
Photo: © UNICEF Bulgaria/2015-0151/Noorani

Data Collection and Dissemination

Synthesis of Findings

mdac
mental disability
advocacy center

Data Collection and Dissemination

Synthesis of Findings

April 2015

ISBN 978-615-80236-5-8

This publication has been produced with the financial support of the Fundamental Rights and Citizenship Programme of the European Union.

Executive Summary

This report was compiled as part of a 10-country EU co-funded project coordinated by the Mental Disability Advocacy Center, Budapest. It starts by providing an overview of UN, CoE and EU instruments relevant to the collection and dissemination of data relating to children with mental disabilities in the justice system. Despite the existence of European and international guidance on data collection, national researchers reported that there was very little statistical or other data relating to disabled children and virtually no disaggregated data according to impairment types. Without such information, the nature and extent of the barriers to accessing justice which face these children remains hidden. This report explains the methodology used in this project and reflects on the experiences of those carrying out the research. It highlights the difficulties or obstacles which researchers encountered in their efforts to identify and access relevant data on this topic.

Recommendations flowing from this workstream can be found in a separate accompanying report.[1]

---

[1] Mental Disability Advocacy Center, *Access to justice for children with mental disabilities – The collection and dissemination of data: Guidance report* (Budapest: MDAC, 2015), available at: www.mdac.org/accessing-justice-children (last accessed 20 April 2015).

1. Introduction

This report has been written as part of a project, co-funded by the European Commission (DG Justice), on "access to justice for children with mental disabilities".[2] The project had four main objectives: firstly to produce guidance based on research findings relating to the collection and dissemination of data on children with mental disabilities (Workstream 1 (WS1)); secondly to provide a detailed account of international and European Standards that apply in the context of access to justice for children with mental disabilities (Workstream 2 (WS2)); thirdly to develop a set of on-line training materials for professionals who come into contact with children with mental disabilities in the justice system (Workstream 3 (WS3)); and fourthly to make sure that research findings are disseminated to and considered by policy makers in all Member States(Workstream 4 (WS4)).

The term "children" will be used to refer to people under the age of 18[3] and the term "mental disabilities" will be used (in the sense it is used by the Mental Disability Advocacy Center) to refer to people who have (or are treated as having) intellectual, developmental, cognitive, and/or psycho-social disabilities.[4] Also of relevance is the guidance on the term "people with disabilities" provided by the UN Convention on the Rights of Persons with Disabilities (UN CRPD). According to this, "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".[5]

Access to justice is a human right recognised by United Nations (UN), Council of Europe (CoE) and European Union (EU) instruments. One of the objectives of this project was to provide a detailed account of the implications and requirements associated with this right in the context of children with mental disabilities. This information can be found in a separate standards and findings report, produced under WS2 of this project.[6] In addition to substantive obligations (such as those relating to accessing justice), human rights law imposes obligations on States to collect and disseminate data on the extent to which they are making progress in fulfilling these substantive obligations. The collection and dissemination of such data has an important role to play in enabling governmental and non-governmental actors within a country to monitor or assess progress in the implementation of substantive human rights obligations (e.g. relating to access to justice) and to identify areas of ongoing concern. It also provides the information relevant to the preparation of government and shadow reports to supranational bodies concerned with the oversight of human rights treaties (such as UN treaty monitoring bodies). It should be stressed that, for the purposes of this report, the term "monitoring" is used in a broad sense to refer to processes for gauging the current state of implementation and progress over time and does not necessarily imply reporting to (or evaluation by) supranational bodies (e.g. EU or UN).

---

[2] See more: www.mdac.org/accessing-justice-children (last accessed 20 April 2015).

[3] This is broadly in line with the UN Coonvention on the Rights of the Child, Article 1.

[4] See more: http://www.mdac.org (last accessed 20 April 2015).

[5] UN Convention on the Rights of Persons with Disabilities, Article 1.

[6] Mental Disability Advocacy Center, *Access to Justice for Children with Mental Disabilitiess International Standards and Findings from Ten EU Member States* (Budapest: MDAC, 2015), available at: http://www.mdac.org/en/standards-and-findings-from-10-EU-states (last accessed 20 April 2015).

The focus of WS1 of this project is the collection and dissemination of data on children with mental disabilities in the justice system. It entailed research into international and European obligations to collect and disseminate relevant data and the current approaches of the 10 project countries to this issue. The two reports produced as part of this Workstream thus draw upon an analysis of relevant UN and European instruments and the 10 country reports compiled as part of this project – for Bulgaria,[7] the Czech Republic,[8] Hungary,[9] Ireland,[10] Latvia,[11] Lithuania,[12] Romania,[13] Slovenia,[14] Spain[15] and the UK.[16] This report presents a synthesis of the country-based findings relating to data collection and dissemination, in light of relevant international and European standards. It aims to identify key provisions in UN, CoE and EU law relating to the collection and dissemination of data in this field and to assess the extent to which such data is currently being collected and disseminated in the project countries. Although some attention will be given in this report to issues which complicate or obstruct the collection and dissemination of such data, recommendations and guidance for how these difficulties might be tackled will be dealt with in the separate accompanying WS1 report.[17]

This report is divided into five main sections (excluding the introduction and conclusion). In the first of these, Section 2, relevant UN, CoE and EU instruments will be analysed. In Section 3, the co-ordination of the work of the national researchers, which produced the reports relied on in this report, will be explained. In Section 4, attention will turn to an analysis of the extent to which data relating to the human rights of children with mental disabilities was available and accessible to researchers in the 10 project countries. In Section 5, attention will focus on their experiences of the process of collecting new data on this topic – experiences which themselves provide useful information on potential barriers and facilitators to the collection of relevant data. Issues to be covered will include the methods used and obstacles encountered. Then, in Section 6, the last of the substantive sections of this report, an attempt will be made to identify some of the key factors which contribute to the lack of data on access to justice for children with mental disabilities. Finally, in Section 7, key conclusions will be set out.

---

[7] Compiled by Marieta Dimitrova, Velina Todorova and Antoaneta Mateeva, the Bulgarian Center for Not-for-Profit Law.

[8] Compiled by Anna Hofschneiderová, Lawyer at Liga lidských práv (League of Human Rights), an NGO headquartered in Brno.

[9] Compiled by Anna Zeller, MDAC and Judit Zeller, Senior Lecturer at the Faculty of Law of the University of Pécs.

[10] Compiled by Eilionóir Flynn and Jenni Kline, University of Galway.

[11] Compiled by Ieva Leimane-Veldmeijere, Annija Mazapša, Santa Skirmante, ZELDA.

[12] Compiled by Ugnė Grigaitė, Project Manager, NGO "Mental Health Perspectives", Lithuania, Vilnius.

[13] Compiled by DanielaUdudec, Georgiana Pascu, Silvia Tabusca and Valerian Stan, NGO Centrul de Resurse Juridice (Center for Legal Resources) in Bucharest.

[14] Compiled by Mojca Urek, Andreja Rafaelič, Senior Lecturer at the Faculty of Social Work of the University of Ljubljana, Slovenia.

[15] Compiled by Ignacio Campoy, Patricia Cuenca, Silvina Ribotta, Universidad Carlos III de Madrid.

[16] Compiled by Rebecca Parry, University of Leeds.

[17] Mental Disability Advocacy Center, *Access to justice for children with mental disabilities – The collection and dissemination of data: Guidance report* (Budapest: MDAC, 2015), available at: www.mdac.org/accessing-justice-children (last accessed 20 April 2015).

2. UN and European Requirements to Collect and Disseminate Data on the Access to Justice

2.1 United Nations

Of key relevance to this section are the UN Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD). The former is some 18 years older than the latter and has been ratified by all EU Member States. The latter has been signed by all EU Member States and (to date) ratified by all but three of them. Unlike the CRC, however, the CRPD has been ratified by the EU itself.

Because the CRPD is the newer of these treaties, and because it contains a specific article on data collection and dissemination, its provisions will be used as the starting-point for this discussion. Reference will also be made to the CRC and to guidance on data collection and dissemination issued by both the CRC Committee and the CRPD Committee. It should be noted that the CRC Committee, unlike the CRPD Committee, has addressed this point in several General Comments. These provide particularly useful reference points.

Parties to both the CRPD and the CRC are required to submit to the relevant treaty monitoring bodies (the CRPD Committee and the CRC Committee respectively), on a regular basis, "a comprehensive report on measures taken to give effect to […] obligations under the present Convention and on the progress made in that regard".[18] States Parties are also required to make their reports widely available to the public,[19] thereby facilitating dissemination of information contained within them. Similar requirements are to be found in other core UN human rights treaties.[20] They lie at the heart of the UN's system for monitoring the domestic implementation of treaty obligations. However, and very importantly, additional data may be provided to the UN treaty monitoring bodies through shadow or alternative reports.

An indication of the high expectations held by UN treaty monitoring bodies of the type of data which States Parties should include in their reports is illustrated by the Reporting Guidelines issued to States by both the CRPD Committee[21] and the CRC Committee.[22] According to the former, States Parties should supply the Committee with "[s]tatistical data on the realization of each Convention right, disaggregated by sex, age, type of disability (physical, sensory, intellectual and mental), ethnic origin, urban/rural population and other relevant categories".[23]

---

[18] CRPD, Article 35. See also CRC, Article 44.

[19] CRPD, Article 36(4) and CRC, Article 44(6).

[20] See, e.g. International Covenant on Civil and Political Rights, Article 40; International Covenant on Economic Social and Cultural Rights, Article 16; Convention on the Elimination of Racial Discrimination, Article 9; Convention on Discrimination Against Women, Article 18; International Convention on the Protection of the Rights of all Migrant Workers and Members of their Families, Article 73.

[21] As it is empowered to do by CRPD, Article 35(3).

[22] As it is empowered to do by CRC, Article 44(5).

[23] UN Committee on the Rights of Persons with Disabilities, *Guidelines on Treaty-Specific Document to be Submitted by States Parties under Article 35(1) of the Convention on the Rights of Persons with Disabilities* (Geneva: UN, 2009), para. 3.2(h).

In addition, the CRPD explicitly articulates a new obligation (separate from, but overlapping with, the Article 35 reporting process) to collect and disseminate data relating to the human rights of adults and children with disabilities. Article 31 requires States to ensure that "appropriate information, including statistical and research data"[24] is collected for purposes of enabling them to develop relevant evidence-based policy and to "assess the implementation of States Parties' obligations […] and to identify and address the barriers faced by persons with disabilities in exercising their rights".[25] This provision goes on to require that this information shall be "disaggregated, as appropriate" and that the process of collecting and maintaining it shall:

> "(a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;" and
> "(b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics."[26]

It is clear from Article 31 that the collection of data alone is not enough – States Parties must also ensure that data of this type is disseminated and made accessible to people with disabilities.[27]

The CRC Committee has repeatedly drawn attention to the importance of data collection in its General Comments. For instance, in its General Comment No. 5,[28] "comprehensive data collection" and "awareness-raising" are listed amongst the "general measures of implementation" addressed in the Comment.[29] The following paragraph is particularly noteworthy for current purposes:

> "Collection of sufficient and reliable data on children, disaggregated to enable identification of discrimination and/or disparities in the realization of rights, is an essential part of implementation. The Committee reminds States parties that data collection needs to extend over the whole period of childhood, up to the age of 18 years. It also needs to be coordinated throughout the jurisdiction, ensuring nationally applicable indicators. States should collaborate with appropriate research institutes and aim to build up a complete picture of progress towards implementation, with qualitative as well as quantitative studies. The reporting guidelines for periodic reports call for detailed disaggregated statistical and other information covering all areas of the Convention. It is essential not merely to establish effective systems for data collection, but to ensure that the data collected are evaluated and used to assess progress in implementation, to identify problems and to inform all policy development for children."[30]

---

[24] CRPD, Article 31(1).
[25] CRPD, Article 31(2).
[26] CRPD, Article 31(1).
[27] CRPD, Article 31(3).
[28] Committee on the Rights of the Child, General Comment No. 5: General Measures of Implementation of the Convention on the Rights of the Child, 2003, CRC/GC/2003/5.
[29] Ibid, para. 9.
[30] Ibid, para. 48.

The importance of effective data collection relating to children in the particular context of the juvenile justice system was stressed by the CRC Committee in its General Comment No. 10,[31] where it stated that:

> "The Committee is deeply concerned about the lack of even basic and disaggregated data on, inter alia, the number and nature of offences committed by children, the use and the average duration of pre-trial detention, the number of children dealt with by resorting to measures other than judicial proceedings (diversion), the number of convicted children and the nature of the sanctions imposed on them. The Committee urges the States parties to systematically collect disaggregated data relevant to the information on the practice of the administration of juvenile justice, and necessary for the development, implementation and evaluation of policies and programmes aiming at the prevention and effective responses to juvenile delinquency in full accordance with the principles and provisions of CRC."[32]

As is apparent from the extracts from the General Comments already quoted, the CRC has drawn attention to the need for data and statistics on the lived realities of children to be disaggregated. The need to include disability as one of the factors shaping this disaggregation emerges clearly from the Committee's General Comment No. 9[33] which notes that:

> "In order to fulfil their obligations, it is necessary for States parties to set up and develop mechanisms for collecting data which are accurate, standardized and allow disaggregation, and which reflect the actual situation of children with disabilities. The importance of this issue is often overlooked and not viewed as a priority despite the fact that it has an impact not only on the measures that need to be taken in terms of prevention but also on the distribution of very valuable resources needed to fund programmes."[34]

Whilst the CRPD Committee has, to date, only published two General Comments, neither of which addresses data collection and dissemination, it is apparent from even the briefest analysis of its Concluding Observations that lack of relevant disaggregated statistical data on the human rights situation of adults and children with disabilities is a matter which has consistently caused concern to the Committee in its consideration of States reports.[35] The following passage in its Concluding Observations on Sweden is a recent example:

> "The Committee regrets the low level of disaggregated data on persons with disabilities. It recalls that such information is indispensable to: understanding the situations of specific groups of persons with disabilities in the State party who may be subject to varying degrees of vulnerability; developing laws, policies and programmes adapted to their situations; and assessing the implementation of the Convention. […]

---

[31] Committee on the Rights of the Child, General Comment No. 10: Children's rights in juvenile justice, 25 April 2007, CRC/C/GC/10, para. 98.

[32] Ibid, para. 98.

[33] Committee on the Rights of the Child, General Comment No. 9 (2006): The rights of children with disabilities, 27 February 2007, CRC/C/GC/9

[34] Ibid, para. 15.

[35] See e.g. Committee on the Rights of Persons with Disabilities, Concluding Observations on Azerbaijan 11th Session (May 2014) para. 49; on Australia, 10th Session 2-13 Sept 2013, para. 53; on Argentina, 8th Session (17-28 Sept 2012), para. 49; on China, 8th Session, (17-28 Sept 2012), para. 47; on Hungary, 8th Session, (17-28 Sept 2012), para. 47; and on Spain, 6th Session (Sept 2011), para. 49.

> 57. The Committee is concerned that data is scarce on matters affecting girls, boys and women with disabilities, including those belonging to indigenous groups."[36]

This Committee has also voiced specific concerns about the lack of data on children with disabilities. For instance, the following paragraph appears in its Concluding Observations on Australia:

> "55. The Committee regrets that the situation of children with disabilities is not reflected in data on the protection of children. It further regrets the paucity of information on children with disabilities, in particular indigenous children, alternative care for children with disabilities and children with disabilities living in remote or rural areas."[37]

Concerns about children's access to justice have recently been expressed in a 2014 resolution of the UN's General Assembly.[38] Particularly relevant for present purposes is the explicit encouragement it gives to States to:

> "develop and strengthen the collection, analysis and dissemination of data for national statistics in the area of children's access to justice and, as far as possible, to use data disaggregated by relevant factors that may lead to disparities and other statistical indicators at the subnational, national, subregional, regional and international levels, in order to develop and assess social and other policies and programmes so that economic and social resources are used efficiently and effectively for the full realization of the rights of the child"[39];

and to

> "incorporate detailed and accurate information relating to access to justice for children, including on progress made and challenges encountered and statistics and comparable data, in their periodic reports and information provided to the universal periodic review mechanism and other relevant United Nations monitoring mechanisms".[40]

---

[36] Committee on the Rights of Persons with Disabilities, Concluding Observations on Sweden, 11th Session, 2014, paras. 55 and 57.

[37] Committee on the Rights of Persons with Disabilities, Concluding Observations on Australia, 10th Session, 2013, para. 55. See also Concluding Observations on Sweden, 11th Session, 2014 paras. 5 and 6; on Hungary, 8th Session, 2012 para. 48; and on Spain, 6th Session, 2011, para. 51.

[38] UN Human Rights Council, Rights of the child: access to justice for children, 25 March 2014, UN A/HRC/25/L.10, available at http://ap.ohchr.org/documents/dpage_e.aspx?si=A/HRC/25/L.10 (last accessed: 20 April 2015).

[39] Ibid, para. 17.

[40] Ibid, para. 19.

2.2 Council of Europe

2.2.1 Child-Focused Provisions

Some emphasis is given to research and monitoring in the Council of Europe's Guidelines on Child-Friendly Justice.[41] These encourage Member States to: "periodically review and evaluate their working methods within the child-friendly justice setting";[42] to "maintain or establish a framework, including one or more independent mechanisms, as appropriate, to promote and monitor implementation of the present guidelines […]"[43] and to "promote research into all aspects of child-friendly justice […]".[44]

Other CoE instruments are also relevant for present purposes. For instance, Article 11 of the newly entered into force Istanbul Convention on violence against women and domestic violence specifies that Parties shall undertake to:

> "collect disaggregated relevant statistical data […] on cases of all forms of violence covered by the scope of this Convention; [and] support research […] in order to study its root causes and effects, incidences and conviction rates, as well as the efficacy of measures taken to implement this Convention."[45]

Parties are also required to designate or establish an official body responsible for co-ordinating the collection of data referred to in Article 11, and analysing and disseminating its results.[46] The CoE's Commissioner for Human Rights has also stated that relevant and reliable data should be collected and preferably disaggregated according to sex, ethnicity, sexual orientation, disability, and age in order to reveal discriminatory practices and to get a comprehensive and valid picture of the situation. The Commissioner further recommends that States should:

> "9. Set up adequate systems for data collection and analysis, including data on disadvantaged groups of people. Collection of sensitive data should be voluntary and coupled with proper safeguards to prevent the identification of individuals belonging to a particular group. Complement official data with relevant information from NHRIs and NGOs."[47]

---

[41] Council of Europe, Guidelines of the Committee of Ministers of the Council of Europe on child friendly justice, Appendix 6, available at: https://wcd.coe.int/ViewDoc.jsp?Ref=CM/Del/Dec(2010)1098/10.2abc&Language=lanEnglish&Ver=app6&Site=CM&BackColorInternet=C3C3C3&BackColorIntranet=EDB021&BackColorLogged=F5D383 (last accessed 20 April 2015).

[42] Ibid, VI(c).

[43] Ibid, VI(d).

[44] Ibid, V(a).

[45] Council of Europe, Convention on preventing and combating violence against women and domestic violence, Article 11(1), available at: http://www.coe.int/t/dghl/standardsetting/convention-violence/convention/Convention%20210%20English.pdf (last accessed 27 April 2015).

[46] Ibid, Article 10(1).

[47] Council of Europe, Thomas Hammarberg Commissioner for Human Rights, Recommendation on systematic work for implementing human rights at the national level (18 February 2009), available at: https://wcd.coe.int/ViewDoc.jsp?id=1408617 (last accessed 27 April 2015).

2.2.2 Disability-Focused Provisions

Two action lines of the Disability Action Plan 2006-2015, adopted by the Committee of Ministers in 2006,[48] are particularly relevant here. Action Line 12 focuses on "legal protection", which includes effective access to justice. Action Line 14 is concerned with "research and development". This takes as its starting point the fact that:

> "The lack of data in relation to people with disabilities is recognised as a barrier to policy development at both national and international levels. We need to encourage and advance comprehensive, diversified and specialised research on all disability issues and co-ordinate it at all levels in order to promote the effective implementation of the objectives set out in this Action Plan."[49]

The second of the objectives of this Action Line is: "to harmonise statistical data collection methodology, nationally and internationally, in order to achieve valid and comparable research information".[50] Specific recommendations set out for States under it include:

> "i. To develop statistical and information strategies for disability policy and standard development based on a social and human rights-based model of disability, and to review the effectiveness of existing national strategies and databases;
> ii. to ensure information gained through needs assessments, whilst being treated as confidential on an individual basis, is used to the greatest effect to inform overall service planning and provision at national, regional and local levels;
> iii. to ensure that mainstream research, where appropriate, provides data about the participation of people with disabilities, covering all relevant areas of this Action Plan;
> iv. to ensure that research, where possible, incorporates a gender dimension facilitating analysis of the situation regarding women with disabilities;
> v. to work towards a co-ordinated approach to research by agreeing common classifications leading to evaluation and analysis across national and international databases; […]
> viii. to involve representatives of persons with disabilities and other relevant stakeholders in the development of research strategy and data gathering;
> xi. to promote the exchange of good practice, sharing of information and close co-operation between relevant bodies to ensure availability of comprehensive data to inform policies;
> xii. to commission relevant research and innovative pilot projects to support policy development which covers all the relevant areas of this Action Plan."[51]

In addition to these Action Lines, the Action Plan contains a section on "Cross-Cutting Aspects" which includes a focus on children and young persons with disabilities.[52] It is there stated that:

---

[48] Recommendation Rec(2006)5 of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015 (adopted by the Committee of Ministers on 5 April 2006).

[49] Ibid, 3.14.1.

[50] Ibid, 3.14.2(ii).

[51] Ibid, 3.14.3.

[52] Ibid, 4.4.

> "Boys and girls with disabilities also have the right to access these same rights, member states need to build knowledge about their needs to inform planning, decisions and practices across a wide spectrum of policy areas."[53]

Thus, the Council of Europe's Disability Action Plan strongly encourages States to engage in monitoring and data collection in relation to human rights issues affecting children with disabilities, including their rights to access justice.

Other CoE instruments also have relevance. These include Recommendation CM/Rec (2004)10 concerning the protection of the human rights and dignity of persons with mental disorders. The Committee of Ministers recommended that states systematically collect reliable anonymised statistical information on the application of mental health law and on complaints.[54] They also suggested that those responsible for the care of persons with "mental disorder" should receive and publish reports from those responsible for quality assurance and monitoring; and receive advice on the conditions of facilities. Recommendation CM/Rec (2009)10 on integrated national strategies for the protection of children from violence also recommends "regular statistical monitoring, on the basis of established methodology, of violence against children at national, regional and local levels in all settings […] [disaggregated according to] gender, age, form of violence, urban or rural household, families' characteristics, level of education and national, social and ethnic origin."[55] The Committee of Ministers further recommended that states collect "quantitative and qualitative data on the length and outcomes of judicial proceedings involving children" and to establish a national database on "children entering, leaving, or changing institutions, and all forms of alternative care and detention facilities, including the recording of all cases of violence against children in such institutions."[56] It is regrettable that disaggregation on the basis of disability is not given a higher profile in these documents.

In *Hovath Kiss v. Hungary*[57] the European Court of Human Rights (ECtHR) found that Roma children had been victims of indirect discrimination contrary to Article 14 of the ECHR and recognised people with mental disabilities to be a group which has experienced historical exclusion and discrimination. It noted that positive steps must be taken by the state to counter this. Data will be needed to monitor the extent of the marginalisation of people with mental disabilities as well as the impact of any positive measures which are introduced to tackle the historic disadvantage and exclusion they have experienced.

