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Access to justice for children with mental disabilities

The Collection and Dissemination of Data: Guidance Report



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The Collection and Dissemination of Data: Guidance Report

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Executive Summary

This report was compiled as part of a 10-country EU-funded project co-ordinated by the Mental Disability Advocacy Center (MDAC). Its starting-point is the lack of information that currently exists about the experiences of children with mental disabilities who are involved in judicial proceedings. Without such information, the nature and extent of the access to justice barriers facing these children remains hidden from view. The report examines a range of indicator systems which have been developed to facilitate efforts to monitor progress in the implementation of the human rights of children and of people with disabilities. Despite some impressive initiatives to ensure that indicators are designed in such a way as to capture

any intersectional disadvantage that might be experienced by children who also have a disability, there was very little statistical or other data relating to them – and still less about children with different types of disability (including psychosocial or intellectual disabilities). The design of information systems capable of producing disaggregated data poses a number of challenges, which are also examined. The report also looks at the ways in which the European Commission and other public bodies with the capacity to fund relevant research could support the efforts of independent researchers to gather more information about children with mental disabilities in the justice system. The report concludes with 15 recommendations.



1. Introduction

This report has been written as part of a project, co-funded by the Fundamental Rights and Citizenship Programme of the European Union, European Commission (DG Justice), on “access to justice for children with mental disabilities”. The term “children” will be used to refer to people under the age of 18.¹ The term “mental disabilities” will be used to refer to people who have (or are treated as having) intellectual, developmental, cognitive, and/or psycho-social disabilities. The guidance on the term “people with disabilities”, provided by the UN Convention on the Rights of Persons with Disabilities (CRPD), will inform various parts of the analysis below. 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”.²

Workstream 1 of this project concerns the collection and dissemination of data about children with mental disabilities in the justice system. It responds to concerns (such as those expressed by the European Commission in Agenda on the Rights of the Child 2011)³ about the lack of reliable data on the situation of children in judicial proceedings and to the importance of ensuring that children with mental (or other) disabilities are not rendered invisible in efforts to remedy the problem. Under Workstream 1, two reports have been compiled, both of which draw on United Nations (UN), Council of Europe (CoE) and European Union (EU) standards to provide the underpinning evaluative framework.

One of the Workstream 1 reports (the “Data Synthesis” report), provides an analysis of relevant findings in the 10 project countries.⁴ It addresses the extent to which relevant data was found to exist in these countries and the extent to which it was available and accessible to researchers. It also explores the challenges and successes experienced by researchers when attempting to collect new data through a range of empirical

research methods. This “Data Synthesis” report concludes that, in all countries, there are serious data gaps which make it extremely difficult or impossible to find out what happens to children with mental disabilities in justice systems around Europe and therefore to track the extent to which progress is being made in strengthening their rights to access justice.

The second Workstream 1 report is the current report – the “Data Guidance” report. Its primary aim is to provide suggestions and guidance to European and national bodies on how these shortcomings might be addressed. In addition, however, it aims to provide a human rights based critique of this subject which will help to advance debate about the collection of data in connection with the implementation and monitoring of the rights of children with disabilities more generally.

This report will be divided into three main sections, besides the Introduction and Conclusion. The first of these (Section 2) will examine standards and initiatives relevant to the establishment of mechanisms for the collection and dissemination of large-scale anonymised data which monitors the access to justice rights of children with mental disabilities in justice system organisations. Section 3 will then explore questions concerning the nature of the age and disability-related information which justice system organisations would need to collect for each child in order to support human rights monitoring of the type discussed in Section 2. Finally, Section 4 will address the collection of data by independent researchers and consider how such efforts might be enhanced and facilitated by governmental bodies.

All three of the main sections of this report will include discussion of relevant UN, CoE and EU law and incorporate recommendations. These recommendations will be brought together and set out in full at the end of the report.



1 This is broadly in line with the Article 1 of UN Convention on the Rights of the Child.

2 CRPD, Article 1.

3 European Commission, 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, 15 February 2011, COM(2011)60 final.

4 Anna Lawson and Rebecca Parry, *Access to Justice for Children with Mental Disabilities. Data Collection and Dissemination: Synthesis of Findings*. (Leeds - Budapest: University of Leeds - MDAC, 2015). Forthcoming.

2.

