects of organisations, including when they had been set up, how they were led and funded and whether there was co-operation with parent organisations.

In all instances organisations had been set up by parents of visually impaired children themselves, although in two counties (SI, SE) the families were also organised as sub-groups of the organisations of visually impaired persons. Poland identified nine organisations of family members and in Sweden two organisations as well as local networks were mentioned.

\(^{59}\) The network of parents and relatives of children and young persons with visual impairment are organised as a subgroup within the Union of the Blind and Partially Sighted of Slovenia and funded by them.

\(^{60}\) The author states that usually parents consult the Romanian Association of the Blind if they have any problems.
Organisations of parents and relatives had been set up in 1950 (DK), the 1960s (SE) in the 1980s – 1990s (PL), and in 1999 (SI). Other counties were not aware of when organisations had been initiated. All family organisations were funded through grants for particular projects, this being – where indicated - either private (DK, IS) or both (EE, NL, SE). Co-operation with family groups was mentioned by Denmark, Estonia and Iceland, with Sweden collaborating with one of the two groups. The Netherlands did not collaborate and the other countries did not answer this question.

**Question 4 asks:**

Are there formal or informal forum/opportunities for children, young persons with a visual impairment or their parents through representative bodies to express concerns or points of view on issues that affect them?

The answers given were as follows:

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Not aware</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opportunities for children to express views</td>
<td>AT, DK, EE, IS, NL, PL, RO, SE, UK</td>
<td>BG61, HU</td>
<td>CH, SI</td>
</tr>
</tbody>
</table>

All of those answering 'Yes' to the question identified organisations of blind and partially sighted people as the main source of assistance for expressing views. Iceland did not answer the question. Other organisations identified were the organisations of parents (DK, SE) Facebook (NL) and a forum on inclusive education (PL).

### 7. Conclusion

The information in the EBU database provides a valuable addition to other comparable information on the rights of disabled children in Europe. The data shows that blind and visually children and young people experience gaps in information and support and also point to the importance of EBU member organisations as an important means for visually impaired children to express their views.

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61 The Association of the Parents of Visually Impaired Children (APVICH) was identified as an organisation that should have more information about this issue.
There is also still potential for the database to be developed further, where the capacity exists. For example, comments could be included on the progress on human rights outcomes in each country. This could provide a further source of information for shadow reports to the CRPD as well as a valuable complementary perspective to reporting by other human rights organisations.

This report is co-funded by the "Rights, Equality and Citizenship Programme" Programme of the European Union.