---

[53] Ibid.

[54] Article 38 – Statistics, advice and reporting, CM/Rec (2004)10, available at: https://wcd.coe.int/ViewDoc.jsp?id=775685#RelatedDocuments (last accessed 05 May 2015).

[55] Appendix 1 CM/Rec (2009)10 para. 7, available at: https://wcd.coe.int/ViewDoc.jsp?Ref=CM(2009)146&Language=lanEnglish&Ver=final&Site=COE&BackColorInternet=DBDCF2&BackColorIntranet=FDC864&BackColorLogged=FDC864 (last accessed 10 November 2014).

[56] Ibid.

[57] European Court of Human Rights, *Horváth and Kiss v. Hungary,* Application no. 11146/11, judgment 29 January 2013, available at: http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-116124#{"fulltext":["11146/11"],"itemid":["001-116124"]} (last accessed 20 April 2015).

2.3 European Union

In its Agenda on the Rights of the Child 2011,[58] the European Commission drew attention to the problematic lack of reliable data on children in judicial proceedings. The European Disability Strategy (2010-2020)[59] also refers in its overall objectives §2 and in point 3 of §2.2 to the importance of collecting data. The Victims Directive 2012[60] now imposes an obligation on Member States to "communicate to the Commission" on a three-yearly basis "available data showing how victims have accessed the rights set out in this Directive".[61] Further light is shed on this obligation both by recital 64 and also by subsequent guidance issued by the Commission. According to recital 64:

> "Systematic and adequate statistical data collection is recognised as an essential component of effective policymaking in the field of rights set out in this Directive. In order to facilitate evaluation of the application of this Directive, Member States should communicate to the Commission relevant statistical data related to the application of national procedures on victims of crime, including at least the number and type of the reported crimes and, as far as such data are known and are available, the number and age and gender of the victims. Relevant statistical data can include data recorded by the judicial authorities and by law enforcement agencies and, as far as possible, administrative data compiled by healthcare and social welfare services and by public and non-governmental victim support or restorative justice services and other organisations working with victims of crime."

The Commission's DG for Research and Innovation and DG Justice play an important role in supporting and initiating data collection in the broad area of access to justice. A series of projects to combat violence and enhance access to justice for victims of crime and victims of domestic violence (with a focus on women, children and sexual minorities) have been funded by the European Commission as part of the Daphne programme, including one on violence and bullying of young people with learning disabilities.[62] DG Justice also funds the present project, focusing on access to justice for children with intellectual and psycho-social disabilities.

Finally, it is important to recognise the important role played by the EU Agency for Fundamental Rights (FRA) in the collection and dissemination of relevant data. The FRA, established in 2007

---

[58] Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, *An EU Agenda for the Rights of the Child*, COM/2011/0060 final, available at: http://ec.europa.eu/justice/policies/children/docs/com_2011_60_en.pdf (last accessed 20 April 2015).

[59] Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*, COM/2010/0636 final, available at: http://eur-lex.europa.eu/legal-content/en/ALL/;ELX_SESSIONID=WY5WJB5QGfrgRfhBvcy7tmnzLVt9pPGMMtDCDJX5bJHlnMp5FdJQ!-32536369?uri=CELEX:52010DC0636 (last accessed 20 April 2015).

[60] Directive 2012/29/EU of the European Parliament and of the Council of 25 October 2012 establishing minimum standards on the rights, support and protection of
victims of crime, and replacing Council Framework Decision 2001/220/JHA, OJ L 315, 14/11/2012, p. 57-73, at para. 21.

[61] Ibid, Article 28.

[62] Enable, Fenacerci and Lev, *A campaign by people with learning disabilities against violence and bullying of young people with learning disabilities in Europe*, (2000) available at: http://ec.europa.eu/justice_home/daphnetoolkit/files/others/europe_violence/2.1.pdf. (last accessed 20 April 2015).

to provide relevant EU institutions and Member States with "assistance and expertise relating to fundamental rights",[63] has a remit extending to the collection, recording, analysing and dissemination of "relevant, objective, reliable and comparable information and data"[64] and the development of methods and standards "to improve the comparability, objectivity and reliability of data at European level".[65] Its disability-related work to date has focused on the fundamental rights of people with intellectual and psycho-social disabilities. The specific focus of its current disability-related work, due to be published in 2015, has strong connections with access to justice for children with disabilities, being the harassment of children with disabilities.[66]

---

[63] Council Regulation 168/2007 of 15 February 2007 establishing a European Union Agency for Fundamental Rights, Article 2.

[64] Ibid, Article 4(1)(a).

[65] Ibid, Article 4(1)(b)

[66] See FRA's current project, which aims to collect and analyse existing evidence on targeted violence and abuse against children with disabilities, available at: http://fra.europa.eu/en/project/2012/children-disabilities-targeted-violence-and-hostility (last accessed 20 April 2015).

3. Co-Ordination of the National Research

Between September 2013 and March 2014, researchers in the 10 project countries compiled information about access to justice for children with mental disabilities in their countries in accordance with a structured template – the "data-gathering template".[67] Before providing further details about this template and the co-ordination of the national research, a few words should be said about the researchers themselves.

Researchers in this project have a range of disciplinary and professional backgrounds. These include lawyers working in human rights NGOs, with expertise in legal practice, advocacy and research (Bulgaria, Czech Republic, Hungary, Latvia and Romania); academic lawyers with particular expertise in access to justice and disability rights (Ireland and UK) and in child rights (Spain); academic social scientists with expertise in disability and social work (Slovenia and UK); and practicing social scientists with expertise in social work research and practice (Lithuania). This range of discipline and vocation was central to the project design. It provides a rich basis for the multidisciplinary dialogues which are so essential to achieving progress in fulfilling the human rights of children with intellectual and psycho-social disabilities in the access to justice context. It also coloured the nature of the co-ordination of the research and the guidance provided to national researchers in that assumptions could not be made that all researchers would possess knowledge and skillsets particular to one of the disciplines.

The data gathering template was drawn up by co-ordinators of WS1 (UK) and the project manager in consultation with members of the Expert Panel. It contained questions on monitoring (relevant to WS1) as well as questions on more substantive standards and practices (relevant to WS2). All questions were derived from an analysis of international and European standards and guidance with particular emphasis on the CoE's Child-Friendly Justice Guidelines.

The template was divided into 5 main sections:

- justice system context;
- residential proceedings;
- educational proceedings;
- criminal proceedings (including those in which a child with intellectual or psycho-social disabilities is the victim and those in which such a child is the alleged offender); and, finally,
- key concerns.

National researchers completed this template in three (overlapping) phases. In the first phase, they used only desk-based research, drawing upon academic publications, materials published by official bodies (e.g. governmental websites and reports) and those of ombudsmen, human rights and equality bodies as well as those of NGOs.[68]

---

[67] See Annex 1 below.

[68] For guidance on the sources suggested to researchers, please see the Guidance on Phases 1 and 2 of the research, available in Annex 2 and 3.

In the second, assistance in identifying and accessing potential additional sources (for further desk-based research) was sought from relevant professionals. These two phases thus focused on identifying and analysing existing data – whether publicly available or maintained in libraries or databases with more restricted access.

By contrast, the third phase entailed using empirical research methods to gather new data. The process was not strictly sequential and divisions between the three phases of the research were not watertight. For instance, most researchers reported that in the course of their empirical work, they discovered additional desk-based material which they then incorporated into their reports.

A phased approach to the completion of the template was adopted for three main reasons:

- Management support - National experts were asked to submit their findings after the time allocated for each of the three phases. This enabled the Project Management Team to maintain oversight of the nature and quality of work being carried out at the national level and also helped the national researchers to structure their project-related workload.
- Research design – Thorough research using the techniques of the first two stages provided important groundwork for the design of the empirical work conducted in the third stage. It enabled national researchers to identify those questions (included in the template but unanswered by desk-research methods – even after assistance and advice from key professionals) on which their empirical inquiries would need to focus.
- Data collection experience – WS1 of the project (for which this report is a deliverable) focuses on relevant data-collection and dissemination. A phased approach to the completion of the template enabled the workstream co-ordinators to gauge the extent to which existing data was available and accessible to the national researchers. It also allowed us to ask them, at the end of each phase, about their research experiences – including perceptions of key barriers and facilitators.

Before each of the three phases of data collection, national researchers were supplied with guidance.[69] For phases 1 and 2, the guidance was purely in written form. For phase 3, however, additional guidance and discussion was provided in a face-to-face meeting of the Project Management Team and country researchers held in December 2013.

The co-ordinators of WS1 and WS2 decided that national researchers should have considerable discretion as to the detail of their research design in order to allow them the flexibility to respond to the particular focus of the inquiries that needed to be made in their country and to enable them to navigate (within the timeframe of the project) any applicable ethical review procedures. However, in order to ensure a basic level of consistency of approach, researchers were requested to include in their empirical work at least four focus groups and at least four semi-structured or unstructured interviews with people who had experience of relevant access to justice issues. More details about the methods selected are provided in Section 5.2 below.

---

[69] See Annexes 2, 3 and 4 at the end of this report.

4. Identifying and Accessing Existing Data

4.1 Introduction

The evidence for this section of the report is based on the work carried out by the national researchers in the first and second phases of their work on Workstreams 1 and 2. These have been described above in Section 3 and do not therefore need lengthy discussion here. By way of a brief reminder, however, the methods used by the researchers in these phases of their report-writing were classic desk-based research methods.

The first of the two main parts of this Section (Section 4.2) will focus on the extent to which data currently exists – i.e. on its availability. The second, (Section 4.3) will focus on the extent to which such data as does exist is disseminated – ie its accessibility to researchers and the public. As explained in Section 2 above, Article 31 of the CRPD requires States both to collect and to disseminate data that will enable effective human rights monitoring. It should be noted, however, that the distinction between the availability and accessibility of data cannot be drawn in bright-line terms in an independent research project such as this. This is because there may be situations in which official data does exist but it is not publicly available or it is so difficult to find that researchers were unable to discover it within the projects timeframe. This difficulty is well-illustrated by the following difficulty explained by the Romanian researchers:

> "One of the main challenges in writing the report was the scarcity of the publicly available data regarding children with mental disabilities. While some institutions provided data on minors in general, especially in residential institutional settings, there was little mention regarding the special situation of children with disabilities. Consequently, the seeking of information required the team of authors of this report to send public information requests to a large number of public authorities."[70]

Unless and until those requests are answered by the authorities, it is impossible to be sure whether or not relevant data is available. If it transpires that it is "available", it still may not necessarily be "accessible".

4.2 Availability of Existing Data

All the researchers reported significant data gaps in relation to the access to justice rights of children with mental disabilities. They also drew attention to the immense amount of research required in order to be confident that no relevant data existed. The process was particularly challenging in aspects of the subject in which researchers were not specialised and, given the multidisciplinary focus of the template, all the researchers were inevitably more specialised in some aspects of it than others.

---

[70] Mental Disability Advocacy Center, *Access to Justice for Children with Mental Disabilities International Standards and Findings from Ten EU Member States* (Budapest: MDAC, 2015), Country report, Romania (n8), 99, para. VII.

Researchers drew specific attention to the lack of systematically collected relevant statistical data – information which has an important role to play in any system for monitoring progress over time by reference to "outcome indicators" (a process which will be explained more fully in the accompanying WS1 guidance report).[71] In some instances, organisations were placed under explicit duties to collect statistical data, disaggregated according to various factors including disability, but there was no evidence (e.g. on the organisation's websites) that they had done so.[72] In others, official statistics were collected on certain types of legal proceedings but not those of principal relevance to children with mental disabilities. Thus, in the Czech Republic, the Ministry of Justice collected disaggregated data for proceedings concerning taxes, construction permits, environmental issues, transport, internal administration, finances, administrative offences and local self-government – but not, for example, education proceedings.[73]

Even where statistical evidence was available, it was rarely disaggregated to include disability, let alone different categories of disability. Thus, the Irish Central Statistics Office Quarterly National Household Survey on crime victims, like the England and Wales Crime Surveys, does not ask about disability (and does not include people under 18). Researchers in Spain observed that official statistics on access to justice issues for children were disaggregated by reference to ethnicity and gender but not disability. Similarly, the UK's Social Trends report disaggregates crime victims according to age, ethnicity and gender but not disability. In addition, Romanian statistics on offenders, and Lithuanian statistics on crime victims,[74] contain no reference to disability – although they do disclose gender and child/adult status.

In some countries, however, there were some relevant official statistics. For instance, figures kept by the Czech Ministry of Labour and Social Affairs on child victims (of crimes and other alleged wrongs) who made complaints to the social and legal protection authorities, did document whether or not the children in question had disabilities – although not the type of disability. Interestingly, although Spain and Slovenia explicitly criminalised disability hate crime, pending the implementation of specialist services in Spain (introduced in 2012), the UK is currently the only country to collect statistical data on it. For instance UK data reveals that in 2012/13, the police recorded 1,841 disability hate crimes, accounting for four per cent of all hate crimes recorded by the police in that period.[75] However, data is not disaggregated further by categories of disability.

Another important point on which there was surprisingly little data was requests for (or provision of) special measures or adjustments. Statistics on one form of support were collected in the UK,

---

[71] Mental Disability Advocacy Center, *Access to justice for children with mental disabilities – The collection and dissemination of data: Guidance report* (Budapest: MDAC, 2015), available at: www.mdac.org/accessing-justice-children (last accessed 20 April 2015).

[72] For example, in the UK, Cafcass has an obligation under s.149 of the Equality Act 2010 (the Public Sector Duty) to collect data on children involved in public law Children Act cases and private law cases that go beyond the first hearing, including information on age, disability, ethnicity, religion and sex, however this data is not published on the Cafcass website.

[73] Mental Disability Advocacy Center, *Access to Justice for Children with Mental Disabilities International Standards and Findings from Ten EU Member States* (Budapest: MDAC, 2015) Country report, Czech Republic, (n3) page 53, available at: http://www.mdac.org/en/standards-and-findings-from-10-EU-states (last accessed 20 April 2015).

[74] Although in Lithuania, information is available on the number of child victims or offenders who opted to classify themselves as "disabled" at the pre-trial stage, available at www.ird.lt, 191. This data does not permit more specificity about the type of disability a person has.

[75] HO, Office for National Statistics and MOJ, An Overview of Hate Crime in England and Wales, (December 2013), available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/266358/hate-crime-2013.pdf (last accessed 20 April 2015).

the Registered Intermediaries Schemes pilot which was launched in Northern Ireland (NI) on 13 May 2013.[76] Indeed, figures there reveal the number of requests made for "registered intermediarie" and various characteristics of the people making these requests, including their age, ethnicity and (importantly) reason for the request. These statistics were provided on request by the Department for Justice Northern Ireland and such reasons were categorised as follows:

- Young age (26 requests)
- Language delay/disorder (1 request)
- Mild/moderate learning disability (29 requests)
- Moderate learning disability (7 requests)
- Severe learning disability (8 requests)
- Autistic Spectrum Disorder (8 requests)
- Attention Deficit Disorder (4 requests)
- Multiple Sclerosis (1 request)
- Down's Syndrome (3 requests)
- Cerebral palsy (1 request)
- Deaf mute (1 request)
- Selective mutism (2 requests)
- Schizophrenia (3 requests)
- Dementia (2 requests)
- Depression (3 requests)
- Mental health issues (1 request)
- Aphasia (dense stroke) (1 request)
- Brain injury (3 requests).[77]

Important information about the practical operation of systems designed to support children (although not specifically those with disabilities) in the justice system is provided by several research studies in the UK[78] and in Ireland.[79] These reports contain data relating to usage and availability of the support, as well as to other matters.

A number of research studies[80] have provided data on the extent to which the views and perspectives of children are sought and taken into account in various forms of proceedings. In some, the focus was on the perceptions and views of children themselves.[81] In others, it was on

---

[76] See more: http://www.dojni.gov.uk/registered-intermediary-schemes (last accessed 21 March 2015).

[77] Mental Disability Advocacy Center, *Access to Justice for Children with Mental Disabilities International Standards and Findings from Ten EU Member States* (Budapest: MDAC, 2015), Country Report, UK (n11), page 82.

[78] See, for example, Judith E. Timms, Sue Bailey and June Thoburn, *Your shout too!: a survey of the views of children and young people involved in court proceedings when their parents divorce or seperate*. [NSPCC Policy Practice Research Series], (London: NSPCC, 2007), Executive summary, page 9.

[79] See, for example, Nicola Carr, Guiding the GALs: A Case of Hesitant Policy-making in the Republic of Ireland, 3 Irish Journal of Family Law (2009) 60-71; and Carol Coulter, Interim Report- Child Care Law Reporting Project (November 2013) page 15, 47-48, available at http://www.childlawproject.ie/wp-content/uploads/2013/11/correctedinterimreport.pdf (last accessed 21 March 2014)

[80] See, for example, Ursula Kilkelly, A Children's Rights Analysis of Investigations, Commissioned by the Ombudsman for Children (April 2011) 5; J Plotnikoff and R. Woolfson, "Measuring Up? Evaluating Implementation of Government Commitments to Young Witnesses in Criminal Proceedings," (NSPCC and Nuffield Foundation: London, 2009).

[81] See, for example, Judith E. Timms, Sue Bailey and June Thoburn, *Your shout too!: a survey of the views of children and young people involved in court proceedings when their parents divorce or seperate*. [NSPCC Policy Practice Research Series], (London: NSPCC, 2007), 15.

the perspectives and views of parents about the way in which their children were treated.[82] In others, it was on the perspectives and views of professionals who work in the justice system.[83]

Besides the lack of systematically collected official data, many researchers reported a virtual absence of relevant academic and professional literature. For instance, researchers in the Czech Republic reported an absence of such literature on this subject and suggested that this indicated that access to justice for children with mental disabilities lay outside the areas of interest of experts. Researchers in Hungary reported that, whilst there was literature on children with mental disabilities in the substantive fields (e.g. of education and criminal justice), this rarely took a human rights perspective and seldom-tackled access to justice related issues. Interestingly, the Slovenian researchers reported that they had found useful material in databases of student work (undergraduate as well as Masters and Doctoral theses). This might possibly suggest that the subject is beginning to attract attention and thus to promise experts for the future.

Before turning to variations between countries on the availability of data, it should be noted that several researchers (including those in Ireland and Lithuania) drew attention to the fact that more data and research was available on children with intellectual disabilities than on children with psycho-social disabilities – data on the latter being particularly difficult to find. In addition, it was noted (e.g. by the Spanish researchers[84]) that although some relevant survey data was available on adults with intellectual and psycho-social disabilities, this did not include data on children with intellectual and psycho-social disabilities.

Despite agreement on the current inadequacy of levels of data on access to justice for children with mental disabilities, a number of differences between the approaches of the different countries can be identified. Whilst these may in part be associated with variations in the backgrounds and expertise of the researchers, it seems clear that there are significant differences in the availability of data in different countries, which should not be overlooked.

For instance, in some countries (e.g. Spain and the UK) researchers reported that substantial access to justice data existed for children generally, although not to the same extent for people with disabilities or for children with intellectual or psycho-social disabilities.[85] In other countries (e.g. Latvia and Lithuania), researchers reported the existence of some access to justice data (although limited) on children generally and people with disabilities generally but none on children with intellectual or psycho-social disabilities specifically. In others (e.g. the Czech Republic and Slovenia) it was reported that access to justice data was not systematically collected even for children generally or for people with disabilities generally.

---

[82] See, for example, Children in Scotland, FSDC Parent Participation Project - Survey 1, July 2013).

[83] See, for example, Romania Governmental narrative report, 2011-2016 "The improvement of the organizational efficacy of the child protection system in Romania."

[84] Referring to data in Survey on Disability, Personal Autonomy and Dependency (AGE), National Institute of Statistics Spain, 2008 (Cecilia Esparza Catalán; Survey of Disability, Personal Autonomy and Dependency (AGE) 2008 Major Reports Portal, ISSN 1885-6780, No. 108, April 2011. (Superior Council for Scientific research (CSIC)). Note that no data is available from these sources on offenders with disabilities (whether adult or child).

[85] There were, however, some important initiatives for the collection of data relating to access to justice issues and children with intellectual or psycho-social disabilities – e.g., in Spain the Civil Guard's commissioning of data collection on the interaction of people with various types of disability: José Luis Gonzalez, Jacobo Cendra and Antonio L. Manzanero, Prevalence of disabled people involved in Spanish Civil Guard's police activity, in *Research in Developmental Disabilities*, (34, 2013, pp. 3781-3788); and in the UK it was reported that important information about the access to justice of children with mental disabilities was provided by organisations such as the Howard Penal Reform and Prison Reform Trust.

Variation also existed in the relative availability of data reported to exist in the different types of proceeding. Researchers in Ireland and Lithuania reported that data on children with intellectual and psycho-social disabilities in the context of civil proceedings was sparse but that, in criminal proceedings, it was even more limited. Ireland's researcher also noted that there was no automatic process to determine whether a child needs extra support in order to participate in proceedings and in general court reporting on cases involving children in Ireland was very limited. In the Czech Republic the researcher found the opposite to Ireland and Lithuania in that more data was available concerning children in criminal proceedings. However, the researcher still considered that the data gathered was still quite insufficient. In Hungary, the researchers again reported a significant relative shortage of information on criminal proceedings and children with intellectual and psycho-social disabilities, but found that more data was available on education than on issues related to where or with whom such children should live.

Researchers unanimously indicated that, whilst information was available (although not necessarily easily accessible) about applicable laws and policies, there was much less information about the practical implementation and impact of those laws and policies. The following words of the Hungarian and Lithuanian researchers capture this concern very effectively:

> "The largest problem that emerged during the research, therefore, is that there is no traceable evidence that the regulatory framework really comes to effect in the everyday practice of the certain institutions and state (or other) organs. The relevant literature is silent concerning the participation of children in various proceedings as well."[86]
>
> "Another major problem I found was that identifiable information mainly provided me with merely theory and legal information, and hardly anything on the actual practical examples, critics or alternative sources for "unofficial" but crucial information. There is a massive gap between what is "guaranteed" in theory by the measures that are legally in place in Lithuania, and what actually happens in practice. It is crucial to record and analyse this gap within our research reports."[87]

This problem proved particularly frustrating for researchers who reported that, despite the absence of publications or other data on the point, it was widely known either that relevant laws were not observed in practice (e.g. Lithuania) or implemented very differently in different geographical regions or authorities (e.g. Czech Republic). In some countries (e.g. Ireland, Spain and the UK), important information relating to the actual practice and impact of laws and policies could sometimes be found in reports by (or commissioned by) NGOs,[88] equality

---

[86] Phase 1 methodology questionnaire, Hungary, available at http://www.mdac.org

[87] Phase 1 methodology questionnaire, Lithuania.