Collecting and Disseminating Data for Monitoring Progress in the Implementation of Access to Justice Rights for Children with Mental Disabilities

2.1 Introduction

Effective systems for monitoring the extent to which change is occurring play a crucial role in the implementation of the commitments made by governments through human rights and discrimination law. The information collected through such monitoring systems exposes the existence and extent of inequality or disadvantage. This increased visibility may itself prove a powerful lever in reform initiatives and in decisions about allocations of resource. The collection of data concerning people who have characteristics placing them at the intersection of two types of disadvantage (such as disability and childhood) presents additional complexity but is essential in any monitoring system which seeks to identify and track particular issues of marginalisation to which such people might be exposed.

In this section, attention will first be directed to relevant standards relating to the collection of data for purposes of monitoring the access to justice rights of children with mental disabilities. This will be followed by an analysis of guidance on the construction of indicators to facilitate such monitoring and the extent to which current European indicator systems include the experiences of children with mental disabilities in judicial proceedings. Finally, before setting out suggested recommendations, a few words will be devoted to the subject of the dissemination of relevant data.

2.2 Standards Relating to the Collection of Data about Children with Mental Disabilities in the Justice System

Requirements relating to the collection of data on children with disabilities in the justice system are to be found both in the CRPD and the Convention on the Rights of the Child (CRC). Parties to both these treaties are required to submit to relevant treaty monitoring bodies (the Committee on the Rights of Persons with Disabilities and the Committee on the Rights of the Child respectively), on a regular basis, comprehensive

reports on the measures they have taken to give effect to their treaty obligations and on progress made in ensuring that rights conferred by the treaties are enjoyed in practice.⁵ Guidance on the form these reports should take, and on the type of data they should include, are issued by the two committees in the form of “reporting guidelines”, some reference to which will be made below. Innovatively, and in recognition of the

⁵ CRPD, Article 35 and CRC, Article 44.

historic invisibility of disability in human rights monitoring, the CRPD articulates an additional new obligation (separate from, but overlapping with, the State 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”⁶ 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”.⁷ This provision goes on to require that this information shall be “disaggregated, as appropriate” and that the process of collecting and maintaining it shall comply with legally established safeguards (such as regulations on data protection) and principles of ethical research.⁸

The CRC Committee has drawn attention to the importance of data collection in a number of General Comments.⁹ In relation to the particular context of the juvenile justice system, the CRC Committee stated in its General Comment No. 10 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.”¹⁰

A recent UN General Assembly resolution also urged States to strengthen their efforts to collect data on children in the justice system.¹¹ According to this, efforts are needed 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”¹²;

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”.¹³

Some attention is also given to data collection in relevant CoE instruments. The Guidelines on Child Friendly Justice¹⁴ encourage Member States to: “maintain or establish a framework, including one or more independent mechanisms, as appropriate, to promote and monitor implementation of the present guidelines,”¹⁵ and to “promote research into all aspects of child-friendly justice”.¹⁶ Action Line 14 of the CoE’s Disability Action Plan 2006-2015 is concerned with research and development and 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.”¹⁷

6 CRPD, Article 31(1).

7 CRPD, Article 31(2).

8 CRPD, Article 31(1).

9 See, for example, Committee on the Rights of the Child, General Comment No. 5: General measures of implementation of Convention on the Rights of the Child, 27 November 2003, CRC/C/GC/2003/5 – especially paragraph 9.

10 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.

11 United Nations, General Assembly, Human Rights Council, resolution No. 25/6: Rights of the child: access to justice for children, 25 March 2014, UN/A/HRC/25/L.10. of the Child, General Comment No. 10: Children’s rights in juvenile justice, 25 April 2007, CRC/C/GC/10, para. 98.

12 Ibid, para. 17.

13 Ibid, para. 19.

14 Guidelines of the Committee of Ministers of the Council of Europe on child-friendly justice, available at http://www.coe.int/t/dghl/standardsetting/childjustice/publicationsavailable_en.asp (last accessed: 15 December 2014)

15 Ibid, VI(c) and (d).

16 Ibid, V(a).

17 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, available at http://www.coe.int/t/e/social_cohesion/soc-sp/Rec_2006_5%20Disability%20Action%20Plan.pdf (last accessed 15 December 2014), Part 3.14.1.

The second of the objectives of this Action Line, which contains twelve important specific actions, is: “to harmonise statistical data collection methodology, nationally and internationally, in order to achieve valid and comparable research information”.¹⁸

The EU Victims’ Rights Directive¹⁹ 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”.²⁰ Further light is shed on this obligation both by recital 64 and also by subsequent guidance issued by the Commission. According to recital 64:

“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.”