[88] See,for example, in the UK, the important work carried out by the Howard League for Penal Reform, available at: http://www.howardleague.org/young-adults/ (last accessed 20 April 2015), which revealed the disproportionate numbers of young people in prisons with mental health conditions and with learning difficulties; and, in Spain, The CERMI´S Reports "Derechos Humanos y Discapacidad" (Human Rights and Disability), available since 2008, which include a statistical analysis of complaints submitted to CERMI and a summary of the actions undertaken by Spanish and Communities Ombudsmen and Permanent Specialized Office in disability issues. See also, in Ireland, the Irish Penal Reform Trust, *Detention of Children in Ireland: International Standards and Best Practice*, (Dublin: IPRT, 2009); Helen Bartlett and Elaine Mears, *Sexual Violence Against People with Disabilities: Data collection and barriers to disclosure*, (Galway: Rape Crisis Network Ireland 2011); and Shane Kilcommins et. al *An International Review of Legal Provisions and Supports for People with Disabilities as Victims of Crime*, (Dublin: Irish Council for Civil Liberties, 2013).

bodies,[89] and ombudsmen (the value of the latter being particularly stressed by researchers in the Czech Republic and Slovenia). However, and despite some very valuable exceptions[90] the focus of such reports was generally on children, people with disabilities, or adults with intellectual or psycho-social disabilities and rarely specifically on children with intellectual or psycho-social disabilities.

4.3 Accessibility of Existing Data

All the researchers reported significant obstacles in accessing information about access to justice for children with mental disabilities. This applied to information about the legislative and policy framework; information about court and tribunal procedures and rulings; and information about the use of the justice system by children with disabilities, including how they experienced it in practice.

As regards the legislative and policy framework, children with mental disabilities tended not to receive an explicit focus. Accordingly, in order to ascertain their position within this framework, numerous different fragmented sources (e.g. dealing with children generally and adults with disabilities generally) had to be analysed. In addition, different regulatory frameworks often governed the different types of proceeding addressed in the template. The number and complexity of these sources varied from country to country – a factor which clearly impacted on the accessibility of the information in question. Researchers in Hungary drew attention to the challenges of accessing relevant information, given the "multileveled, complicated, sometimes even unclear statutory regulation of the status of children in various proceedings".[91]

The difficulties caused by fragmentation of sources were exacerbated in many cases by the fact that those sources were themselves difficult to locate and access. A particular problem in some countries was that court and tribunal decisions involving children with mental disabilities were not officially reported – in Ireland, for example, there are no written judgements made in administrative proceedings relating to residence or education. Another difficulty (encountered by researchers in Latvia, for example) was that there was no quick way of searching within databases of court decisions for those concerning children with intellectual or psycho-social disabilities. Latvian researchers thus had to read the decisions which related to children's rights in order to identify relevant ones – and, out of the hundred cases they read, only six proved to raise mental disability issues. This could easily be overcome if official statistics were disaggregated according to impairment type, making them more accessible.

Even where a relevant law could be identified, its exact meanings and implications for children with intellectual or psycho-social disabilities were sometimes difficult to ascertain. This problem

---

[89] See, for example, Claire Edwards et. al., Access to Justice for People with Disabilities as Victims of Crime in Ireland, School of Applied Social Studies and Centre for Criminal Justice and Human Rights, Faculty of Law, University College Cork, (February 2012), commissioned by the National Disability Authority.

[90] Jenny Talbot, *Prison Reform Trust, Fair Access to Justice? Support for Vulnerable Defendants in the Criminal Courts*, (London: Prison Reform Trust, 2012); Hon Lord Bradley, *The Bradley Report – Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system* (London: DH Publications, 2009); Office of the Children's Commissioner, *I think I must have been born bad: emotional wellbeing and mental health of children and young people in the youth justice system*, (London: Office of the Children's Commissioner, 2011); and Lisa Jones et al. "Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies", (London: Lancet, 2012) 899-907.

[91] Phase 1 Questionnaire, Hungary.

was noted by Hungarian researchers in relation to new laws which as yet had not been interpreted by court decisions or by relevant analytical literature. The Bulgarian researchers also identified the introduction of new laws on access to justice for children in 2013 as an obstacle to finding clear explanations (as well as recruiting professionals with relevant expertise in the empirical work). Given that most of the countries were engaged in processes of law reform inspired by the Guidelines on Child Friendly Justice, it seems unlikely that this difficulty will be an isolated experience.

As regards data about the actual experience of children with intellectual or psycho-social disabilities in accessing justice, as explained in 4.2 above, in most countries very little data existed. Official data on access to justice for children with mental disabilities was not available in any of the countries. Other sources of data tended to take the form of one-off studies which were often outdated. Further, without systematic monitoring over time, it was often impossible to assess trends and the impact on this group of people of different law and policy interventions.

In relation to both laws and policies on the one hand, and lived realities on the other, many researchers reported that where information was available on websites (of governmental bodies and NGOs) it was frequently outdated and misleading. A good example is the following from Latvia:

> "For instance, the Inspectorate of Children's Rights has a nice website, but still in several places reference is made to the Ministry of Children and Families, which has not existed […] for several years. Also we had doubts about several helplines websites, as information seemed outdated […]"

This was, however, not a universal experience. For instance, in the UK it was reported that government and public websites tended to be reliably kept up-to-date.

5. Collecting New Data

5.1 Introduction

This section focuses on our findings concerning the process of conducting empirical research to gather new data on access to justice for children with mental disabilities. It is divided into two main parts. In the first of them (Section 5.2), the different empirical methods used by the national researchers will be explained, together with their evaluations of the effectiveness of these methods and identifications of any obstacles which restricted their potential value. In the second (Section 5.3), our encounters (positive and negative) with ethical review processes will be discussed.

5.2 Methods Used by National Researchers

5.2.1 Interviews

As requested in the guidance provided by the WS1 and WS2 co-ordinators, all country researchers used interviews in the empirical phase of their research. When asked to gauge how appropriate they had found this method for collecting data to complete the template, half of the researchers responded that they found it "very appropriate" and the other half found it "quite appropriate." All but one referred to the considerable value of the interviews in providing information which was not available from desk-based research. Indeed, several mentioned that interviews were the most useful of the methods they had used and that the reports could not have been completed without them. The Bulgarian researchers considered that the value of the interviews was enhanced when participants were given the desk research findings to read beforehand.

National researchers reported that they were able to recruit participants for the interviews from a wide range of relevant professions, including: the police (e.g. Latvia, Hungary and the UK); social workers (e.g. Lithuania, Slovenia and the Czech Republic); psychologists (eg Hungary, Slovenia and Spain); lawyers and prosecutors (e.g. Czech Republic and Spain); and judges (e.g. Ireland and Latvia). National researchers also interviewed service users, including: parents of children with disabilities (e.g. Hungary and the UK) and children or young people with mental disabilities (e.g. UK, Lithuania and Slovenia). Nevertheless, some frustrations were expressed. For instance, the Czech researchers reported difficulties in recruiting professionals who worked in the justice system. They attributed this to the fact that they work for a human rights organisation. In Ireland, it was noted that the process of obtaining ethical approval for interviewing children was more than six weeks. It was therefore not possible to obtain approval to include children within the timeframe allocated for the empirical phase. It was also noted that the bureaucracy associated with contacting professionals working in the justice system had made the recruitment process slow and complex.

5.2.2 Focus Groups

All researchers attempted to organise focus groups but, in some cases, it was not possible to hold as many as the four which had been suggested by the WS1 co-ordinators. When asked about the appropriateness of this method, the responses of the researchers varied from "very appropriate" to "inappropriate". A number of researchers (including those from Bulgaria, Latvia and the UK) found the method extremely valuable. In Latvia, researchers suggested that the focus groups had been particularly helpful because they had been held after data had been gathered from interviews (and desk research) and participants were thus presented with emerging findings and asked to reflect upon them. Similarly, researchers in Bulgaria stressed that it was the combination of focus groups and interviews that was particularly valuable. In the UK, the focus groups generated very useful conversations between different types of professionals working in the field, as well as representatives of relevant DPOs and child-focused NGOs.

Many of the researchers referred to the complex and time-consuming process of organising focus groups – a task made particularly challenging because of the need to include professional people with busy schedules and find a mutually convenient time. In the UK, these challenges initially appeared insuperable but were significantly eased by offering evening times with meals included.

5.2.3 Court Observations

This method was discussed in a project meeting as one possible method that researchers might consider using. In the event, it was used by researchers in only one country – Lithuania. The researcher from Lithuania reported that obtaining permission for the observations was quite challenging, despite the fact that the civil proceedings observed were formally open to the public. In addition the researcher expressed that they found the experience quite challenging due to the fact that the proceedings were very personal. However, once permission had been granted they were able to observe 10 court hearings and found that data gathered was useful because this method provided an excellent opportunity to see how things really work in practice.

Researchers in other countries explained that they had decided not to use court observations for reasons that were broadly the same. Key considerations had been the additional time and complexity of obtaining approval to conduct an observation resulting from the fact that relevant proceedings involving children were held in private.

5.2.4 Media Content Analysis

This method was used by researchers in Ireland, Latvia and Lithuania, although there were differences in the approaches taken. In Ireland, for example, media analysis focused on one notable case involving a young person with mental disabilities, as recommended by an interviewee participant. The researcher then examined newspaper articles that reported the case as well as looking at the High Court appeal judgement to determine how the (court-determined) facts of the case compared with the media reporting. However, in Latvia and Lithuania, researchers initially carried out web-based searches, using keywords associated with children with mental disabilities in administrative, civil and criminal domains, to identify relevant cases. In Lithuania 12 unique cases were subsequently identified and examined, the majority of cases related to children with mental disabilities who had been victims of crime. However four related to adults with mental disabilities and were selected for comparative reasons.

Latvia and Lithuania's researchers said that they would not have used this method on its own but found that it proved to be a necessary addition to the empirical phase due to the fact that it provided information regarding how children with mental disabilities are portrayed in the popular media, which plays a major role in shaping public opinion. Ireland and Lithuania's researchers both acknowledged that their media analysis sample size was small and as such data could only be analysed in a qualitative way. However, they also reported it to be helpful in revealing the different perspectives adopted by the media to the provision of reasonable accommodations and supports to victims with mental disabilities, on the one hand, and offenders with mental disabilities on the other.

5.2.5 Electronic Surveys

This method was used in Latvia to seek the input of judges due to the difficulty of recruiting judges to participate in interviews or focus groups. An internet platform survey was drafted and made available to 34 district courts for a period of one week, which resulted in contributions from 12 judges. The Latvian researchers mentioned that, despite the small sample, this method provided a good overview of the opinions of practicing judges. They also found that judge's comments, regarding necessary changes or improvements, were particularly useful.

5.2.6 Questionnaires

These were used in Latvia. Researchers of ZELDA found that this method was the only way they could gather more statistical data. They designed two different questionnaires. The first was sent to 38 municipal administrative commissions in order to establish their practice of applying compulsory measures of a correctional nature. Although not all of the administrative commissions provided answers, the response rate was quite high, receiving 26 replies, and for this reason the method was considered to be quite successful. However data gathered from the second questionnaire, which was sent to 61 municipal Orphan's courts, was reported as being less successful, with only 12 Orphan courts responding to questions concerning the rights of the child. Researchers of ZELDA did, however, find that this method established the fact that Orphan's courts could provide more detailed data regarding children with mental disabilities.

5.3 Research Ethics

5.3.1 Guidance on Ethical Issues

Research ethics were discussed in the meeting between the country researchers and the Project Management Team held in Budapest in December 2013. The University of Leeds' checklist of ethical issues to be considered at the outset of any empirical research project was made available to all researchers.[92] So too was its model consent form.

---

[92] This is a restricted access document, shared with the consent of the University of Leeds ethics team.

Discussion focused on two central issues. First, it addressed the importance of ensuring that research design and methods were inclusive of people with disabilities. In particular, in this project, it was important to capture the voice of people with intellectual and psycho-social disabilities who had been involved in the justice system as children. Second, discussion focused on the importance of respecting the "do no harm" principle whilst conducting research. In particular, in the context of this project, thought needed to be given by researchers to whether contemplated research designs or methods could expose a child or adult with disabilities to any form of additional risk or danger (e.g. of retribution for disclosing negative experiences by a person in some sort of position of authority or power over them). Should any such possibility be identified, then the design or method would need to be amended.

Discussion also focused on the principle of ensuring that participation in the research was on the basis of free and informed consent. In order for consent to be "informed", researchers must ensure that full details of the project were disclosed and explained and presented in a way that was accessible and comprehensible to each potential participant. "Free consent" meant that individuals themselves should decide whether they wished to participate, even if they were a child or an adult under guardianship – the consent of a parent or guardian on their behalf would not suffice. Participants were made aware that they could withdraw from the study at any time. Researchers also ensured that participants were aware that information gathered would remain confidential unless they uncovered information relating to illegal activity or intent to engage in illegal activity; or information that had a potential harm to children or vulnerable adults. If this did happen, researchers were asked to seek guidance from the project coordinators before raising the matter with the relevant authority.

5.3.2 Ethics Review Processes

In most of the project countries (including Bulgaria, the Czech Republic, Hungary, Latvia, Lithuania and Slovenia), researchers did not require formal approval for their research design from any research ethics body. In Bulgaria, Hungary and Latvia researchers opted not to include children or adult participants with mental disabilities mainly due to not being able to recruit participants within the time constraints. They all stressed that it was not due to ethics procedures because such procedures do not apply to this type of socio-legal research. In the Czech Republic, Lithuania and Slovenia interviewees or participants in focus groups did include children and young people with mental disabilities. However, researchers also found that ethical approval was only required in their country if they intended to carry out medical or psychological research. Researchers reported that the most common practice was to ask for informed consent from the parent's or child's legal guardian or/and permission from the institution where the child was resident. Slovenia noted how this was made easier for them as a student at the university worked at the institute where they carried out interviews with three 18-year-olds who had mental disabilities.

In Ireland, Spain and the UK, however, approval from ethics committees was required before (in Leeds' case) any empirical work could commence. In Ireland ethics approval is required for research that involves "human participants", which includes children and persons with mental disabilities. However, the Spanish researcher found that their internal university procedure, which included approval for interviewing vulnerable groups, was quite informal comprising of two meetings with the head of data protection, where issues such as consent and confidentiality were discussed. In the UK and Spain, the relevant body was a University Ethics Committee based at the researcher's institution, whereas for Ireland it was an external institution, the National

University of Ireland Research Ethics Committee. The difference in the internal and external ethics processes reflected considerably in the time required to process the applications. Thus, in the UK, approval was granted within two weeks (although the application was fast-tracked – ordinarily the process can take up to six weeks), whereas in Ireland it took almost three months. Researchers from the UK and Ireland indicated that the process required considerable attention to detail and thus writing the application was time-consuming. However, this process itself prompted further careful reflection on ethical issues and was therefore helpful to all three countries.

Whilst the absence of ethical review processes resulted in considerable freedom and flexibility about research design and methods, many of the researchers (e.g. from Bulgaria, the Czech Republic) expressed the view that this did not outweigh the benefits of having well-functioning ethical review processes which provided helpful oversight and guidance. Nevertheless, as was recognised (e.g. by researchers from the Czech Republic), there was also the potential for research ethics approval structures to operate in a way that caused serious delays and disruption to research and also to become overly controlling thereby stifling important research work.

6. Factors Restricting or Complicating the Collection and Dissemination of Relevant Data

The factors considered below are ones which emerge from the 10 country reports, as ones which restrict or complicate processes of gathering existing or new data on access to justice for children with intellectual or psycho-social disabilities. Many of them raise important ethical issues which unquestionably need to be taken into account in the design and operation of such processes. However, they also have the potential to be applied in a way that unduly obstructs important human rights monitoring and policy development in this field.

6.1 Data Protection Regulation

UN, CoE and EU requirements relating to the protection of data are addressed in the WS2 report for this project[93] and will therefore not be duplicated here. As explained there, powerful legislative requirements to protect the personal data of children generated in court proceedings were to be found in all 10 countries,[94] despite the fact that, in several, there were concerns that these did not operate in practice to protect children with disabilities from being identified in damaging media reports. As mentioned above, UN human rights law clearly requires the collection and dissemination of data on the engagement of children with disabilities in the justice systems to be conducted in accordance with principles of data protection and ethical research. This obligation to comply with such considerations is made explicit in Article 31 of the CRPD which stipulates that processes of data collection and dissemination must:

> "(a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;" and
> "(b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics."[95]

Nevertheless, it appears that data protection requirements indirectly contribute, in some of the countries, to the present dearth of information on access to justice for children with intellectual and psycho-social disabilities. Health-related information is generally categorised as particularly sensitive information and access to it is therefore subject to stringent conditions. This means that information relating to the handling of cases concerning children with mental disabilities will often be impossible for researchers to access unless it is collected and disseminated by the justice system itself – which, of course, should be in a way that protects privacy and thus ensures that particular individuals are not identifiable. Researchers in Ireland and Latvia reported that, in

---

[93] Mental Disability Advocacy Center, *Access to Justice for Children with Mental Disabilitiess International Standards and Findings from Ten EU Member States* (Budapest: MDAC, 2015), available at: http://www.mdac.org/en/standards-and-findings-from-10-EU-states (last accessed 20 April 2015).

[94] See, for example, Bulgaria, Child Protection Act, Article 16; Czech Republic, Act No. 141/1961 Coll., the Criminal Procedure Code, s. 8; Hungary, the Civil Procedure Code and the Criminal Procedure Code; Latvia, Civil Procedure Law, Administrative Procedure Law and Criminal Procedure Law.

[95] CRPD, Article 31(1).

the interests of data protection, cases involving children were frequently not made publicly available, even in an anonymised form. The difficulties thus posed for researchers attempting to collect data in this field are powerfully illustrated by the following quote from the Latvian researchers (from the organisation ZELDA):

> "On 14 January 2014 RC ZELDA applied to the Data State Inspectorate requesting more detailed […] statistical data on decisions taken and appealed at the court,]…] cases related to children with mental disabilities and who can give consent to data processing of [data on a] child with mental disability. On 17 February 2014 the Data State Inspectorate replied, that it [would take] too much time and resources to provide answers to the questions of RC ZELDA, thus no information can be provided."[96]

Accordingly, in light of the stringency of data protection laws and their impact on the capacity of independent researchers to gather information in this field, the State has a particularly heavy responsibility to ensure that it collects and disseminates data on the interaction of children with the justice system in a way that permits disaggregation according to broad categories of impairment or disability (as well as the other characteristics identified in the CRPD Committee's Reporting Guidelines) and ensures that the people in question remain unidentifiable.

Finally, although making data available and accessible for purposes of human rights monitoring is the focus of this report, this section would not be complete without some acknowledgement of an additional problem associated with overly restrictive data protection laws in some of the project countries. This problem concerns the barriers which data protection restrictions impose on professionals working within the justice system sharing data with other professionals also working in the system or with other bodies which have records of a child's assessment of needs and adjustments. This problem was outlined in the Latvia report – although it was indicated that the difficulties might have been somewhat reduced by the Law on Rights of Patients 2013 (which allows police officers to access the contact details of a child's doctor).

6.2 Research Ethics Procedures

In the Czech Republic, Hungary, Latvia, Lithuania and Slovenia ethical approval is only required if medical research is being carried out. Lithuania's researcher contacted the Lithuanian Bioethics Committee and their advice was approval would not be required if she avoided involving any of the medical institutions, medical professionals or medical matters otherwise the process would take up to two months and could cost up to €700. In Ireland preparing the papers to submit to the ethics committee took longer than expected due to this being the first time researchers had had to go through this process. Once the application was submitted it was then reviewed at the next Research Ethics Committee Meeting, normally within a month. The application is then reviewed by no fewer than 7 members of the ethics committee. At this point the Committee asked Ireland's researcher to answer specific questions. Once this had been complied with, however, it still took a further 5 weeks before approval was received.

---

[96] Mental Disability Advocacy Center, *Access to Justice for Children with Mental Disabilities International Standards and Findings from Ten EU Member States* (Budapest: MDAC, 2015) Country report, Latvia (text accompanying) (n6), available at: http://www.mdac.org/en/standards-and-findings-from-10-EU-states (last accessed 20 April 2015).

As with data protection laws, ethical review procedures perform an extremely important function and generally operate to improve the quality of research. They are particularly relevant to research studies seeking personal data – e.g. about experiences of or perspectives on legal proceedings. As noted above, however, such processes can be extremely time-consuming – especially where the research involves children and people who have intellectual or psycho-social disabilities (as illustrated by the experience of Ireland in this project). This can operate to limit the amount of data available on the experiences of such people.

6.3 Access to Professionals

Most researchers experienced some difficulties in gaining access to professionals in the justice system. For instance, the reason why Latvia's researchers surveyed judges was because of the difficulties associated with recruiting judges for interviews. Researchers in Bulgaria and Slovenia found that while relevant professionals were keen to contribute they weren't able to commit to long interviews due to their workloads. In the UK the process that researchers have to go through in order to have access to judges is both complex and time-consuming. For example, before the Ministry of Justice would even accept an application ethical approval must already have been granted for the impending research. In addition the researcher must set out how the research will benefit the judiciary or the courts; the aims and objectives of the research; the proposed methodology; and the prepared questions in advance. The application is then considered by the relevant senior judge, which means the process can take considerable time and for this reason the researcher did not include them in Phase 3.[97]

6.4 Assessment and Categorisation

Any effective system for monitoring progress toward human rights realisation over time requires the establishment of baseline measures and the development of relevant indicators. The CRPD Committee (as already explained) has requested "[s]tatistical data on the realization of each Convention right, disaggregated by sex, age, type of disability (physical, sensory, intellectual and mental), ethnic origin, urban/rural population and other relevant categories".[98] While indicator systems will be grappled with more fully in the accompanying WS1 report, some discussion of the complexities surrounding assessment of needs or adjustments and disability-related categorisation processes is required here as it was an issue which attracted attention in the country reports.

A number of researchers linked the dearth of data about children with mental disabilities in the justice system to the lack of routine procedures for assessing whether children about to engage in legal proceedings had some form of disability and whether any associated adjustments or support might be required. The absence of such routine assessments before criminal proceedings was noted in the reports for Spain and Ireland. In both countries, however, judges have the power to request such assessments on their own initiative and information may be available from pre-existing assessments (e.g. relating to education). Nevertheless, there was

---

[97] See Courts and Tribunals judiciary, Judicial participation in research projects, August 2014, available at: http://www.judiciary.gov.uk/publications/judicial-participation-in-research-projects/ (last accessed 19 April 2015).

[98] UN Committee on the Rights of Persons with Disabilities, *Guidelines on Treaty-Specific Document to be Submitted by States Parties under Article 35(1) of the Convention on the Rights of Persons with Disabilities* (Geneva, UN, 2009), para. 3.2(h).

concern that not all children with intellectual or psycho-social disabilities would be identified in these systems and thus that appropriate adjustments to court process or case outcomes would not be made for them.

In the UK, routine health assessments (which address mental health) are administered to children and young people who enter the criminal justice system as alleged offenders.[99] These seem to be particularly helpful in highlighting possible links between mental health and offending. Nevertheless, they have attracted parliamentary criticism for not giving sufficient weight to the communication difficulties and support requirements which young offenders may have.[100]

Another concern that emerged strongly from several reports was an overly rigid and heavily medicalised approach to categorising children as having intellectual or psycho-social disabilities. According to the Lithuania report, for instance, acquiring the label of an intellectual disability at a young age sets a child on a pre-determined path through various social structures and systems with no room for flexibility of response to their particular needs or circumstances. Similar points were made in the Bulgaria report, which explained that the medical diagnosis of a relevant disability allowed access to various disability benefits or pensions but also prevented the person diagnosed from taking various educational and professional qualifications and thus significantly restricted their life opportunities.

Thus, it is clear from this discussion that systems by which people are categorised as having an intellectual or a psycho-social disability may themselves operate to disadvantage and stigmatise individuals. This creates complexity for human rights monitoring systems which require some means of identifying people with different types of impairment in order to monitor their presence within the justice system, their rates of satisfaction and the types of adjustment or accommodation made for them. As is demonstrated by the discussion of the UK, any systems for screening or assessing children at the outset of legal proceedings should not simply focus on labelling them with a particular condition, but should also entail a careful individualised assessment (based on interaction and dialogue with them) about the particular individualised adjustments and supports that they will require in order to participate effectively in the process and to ensure appropriate and fair outcomes.

6.5 Rapid Change/Instability

Another factor that, at least in some countries, appears to complicate processes for developing effective data collection systems is rapid and frequent change within the applicable law and associated practice. This is powerfully illustrated by the Hungarian report. According to this,

> "The Hungarian Child Protection Act has been modified 937 times since 1997, a new Civil Code [101] and Criminal Code[102] entered into force recently; amendments have been

---

[99] For England and Wales, the Comprehensive Health Assessment Tool programme (Asset); and, for Northern Ireland, the Youth Justice Agency Assessment Tool (YJAA).

[100] The Case Management Guidance further specifies that YOTs, when determining welfare issues, must include reference to "mental health concerns, learning difficulties, learning disabilities or speech, language or communication issues) that […] will assist the court in having regard to the welfare of the young person." Youth Justice Board for England and Wales, Guidance Manage bail and remands: section 3 case management guidance, in *Case Management Guidance*, (London: Youth Justice Board for England and Wales, 2014), 294.

[101] Civil Code of the Republic of Hungary, Act V of 2013

[102] Criminal Code of the Republic of Hungary, Act C of 2012

made to the Civil Procedure Code[103] and the Act on Law Enforcement in connection with child-friendly justice guidelines.[104] Although experts welcome the new child-friendly viewpoint, frequent changes and new regulations make it impossible for professionals to have a clear overview of the regulatory framework. Very different interpretations of legal regulations are often sources of difficult situations as well."[105]

---

[103] Hungary, Code of Civil Procedure, Act XIX of 1998

[104] Act LXII of 2012 and Act CCXLV of 2013

[105] Mental Disability Advocacy Center, *Access to Justice for Children with Mental Disabilities International Standards and Findings from Ten EU Member States* (Budapest: MDAC, 2015) Country Report, Hungary, (n4) section 5.3, available at: http://www.mdac.org/en/standards-and-findings-from-10-EU-states (last accessed 20 April 2015).

7. Conclusion

In conclusion, it is clear that the 10 project countries still have a very long way to go in order to fulfil obligations (such as those imposed by Article 31 of the CRPD) to collect and disseminate human rights data on the access to justice of children with mental disabilities. Without such data, the situation of these children remains invisible. This has obvious implications for identifying denials of access to justice and for engaging in processes of reform. In the words of the Latvian researchers:

> "During all phases of the research, we struggled with the issue of lack of data. The issue was raised also at focus group discussions, but not all the specialists saw it as a problem – however researchers believe that lack of proper data limits the opportunities to provide proper help to children in general, as well as to children with mental disabilities. It also prevents researchers and state institutions from properly evaluating problems at different levels where children with mental disabilities are involved and making necessary improvements for better protection of the rights and interests of the child."[106]

The importance of statistical data relating to children and the justice system was recently recognised in Bulgaria. The lack of it was identified, in the Roadmap to Reform of Juvenile Justice, as a significant weakness of the current system. Clearly, without it, systemic monitoring of the human rights of children to access justice will not be possible.

Systemic monitoring of the inclusion and experience of children with various types of disability in the justice system is required by human rights law. This is clear – as is the fact that current efforts in this regard do not go far enough. Designing and establishing effective monitoring systems is undoubtedly a complex task, requiring careful thought and detailed consultation and involvement of all stakeholders (including disabled people's organisations). The accompanying WS1 report has made a number of recommendations, which States should address in their efforts to establish appropriate systems for collecting and disseminating relevant data in the on-going and systematic way that will permit effective human rights monitoring.

While the obligation to ensure effective monitoring falls on the State, the importance of the contributions made by independent research should not be overlooked. As demonstrated by the analysis above, such research has played a key role in the collection and dissemination of both statistical and qualitative data. The existence of such data has undoubtedly influenced the development of guidance and policy. An example is the guidance issued by the Family Justice Council in the England, to "encourage judges to enable children to feel more involved and connected with proceedings […] and to give them an opportunity to satisfy themselves that the judge has understood their wishes […] and to understand the nature of the judges task",[107] in response (at least in part) to important research carried out by the National Society for the Prevention of Cruelty to Children (NSPCC).[108] The State also has a role in facilitating

---

[106] Mental Disability Advocacy Center, *Access to Justice for Children with Mental Disabilities International Standards and Findings from Ten EU Member States* (Budapest: MDAC, 2015) Country Report, Latvia (n6) final summary,

[107] Judge Clifford Bellamy, Judge John Platt and DJ Nicholas Crichton, "Talking to Children: the Judicial Perspective" (2010) *Family Law* 647, 654.

[108] Judith E. Timms, Sue Bailey and June Thoburn Your shout too!: a survey of the views of children and young people involved in court proceedings when their parents divorce or separate. (London: NSPCC, 2007). [NSPCC Policy Practice Research Series], executive summary, 9.

independent research that has the potential to provide valuable data to supplement that which is collected through official mechanisms. The experiences of the researchers in this project in gathering data on access to justice for children with mental disabilities itself provide useful material on which to reflect for these purposes. Again, it is an issue which will be addressed in the accompanying WS1 report.

Annex 1: Data Gathering Template

Report Framework on "Access to Justice for Children with Mental Disabilities in Administrative, Civil and Criminal Domains"

Template for Data Gathering

List of issues

19 August 2013

On the basis of the following list of issues, national reports will present:

- Existing data on the topic as well as gaps in their availability.
- To what extent, if at all, justice systems are inclusive and child-friendly for children with mental disabilities. Partners will report on the existence of relevant laws, policies and other measures, if these are of good quality in substance and operate well in practice.

Please provide your responses to this list of issues by writing these into the relevant sections of the *Template for Data Gathering: Working Document*.

Guidance on methodologies will be provided to Country Partners at each phase of their research

- **Phase 1**: Desk Research (September-October 2013): Country Partners will use desk research methods (explained in the accompanying guidance) to provide information against list of issues (so far as possible).
- **Phase 2**: Assisted Desk Research (November-December 2013): Country Partners will continue to provide information against the list of issues but now through seeking pointers and assistance (explained in the additional accompanying guidance) in locating data from others.
- **Phase 3**: Empirical Research (January 2013–March 2014): Country Partners will continue to provide information against the list of issues with the help of interviews, focus groups (explained in the additional accompanying guidance) – some preparations for the Empirical Research should be made well in advance. The first part of Guidance Notes for this Phase was sent to Partners in August 2013.

At the end of each phase, Country Partners will complete a short questionnaire on their experiences of using the methodology applied in that phase (successes, limitations, surprises reflections on guidance, etc.).

“Access to Justice for Children with Mental Disabilities” in Administrative, Civil and Criminal Domains will be addressed on the basis of the examples of the following types of cases which may involve non-judicial and judicial proceedings:

Type A Cases (non-judicial and judicial civil proceedings)
Situations involving questions about where or with whom a child with “mental disabilities” should live (including situations of family breakdown, adoption, care proceedings with outcomes such as entry into institutional or foster care, and deinstitutionalisation processes).

Type B Cases (non-judicial and judicial administrative proceedings)
Situations involving questions about where or how a child with “mental disabilities” should be educated (including in segregated educational systems, mainstream schools or at home).

Type C Cases (judicial criminal proceedings)
Situations involving questions about whether a crime has been committed (including those in which a child with “mental disabilities” is the victim, witness or alleged offender).

Please note that:

- For the questions which follow and regardless of the definitions used for different legal purposes in your country, the term “mental disabilities” is being used in a broad sense to include children who have or are diagnosed as having any form of intellectual, cognitive or psycho-social (mental health) disability. This includes Autism, Asperger Syndrome, Attention Deficit Hyperactivity Disorder, and acquired brain injury.

- Questions should be answered to the best of your ability at this stage of the exercise, recognising that not all questions will be relevant in a particular context or will be capable of answer. This part of the exercise is as much about finding out what information does not exist, as discovering what does exist or similar. But where you can answer the questions, you should do so as fully as possible.

Where possible, your answers should provide disaggregated information on the basis of intellectual disabilities and psycho-social disabilities – in other words, you should always be sensitive to the differences between the two and differentiate between them whenever appropriate. You should also aim to include references in your answers to other cross-cutting issues such as gender, age, race and ethnicity.

1. General questions on "Access to Justice for Children with Mental Disabilities"

1.1 The Guidelines of the Committee of Ministers of the Council of Europe on child- friendly justice[109]

Has your country addressed in any way these Guidelines, acknowledged their importance and taken steps to implement them?

If yes –

- When were they *acknowledged*?
- How have they been promoted *and disseminated*?
- What *steps* have been taken to implement them?
- Has *disability* been considered or included in those steps?

1.2 Juvenile Justice System

- Is there a *specialised system* to respond to young people under the age of 18 years, who offend in your country?
- If not, please explain if this is because young offenders *are not prosecuted* in your country but treated in the care system for example. Please describe any other reason.

If yes –

- Describe briefly *how it works* (including whether it is investigative or adversarial).
- Is there a *clear understanding* in your country about the concept of juvenile justice, and the values and principles behind it?
- Is it based on *legislation* or some other clear *policy framework*? If so, please provide details.
- What level of *resources* is devoted to the juvenile justice system (staff and money) with respect to the size of your country and other relevant national indicators such as the Gross Domestic Product?
- To what extent is specific provision made for *children with disabilities* generally, and *children with mental disabilities* in particular, within the juvenile justice system?
- Is there *any official or professional role* in the juvenile justice system which has specific responsibility for children with mental disabilities?
- What (if any) are its strengths and are there *specific examples* of it working well for children with mental disabilities?

---

[109] The Guidelines of the Committee of Ministers of the Council of Europe on child friendly justice were adopted by its 47 member states. They were designed to apply to all circumstances in which all children are likely, on any ground and in any capacity, to be in contact with criminal, civil or administrative justice systems. They are based on key principles: the best interests of the child, care and respect, participation, equal treatment and the rule of law. The scope of the Guidelines is broader than the actual justice system and court proceedings. It is aimed at all professionals dealing with children in and outside judicial proceedings and offers a multidisciplinary approach to engage all sectors such as police, social and mental health sectors in making justice more child-friendly. It offers a comprehensive and inclusive approach to child-friendly justice and also refers to specific protection and assistance measures applicable to children with mental disabilities in particular to support them with communication difficulties, and their psychological, social, emotional and cognitive situation. More information is available at: http://www.coe.int/t/dghl/standardsetting/childjustice/default_en.asp (last accessed 18 April 2015).

- What, if any, are its *weaknesses* and are there *specific examples* of it operating badly for children with mental disabilities?
- Are there any proposals or campaigns for *reform*?

1.3 Support for Accessing Individual Redress

To what *bodies or mechanisms* can any child including those with mental disabilities turn for support in making a complaint or challenging a rights violation (e.g. specialist lawyer, NGO, helpline, police, Ombudsman, equality body, advocacy service)?

For each –

- Describe the *nature and the mandate* of the body or mechanism.
- Describe what *steps* have been taken to make it *available* and *accessible* to children with mental disabilities including when living in *institutional* and *community* settings, for homeless children or for children living in segregated communities (such as Roma children).
- Describe if and how *all children* with mental disabilities, including homeless children or children living in segregated communities are *informed* about their rights and procedures concerning Type A, B and C cases.
- Describe if any evidence exists about the extent of their awareness *of* their rights, and their *knowledge of* where they can safely turn to in order to make a complaint.
- Provide evidence of the *extent to which it has been used* by children with mental disabilities themselves, including when living in *institutional* and *community* settings or by their parents or carers on their behalf.
- If evidence exists of the *satisfaction* or otherwise of children with mental disabilities and/or their parents or carers with using the process, please provide examples.
- Provide evidence of the *outcomes* of cases in which children with mental disabilities or their parents/carers approached the body or mechanism (including court cases or changes in the child's situation).
- What are its *strengths* and are there *specific examples* of the body or mechanism/s providing good support to a child or children with mental disabilities?
- What are its *weaknesses* and are there *specific examples* of situations when it has provided poor support or not been available or accessible to a child with mental disabilities?

1.4 Legal Capacity

Please explain –

- laws, policies and relevant measures governing the legal capacity of *children* without disabilities in your country.
- laws, policies and relevant measures governing the legal capacity of *children with mental disabilities* in your country.
- if it is possible to initiate proceedings for legal guardianship of people with mental disabilities *before the age of 18.*
- if there are measures which enable the *extension of the age of minority* for adults with mental disabilities.

- In what situations and at what age will a child be legally entitled to make their *own decisions*, even if these differ from the preferences of parents or carers, and have them taken into account in court? – Please provide examples of specific cases.
- What *supports* are available to assist and enable children with mental disabilities to exercise their legal capacity and how effective are they?
- whether there are specific *success stories* or *examples* of individual cases in which support enabled a child with mental disabilities to exercise their legal capacity in a way that had an impact on their lives.
- What (if any) are the *weaknesses* in your legal capacity laws for children with mental disabilities and are there *specific examples* of cases in which they operated to disadvantage or damage the life chances of a child with mental disabilities?
- Whether there are any proposals or campaigns for *reform* in particular in the context of the implementation of the UN CRPD in your country.

1.5 Representative Actions

Is it possible for *independent organisations* to institute legal actions on behalf of a child with mental disabilities without that child having to be a party to the proceedings?

If yes –

- *Which organisations* are able to bring such actions (NGOs, equality bodies, Ombudsman, etc.) and in *what circumstances*?
- Are *private individuals*, who are not the child's legal guardian, also able to bring such actions and, if so, in *what circumstances*?
- *How many* times have such actions been brought, by which organisations/ individuals, for *what types* of case and what have been the *outcomes*?
- What, if any, are the *strengths* or benefits of this system and are there specific success stories or *examples* of cases in which such an action made a positive difference to the life of a child with mental disabilities?
- What, if any, are the *weaknesses* of this system and are there *examples* of it having failed a child with mental disabilities?

1.6 Equality and Non-Discrimination Obligations

Are there any legal obligations on courts and/or providers of legal services *not to discriminate* on grounds of disability or to promote disability equality?

If yes –

- Describe the *duties not to discriminate* against children (including whether they require reasonable accommodation to be provided) and where they are set out.
- Describe the *duties to promote* equality for children with disabilities and where they are set out.
- Describe any *actions or strategies* designed to ensure compliance.
- Describe if there is a system of legal aid for children with mental disabilities.
- Are there pro bono legal clinics supporting children with mental disabilities in the justice systems?
- What *NGOs* if any support litigation by or on behalf of children with mental disabilities?

- Provide examples of any specific *cases* which have been brought against courts or providers of legal services for disability discrimination involving mental disability.
- What, if any, are the *strengths* of these laws de jure and de facto and are there *specific examples* of how they improved access to justice for children with mental disabilities?
- What, if any, are the *weaknesses* of these laws de jure and de facto and are there *specific examples* of how they have not worked well to protect the interests of children with mental disabilities?
- Are there any proposals or campaigns for *reform*?

1.7 Data Protection

Are there *any data protection legislation and policies* to protect private and personal data (e.g. name, age, details of medical diagnoses, race and ethnicity, individual assessments, pictures, videos) of children with mental disabilities in particular or children with disabilities in general who are or have been involved in Type A, B and C proceedings?

If yes –
Describe for each

- Relevant *laws*, *policies* and other *measures*, and whether *reference* is made to disabilities in general or mental disabilities in particular.
- Their *strengths* and *weaknesses*, if any, de jure and de facto.
- If reference is made to the *media* in particular.
- The circumstances in which, to whom and for what purpose records or documents containing personal and sensitive data concerning children with mental disabilities may be *disclosed*.
- Whether children with mental disabilities can give *consent* to disclosure of data. If so, in what circumstances.
- How such measures *differ* or are *similar* to those applied to children who do not have mental disabilities and adults who have mental disabilities.
- If there are *examples* of cases where private information concerning children with mental disabilities was disclosed in particular to the *media* and if so, describe the *impact* on these children and their families.
- Whether there are any *personal characteristics* (e.g. gender, age, ethnicity, impairment-type) which appear to exacerbate the *risk* that private information of a child with mental disabilities will be disclosed *abusively*.
- How *effective* is this protection in practice? – Please give examples (if appropriate) of cases where protection *has not* been ensured.
- Whether this protection operates to *restrict* important information for *ensuring* human rights monitoring – if yes, how?
- *Differences* in the data protection of children with mental disabilities in criminal proceedings and in family placement processes in civil courts for example.
- Proposals for *reforms*, if any.

* * *

2. Questions on "Access to Justice for Children with Mental Disabilities" in Type A Cases

Situations involving questions about where or with whom a child with "mental disabilities" should live (including situations of family breakdown, adoption and care proceedings, with outcomes such as entry into institutional or foster care, and deinstitutionalisation processes).

2.1 Are decisions determining where or with whom a child with mental disabilities should live for each situation in Type A cases addressed through the same *structures and mechanisms* (courts, tribunals, etc.) as for children who do not have mental disabilities in your country?

If yes –
Describe

- Relevant *laws, policies or other clear framework* and if reference is made to disabilities in general or mental disabilities in particular.
- The *strengths* and *weaknesses,* if any, of these laws, policies or other framework de jure and de facto for children with mental disabilities.
- The *nature* of these structures and mechanisms.
- If and how these *differ* from and/or if and how they are *similar* to those for adults with mental disabilities concerning their entry into institutional care and/or the process of deinstitutionalisation. If their *availability* is subject to *conditions* and if so, what these are.
- To what extent these are *accessible* to all children with mental disabilities (location? resources?).
- Existing *alternative*(s) to these special structures and mechanisms if they are not available or accessible to children with mental disabilities.
- Proposals for *reforms*, if any.

If no –
Describe

- *Where* each Type A situation could be addressed.
- Briefly how they *differ* from structures and mechanisms for children who do not have mental disabilities.
- Relevant *laws* and *policies* and if *reference* is made to disabilities in general or to mental disabilities in particular.
- Whether such structures and mechanisms are *available* and *accessible* to *all children*. If this is subject to conditions, please explain what these are.
- Proposals for *reforms*, if any.

2.2 Do children with mental disabilities have the right to participate in Type A proceedings?

If yes –
Describe

- Relevant *laws*, *policies* and other *measures* concerning participation and whether *reference* is made to disabilities in general or mental disabilities in particular.

- *Strengths* and *weaknesses*, if any, of these laws, policies and other measures for children with mental disabilities.
- Whether children with mental disabilities are *informed* about this right, and if so, by whom, how and at what stage of the proceedings.
- Whether the right to participate is *explicit* and, if not, whether children with mental disabilities can nonetheless participate.
- If there is evidence that children are *aware* of their right to participate in such proceedings.

If there are any measures to support the needs of children with mental disabilities in relation to their participation in proceedings.
If yes –
Describe

- These measures including *communication methods and arrangements*, for example, to provide age and ability appropriate information, preparation and support, interpretation, and child-friendly court environments.
- *Who* provides such measures?
- Whether children with mental disabilities are given the opportunity to *express* preferences about the type of support or adaptation of the proceedings which they would like, or need.
- The *strengths* and *weaknesses* of these measures, if any, with *examples* of where it operates well for children with mental disabilities and where it does not operate well for them.
- Whether the particular needs of children with mental disabilities in relation to their participation in the proceedings are *assessed* and whether such assessments are done *routinely*.
- If assessments are not *free* of charge, explain who pays for them.
- Whether the existence of a *previously diagnosed* mental disability is recorded and taken into account when *assessing* the needs of a child in relation to their participation in proceedings.
- Proposals for *reform*, if any.

If children with mental disabilities *do not have the right to participate* in Type A proceedings (the answer to 2.2 above is no) –
Describe

- *Who* represents the rights of children with mental disabilities in Type A proceedings?
- Whether there is *research evidence of the views/experiences* of children with mental disabilities who could not participate in proceedings and if so, what their findings are.
- Whether there is *research evidence* that the absence of this right prevents children with mental disabilities from accessing justice.
- Are the entitlements to participate in relevant processes different for *adults* with mental disabilities than they are for children with mental disabilities and, if so, how?
- Proposals for *reform*, if any.

2.3 Are children with mental disabilities legally entitled to provide evidence in situations of family breakdown, adoption, care proceedings with outcomes such as entry into institutional or foster care, and deinstitutionalisation processes?

If yes –
Describe

- *Laws* governing this right, whether *reference* is made to disabilities in general or mental disabilities in particular.
- If the right of children with mental disabilities to provide evidence is subject to *conditions* (e.g. age, capacity, competence, corroboration), what these are, and the processes for determining whether they are *satisfied*.
- If and how children with mental disabilities are *informed* about this right.
- *Methods* and *means* available to them to provide evidence (e.g. in writing, orally in court, via live video link or via video-recorded interviews), if these are *child-friendly* and *adapted*. How *decisions* are taken on which method should be used and if the child does have an *opportunity* to choose between them.
- If children can choose *not* to give evidence if they do not wish to do so.
- How, if at all, the *right to provide evidence* of children with mental disabilities differs from that of children who do not have mental disabilities.
- How, if at all, the *right to provide evidence* of children with mental disabilities differs from that of adults with mental disabilities.
- The *strengths* and *weaknesses,* if any, of such relevant laws, policies and other measures in theory and in practice, with examples to support whether or not they work well for children with mental disabilities.
- Proposals for *reform*, if any.

If no –
Describe

- Whether there is *any research evidence on children's views/experiences* being excluded from being used as evidence in such cases? If so, what are the findings?
- Proposals for *reform*, if any.

2.4 Do decisions on the placement of children with mental disabilities in Type A cases take account of their expressed preferences?

If yes –
Describe

- Relevant *laws*, *policies* and other *measures* and whether *reference* is made to disabilities in general or mental disabilities in particular.
- *Mechanisms* or *systems* to ascertain their *preferences* and *who* does this.
- If methods of *communication* are adapted to the child's particular communication *needs*. If so, please provide details.
- *Strengths* and *weaknesses de jure* and *de facto* of the provisions for taking into account the expressed preferences of children with mental disabilities.
- If *reasons* for not taking into account their expressed preferences in decisions are *explained* to children with mental disabilities, if this is subject to conditions (age, type and level of impairment).

- How, if at all, the *position* of children with mental disabilities differs from that of children who do have mental disabilities.
- Proposals for *reform* if any.

If no –
Describe

- Whether there is *any research evidence on the views/experiences* of children with mental disabilities of having their expressed preferences disregarded and if so, describe their findings.
- Proposals for *reform*, if any.

2.5 Are children with mental disabilities entitled to their own legal advocate or representation in their own right?

If yes –
Describe

- Relevant *laws*, *policies* and other *measures*, and whether *reference* is made to disabilities in general or mental disabilities in particular.
- If this *right* is subject to any *limitations* (e.g. the existence of a possible conflict of interest with a parent or guardian) or the satisfaction of any preconditions (e.g. relating to age, nature or severity of disability, level of comprehension, etc.). If so, please provide details.
- If the services of these *lawyers* or other representatives are paid for through *legal aid* (funded by the State) and, if so, if there are *limits* on the types of lawyer who may be used (e.g. in terms of expense and qualification), and if there are any concerns that limits on legal aid may restrict the *quality* of legal representation.
- If there is *specialism* in the legal community in your country to support children with mental disabilities.
- Any existing *mechanisms* for ensuring that lawyers can *communicate* appropriately with their clients who are children with mental disabilities, the process to obtain such *support* and whether there are *limits* in their use.
- Proposals for *reform*, if any.