A similar approach is adopted in the proposal for an EU directive on procedural safeguards for children who are suspected or accused of a crime.²¹ Again, this imposes a three-yearly obligation on States to provide the Commission with data which can be used to monitor the extent to which the rights it sets out are being implemented in practice. According to Article 20(2):

“Such data shall include in particular the number of children given access to a lawyer, the number of individual assessments carried out, the number of interviews audio-visually recorded and the number of children deprived of liberty.”

The presence of these data-gathering requirements in current and proposed EU legislation on criminal justice is to be greatly welcomed. So too is the emphasis given to the need to include specific data relating to the situation of children. Profoundly regrettable, however, and slightly surprising, is the fact that no mention is made of disability (alongside age, gender and ethnicity) in either recital 64 or the subsequent Commission guidance on the Victims Directive.²² It is to be hoped that subsequent guidance will be issued for this and other justice directives which will draw attention to the need to include disability in the three-yearly data reports submitted to the Commission. Such an approach would certainly be in line with the Commission’s European Disability Strategy 2010-2020,²³ which seeks to support efforts to implement the CRPD, including by

“Significantly improving monitoring and evaluation by: creating conditions for improving the quality and comparability of data; developing relevant indicators and possibly common targets; collecting reliable data and statistics.”²⁴



18 Ibid, Part 3.14.3(ii).

19 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 315/57.

20 Ibid, Article 28.

21 Proposal for a directive of the European Parliament and of the Council on Procedural Safeguards for Children Suspected or Accused in Criminal Proceedings, 27 November 2013, COM(2013) 822 final.

22 European Commission, DG Justice guidance document related to the transposition and implementation of Directive 2012/29/EU of the European Parliament and 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, 19 December 2013, Ref. Ares(2013)3763804.

23 European Commission, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, COM(2010)0636 final.

24 Ibid.

2.3 Identifying Information to be Collected: The Role of Indicators

2.3.1 Guidance from the Office of the High Commissioner for Human Rights' Indicator Framework

Recent years have witnessed growing interest in the development of rights-based measurement indicators to stimulate, facilitate and structure the collection of relevant data.²⁵ The Office of the High Commissioner for Human Rights (OHCHR), at the request of the UN treaty bodies, has invested considerable effort in this task. This has resulted in the development of a three-fold indicator framework which has already proved extremely influential.²⁶ This is based on developing and populating indicators of structure, process and outcome.

According to the OHCHR, indicators of each of these three types should be used to measure all the key attributes of a particular human right. These attributes should be identified initially by means of a careful reading of treaty provisions and associated guidance from treaty monitoring bodies.²⁷ Indicators of structure are those which concern "the ratification and adoption of legal instruments".²⁸ Indicators of process concern the efforts that a State is making to carry out its human rights commitments (e.g. the amount of funding or number of personnel devoted to the implementation of the juvenile justice system).²⁹ Indicators of outcome "capture attainments [...] that reflect the status of realization of human rights in a given context".³⁰

In order to avoid confusion, it is worth reflecting on the "indicators" identified in the Workstream 2 report, *Access to Justice for Children with Mental Disabilities. International Standards and Findings across Ten EU Member States* (forthcoming). It seems clear that what are referred to in the Workstream 2 report as "indicators" are equivalent to what are described above as "human rights 'attributes'". Thus, they could provide the basis of a human rights monitoring framework on access to justice for children with mental disabilities but clear indicators of structure, process and outcome would need to be elaborated for each. The development of a specific stand-alone indicator framework on access to justice for children with mental disabilities is not, however, one of the recommendations of this

study. Instead, as will be explained below, we recommend the integration of indicators relating to children with different types of impairment or condition (including intellectual disabilities and psycho-social disabilities) into more mainstream systems for monitoring access to justice. We also recommend the inclusion of access to justice in systems for monitoring the rights of people with disabilities – a development that already appears to be happening in systems for monitoring children's rights.

2.3.2 Access to Justice for Children with Mental Disabilities in Existing Indicator Systems

A number of indicator systems relating to children's rights, to the rights of people with disabilities and to access to justice are emerging at the European level. Three leading European examples will be discussed here – the focus being on the extent to which they currently support the monitoring of the access to justice rights of children with mental disabilities.

The first indicator framework to be discussed here is the Disability Online Tool of the Commission (DOTCOM).³¹ This is an online database developed by the Academic Network of Disability Experts (ANED),³² with funding from the European Commission, to track progress in the implementation of the rights of people with disabilities in Europe.