2.6 Do children with mental disabilities have a right to be informed directly in Type A cases about their rights (e.g. their rights to express a preference, to choose between alternative support methods, etc.), the nature of the proceedings, their possible outcomes, and about the decisions on their placement?

If yes –
Describe

- Relevant *laws*, *policies*, or other *measures* and whether *reference* is made to disabilities in general or mental disabilities in particular.
- If the provision of such information is subject to *conditions* (e.g. relating to age, nature and level of impairment). If so, please provide details.
- *Who* informs them and *how* (e.g. orally, in easy-to-read format, through models, etc.).
- If the *right to information* of children with mental disabilities and its implementation differ from that of children who do not have mental disabilities.

- If the *right to information* of children with mental disabilities and its implementation differ from that of adults with mental disabilities.
- *Examples* of *success stories* where the provision of such information enabled children with mental disabilities to advocate for their own rights in proceedings.
- *Weaknesses* and *strengths*, if any, of such laws, policies and other measures in theory and in practice.

2.7 Do children with mental disabilities have the right to object to decisions on their placement?

If yes –
Describe

- Relevant *laws*, *policies* and other *measures* to enable children with mental disabilities to *challenge decisions* made on their placement and whether reference is made to disabilities in general or mental disabilities in particular.
- *Where* decisions can be challenged and *how* will this be addressed.
- If children have access to *independent representation* to enable them to make an objection.
- If measures are in place to ensure that children *know* about their right to object to a decision and if so, what these are.
- Once an objection has been made to a decision, how is that objection *responded* to?
- Evidence where the satisfaction or dissatisfaction of children with mental disabilities with these procedures is highlighted.
- Whether steps are *routinely* taken to check on the *welfare* of children generally, and of children with mental disabilities in particular, at regular intervals after the proceedings. If so, please provide details of this process – including an explanation of *who* does this (e.g. a designated social worker), what *steps* are taken to ensure that the child has an opportunity to provide meaningful input into the process and *how* are complaints by the child dealt with.
- The *weaknesses* and *strengths*, if any, of these laws, policies, and other measures in theory and in practice, with examples.
- Proposals for *reform*, if any.

2.8 Are children with mental disabilities who are placed in institutional living arrangements permitted and supported to maintain contact with family, friends and others in their home communities through visits, correspondence, etc.? If this is subject to conditions please state what these are.

If yes –
Describe

- Relevant *laws*, *policies*, or other *measures* and whether reference is made to disabilities in general and mental disabilities in particular.
- Whether this is *permitted* and *supported* in *practice*, and if so, *how.*
- Whether the processes for children with mental disabilities in institutions differ from rules applicable to *adults* with mental disabilities (or are they both considered as “clients” of residential care arrangements).

- *Examples* where this has enabled children to make complaints or otherwise access the justice system.

2.9 Please provide information and figures, ideally from January 2010 onwards, if it exists in your country, regarding the following:

- How many *family proceedings* which involve decisions about the placement of a child with mental disabilities occur *annually*?
- How many *care or related proceedings*, relating to the placement or continuance of a child with mental disabilities occur *annually*?
- In how many such family and care proceedings are *"special procedures" or individualised adjustments* made each year?
- Are records kept on whether the *child's preference* has been complied with? If so, in how many such cases *each year* does the outcome coincide with the *preferences* of the child and how does this figure compare with that relating to children who do not have disabilities?
- What *criteria* was/were mostly used to determine *placement decisions* for children with mental disabilities (e.g.) age, gender, race, ethnicity and the psychological, social, emotional and cognitive situation?
- The *number of cases of children* with mental disabilities challenging such decisions about their placement annually.

Please also state whether the data is publicly available or not.

If this information is not available -

Describe

- Any available information on the data requested above concerning *adults* with mental disabilities.
- Whether such data will be made *available in the future*. If so, please provide details.

2.10 Describe any studies, reports or other literature/material (government, NGO, academic or other) which evaluate the appropriateness or effectiveness of the approaches and measures described above. Please draw particular attention to any proposals for reform and the arguments on which they are based.

2.11 Describe if needed, specific examples of cases or situations relating to placements in which the rights of a child with mental disabilities were effectively protected by the justice system.

2.12 Describe if needed, specific examples of cases or situations relating to placements in which the rights of a child with mental disabilities were not effectively protected by the justice system.

* * *

3. Questions on "Access to Justice for Children with Mental Disabilities" in Type B Cases

Situations involving questions about where or how a child with "mental disabilities" should be educated (including in segregated educational systems or mainstream schools, or at home).

3.1 Describe the context in which decisions on where children with mental disabilities should be educated are made by providing information on:

- The *nature* of relevant structures and mechanisms (non-judicial relevant administrative structures such as local authorities, and/or courts, tribunals, other), and briefly *how* they work.
- How children with mental disabilities and their parents are *informed* about the existence and functioning of such structures and mechanisms.
- If there is evidence that children with mental disabilities and their parents *are aware of* their existence and functioning and if so, please provide details.
- Relevant *laws*, *policies* or other clear *frameworks* governing them and whether *reference* is made to disabilities in general or mental disabilities in particular.
- The *strengths* and *weaknesses* of these laws, policies or other frameworks in theory and in practice, if any.

3.2 Briefly describe how these decisions are made by providing information on:

- *Procedures* and *steps* of the decision-making process (perhaps by providing an organogram) and the general *time-frame*.
- *Who* is involved?
- What *information* and *criteria* will be used to make the decision on the placement?

3.3 Are there processes and systems in place for determining the particular needs and circumstances of children involved in proceedings relating to Type B cases?

If yes –
Describe

- Relevant *laws*, *policies* or other *measures*, and whether *reference* is made to disabilities in general or mental disabilities in particular.
- *Their strengths* and *weaknesses*, if any, de jure and de facto.
- If these include any *routine assessment* of whether the child has a mental or other disability. If so, please explain *why, how, and when* such assessments are carried out.
- What professionals are involved?
- How mental disability is *defined* in these processes.

- Whether the existence of a *previously* recorded diagnosed mental disability is *taken into account* in determining the needs and circumstances of the child.
- Cases with *examples* of where this operates well for children with mental disabilities and where this does not operate well for them.
- What *input* children with mental disabilities and their families have in the process.
- Proposals for *reform*, if any.

If no –
Describe

- If there is any *research evidence of children's views/experiences* of having their needs ignored in this process and if so, what are the findings?
- Proposals for *reform*, if any.

3.4. Are children with mental disabilities legally entitled to have their views sought concerning decisions on where they should be educated?

If yes –
Describe

- Relevant laws, *policies* or other clear frameworks and whether *reference* is made to disabilities in general or mental disabilities in particular.
- *Strengths* and *weaknesses*, if any, *de jure*.
- If this is subject to *conditions* (e.g. age, capacity, competence, corroboration) and what these are. If so, please explain what the *processes* are for determining whether conditions are satisfied.
- If and how children with mental disabilities are *informed* about this right.
- If there is evidence that children *are aware of this right*, and if so please provide examples.
- Methods and *means by which* they might express a view – e.g. in writing, orally in court, via live video link or via video-recorded interviews, and if these are child-friendly and adapted.
- Who decides which *method* should be used?
- If the child with a mental disability is given the *opportunity to choose* which method they prefer.
- If there is *any process of negotiation* where children with mental disabilities and their parents will have an opportunity to make a case for a particular school.
- Whether children can *choose* not to express a view if they do not wish to do so.
- How, if at all, does the right of children with mental disabilities to express a view *differ* from that of children who do not have mental disabilities?
- *Examples* of cases where this *operates* well for children with mental disabilities and where it does not.
- Proposals for *reform,* if any.

If no –
Describe

- If there is *any research evidence of children's views/experiences* of not being consulted in this process and if so, what the findings are.
- Proposals for *reforms*, if any.

3.5. Do decisions on where children with mental disabilities should be educated take into account their expressed views?

If yes –
Describe

- Relevant *laws*, *policies* and other *measures* and whether reference is made to disabilities in general or mental disabilities in particular.
- *Mechanisms* or *systems* to ascertain their *views* and *who* is responsible for ensuring this happens.
- Whether methods of *communication* are adapted to the child's particular communication *needs*. If so, please provide details.
- What happens when the expressed views of the child *differ* from that of his or her parents? Please provide examples.
- Whether *reasons* for not taking into account their expressed views in decisions is *explained* to children with mental disabilities, and if this is subject to *conditions* (age, type and level of impairment).
- *Strengths* and *weaknesses* de jure and de facto of the provisions for taking into account the expressed views of children with mental disabilities.
- How, if at all, the *position* of children with mental disabilities differs from that of children who do not have mental disabilities.
- Proposals for *reform,* if any.

3.6. Are children with mental disabilities entitled to their own legal advocate or representation in their own right in Type B cases, in particular in cases where their views differ from their parents or carer?

If yes –
Describe

- Relevant laws, *policies* or other clear frameworks and whether *reference* is made to disabilities in general or mental disabilities in particular.
- *Weaknesses* and *strengths*, if any, of these laws, policies or other measures de jure and de facto.
- If children with mental disabilities are *informed* about their right to their own legal advocate and if so, how.
- If there is evidence that children with mental disabilities *know* about this right (provide examples where this has been used, and of where children challenged the decision on their education).
- If this right is subject to *any limitations*.
- If this is subject to any *preconditions* (e.g. relating to age, nature or severity of disability, level of comprehension, etc.).
- Whether there are any *mechanisms* for ensuring that lawyers can *communicate appropriately* with their clients who are children with mental disabilities.
- Whether the services of lawyers are paid for through *legal aid* (e.g. funded by the State).
- If representation is *state funded* whether there are *limits* on the types of lawyer who may be used (e.g. in terms of expense and qualification).
- Whether there are any *concerns* that limits on legal aid may *restrict the quality* of legal representation.

- Examples of cases where these *laws*, *policies* and other *measures* work well in practice.
- The *number of cases annually* where this right was used by children with mental disabilities to decide on where they should be educated.
- The *number of cases annually* where this right was used by children with mental disabilities to challenge decisions made and the percentage of successful outcomes.

If no –
Describe

- What *processes* are in place if there is a *conflict of interest* between the preference of the child with mental disabilities and their parent/carer or guardian ad-litem in type B scenarios.

3.7. Do children with mental disabilities have a right to be informed directly in Type B cases about their rights (e.g. their rights to express a view, to choose between alternative support methods, etc.), the nature of the proceedings, their possible outcomes, and about the decisions on where they will be educated?

If yes –
Describe

- Relevant *laws*, *policies*, or other *measures* and whether *reference* is made to disabilities in general or mental disabilities in particular.
- If the provision of such information is subject to *conditions* (e.g. relating to age, nature and level of impairment). If so, please provide details.
- *Who* informs them and *how* (e.g. orally, in easy-to-read format, through models, etc.).
- *Examples* of *success stories* where the provision of such information enabled children with mental disabilities to advocate for their own rights in proceedings.
- *Weaknesses* and *strengths*, if any, of such laws, policies and other measures in theory and in practice.
- Proposals for *reform*, if any.

3.8. Do measures exist to facilitate the participation of children with mental disabilities in type B situations, in particular through the use of alternative communication methods?

If yes –
Describe

- Relevant *laws*, *policies*, or other *measures* and whether *reference* is made to disabilities in general or mental disabilities in particular.
- If available support is *adapted* to the age, evolving capacities and needs of the child.
- By *whom* is support provided?
- Whether it is *easily* accessible and available.
- Whether children with mental disabilities are given opportunities to *express preferences* about the *type* of support or adaptation of the proceedings which they would like.

- *Examples* of cases of where this operates well and where it does not for children with mental disabilities.

3.9. Do children with mental disabilities and their parents or carers have the right to challenge decisions on where they will be educated?

If yes –
Describe

- Relevant *laws*, *policies* and other *measures* to enable children with mental disabilities and their parents or carers to challenge decisions made on where they should be educated and whether reference is made to disabilities in general or mental disabilities in particular.
- *Where* decisions can be challenged.
- Whether children with mental disabilities and their parents or carers are *informed* and know about their right and the process to challenge a decision, and if so, *how* and by *whom*.
- Whether the process is *accessible*.
- The *number of cases* where children with mental disabilities and their parents challenged decisions about their placement annually and their outcomes.
- Whether steps are *routinely* taken to check on the *welfare* and *happiness* of children generally, and of children with mental disabilities in particular, at regular intervals after the proceedings. If so, please provide details of this process – including an explanation of *who* does this (e.g. a designated social worker), what *steps* are taken to ensure that the child has an opportunity to provide meaningful input into the process and *how* are complaints by the child dealt with.
- The *weaknesses* and *strengths*, if any, of these laws, policies, and other measures in theory and in practice, with examples.
- Proposals for *reform*, if any.

3.10. When children with mental disabilities are placed in residential education settings are they permitted and supported to *maintain contact* with family, friends and others in their home communities? (If this is subject to conditions, please state what these are.)

If yes –
Describe

- Relevant *laws*, *policies*, or other *measures* and if reference is made to disabilities in general and mental disabilities in particular.
- The extent to which this is *permitted* and *supported* in *practice.*
- *Examples* of the quality of how contact is supported (overnight visits? Lengthy day or long stay? Quality of facilities?)
- *Examples* where this has enabled children to make complaints or otherwise access the justice system.

3.11 Please provide *information and figures*, ideally from January 2010 onwards, if it exists in your country regarding the following:

- The number of *cases* to decide where children with mental disabilities should be educated, and the number of court cases where parents or children with mental disabilities challenge a decision *annually*.
- How do these numbers *compare* with the numbers of cases concerning the education of children with disabilities *of all types* and the education of children who have *no disabilities*?
- In how many such education cases concerning children with mental disabilities each year are *"special procedures"* or *individualised adjustments* made to facilitate the child's participation in the proceedings?
- In how many such cases each year does the *outcome coincide with the preferences* of the child and how does this figure compare with that relating to children who do not have disabilities?
- How do education-related decisions for children with mental disabilities *take into account* their age, gender, race and ethnicity, and their particular mental disability (e.g. psychological, social, emotional and cognitive situation)?

Please also state whether the data is publicly available or not. If this information is not available -

Describe
- Any available information on the data requested above concerning *adults* with mental disabilities.
- Whether such data will be made *available in the future*. If so, please provide details.

3.12. Describe whether there are any existing studies, reports or other literature/material (government, NGO, academic or other) that evaluate the appropriateness or effectiveness of the approaches and measures in Type B situations, drawing particular attention to any proposals for reform and the arguments on which they are based.

3.13. Describe, if needed, specific examples of cases or situations relating to education in which the rights of a child with mental disabilities were effectively protected by the justice system.

3.14. Describe, if needed, specific examples of cases or situations relating to education in which the rights of a child with mental disabilities were not effectively protected by the justice system.

* * *

4. Questions on "Access to Justice for Children with Mental Disabilities" in Type C Cases

Situations involving questions about whether a crime has been committed (including those in which a child with "mental disabilities" is the victim, witness or alleged offender).

4.1 Court/Tribunal Structures

Describe:

- The *nature* of structures and mechanisms (e.g. courts, tribunals, alternatives to judicial proceedings, etc.) for proceedings of Type C in your country and whether these *differ* in cases where a victim, a witness or an alleged offender is a child with a mental disability from those in which the child does not have a mental disability.
- Relevant *laws*, *policies* and other clear *frameworks* governing them, whether *reference* is made to disabilities in general or mental disabilities in particular.
- The *quality* and *adaptability* for children with mental disabilities.
- Whether such structures are *accessible* by all children. Where are these structures situated? Are they accessible by children who live in institutions or outside main cities?
- Proposals for *reforms*, if any.

4.2 Evidence

Are children with mental disabilities who are victims, witnesses, or alleged offenders legally *entitled* to provide *evidence*?

If yes –
Describe

- Relevant *laws*, *policies* and other *measures* governing this right and explain their *strengths* and *weaknesses*, if any.
- If this is subject to *conditions* (e.g. age, capacity, competence, corroboration), please explain what these are and the processes for determining whether they are satisfied.
- Available *means* for children with mental disabilities to provide evidence – e.g. in writing, orally in court, via live video link or via video-recorded interviews. If this is subject to *conditions*, please explain what these are and the processes for determining whether they are *satisfied*.
- How it is decided which methods should be used and if children with mental disabilities have an *opportunity to choose* between them.
- How it *operates* in practice - including for children who are homeless or living in residential institutions.
- Whether *judges* are required to give any *warning* to juries or other fact-finding bodies (if used) about the weight to be attached to the evidence of a child with mental disabilities. If so, please provide details about the *nature* of any such warning and with examples, *how* this is done.
- For all questions above, how, if at all, does the *position* of children with mental disabilities *differ* from that of, first, adults with mental disabilities and, second, children who do not have mental disabilities? Ensure that your answer addresses

the *theoretical* position laid down by legal instruments or cases and the position in *practice*.

4.3 Investigative Stages

4.3.1 Are there any measures or procedures (or special measures) whereby the police are required or encouraged to alter their standard methods in order to communicate with children who have mental disabilities in a way that respects their age, evolving capacities, communication difficulties and specific needs in relation to their participation in proceedings?

If yes –
Describe

- If these *measures* are available and applicable to children who are victims, witnesses or alleged offenders.
- How, if at all, do they *differ* from the procedures which apply to children who are not classified as having a mental disability?
- Relevant *laws*, *policies* and other clear *frameworks*, if *reference* is made to disabilities in general or mental disabilities in particular, and their *strengths* and *weaknesses,* in substance and in practice, for children with mental disabilities.
- If a *failure* of the police to adapt their procedures to take into account the particular circumstances of a child with mental disabilities is *actionable* as disability discrimination. If so, please explain *who* may bring such claims in your country and also describe any *examples* of cases in which such actions have been brought, and cases which were not brought although they should have been.

4.3.2 Are there any measures or procedures to ensure police interviews of children with mental disabilities are respectful and appropriate?

If yes –
Describe

- Relevant *laws*, *policies* or other clear *frameworks* and whether reference is made to disabilities in general or mental disabilities in particular.
- The *nature* of such measures which may be taken, along with any *conditions* to which they might be subject (e.g. age, or type or level of impairment).
- *Who*, at the police station, is responsible for implementing such measures and are there specific *guidelines* for them to follow?
- If these are *applicable* to children with mental disabilities who are witnesses in criminal proceedings, victims and/or alleged offenders.
- *How* such measures or procedures are accessible for and/or by children with mental disabilities.
- Whether and how these procedures *differ* from those used to control police interview of adults and/or children who do not have mental disabilities or adults who have mental disabilities.
- *Examples* of cases, with evidence, where such measures ensured *fairness* and *respect* in proceedings for children with mental disabilities.
- *Examples* of cases, with evidence, where such measures were *not* effective.
- Proposals for *reform*, if any.

4.4 Victims who are Children with Mental Disabilities

4.4.1 Do *official records* (e.g. the reports of police or prosecuting authorities) indicate whether victims of crimes (or alleged criminal acts) have particular types of disabilities, including intellectual and/or psycho-social disabilities?

If yes –
Describe

- The *nature* of these records. Do they relate to complaints? Prosecutions? Convictions?
- Relevant *laws, policies and other measures* governing the provision of this information and whether reference is made to disabilities in general or mental disabilities or intellectual disabilities and/or psycho-social disabilities in particular.

4.4.2 Please provide information and figures, ideally from January 2010 onwards, if they exist in your country, regarding the following:

- Is *information included in official records* concerning the type of disability, the age, gender, ethnicity and the nature of the crime in question? To what extent is such information detailed and specific?
- The total number and proportion of *complaints, prosecutions and convictions each year* in which the victim is recorded as having a disability of any kind; as having a mental disability; and as being a child with a mental disability.
- The proportions of *different types of crime or alleged crime* (violence, sexual, theft, etc.) in which children with mental disabilities are recorded as victims and how these compare with the types of crime or alleged crime in which children generally are victims and also those in which children with all types of disability are victims.
- The *places* in which crimes (or alleged crimes) against children with mental disabilities take place (schools, family homes, residential institutions, parks, public places, etc.) and how these compare with the places in which crimes (or alleged crimes) against children generally and also against children with all types of disability take place.
- The number of recorded cases where crimes (or alleged crimes) are *committed by people in the circle of trust* of a child with mental disabilities (e.g. parent, member of the family, primary caregiver).
- If there are any *personal characteristics* (e.g. gender, age, ethnicity, impairment-type) which appear to exacerbate the *risk* that a child with mental disabilities will be the victim of a crime (or alleged crime).

If no or limited information is available –
Describe

- Any available information on the data requested above concerning *adults* with mental disabilities.
- Whether such data will be made available in the *future*. If so, please provide details.

4.4.3 Does your country explicitly recognise disability *hate crime* or *crime motivated by hostility* toward disability?

If yes –
Describe

- Relevant *laws, policies and other measures* and whether reference is made to disabilities in general or mental disabilities in particular.
- All the *points addressed by 4.4.2* above but in relation to disability hate crime or crime motivated by hostility toward disability.
- Proposals for *reform*, if any.

4.4.4 Are there certain types of crimes, such as sexual violence, for which *exceptions* have been made in your country in general to rules laying down time limits within which complaints must generally be made if prosecutions are to take place?

If yes –

- Do these *exceptions* include disabilities in general or mental disabilities in particular?

If yes –
Describe

- Relevant *laws, policies and other measures* and whether *reference* is made to disabilities in general or mental disabilities in particular.
- *Procedures* for *adults* with mental disabilities to have the right to file a complaint *beyond the time* limit for crimes committed against them when they were children.
- The *strengths* and *weaknesses*, if any, of these laws, policies, other measures and procedures described above, with examples of cases, if possible.

4.4.5 Have steps been taken in your country to *prevent* crimes against children with mental disabilities?

If yes –
Describe

- Which *public bodies* (including schools, police, social workers), *independent bodies* (including Ombudsmen, NGOs) or others are taking these steps?
- Their *nature* (campaigns, seminars, other awareness-measures) and to *whom* these measures are addressed (children themselves, parents, carers, others), if this is part of measures concerning children in general or if they *specifically* concern children with mental disabilities.
- Measures, if any, to *help children* with mental disabilities *recognise situations* where a crime against them or their peers has or is being committed, in particular for children without parental care and/or living in residential institutions or if abused in the "circle of trust".
- Measures, if any, to *help parents* or *carers* to *recognise* situations where a crime against children with mental disabilities has or is being committed, in particular against children in residential institutions.

- Measures to ensure that children with mental disabilities, their parents and carers are *aware* of how to make a *complaint* if they feel that such a situation has occurred.
- If there are any *examples* of *success stories* where such measures empowered children with mental disabilities to look for help and/or access justice.
- Any *studies* or *reports* on the effectiveness of any such efforts, including discussion of any evidence of the extent of unreported crime against children with mental disabilities and the reasons for it being unreported.

4.4.6 Are measures taken in your country to ensure access to justice for homeless children with mental disabilities who are victims of crime?

If yes –
Describe

- Relevant *laws*, *policies* and other *measures*, if *reference* is made to disabilities in general or mental disabilities in particular, and their *strengths* and *weaknesses* if any.
- *How* this is carried out, and by *whom*?
- If these measures are subject to *conditions* (age, type and level of impairment, etc.). If so, please provide details.
- The *process* to bring these children to justice in *theory* and in *practice*.
- *Examples* of cases where they successfully accessed justice and cases where they were prevented from accessing justice.
- Proposals for *reform*, if any.

4.4.7 Are there any *measures to protect* children with mental disabilities during criminal proceedings from additional harm, including intimidation, reprisals and secondary victimisation?

If yes –
Describe

- Relevant *laws*, *policies* and other *measures*, if reference is made to disabilities in general or mental disabilities in particular, their strengths and weaknesses, if any, in theory.
- The *nature* of such measures which may be taken, along with any *conditions* to which they might be subject (e.g. age, or type or level of impairment).
- If these are *applicable* to children with mental disabilities who are witnesses in criminal proceedings as well as to those who are victims.
- If there are *differences* with those applicable to children who do not have mental disabilities.
- If there are special *precautionary measures* which apply to children with mental disabilities where alleged crimes were committed by people in their *"circle of trust"*, including in residential institutions.
- How these measure *operate* in practice.
- Proposals for *reform*, if any.

4.5 Alleged Offenders who are Children with Mental Disabilities

4.5.1 General information on children and criminal responsibility

Describe

- The *age* of criminal responsibility in your country.
- *Adjustments or special procedures* which are generally put in place for children without disabilities who are charged with crimes, including in specialised units within the police, the judiciary, the court system and the prosecutor's office.
- Existing procedures for children who committed crimes *under the age* of criminal responsibility.

4.5.2 Do *procedures* and *structures* differ from your answer in 4.5. when the alleged offender is a child with a mental disability?

If yes –
Describe

- Relevant *laws, policies and other measures* and if reference is made to disability in general or mental disability in particular.
- If this is *dependent* on the type or severity of the disability or other and if so, please specify with examples.
- The *role* played by prosecutors, court officials, social services and others in ensuring that *child-friendly* and *individually-tailored* approaches to the needs of children with mental disabilities in relation to their participation in proceedings are used throughout the investigation and trial process.
- The systems used to ensure that a child with mental disabilities who is alleged to have committed an offence is able to *understand* the proceedings and *communicate* effectively before and during any trial.
- The *strengths* and *weakness*, if any, of relevant laws, policies and other measures in *theory* and in *practice*, with *examples* to support this information.

4.5.3 Are children with mental disabilities who are alleged offenders *entitled* to be *informed* about their rights, procedures, the reasons for their detention and the possible longer-term outcomes when taken into custody or otherwise detained in connection with criminal proceedings?

If yes –
Describe

- Relevant *laws, policies and other measures* and if *reference* is made to disability in general or mental disability in particular.
- How this is done, at what stage or stages of the proceedings and by whom.
- If this is *dependent* on the type or severity of the disability or other and if so, please specify with examples.
- *Strengths* and *weaknesses*, if any, of these laws, policies or other measures in substance and practice, with examples.

4.5.4 Are there *situations*, *circumstances* or *places* in which children with mental disabilities may be *detained* in connection with criminal proceedings *different* from those in which children without disabilities may be detained?

If yes –
Describe

- Relevant *laws, policies and other measures*, and whether reference is made to disabilities in general or mental disabilities in particular.
- *Strengths* and *weaknesses*, if any of these laws, policies and other measures in substance.
- The *nature* of these situations, circumstance and places.
- *Where* children with mental disabilities are detained in relation to these situations, circumstances and places (placed in facilities with other children or adults with mental disabilities; with other children or adults with disabilities of all types; with other children or adults who may or may not have disabilities; and whether or not there is gender-based or age-based segregation).
- Existing *systems* to ensure that the conditions of detention are *appropriate* for the child and the provision of any disability-related *adjustments* or *support* they require.
- The extent to which children with mental disabilities who are detained in connection with alleged criminal conduct will be *permitted* and *supported* to maintain *contact* with *family*, *friends* and others in their communities through visits, correspondence, etc.
- Existing *opportunities* for children with mental disabilities to voice *complaints* or *concerns* to staff within the institution or to people outside the institution.
- *Examples* of cases or other evidence of where and how such laws, policies and measures *operate* well or not for children with mental disabilities.

4.5.5 Please provide information and figures, ideally from January 2010 onwards, if they exist in your country regarding the following:

- The total number and proportion of *complaints, prosecutions and convictions each year* in which the alleged offender is recorded as having a disability of any kind; as having a mental disability; and as being a child with a mental disability.
- The proportions of *different types of crime or alleged crime* (physical or sexual violence, theft, etc.) in which children with mental disabilities are recorded as an alleged offender and how these compare with the types of crime or alleged crime in which children generally are alleged offenders and also those in which children with all types of disability are alleged offenders.
- The *places* in which crimes (or alleged crimes) committed by children with mental disabilities take place (schools, family homes, residential institutions, parks, public places, etc.) and how these compare with the places in which crimes (or alleged crimes) by children generally take place and also crimes (or alleged) by children with all types of disability.
- If there are any *personal characteristics* (e.g. gender, age, ethnicity, impairment-type) which appear to exacerbate the *risk* that a child with mental disabilities will become an alleged offender of a crime.

4.6 Cross-Cutting Data for Type C Cases

4.6.1 Is the following data available?

- The *total number of criminal cases* each year (ideally since January 2010) which are known to have involved children with mental disabilities as victim, witness or alleged offender.

If yes –

- How does this number *compare* with the number of criminal cases over the same time periods involving children who have disabilities of all types and with the number of criminal cases involving children without disabilities? If possible, please break down these figures for the categories of victim, witness and alleged offender.
- Do children with mental disabilities receive *comparable sentences* for the same offence as those without disabilities?
- Does *level of capacity* and *understanding* influence the courts' view of the child's culpability and if so how are these factors taken into account?

4.6.2 Describe

- How *"mental disability"* is being *defined* for purposes of the above figures (section 4.6.1) and the processes by which children are classified as being disabled (with a "mental disability" or some other impairment).
- If children are *routinely assessed* for the existence of some form of disability or impairment at the *outset* of legal proceedings in criminal cases, *how* and by *whom.*
- Your *evaluation* of the *appropriateness* of any such processes and the *reliability* of the figures.
- How *private and personal data* (name, age, personal characteristics, race and ethnicity, individual assessments, pictures, videos) of children with mental disabilities who are or have been involved in judicial proceedings are *protected*, in particular from the media, and specify whether such measures *differ* or are *similar* to those applied to children who do not have mental disabilities.
- *Under what circumstances*, *to whom*, and for *what purpose* are records or documents containing personal and sensitive data of children with mental disabilities disclosed?

4.7 Literature and Evaluations

- Please provide details of *any studies, reports or other literature/material* (government, NGO, academic or other) which *evaluates* the appropriateness or effectiveness of the approaches and measures described in your answers to this section (Section 4, regarding Type C proceedings). Please draw particular attention to any proposals for reform and the arguments on which they are based.

5. Summary: Key Concerns

Describe the *key practical barriers* to access to justice for children with mental disabilities and if these will vary depending on the impairment type and degree, age, gender, ethnicity, or other characteristics. Please provide examples including the use of real-life stories.

Annex 2: Phase 1 Guidance

Workstreams 1 and 2
Data Collection and Standards

Phase 1: Desk-Based Research

1. Aims

1.1 Summary

- To begin the task of providing information about access to justice for children with mental disabilities in your country;
- To gain a clear understanding of the extent to which that information is available to researchers using standard desk-based research methods and nothing more;
- To identify some of the barriers and limitations which researchers may encounter when using desk-based research to attempt to gather this information; and
- To identify research strategies and approaches that may prove helpful to include in future guidance to such researchers.

1.2 Textual Explanation

The aim of Phase 1 is to use desk-based research to collate, synthesise and summarise mostly textual data as is available from sources which are published or otherwise publicly available. The questions into which you are asked to conduct this research (in all 3 phases of Workstreams 1 and 2) are set out in the accompanying data-gathering template document.

The aim of Phase 1 is to ascertain what information on these topics is publicly available in your country[110] and discoverable through desk-based research. In Phases 2 and 3, you will be asked to use different research techniques to work on supplementing the information gathered in Phase 1. It is therefore important that you use only desk-based research in this first phase as only by doing so will it be possible for us to gauge, at the end of Phase 1, the extent of the data which is currently easily accessible and available to researchers in your country.

---

[110] This includes academic journals for which you may require a subscription. As stated in section 4.2, please email us if you are unable to access such sources and we can attempt to download those.

2. Meaning of Desk-Based Research

NB Desk-based research falling into Phase 1 of this project **does not** include:

- Using sources which cannot be easily located without the assistance of people working in the justice system or allied professionals;
- Using sources which can be accessed only after the payment of a fee; and
- Using empirical research techniques such as issuing questionnaires or conducting interviews or focus groups.

For purposes of this project, desk-based research means gathering information and data from the following types of sources:

2.1 Academic and Practitioner Books

You will need to consult academic books from several disciplines (e.g., law, sociology, social policy, criminology, social work, education). Even within these disciplines, relevant books are likely to span several fields. For instance, relevant law books might include textbooks, practitioner texts, casebooks and monographs[111] in family law, education law, criminal law, equality and discrimination law, disability law, human rights law, civil procedure, criminal justice, evidence law and social welfare law.

2.2 Journal Articles

Journals (sometimes known as "periodicals") are published on an ongoing basis and contain a series of in-depth articles which report on new research or other developments and provide analytical and theoretical critique. Journals relevant to this subject will be linked to a range of disciplines along the lines mentioned under "academic books" above.

2.3 Legislation

This might include written constitutions, statutes or statutory codes, secondary legislation (sometimes known as statutory instruments), regional or local legislation. Please also consult sources which help to throw light on relevant legislation – including official debates in parliament leading up to the enactment of the relevant statute; official explanatory notes issued by the government to explain the meaning of the various sections of the statute; and other official guidance, such as codes of practice issued by an equality body or ombudsman in order to help the public and potential duty-bearers to understand the rights and duties created by the statute.

---

[111] "A monograph is a specialist work of writing on a single subject or an aspect of a subject, usually by a single author." Wikipedia (2015), available at: http://en.wikipedia.org/wiki/Monograph (last accessed 20 April 2015).

2.4 Court, Tribunal, Ombudsman[112] or Other Case Reports

Consider both officially reported cases and unreported cases (often reported in newspapers or by NGOs).

2.5 Government or Parliament Literature and Reports

For example: consultation documents and responses; White Papers (Bills) or Command Papers; Law Commission reports; and committee reports.

2.6 Statistical Records

Both official statistics (those gathered by governmental bodies) and statistics gathered via previous polls or from existing studies.

2.7 Information and Reports of Equality Bodies, National Human Rights Institutions or Ombudsman Offices

This could include guidance, reports based on previously undertaken empirically-led research by such organisations or responses to government consultations, data on complaints and their outcomes, and proposals for reform. There is no consistency in the type of information and reports which such bodies collect and make available, and so please note that this list is only indicative and you should investigate whether other types of relevant information are made available by such bodies in your country.

2.8 NGO Literature and Reports

You will need to identify the various NGOs in your country which might issue news, research, reports, proposals and critiques, etc., on relevant issues. These might include organisations primarily focused on children, disability and psycho-social and/or intellectual disability; and access to justice. More general human rights organisations may also have helpful material. Please ensure that you consider national as well as local organisations. Search under news; research and archives. You might also find that relevant NGO material is available in other archives – e.g. the Centre for Disability Studies (University of Leeds) archive[113] contains a great deal of NGO material.

2.9 News Archives

Both national and regional newspaper archives should be consulted. In addition, there may be relevant news items presented via other media such as radio, television, or new media. Please note

---

[112] "An official appointed to investigate complaints against maladministration by central government and the civil service." Oxford English Dictionary, (Oxford: Oxford University Press, 2010). Examples of maladministration include: an organisation not following its own policies or procedures; rudeness, delay in taking action or failing to take action; treating someone unfairly compared to others; and giving wrong or misleading information.

[113] http://disability-studies.leeds.ac.uk/library/ (last accessed 20 April 2015)

that these sources are often available in a variety of different forms (e.g. hard copy, website, part of an electronic database or archive).

2.10 Information About Your Country in Multinational Sources

Extremely useful information about relevant developments in your country will be contained in multinational sources, such as:

- projects and studies;
- international NGO reports; and
- UN and European bodies which monitor and promote human rights.

3. Guidance on Identifying Sources

3.1 Books

Useful starting-points for identifying relevant books are:

- Academic libraries, practitioner libraries or government libraries.

Also very useful are resources such as:

- WorldCat.org, which allows you to search the collections of libraries in your community and thousands more around the world. It also lets you find an item of interest and then locate a library near you that owns it. Usually you will link directly to the item record on the library's website. The actions available to you on that page will vary from one library to another. You may be able to join a waiting list, reserve the item, check it out or even have it shipped or delivered
- http://www.bookbutler.com – this can help you identify the cheapest deals on books)
- Amazon – even if you do not buy from Amazon, it makes a great search engine for books you may wish to access elsewhere (library, Bookbutler)
- Google Books
- Google Scholar – details on how to navigate round this site are provided at 4.2.1

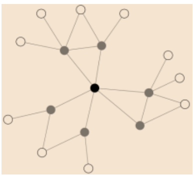
To navigate around these books, and identify relevant material within them, you might find it helpful to use their contents lists and indexes. In addition, for law books, tables of cases and statutes might also be helpful.

Note: if you identify a relevant book which is not available in your local library, you might be able to obtain it through an inter-library loan system or by making a visit to a bigger library. If you do not currently have access to an academic library, please investigate whether this would be possible for purposes of the project and let Stéphanie know if you encounter any serious obstacles to this.

3.2 Journal articles

The types of articles you should be searching for are academic and practitioner-oriented articles in different disciplines or specialities (along the same lines as those listed in "Academic or Practitioner Books" at 2.1).

Hard copies of journal articles are also available in academic (and sometimes in practitioner or public) libraries. To locate a journal article it is easier to search for the journal first and then locate the article after. Firstly to see if your academic library holds the journal you are interested in, search the library catalogue with the full journal name (do not use abbreviations) e.g. "Modern Law Review" rather than "MLR". Most journals are now available electronically as well as through databases or online (please refer to the guidance on how to use search engines below at point 4).



Note: "Snowball Sampling" is a very useful way of identifying further relevant books and journal articles. This is a very simple technique of checking references in the bibliography/footnote sections of the article to discover further materials/articles that are of relevance.

3.3 Legislation

If you are attempting to identify and analyse legislation in an area of law with which you are not familiar, you may find it helpful to begin by identifying and reading books or journals or other literature on the topic. This is likely to help you to identify and understand relevant legislation as well as helping you to identify some of its strengths, weaknesses and gaps.

Legislation will often be freely available online. It is also likely to be available in hard copy in academic and government libraries. Legislation can often be identified by searches (please also refer to the table of databases at 4.3.1 below). In addition, the tables of statutes in relevant books may be helpful, as may footnotes and other references in books, journal articles and reports.

3.4 Court, Tribunal, Ombudsman and Other Cases

In order to identify relevant case law a good starting point is often to consult the table of cases in law textbooks, practitioner books and in the footnotes of journal articles. In addition, reports of case decisions may themselves refer to other relevant cases on the topic. Further, details of cases are often available online – sometimes on the websites of the tribunal or ombudsman office which decided or intervened in the case.

Digests are useful for finding case law by key words or citations. In addition, legal databases like Lexis and Westlaw UK or Westlaw International are very good for locating cases. However, there are often free online sources where case law can also be located. For example, HUDOC is the case law database for the European Court of Human Rights. In the UK there is also British and Irish Legal Information Institute (BAILII). Moreover Courts often have their own website where cases are listed for hearings and official transcripts are available. The extent to which this occurs in your country is itself something of great interest in Phase 1 (see Section 6 below).

3.5 Government/Parliament Literature and Reports

These may be identified through the "snowball sampling" technique mentioned above. They may also be identified by searches on government or parliament websites and through other searches. Again, the extent to which such materials are available online and in an accessible format is in itself of interest to Phase 1.

3.6 Statistical records

It might be helpful to identify the website of your official statistics office and begin your searches there. Relevant statistics may also be available in websites or other publications of your courts, police or prosecution offices, ombudsman office, equality or human rights body.

3.7 Information and Reports of National Equality Bodies, National Human Rights Institutions or Ombudsman Offices

Snowball sampling and website searching would be helpful techniques for identifying possible relevant sources under this heading.

3.8 NGO literature and reports

Snowball sampling and website searching would be helpful techniques for identifying possible relevant sources under this heading.

3.9 News archives

Online archives would seem to be the most obvious means of identifying possible relevant news items.

3.10 Multinational Sources

Other multinational projects and studies are likely to publish reports on issues of relevance to our project. These will often contain very valuable information on particular countries included in the study. A recent example is:

> Marta Ballesteros, Karolina Jurkiewicz and Nathalie Meurens, *Member States Policies on Children with Disabilities* (European Parliament, June 2013) available at: http://www.europarl.europa.eu/studies (last accessed 20 April 2015)

Please let Stéphanie know of any others which you come across so that she can circulate details to everybody and that we thereby share information as much as possible.

Other helpful multinational sources of information about your country are international NGOs focusing on relevant issues, for instance, MDAC, Eurochild and Child Rights Information Network.

Again, please let Stéphanie know of any others you find useful so that we can circulate details and share information.

The websites of UN and European bodies which monitor human rights will have useful information about your country. For instance, the websites of the UN Committee on the Rights of Persons with Disabilities and the UN Committee on the Rights of the Child will have any reports your country has submitted to those Committees and also any concluding observations which those Committees have issued about them. Similarly, the website of the European Social Committee will contain information about reports submitted by your country in connection with the European Social Charter (or the Revised European Social Charter) and the Committee's assessments. Another relevant Council of Europe Convention, which it is worth tracking for national implementation, is the Convention on the Protection of Children against Sexual Exploitation and Sexual Abuse (Lanzarote Convention). Finally, information on websites of bodies such as the EU Agency for Fundamental Rights and the Council of Europe's Commissioner for Human Rights might well prove helpful.

4. Guidance on Carrying Out Electronic Searches

4.1 Before you begin

Before you begin your search, you should take a few moments to think about the keywords you will be using in your search. Also, will you want to conduct your search in English and in the language used in your country (if different)? In that case you should develop one list of keywords for each language.

4.1.1 Keywords, synonyms and related terms

We cannot tell you exactly what keywords to use, as these will differ depending on the language and context within which the search is conducted. This section does, however, provide guidance that should enable you to develop your own. It also provides examples of keywords that would work in the UK context.

The following is a list of key concepts arising from our project title:

- access
- justice
- children
- "mental disabilities"

If we were to stick to the terms identified from our project title, we would overlook a number of relevant sources, which may talk about the same topic, but use different words. For example, the term "mental disabilities" is not commonly used in the UK today. Searches should therefore include the terminology that is particular to each country context.

Each country delegate should develop their own synonyms and related words from the list of key concepts above. The table below presents an example of relevant keywords:

UK Example			
Access	**Justice**	**Children**	**Mental disabilities**
Inclusion	"Criminal justice system"	"Young people"	"Mental health problems"
Discrimination	"Civil Justice System"	Juvenile	"Learning disabilities"
Human rights	"Victim support"	Infant	"Learning difficulties"
		Minors	"Psycho-social disability"
		Teenager	"Mental disability"
			"Intellectual disability"
			"Cognitive disability"

Note: this is for illustration only. Some of those terms will make sense in the UK context, but not necessarily elsewhere. For example, "learning difficulties" is used instead of "mental disabilities" by the UK self-advocacy movement. In the USA, this term would not be associated with this group and would instead apply to people with educational labels of "specific learning difficulties", such as dyslexia – a population that is not relevant for the purposes of this research.

4.1.2 Broadening your Search

As you can see in the table in the previous section, we struggled to find synonyms for "access" and "justice". The terms in the table are mostly related words. "Access" and "justice" are broad terms and often they are not used in everyday speech and written text that refers to issues that are relevant to our project. It is therefore helpful to follow an initial broad search with more specific searches that refer to "Type A, B and C" proceedings. Below are the descriptors of these proceedings. Keywords have been highlighted:

Type A Proceedings

Disputes about where or with whom a child with "mental disabilities" should live (including situations of "family breakdown", "adoption", and "care proceedings" with outcomes such as entry into "institutional or foster care").

Type B Proceedings

Disputes about where or how a child with "mental disabilities" should be "educated" (including in "segregated educational systems" or "mainstream schools").

Type C Proceedings

Disputes about whether a "crime" has been committed (including those in which a child with "mental disabilities" is the "victim", "witness" or alleged "offender").

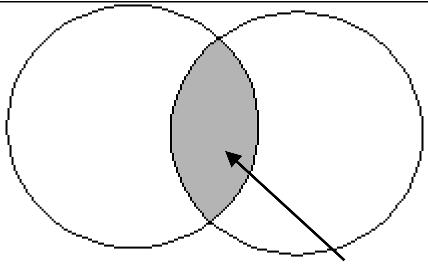
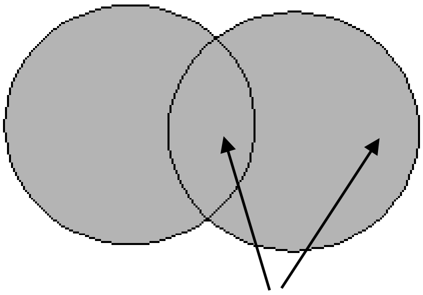
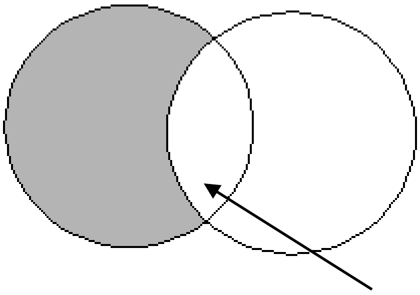
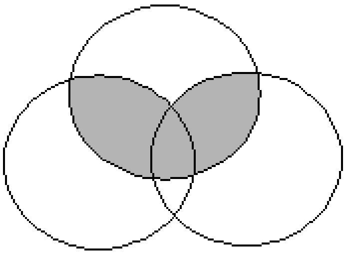
As in the example given earlier, your next step will be to identify closely-related words and synonyms, e.g. as well as "education", try "segregated schooling", "mainstream schooling", "Special Educational Needs" (SEN) and so forth. As before, ensure that the terms you choose reflect the language that is used to discuss these issues in your country.

4.1.3 Further tips on searching

- Try to use broader categories, e.g. as well as “mental disability” use “disability”.
- Also try to use narrower categories, e.g. as well as “crime” use “sexual abuse” or “financial abuse”.
- Note that only significant words, not common words, such as *the, of, an,* and *that* should be used in the search.
- Avoid using phrases such as “children with mental disabilities”, or whole sentences, such as “How do children with mental disabilities access justice?”
- Make sure that keywords that include more than one word are always stated in inverted commas. For example, if you type *mental disability* into a search engine, it will return any hits that include *mental* and any hits that include *disability*. If you use *“mental disability”*, the search engine will only search for these words together and in the order you have specified.
- Use an asterisk (*) to search all forms of a root word or variable endings. This is also called truncation. E.g. disab* will return results for disabled, disability, disabilities.
- Use wildcards. Note: these differ from search engine to search engine. Typically, they would be *, # or ?. This is useful when searching for terms with multiple spellings, unknown characters or various endings. For example, “challenging behavi?r” searches both, for UK spelling (behaviour) and US spelling (behavior).
- Google also uses ~ to search for a term or one of its synonyms. (This is currently supported on Web and Directory search.) For example, ~education will also return “training”, “learning”, etc. However, please do not rely on this tool, as many of our searches use specific terminology, which will not easily be picked up by the web-based dictionary.