Currently, DOTCOM presents information on laws and policies concerning 43 different issues, selected for their relevance to the European Disability Strategy 2010-2020 and the CRPD. These 43 issues are organised into eight themes or headings, which are: A, the status of the CRPD; B, the general legal framework for disability rights; C, accessibility legislation and standards; D, independent living; E, education and training; F, employment; G, disability statistics and data; and, H, awareness-raising, training and international action. Under each theme there are currently between three and nine items – each one representing a specific action or CRPD obligation. For each individual issue there is a factual summary description, written in English, with supporting web links to national legislation, official sources or other documented evidence. In total, the DOTCOM database describes and evidences more than 1,500 distinct policy

25 See generally, Todd Landman and Edzia Carvalho, *Measuring Human Rights* (London: Routledge, 2010).

26 OHCHR Human Rights Indicators: A Guide to Measurement and Implementation (New York/Geneva: UN, 2012) HR/PUB/12/5; OHCHR, *Report on Indicators for Promoting and Monitoring the Implementation of Human Rights* (New York/Geneva: UN, 2008) HRI/MC/2008/3; OHCHR, *Report on Indicators for Monitoring Compliance with International Human Rights Instruments* (New York/Geneva: UN, 2006.) HRI/MC/2006/7.

27 Ibid, OHCHR 2008, paras. 6 and 7.

28 Ibid, OHCHR 2008, para. 18.

29 Ibid, OHCHR 2008, paras. 19 and 20.

30 Ibid, OHCHR 2008, para. 21.

31 <http://www.disability-europe.net/dotcom> (last accessed: 15 December 2014).

32 <http://www.disability-europe.net/> (last accessed: 15 December 2014). See also the more detailed analysis of this system provided in: Anna Lawson and Mark Priestley, "Potential, principle and pragmatism in concurrent multinational monitoring: disability rights in the European Union", *International Journal of Human Rights*, 17(2013): 739-757.

measures and contains over 3,000 links to supporting sources. However, DOTCOM does not contain information that could be used to populate outcome indicators.³³ The data it contains is limited to information relevant to indicators of structure and process.

It is evident from the above list of DOTCOM themes that access to justice does not feature amongst them. Neither does it feature explicitly in the titles of any of the subsidiary items within each theme. However, some information relevant to the justice system is contained within several of these items. For instance, item B1, entitled "Anti-discrimination legislation" may well reveal whether there is a prohibition of disability discrimination by providers of legal services. Similarly, information about children with disabilities is not highlighted in the titles of the DOTCOM themes and items but is likely to be contained within various of them. However, it seems safe to conclude that searching DOTCOM for information about laws and policies relating to access to justice for children with mental disabilities is likely to yield very little relevant information.

The second indicator framework that will be considered here has been developed by the EU Agency for Fundamental Rights (FRA) and concerns children's rights particularly in areas of EU competence.³⁴ Its aim is to provide guidance to assist the FRA in its own data collection work and which might also assist States in their own data collection efforts concerning children's rights. Accordingly, it takes the form of a framework but does not itself include any country-specific data.

This indicator framework consists of four core domains. These are: family environment and alternative care; protection from exploitation and violence; adequate standard of living; and education, citizenship and participation in activities related to school and sport. Within each of these domains there are subgroups within which there is a series of indicators. Some of the subgroups, particularly in the first two domains, concern access to justice. For instance, the "existence of child-sensitive family justice processes" and the "enforcement of custody, access and maintenance orders" appear under the heading of "separated children due to cross-national divorce and parental separation", situated within the first domain of "family environment and alternative care". Also within this domain are "participation of children in immigration processes" and the "adaptability of immigration processes to the vulnerabilities of separated children", which appear under the heading of "separated children due to migration". Under each of these specific

headings appear more detailed indicators which are organised in accordance with the OHCHR's structure, process, outcome typology. In populating these indicators, FRA urges that all data should be disaggregated on the basis of disability as well as race, age, gender, religion and sexual orientation.³⁵

The FRA's guidance on indicators of children's rights provides a valuable platform on which States and others might construct detailed indicator frameworks for monitoring children's rights under EU law. For systems designed specifically to monitor their access to justice rights, however, further attention must be given to the precise issues (or "rights attributes") to be monitored and also to the indicators by which this might be achieved. The emphasis given by FRA to disaggregation on the basis of disability is also extremely welcome. It should be noted however that, as will be explained in Section 3 below, this level of disaggregation does not go far enough to comply with the demands of the CRPD. Further, as our research has demonstrated, this guidance has not yet resulted in the development of comprehensive indicator systems for monitoring the access to justice rights of children with mental disabilities on the ground.³⁶ It is also clear from our research that, at present, there would be very little data available to populate any outcome indicators in such systems.