4.1.4 Boolean Operators: AND, OR, NOT

Most online databases and Internet search engines support Boolean searching, which connects keywords with Boolean operators. The three basic operators are **AND**, **OR** and **NOT**. Here is how they work:

 “Mental Disab*” AND child*	Type AND between your keywords to narrow your search. The search engine will only retrieve those web pages that contain both words. Using AND will decrease the number or hits in your result list.
 “Mental Disab*” OR “Learning Disab*”	Type OR between your keywords to broaden your search. The search engine will retrieve those web pages that contain at least one of these words. Using OR will increase the number of web pages in your result list. Use OR between keywords that are synonyms or have similar meanings.
 “learning difficult*” NOT dyslexia	Type NOT before a keyword to exclude that keyword from your search. Using NOT will decrease the number of hits in your result list. The best use of NOT is when you are searching for a keyword that may have multiple meanings.
 (“learning difficult*” OR mental disab*) AND law	Combining Boolean Operators Use **parentheses ( )** to keep combination searches in order. This is called **nesting**. In the example, the search engine will retrieve articles or web pages that must contain the word “law” and at least one of the phrases in parentheses.

4.2 Web Searches

You will be in the best position to judge which web-based search engine will return the most comprehensive list of results in your country. You may decide to test more than one search engine to start with, before you settle on one main tool or decide to run all your searches on several search engines, in order to broaden the final results.

Once you have decided which search engine to use, take some time to familiarise yourself with the search engine and have a look for guidance on the use of that particular tool. For example, the Google guide can be accessed here: http://www.googleguide.com/index.html

Search engines differ slightly in their preferred use of wildcards and truncations, so it's worth checking.

However, in any web search you should critically appraise the results you find. How trustworthy and reliable is the information you found?

4.2.1 Using Google Scholar

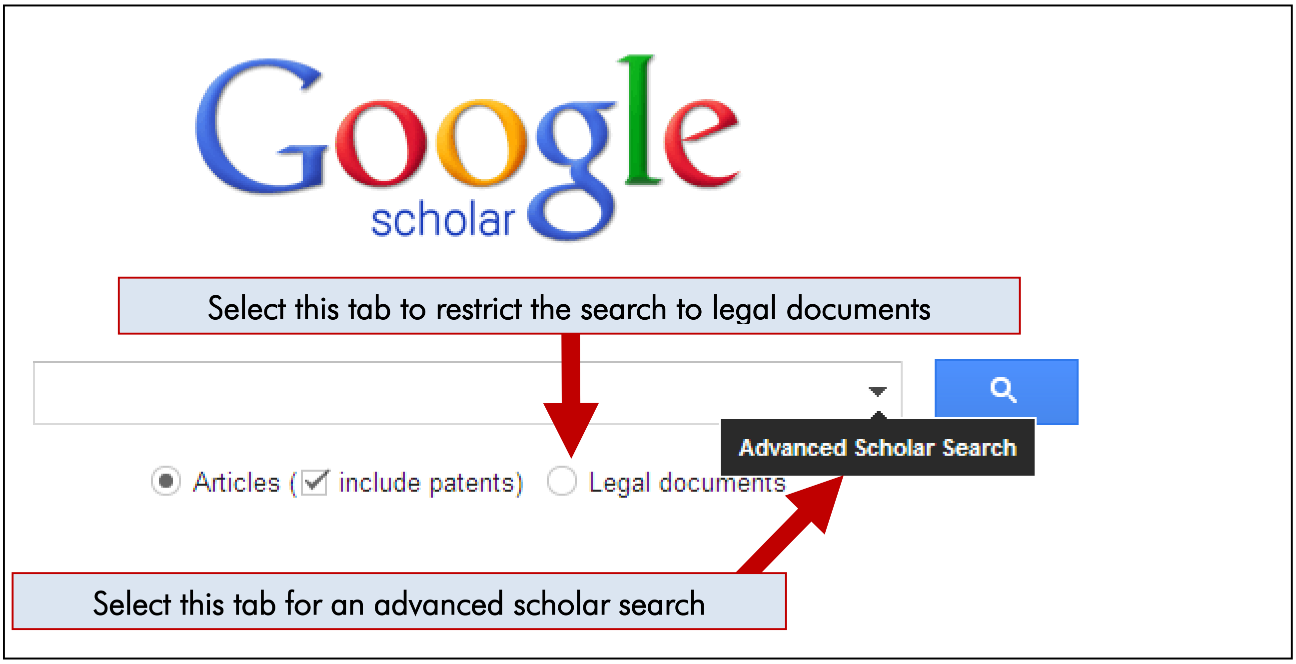
Google Scholar is a popular option for searching for academic sources, including academic journal articles, Google Books and information posted on university websites.

In order to access Google Scholar:

- Go to a Google website e.g. www.google.co.uk
- Select "more", then "even more" on the banner across the top of the screen
- Scroll down to "Specialist Search" and select "Scholar"

Or simply follow this link: http://scholar.google.co.uk.

The image below displays the main search engine site and points to the "advanced scholar search" tab and the "legal documents" tab:



Select this tab to restrict the search to legal documents

Select this tab for an advanced scholar search

Please let us know if you find key sources (e.g. academic journal articles) that you are unable to access and we can try to access these for you.

4.3 Database Searches

Possible relevant databases include legal ones, such as Lexis, Westlaw or Hein Online (but please note your country is likely to have others) and literature databases such as ASSIA (Social Science). They also include journal indices, which do not provide full text articles, but are helpful as they do include abstracts and information about where the full text article is located.

4.3.1 Country-Specific Legal Database searches

A good starting point is the EUR-Lex database as this now provides links to national legal databases via N-LEX, the common gateway to national law, available at: http://eur-lex.europa.eu/n-lex/index_en.htm. When you access N-LEX index page you can select your country from the list presented on the left-hand side of the page. The following table identifies some free legal and newspaper databases in partner countries. However, this list is by no means exhaustive and there may be further databases available in your country.

Database Name	*Available in…*
N-LEX; Latvijas Vēstnesis; Likumi.lv; and LETA	Latvia
N-LEX; Lietuvos Republikos Seimas; Legal Information Center at Ministry of Justice: http://www.llrx.com/features/lithuanian2.htm	Lithuania
N-LEX; NEMZETI JOGSZABÁLYTÁR; Intro to Hungarian Law Research: http://www.llrx.com/features/hungarian.htm	Hungary
N-LEX; IUS INFO; URADNI LIST	Slovenia
N-LEX; Lex.bg; State Gazette	Bulgaria
N-LEX; Repertoriul legislatiei României; Repertoriul legislative	Romania
N-LEX; CY LAW	Cyprus
N-LEX; Boletín Oficial del Estado Iberlex	Spain
N-LEX; Irish Statute Book; BAILII	Ireland

4.4 Assistance and Training

Note that guidance on using particular databases or search engines is generally provided in context. There may also be support available from technicians or library assistants. Please use any assistance which is available if it would help you to make effective use of the systems available.

5. Referencing

5.1 Why is referencing required?

Accurately citing the source you have used enables others to find and use that source. Furthermore, acknowledgement of other people's ideas or work is essential in order to avoid plagiarism (a serious academic offence) and demonstrates the range, variety, reliability and trustworthiness of your research.[114] In addition, a well-referenced research report provides a much more convincing and authoritative basis for advocacy and therefore has the potential to be much more influential than a poorly-referenced report.

Please note that some sources are more authoritative than others and that your report will be regarded as more authoritative and convincing if it contains references to respected, trusted sources (themselves based on rigorous research and analysis) wherever possible.

5.2 When to Reference

It is important to provide references if you:

- are quoting text word for word directly from a source, whatever the source.
- are including diagrams or tables of data from another source.
- are discussing the ideas or research of another person in your own words.
- are paraphrasing the ideas from two separate sources linking them together using your own words.
- are making an observation or assertion about what the law requires – in which case you should refer to the statute, case or other authority for that point of law;
- are making an observation or assertion about what the policy is in your country – in which case you should refer to the document, decision or other source in which the policy was formulated or adopted.

Note: you need not use citations when mentioning facts that are commonly known.

5.3 Footnotes

We will be using a footnote style of referencing, which means all citations should appear in footnotes and not in endnotes or in in-text citations, such as "(Brown, 2007)". Whenever you paraphrase or quote a source or use the ideas of another person, you need to insert a footnote

---

[114] See Cardiff University, *Tutorial on Referencing*, available at: https://ilrb.cf.ac.uk/citingreferences/oscola/tutorial/page01.html (last accessed 10 July 2013)

marker after the full stop at the end of the sentence or after the word or phrase to which it relates and then insert the reference in the footnote pane.[115]

Note: Microsoft Word provides free tutorials on how to use footnotes in Word documents, please follow the link below:

> http://office.microsoft.com/en-gb/word-help/insert-delete-or-edit-footnotes-and-endnotes-HP001226522.aspx

You can also cross-reference sources that have previously been cited in full. For example, where footnote 20 gives the full citation:

> [20] *Dordevic v Croatia* [2012] ECHR 1640

- if the footnote immediately after also refers to a quote from the same paragraph it would be referenced using "Ibid.":
  [21] Ibid.
- if it is the same case but the quote is from a different page:
  [21] Ibid., page 4.
- if it is not the immediately preceding note, refer to the earlier footnote:
  [30.] *Dordevic v. Croatia*, supra. note 20, page 4.

5.4 Reference style

In order to effectively manage the volume of work and reports to be submitted by each partner country and to ensure a reasonably consistent approach, it would be helpful if efforts could be made to reference sources in ways as close as possible to the guidance set out here. Inevitably, however, there will be differences between countries – particularly when referencing legal sources – and some variation in referencing style is likely to be inevitable.

5.4.1 Books

In footnotes the author's name should appear in full where possible (but, if you do not have the full first name, an initial followed by their last name will suffice); then the name of the book in italics, then, in (), the name of the publisher and the year of publication – e.g.:

> Colin Barnes and Geof Mercer, *Exploring Disability,* (Polity Press, 2013).

If you need to pinpoint a particular page or pages, please just add this to the end – e.g.

> Colin Barnes and Geof Mercer, *Exploring Disability,* (Polity Press 2013) 70, page 72.

---

[115] See Cardiff University, *Tutorial on Referencing*, available at: https://ilrb.cf.ac.uk/citingreferences/oscola/tutorial/page01.html (last accessed 10 July 2013)

Contributions to edited books should be referenced as follows:

> Louise du Toit, "The Conditions of Consent" in Rosemary Hunter and Steve Cowan (eds.), *Choice and Consent: Feminist Engagements with Law and Subjectivity,* (Routledge, 2007).

5.4.2 Journal Articles

Author's name, article title, year in (), volume and issue number if available, name of journal, start page, e.g.:

> Anne-Marie McAlinden, "An Inconvenient Truth: Barriers to Truth Recovery in the Aftermath of Institutional Child Abuse in Ireland" (2013) 33(2) *Legal Studies* 189.

and when pinpointing place a comma between the first page of the article and the page pinpoint e.g.:

> Anne-Marie McAlinden, "An Inconvenient Truth: Barriers to Truth Recovery in the Aftermath of Institutional Child Abuse in Ireland" (2013) 33(2) Legal Studies 189, 193.

Online journals should also include the URL address and the date accessed:

> Graham Greenleaf, "The Global Development of Free Access to Legal information" (2010) 1(1) European Journal of Law and Technology, available online at http://ejlt.org//article/view/17 (last accessed 27 July 2010).

5.4.3 Websites and Blogs

> Oliver Lewis, "A Social Paradigm of Mental Health" (*Oliver Talks*, 7 June 2013), available online at http://www.mdac.info/en/olivertalks/2013/06/07/social-paradigm-mental-health (last accessed 27 July 2010).

5.4.4 Newspaper Articles

> Jane Croft, "Supreme Court Warns on Quality" (Financial Times, 1 July 2010).

5.4.5 Cases

In the UK the correct way to cite case law is to give the party names first, followed by the year in [], then the report name and then the start page, e.g.:

> *Arscott v The Coal Authority* [2004] Environmental Law Reports 6.

If this type of format makes sense for the citation of cases in your country, please adopt it. However, if it is not appropriate, or not conventional, please just cite cases in the way in which they are generally cited in your country but do not use abbreviated names for reports, etc. (please write them out in full). If you need to pinpoint a particular paragraph or page, please provide the full reference and add, at the end of it, page xx or , para. xx.

5.4.6 Statutes and Legislation

You should use the style which is conventionally adopted in your country. It would be helpful to us if you could translate the name of the statute into English and include a list of translations at the end of the document.

5 Bibliography

Please add, at the end of your report, a bibliography which lists the literature you have cited (and does not include anything not cited). This should be organised alphabetically according to the author's last name.

6. Writing Style

Please focus on clarity and keeping your sentences short and your meaning clear.

Please work within the framework of headings, etc., mapped out in the data gathering template.

If you are using abbreviations or acronyms ensure that a glossary of terms is included at the end of your document. Please also ensure that the first time you mention the name you write out the full version followed by the acronym in brackets.

7. Phase 1 Methods Feedback

At the end of Phase 1, you will be requested to complete a short questionnaire about your experience of using desk-based research to locate answers to the questions set out in the data gathering template. Questions are likely to include:

- Your suggestions about the guidance – whether there is anything about it that could have been improved or whether there is anything that should be added (including databases, etc. that are relevant to your country)

- Any major obstacles you encountered when trying to access relevant information using these methods.

- The extent to which relevant data is publicly available and easily discoverable in your country and where, if anywhere, there are major data gaps.

Annex 3: Phase 2 Guidance

Workstreams 1 and 2
Data Collection and Standards

Phase 2: Facilitated Desk-Based Research

30 October 2013

1. Aims

1.1 Summary

- To progress the task of providing information about access to justice for children with mental disabilities in your country;
- To gain a clear understanding of the extent to which relevant information, not available from classic desk-based research methods, can be identified when assistance or facilitation is provided;
- To identify some of the barriers and limitations encountered in attempts to seek assistance and facilitation; and
- To identify research strategies that may prove helpful to include in future guidance to other researchers.

1.2 Textual Explanation

The aim of Phase 1 was to use desk-based research to collate, synthesise and summarise such data as is available from sources which are published or otherwise publicly available. The aim of Phase 2 is to supplement the information you have already found by seeking assistance or guidance from professionals or specialist databases or other sources.

NB: Phase 2 does not consist of collecting any information in the form of interview data in which your additional information or data consists of what was disclosed to you during the interviews. It consists instead of gathering additional data in the nature of literature, reports or statistics (of the type you have been gathering in Phase 1) of which you were previously unaware or unable to access. The idea is that you seek out advice and assistance from relevant professionals or information-keepers and pursue any additional sources of information which they recommend.

2. Meaning of Facilitated Desk-Based Research

NB: Facilitated desk-based research falling into Phase 2 of this project **does not** include:

- Using empirical research techniques such as issuing questionnaires or conducting interviews or focus groups.

For the purposes of this project, facilitated desk-based research means gathering data from (desk-based) sources which cannot be easily located without the assistance of professionals working in areas relevant to this project or without joining professional bodies or specialist libraries or other services.

3. Potential Types of Relevant Professional, Library or Other Service

Professionals whom you might wish to approach as part of this phase of the project, and bodies or libraries which it might be useful to join, will vary from country to country. However, the following list is intended to provide examples and ideas that may then be adapted to your specific situation.

(a) People working in courts or tribunals that regularly hear cases relating to children.

(b) People working in social services relating to children with disabilities, focusing on issues of family or other living arrangements.

(c) People working in education services for children with disabilities.

(d) People working in prosecution authorities with expertise or experience in dealing with crimes committed by children.

(e) People working in probation services specialising in crimes committed against children with disabilities.

(f) People working in social or other services focusing on providing support to children with disabilities who are victims of crime or bullying.

(g) Specialist professional libraries (e.g. court or social work libraries).

(h) Data banks (such as the UK Data Archive) which contain data (e.g. interview and focus group transcripts) collected in previous research projects, etc.

NB: If you become aware of a specialist data bank or library relevant to this study which costs a significant amount of money to join or access, please let Stéphanie know.

4. Guidance about Additional Sources for which to Search or Seek Advice

Please note that the purpose of Phase 2 is to supplement the information you have already been able to identify for Phase 1. It is therefore important to plan the issues on which you will be seeking advice and assistance in Phase 2. The obvious starting-point is to read through the questions in the template and the information you have already obtained through the Phase 1 desk research. Note the issues on which you believe there are important gaps or shortages. Some of these may be issues which will be difficult to address except by collecting new empirical data through interviews, focus groups, etc. This will be the task of Phase 3 and is not therefore of immediate concern in Phase 2. In this phase, you are urged to focus on seeking assistance and advice in collecting information which will address other gaps in your Phase 1 research.

5. Referencing

It is very important to the project that you identify clearly (using footnotes) how you have located information. If it is through a source made available to you (or even brought to your attention) by advice or assistance from a particular professional, please explain this in a footnote. This would help us to differentiate between information gained through Phase 1 methods and Phase 2 methods.

6. Phase 2 Methods Feedback

At the end of Phase 2, you will be requested to complete a short questionnaire about your experience of using facilitated desk-based research to locate answers to the questions set out in the data gathering template. Questions are likely to include:

- Your suggestions about the guidance – whether there is anything about it that could have been improved or whether there is anything that should be added (including databases, etc. that are relevant to your country).

- Any major obstacles you encountered when trying to access relevant information using these methods.

- The extent to which relevant data is publicly available and easily discoverable in your country and where, if anywhere, there are major data gaps.

Annex 4: Phase 3 Guidance

1. Background

A first draft of this document was sent to you on 18 August 2013 while you were working on your Context Report. The aim of this first draft was to help you prepare for the fieldwork stage of your data gathering by exploring possible ethical processes you will need to go through.

As requested in Stéphanie's e-mail on 26th June 2013, you provided information in response to the following requests:

> Please gather information concerning what is required from your country's **Ethics Committee** to obtain a research permit, if this is needed for the Project.
>
> Please send me information concerning:
>
> - Costs
> - The type of information you will need to present: what will they be looking at precisely?
> - Are there any deadlines for submission (committees might meet once a month? More?)?
> - What is this permission for: interviewing adults or children with disabilities strictly or NGOs or others?
> - Possible challenges in obtaining this permit?

In addition, some of you were able to send Stéphanie a summary of the information you gathered about all relevant ethical review processes in your country – including your assessment of difficulties they create with designing an ideal methodology for this project. We will need all this information in order to write our overall methodology report.

Your answers revealed that most of you do not require a research permit to carry out the forthcoming fieldwork. However, some of you will need to provide specific information on the field work, its scope, methodologies used, questions, and target groups in order to secure ethical approval.

This second draft aims to provide you with additional guidance on research design and other matters that should be taken into account when preparing an ethical approval application. Whether or not you need to apply for such approval, you should read the information about research design below with care as it is something which you need to think about before the end of November, even though you will not need to finalise your design until just after our December meeting in Budapest.

2. Aims

In Phase 3 of your work on the data gathering template (or list of issues), you will be asked to use fieldwork research to gather data to help complete the template and supplement the information gathered in Phases 1 and 2.

Please note that you should begin carrying out the field work in early January 2014 and that it is vital therefore to have obtained all necessary ethical approvals before then. As mentioned in our various exchanges with you and in the latest version of this document, the process takes time, so you should have begun working on this preparatory work, alongside the development of your context report and your Phase 1 (desk-based) research. On the basis of the information you found (about timelines, etc.) to guide your decisions about when you needed to submit your application for ethical approval which you sent us on 16 September 2013.

This revised document contains the same information on ethical processes and possible methodologies you may use in Phase 3, to enable you to proceed with your ethics applications (if applicable) which was provided in the first draft.

Our intention here is to define further minimum requirements with respect to activities you will be expected to carry out in your field work to complete the data gathering where data could not be found with desk research and assisted desk research. In addition, we will provide you guidance on how to obtain information on experiences of access to justice for children with mental disabilities in the administrative, civil and criminal domains which may very well conflict with your findings in Phases 1 and 2 for the same questions but also complement them.

Please note that a more fully developed version of this Phase 3 guidance will follow at a later stage after the meeting we will have with coordinators and researchers in December 2013 in Budapest. This meeting will help you finalise the preparation for your empirical research. This is a matter which each of you will need to decide and on which you might reach different conclusions.

We will not be imposing a rigid methodological structure on you for Phase 3 as we would like to ensure that there is enough flexibility for each country to develop an approach which is appropriate for that country. Nevertheless, in order to achieve some consistency, we will set out minimum requirements as to how your research should be conducted. You are of course free to identify additional steps you will take to gather empirical data as part of Phase 3. These minimum requirements are:

- At least 4 separate focus groups, consisting of approximately 5-8 participants. Each of these focus groups should address one of the topics/sections of the Data Gathering Template (i.e. disputes concerning the residence and living arrangements of children with mental disabilities; disputes concerning the education of children with mental disabilities; processes concerning children with mental disabilities accused of committing crimes; and processes concerning children with mental disabilities who are victims of crime). These focus groups should include relevant professionals and must demonstrate a balanced and considered approach to issues relating to children with intellectual disabilities, on the one hand, and children with psycho-social disabilities on the other (either through the mix of people selected to participate in each group or by ensuring that 2 separate groups are held on each of the 4 topics, one focusing on intellectual disability and the other on psycho-social disability).

- At least 4 one-to-one interviews (semi-structured or unstructured) with people who have experience of each of the 4 different issues either because they were involved in relevant proceedings or disputes when they were a child with an intellectual or psycho-social disability or because of their work in an NGO which represents children with mental disabilities. You will need to provide a convincing rationale for your choice of interviewees and again to be mindful of the need to ensure equal consideration of intellectual disability and psycho-social disability.

- Each country has been awarded a specific lumpsum for fieldwork costs. Please refer to your respective budgets and its relevant budget lines for "fieldwork costs for WS1". *(Please note that as we are now running activities for WS1 and 2 in parallel, we will add "WS2" to this budget line in MDAC overall budget and possibly "WS3" but this will depend on the remaining funding)* which will be used for Phase 3 research. It is your responsibility to ensure that your research design can be delivered within this budget. Please remember to include in your calculations costs associated with the following:

  - Equipment you might require for the focus groups or interviews (e.g. for audio-recording);
  - Travel expenses for you and your research participants;
  - Room hire and refreshments;
  - Transcription of focus groups and interviews.

Please also note that we need to keep track of your ideas about methods and to play a role in ensuring focus, relevance and appropriateness. We also need to be totally familiar with your proposed approach so that we can provide you with necessary guidance on using the various methods at the beginning of Phase 3. It is therefore essential that, if you are proposing to use a method other than focus groups or interviews that you let Stéphanie know before the beginning of December so that we can ensure that any training-related issues it generates are addressed in our December meeting.

In addition to the above guidance on methods and research design, please bear in mind that (to reduce the risk of complex ethical issues or objections) we advise that you should not attempt to recruit participants through medical professionals or through medical institutions. Please also note that it might be more useful and easier to interview young people with mental disabilities (e.g. over the age of 18 or over the age of 16) rather than younger children.

Finally, you will need to ensure that all the data you collect is stored safely and that the privacy of your research participants is protected. This will include taking steps to anonymise your data as soon as it is collected. If you need further guidance on this, or on issues relating to obtaining consent for purposes of completing ethical applications, please contact Stéphanie.

3. Research Ethics Procedures

3.1 Brief justification and historic background

Ethics is concerned with the attempt to formulate codes and principles of moral behaviour. Ethical decisions in research arise when we try to decide between one course of action and another not in terms of expediency or efficiency but by reference to standards of what is morally wrong or right.

The history of research ethics begins with the tragic history of research abuse by Nazi doctors during World War II. Cruel medical experiments that were conducted on people who were held in concentration camps against their will induced much suffering and often lead to death.

As a result the 1947 Nuremberg Code and other international codes of ethics were written to protect research participants. Under this code, the physicians were convicted for crimes against humanity[116]. Today, standards in research require that subjects participate voluntarily and are informed of the risks of the research.

Unethical social research may not usually cause death directly, but it can nonetheless cause significant harm, which is why we, too, may need to seek ethical permission for our fieldwork component.

You might also find that there are some peculiarities in ethics committees in some Central and especially Eastern European countries. Some evidence suggests that issues such as mental health care, but also research (especially social research), might have been strongly misused and abused by the past totalitarian systems in this region and that we can still feel effects of that legacy today.

These effects are very different in different contexts—from the underestimation of ethical issues to artificially raising the bar too high. In fact, some would argue that bioethical committees emerged for one reason: clinical drug trials were coming very aggressively to the region. The drug companies then helped governments to prepare the rules for approval of these clinical trials. The costs for ethical approval were introduced as part of such negotiations. These are nothing for drug companies, but they are a serious challenge for NGOs and other institutions who cannot always afford such payments.

3.2 Broad research ethics frameworks

Please familiarise yourself with the main ethical frameworks that apply in your country and to your area of study. In your ethics application, you should be prepared to answer questions on all of the categories listed in this framework.

For example, the *British Sociological Association Statement of Ethical Practice* can be accessed here:

---

[116] Shuster, Evelyne, Fifty Years Later: The Significance of the Nuremberg Code, *New England Journal of Medicine*, 337(20) (1997), pp. 1436-1440), available at: http://www.nejm.org/doi/full/10.1056/NEJM199711133372006 (last accessed 18 April 2015).

http://www.britsoc.co.uk/about/equality/statement-of-ethical-practice.aspx

When it comes to the researcher's relationships with participants, the guidance includes the following statements:

- The physical, social and psychological well-being of research participants should not be adversely affected by the research.
- Research relationships should be characterised by trust and integrity.
- Participation should be based on the freely given informed consent.
- Do not give unrealistic guarantees of confidentiality.
- Care should be taken not to compromise existing relationships within the research setting.
- Researchers should attempt to anticipate, and to guard against, consequences for research participants that can be predicted to be harmful.
- Researchers should attempt to find ways to minimise or alleviate any distress caused to those participating in research.

A research ethics application that abides by this framework would need to include information on how these points will be facilitated.

3.3 Access points and their ethical requirements

Think about organisations through which you are likely to seek access to potential participants. For instance, for the table below a fictitious "Respondent A" was created.

Personal attributes: Respondent A	**What does this tell us?/ What else do we need to know?**	**Possible access points**
Age: 15	School-aged	School/education authority
Mental disability: Yes (intellectual disability)	Does he have a social worker?	Social services authority
	Does he use any specialist social care services? (Respite care, etc.)	Social care service provider
	Does he use specialist health services?	Health service provider
Been to court as "victim" in an alleged child abuse case	This experience makes a relevant case study for our study	

		Known to courts	→	Courts/justice system
Case was discussed in a recent newspaper article	→	Known to reporter	→	Reporter/newspaper

As you can see, there are a number of different access points to "respondent A" or indeed to any of our respondents. For most of these access routes, we will require ethical permission.

To avoid over-complications, think about the most fruitful route (so the one where you are most likely to access the most respondents of the types you require) and start the process of preparing to apply for ethical permission via this route. Before you proceed, investigate the types of difficulty that this form of ethics application might encounter – e.g. in terms of cost, time, level of detail required and likelihood of success. Please make a note of these and send them to Stéphanie – it is valuable data that we will need to include in the final methodology report. If your ideal access route would entail an ethics application process which would be difficult to negotiate within the time and resource constraints of this project, consider whether there is an alternative access route with a different ethics process attached and, again, investigate potential difficulties before preparing your application.

For example, in the UK context, accessing respondents via the health system is a long-winded and for social research perhaps overly-complex process, as their ethics procedure is much more thorough, because it is aimed at much riskier medical research. In the case of "Respondent A", using a social services or education authority for access will nonetheless take time and preparation, but should be more straightforward.

The final access route identified in the earlier diagram may not require ethical permission. In case you are unable to receive an ethics permit, it might still be worth thinking creatively about such ways in which you can speak to people without the need to go through services. In the example we give, one such way would be to ask a reporter who wrote about a relevant case study to forward your contact details to their source, giving them the option to contact you, in case they would like to share their story for the purpose of this research.

3.4 Research ethics, children and other "vulnerable" participants

Additional ethical issues arise in research with children or adults who, for reasons such as mental disabilities, are viewed as "vulnerable" participants.

For example, as children will have varying degrees of consent capacity, the consent of the child should be sought in addition to that of the parent. When seeking to enable respondents to make informed decisions about their participation, you will need to provide information that can be understood by the child or adult with mental disabilities. Researchers should furthermore have regard to issues of child or adult protection and make provision for the potential disclosure of abuse.

You should expect research ethics applications to be more complex and guidance to be much tighter if you are planning to engage such groups.

For instance, there are separate ethics procedures in place for research with the UK's National Health Service's (NHS) staff, compared to those for patients. Staff are considered "less vulnerable". When conducting research with patients, more through checks are applied. Furthermore, additional criteria need to be satisfied if children or "vulnerable adults" are involved.

You need to consider whether you can realistically complete your ethics application within the timeframe and budgets we have available. However, please do not let the fact that gaining access to this group of respondents is more complex put you off! If you think you could gain useful insights from this group (perhaps you have worked with them before and feel confident in communicating with children with mental disabilities), stick with this idea and investigate the difficulties associated with applying for ethical approval. Again, please let Stéphanie know of any difficulties that you identify...

You will not be able to gain the same kinds of insights from substitute respondents (such as carers, parents, professionals). Nonetheless, if ethical approval for conducting research with children or adults with "mental disabilities" proves impossible, you will need to select this route.

4. Developing your research questions

When preparing your ethics application, you will need to answer very specific questions about the format of your fieldwork research, the **kinds of questions** you are going to ask and **what exactly will happen to your respondents**. As you are finalising your desk research and will soon start your assisted desk research, you should have a better idea of which questions from the Data Gathering Template (list of issues) have a better chance to be answered with your fieldwork. Your fieldwork will be important for completing various parts of the template which you have not been able to address on the basis of Phase 1 or 2 research. For instance, it is likely to prove important for collecting evidence of:

- the strengths and weaknesses of the existing system;
- personal experiences;
- details of case studies and positive/negative examples;
- whether laws and policies which appear to be human rights-compliant on paper are in fact working effectively in practice; and
- information about possible ways in which the system might be reformed.

Tip: As you are becoming increasingly familiar with the body if information available in your country, read and re-read the list of questions in the report framework. Highlight any topics on which you will want to gather further information at the fieldwork stage. Draft a list of questions you may ask. Remember, you can always go back to these and delete questions that are no longer needed after you identify further information from the literature.

It would be useful to organise your questions according to **the structure of the Data Gathering Template** and therefore per domain (administrative, civil and criminal). You should also try to obtain practical feedback concerning relevant general questions in section 1. These questions may very well be "warm-up" ones.

In addition, questions should also be organised per stakeholder group (for this please refer to your stakeholder analysis). These target groups should include:

- **Representatives of relevant ministries;**
- **Legal professionals (lawyers, barristers, judges, prosecutors);**
- **Representatives of law enforcement authorities;**
- **Relevant professionals working with and for children with mental disabilities (but not from healthcare), including personal care assistants;**
- **Relevant NGOs and Ombudspersons;**
- **Disabled people's organisations (DPOs);**
- **Parents/close members of families of children with mental disabilities;**
- **Children and young people with mental disabilities (with parental consent); and**
- **The media (more appropriate in criminal cases)**

Bear in mind that you should also select your interlocutors to obtain information on **cross-cutting issues** such as the impact of gender, age, ethnic origin, status, etc. on access to justice for children with mental disabilities.

Where possible, you should aim at including **identical questions** for each so that we can compare differences in experiences and approaches.

To respond to the objectives listed above, here are examples of possible questions to obtain information on the experience of your possible target groups. Please note that this is a non-exhaustive list of questions and you may consider additional stakeholder groups. These are here to guide you in your individual interviews and in focus groups whether your do those in a semi-structured or non-structured manner as **these are the issues to be kept in mind.**

DECISIONS CONCERNING EDUCATION OF CHILDREN WITH MENTAL DISABILITIES	
Target Group	**Examples of Questions**
Legal Professionals	**Introduction** What is your experience of representing the rights of a child with mental disabilities when deciding on his or her education? (Lawyers?) **THEME: Structures and Mechanisms** • Are children present in each case? What are the barriers to their presence? • Are structures and mechanisms accessible to all children with mental disabilities? What should and could be improved? What would you say is adapted to the needs of children with mental disabilities during proceedings and what is not? • Can you give us a positive example of a case in which you things worked very well? • Can you give us any specific negative examples and the way in which they affected people with disabilities? **THEME: Right to Information** • Do you inform them about their rights, nature of proceedings and possible outcomes and advise them directly? If so, do you use a particular approach or communication methods? Are you provided with particular support to do this? • If not, do you always communicate with parents only? In your opinion, what should be improved and how? Do you have positive examples where communication worked well? **THEME: Right to Participation** • Are there any conditions for a child to be allowed to express his or her opinion? How is this decided and by whom? • When a child can express his views, do you always take these seriously? Into account? If not, are reasons given to children for not doing so? • What happens when the expressed views of the child differ from that of his or her parents?
NGOs, Ombudspersons	**Introduction** • Describe your work in this field and how it could contribute to this project. • What is the general perception in your country of inclusive education? • Strengths and weaknesses of laws, policies and other frameworks for children with mental disabilities? • Is a particular group of children more affected by violations to their right to access justice? (Roma children, girls, children of a certain age, children in institutions, children without parental

	care?) • What are the main challenges to ensure justice for children with mental disabilities when deciding on where they should be educated? • Describe the role of parents in this process. • Do you know of good practices (alternative communication methods) to support and protect them during this process? Are these child-friendly, available and accessible? • Describe any action plan, programme, proposals for reforms that you know of to support the access to justice for children with mental disabilities when deciding where they should be educated.
Parents and Families	Introduction • Explain how, where and by whom your child was/is being educated. • How is/was the decision made? • Who was involved? THEME: Structures and Mechanisms • Where was it decided? How did you know about the relevant structure? Was it far away? Did you go yourselves? Or were you and your child legally represented? • Did you know of any other alternative? If there was any, did you take the decision on where to go on your own? With your child? Lawyer? Other professional? THEME: Right to Participation • Could your child go with you? Did you ask your child whether he or she was willing to come? Did you explain to him or her what was going to happen there? • Was your child allowed to participate in procedures? • Was your child provided with communication support? • If yes, did you think that this was helpful to reach a fair decision? • To what extent were you involved in this process? In the end, was the final decision, your decision? If not, what steps could you take to change this decision? • Do you know if your child agreed with it/with you? THEME: Right to Information • Do you know what your rights and that your child's are when making such decision? Was your child informed of his or her rights? If yes, how, when and by whom? THEME: Right to be Protected • Do you think that any of your child's rights were violated during this process because he or she has a disability? Other?
Young people with	Introduction

mental disabilities	• Explain how, where and by whom you are/were educated. • Are/were you satisfied with the decision on where you should be educated? • Do you know who was involved in that decision? Were you? THEME: Structures and Mechanisms • Do you know where the decision took place? • Were you allowed to be present? If not, why (was it explained to you)? • Was it accessible (far away from home/institution?)? • What did you think of the structure you went to? Was it suitable for children? Adapted to your needs? THEME: Right to Participation • Did you participate in the proceedings? If yes, what was your experience of this? Were you asked if you needed anything? Any support? Did you think it was helpful? Could you say what type of support you wanted and needed? Did you understand what was going on and what rights you had? Who explained what to you, and when? • If not, would you have wanted to participate? Did you think it was normal that you couldn't? Unfair? • Did you express your preference as to where you should be educated? If so, to whom and when? Do you think your views were taken seriously? Were they taken into account? Were reasons given to you for not taking your preference into account? If you did not agree with the decision, do you know if you could have taken steps to change that decision?

5. Overview of possible methodologies you should try and might then use

5.1 Quantitative vs. qualitative research

Quantitative and quantitative methods are the two general methodological approaches. While they are not totally opposing approaches, they do adopt a very different position on the fundamentals of the relationship between ideas and evidence.

As the name suggests, quantitative research is the numeric measurement of specific aspects of phenomena. It aims to make generalisable findings, which is why quantitative research usually aims to feature large samples, representing a broad cross-section of the community.

Qualitative research is the **intensive study of as many features as possible of one or a small number of phenomena**. It seeks to gain understanding by depth and is not as interested in breadth as is quantitative research. Qualitative researchers seek meaning. **Meaning** is achieved by looking at all aspects of the same phenomenon to see their inter-relationship and to establish how they come together as a whole. The field work for this project will be qualitative, but you may well come across quantitative work, carried out by others, which is useful in answering questions in the template. The qualitative methods discussed here are **interviews** and **focus groups**.

5.2 Interviews

5.2.1 Introduction

Qualitative interviews have a relatively informal style, for example, with the appearance in face-to-face interviewing of a conversation or discussion rather than a formal question and answer format.

Researchers usually assume that people's knowledge, views, understandings, interpretations, experiences, and interactions are **meaningful properties**. A purpose of interviews is to listen to people, to gain access to their accounts and articulations.

At the beginning of the interview, the researcher has a number of **topics**, **themes** or **issues** which they wish to cover, or a set of starting points for discussion, or specific "stories" which they wish the interviewee to tell. The researcher is unlikely to have a complete and sequenced script of questions, and most qualitative interviews are designed to have a **fluid** and **flexible** structure, and to allow researcher and interviewee(s) to develop unexpected themes.

There are two main ways of structuring qualitative interviews, as discussed in the following.

5.2.2 Semi-structured interviews

In semi-structured interviews the researcher has a list of specific questions or topics to be covered (**interview guide**). Depending on the preference of the researcher, the questions may be fully written out or the interview guide may simply include short phrases or single words as reminders of the topics the interviewer seeks to cover.

Questions **may not follow the exact schedule** of the interview guide and questions can be asked that were not originally thought of by interviewer. For example, if the respondent offers a potentially interesting piece of information, the interviewer can probe and follow this up and perhaps even include this topic in the list of questions for subsequent interviews.

To illustrate what an interview guide may look like, a sample is reproduced in the box below. Please note that this is taken from a book chapter that is not yet published.[117] The interview guide relates to a study by Sheard,[118] which explored how 40 women interviewed in the North of England use spaces in the night time economy and consumed alcohol, alongside their fears for potential violence against them.

---

[117] Hollomotz, A. and Sheard, L., "Asking open questions: Semi-structured interviews", in Scott-Jones, J., Cain, L. and Pollock, G. (eds), *Ready-Made Research Methods: Becoming a social researcher*, London, Palgrave.

[118] Sheard, L., "'Anything Could Have Happened': Women, the Night-time Economy, Alcohol and Drink Spiking", *Sociology*, 45(4) (2011), pp. 619-633.

Night time economy (NTE) including pubs, clubs and bars

Where would you go out on a night?

- With whom? Why?
- The city centre? Suburb? Both?
- Do you feel safe in these places? Why/why not?
- Have you ever encountered any threats to safety when on a night out?
- Have you seen violence in the NTE? What are your thoughts about this in relation to own safety?
- What steps would you take to try and ensure your personal safety on a night out?

Role of alcohol

- Do you think your own alcohol consumption affects your perceptions of safety or actual safety? How? Probe for specific examples.
- Retrospective safety – anything you did under influence of alcohol which you later regretted or thought was risky/stupid/daring/brave? Why did you do this? What informed your decision making at the time? Would you have done this sober?
- "Drink spiking" – is this a concern to you? Why and how?
- What precautions would you take to try and ensure personal safety? What precautions would your friends take?

5.2.3 Unstructured interviews

Hollway & Jefferson[119] are critical of semi-structured interviews, as these

> "come under the question-and-answer type, where the interviewer sets the agenda and in principle remains in control of what information is produced. In this mode, the interviewer is imposing on the information in three ways: "by selecting the theme and topics; by ordering the questions and by wording questions in his or her language"[120].

Unstructured interviews stand outside this framework. Even though there is less structure, the interviewer **still pursues a purpose and a set focus.** The interview guide is replaced by a prompt sheet, which captures a list of topics that the researcher could pursue.

There are a vast range of forms of unstructured interviewing methods to choose from, including narrative, oral life history and bibliographical methods. The **open-ended** nature of these interviews requires a high level of skill from the facilitator. We would therefore not recommend these immediately to the novice researcher. The practice of semi-structured interviewing may be more suitable for those who feel less confident, as the interview guide provides more structure than a prompt sheet.

5.2.4 Formats

Qualitative interviews may take place **face-to-face**, over the **phone** or on the **Internet** (using Skype, for example). One way of doing qualitative interviews via e-mails is to post one question at a time,

---

[119] Hollway, W. and Jefferson, T., "Researching defended subjects with the free association narrative interviewing method", in Cook, H.J.B., Sanjoy and Hardy, Anne (ed), *History of the social determinants of health: Global histories, contemporary debates*, (2009) Hyderabad, Orient Black Swan.

[120] Bauer 1996:2 cited in Hollway & Jefferson 2009, p.301

to await a response (but usually provide a time limit within which interviewees should get back to you) and to then follow this up with the next question.

5.3 Focus groups

5.3.1 Introduction

Focus groups are **group interviews**. They typically bring together people who possess **certain characteristics** that are of interest to the researcher, to provide qualitative data in a **focussed discussion** in order to help understand the topic of interest[121].

Below, these points are further explained:

Focus groups are **typically composed of 5 to 10 people**. The group must be small enough for everyone to have the opportunity to share insights and yet large enough to provide diversity of perceptions and perspectives.

Focus groups are composed of participants who are **similar to each other** in a way that is important to the researcher (e.g. age, gender, occupation, interests, etc.).

The goal of focus groups is to collect data that is **of interest to the researcher**, typically to find out about a **range of opinions** held by people across several groups. The researcher then compares and contrasts data from across groups. In order to do that the general advice is that **at least three groups are needed**. (However, note that we said the absolute minimum requirement in this project will be two groups.) Focus groups differ from other group interactions, where the aim is to come to some conclusion at the end of a discussion, to reach consensus, provide recommendations or make decisions amongst alternatives. Here, we are particularly interested in taking account of a **diversity** of opinions.

When writing up your findings, take care to point out differences in opinion across groups and types of respondents (if different).

The **questions** in a focus group are carefully **predetermined** and **sequenced** so that they are easy to understand and **logical** to the participant. That means that they should be phrased using language/terminology that participants use. (For example, adjust your use of language in focus groups with lawyers, compared to the language you would use on focus groups with children with MD.) It also means that, if you are aiming for a semi-structured format, questions should logically follow on from one another. For example, do not jump from questions about court proceedings to questions about inclusive education, back to questions about court proceedings.

The focus group moderator uses open-ended questions. These questions appear spontaneous but are carefully developed after considerable reflection and input.

In focus groups the researcher creates a **permissive environment** that encourages participants to share perceptions and points of view. The discussions are relaxed and often participants enjoy sharing their ideas and perceptions.

---

[121] Krueger, R.A. and Casey, M.A., *Focus groups: a practical guide for applied research*, (London: SAGE, 2009).

5.3.2 Moderating focus groups: A brief guide[122]

- Be **interested** in the participants – show **positive** regard: Moderator respect for participants is one of the most influential factors affecting the quality of focus group results.
- The moderator must truly believe that **participants have valuable wisdom**: No matter what their level of education, experience or background. Even if the participants may have limited knowledge, hold opinions opposing values to those of the researchers or have seemingly fuzzy logic, still the moderator should listen attentively and sensitively. Lack of respect quickly telegraphs to participants and essentially shuts down meaningful communication. Why should participants share their personal feelings when the moderator is arrogant? As with interviews, empathy and positive regard are vital.
- Be a **moderator**, not a participant: Your role is to guide discussion and listen to what is said, but NOT to participate, share views, engage in discussion, or shape the outcome of the group interview.
- Be ready to hear **unpleasant** views: Sometimes the researcher has a personal commitment to their topic. In that case it can be hard to listen to respondents who might have limited knowledge and offer half-truths and criticise things that are near and dear to their heart. You might find it hard to smile sincerely and say "thank you" after a respondent has contributed disablist views, for instance. However, if you challenge the respondent instead of listening, you will not gather accurate data on the respondent's views, as they may just hold them back.
- You cannot moderate all groups: Participants must feel comfortable with the moderator. They must feel that the moderator is the appropriate person to ask the questions and that their answers can be openly offered and discussed. Conscious considerations should be given about factors such as age, gender, language, ethnicity, socio-economic characteristics and so forth. If a group will not accept you, find it hard to speak openly or deem you incompetent conversations will not flow easily.
- Use your unique **talents**: Each individual brings unique skills and abilities to the moderating experience. Copying the style of another does not work if it seems artificial to you. When the moderator is comfortable and natural, participants will feel more relaxed and willing to share. How will others know that you are interested in what they are saying? How do participants know that you care about the topic and that you place value on what they are saying? Each of us is unique and while there are some global strategies (eye contact, smiles, active listening, repeating comments), each moderator will display these in different ways.

5.3.3 Formats

As with interviews of individuals, focus groups can be conducted **face-to-face**, but also **online**, for example using online chat room facilities or technologies, such as Skype.

Focus groups can be **semi-structured** or **unstructured.** The latter format is more common and easier to facilitate in focus groups, compared to individual interviews.

---

[122] Richard A. Krueger, *Moderating focus groups* (London: SAGE, 1998).

5.3.4 Use of vignettes/case studies as discussion material

One way of starting off conversations in focus groups or getting participants to talk when conversations have stalled (the "joker up the sleeve", so to speak), is to consider using a vignette. This could be a **short video clip, recording or written story** (best supported by pictures if used with children with MD) of a relevant case study. Perhaps you can look out for suitable material in Phase 1 and 2? More guidance on the use of vignettes will follow closer to Phase 3.

5.3.5 Individual interviews or focus groups?

Whether you conduct individual interviews or focus groups will depend on **the types of questions you ask and the types of data** you are after. It may also be determined by practical and resource implications.

For example, focus groups can be **"cheaper"** to conduct, as you can interview several respondents at one time. This can save on researcher **time** when transcribing or summarising the findings. On the other hand, they are also harder to organise.

You will need to make sure that a number of people can get together at the same time and in the same place. If the latter is not possible, you may be able to escape to an online format. Either way, always make sure that you **over-recruit**, as not all participants who said they will come will turn up. For example, make sure ten respondents have confirmed their attendance if your aim is to have at least five participants.

W www.mdac.org mentaldisabilityadvocacy @MDACintl