The third indicator system is specifically concerned with the access to justice rights of children and is therefore of particular significance. This is the master list of indicators for Children in Judicial Procedures currently being compiled as part of a large-scale European Commission funded study – "Study to collect data on children's involvement in criminal, civil and administrative judicial proceedings".³⁷ As well as the master list of indicators for criminal proceedings and also for administrative and civil proceedings, the study aims to bring together relevant data from EU Member States to populate these indicators and to identify areas in which there are data gaps. Immensely useful though this exercise undoubtedly is, it includes very little disaggregation on the basis of disability (even in the idealised master list). It may be that disability will be integrated as the outcome indicators are populated. However, its low profile to date is disappointing as initiatives such as this have the potential to provide a powerful catalyst to data collection efforts. If disability is not adequately integrated into them, children with mental and other disabilities will continue to be invisible in the data that is gathered and presented. The European Commission is therefore to be encouraged to fund future work, building on this study, which will have a greater focus on children with disabilities.

33 Statistical evidence that would be appropriate for populating outcome indicators has been collected by ANED as part of its 'Indicators of Disability Equality in Europe' framework, but this information is published on its website in a series of thematic reports which have not (yet) been integrated into the DOTCOM database. As yet, the justice system has not been the subject of any of these reports.

34 <http://fra.europa.eu/en/publication/2012/developing-indicators-protection-respect-and-promotion-rights-child-european-union> (last accessed: 15 December 2014).

35 Ibid, p. 80-81 and 139.

36 Although, for an example of a useful more broadly-based indicator system for children's rights, see the Children's Monitoring Framework developed by the UK's Equality and Human Rights Commission - EHRC, Research Report 76, Developing a Children's Monitoring Framework: Selecting the indicators.

37 Available at: <http://www.childreninjudicialproceedings.eu/Home/Default.aspx> (last accessed: 15 December 2014).

Before leaving the subject of indicator systems, two further indicator frameworks need to be mentioned – the indicator framework on juvenile justice developed by UNICEF and the Council of Europe’s Assessment Tool on Child Participation. UNICEF’s juvenile justice indicator framework provides extremely helpful practical advice and guidance on the gathering of data and the development of appropriate information systems. However, regrettably, it has no mention of disability although it does stress that data should be collected in such a way as to enable disaggregation on the basis of factors such as age, ethnicity and gender.³⁸ The CoE’s assessment tool, by contrast, does place heavy emphasis on the need for

disaggregation and refers explicitly to disability – although not to the need for further disaggregation according to impairment type.³⁹ The ambit of this tool is broader in scope than access to justice, as it covers a child’s participation in a wide range of spheres of life. Nevertheless, several of its ten indicators do relate to participation in judicial proceedings. For instance, Indicator 4 is the “existence of mechanisms to enable children and young people to exercise their right to participate safely in judicial and administrative proceedings”; Indicator 5 is “child-friendly individual complaints procedures are in place”; and Indicator 7 is “children are provided with information about their right to participate”.



2.4 Dissemination

The final issue to be addressed in relation to data used to monitor the human rights situation of children with mental disabilities is that of dissemination. The value of this form of data is to expose patterns of disadvantage and exclusion not only to people working in the justice system or to government officials but also to the public more generally. An obligation to disseminate this data, and to make it accessible to people with disabilities, is set out clearly in Article 31 of the CRPD.⁴⁰ Further,

States Parties are urged by relevant reporting guidelines, not only to include relevant data in their reports for the CRC Committee and the CRPD Committee, but also to disseminate them widely and make them available to the public.⁴¹ It should be remembered that dissemination of relevant data plays a crucial role in informing advocacy initiatives and active civil society engagement.



2.5 Recommendations

A. In systems for monitoring disability rights, such as DOTCOM, efforts should be made to give access to justice rights a higher profile. In addition, disability rights monitoring systems should provide data disaggregated on the basis of age wherever possible.

B. Systems for monitoring the access to justice rights of children should include structural, process and outcome indicators particularly relevant to children with disabilities.

C. Anonymised data relating to children with disabilities in judicial proceedings should regularly be made publicly available in formats which are accessible to people with disabilities.

38 United Nations Office on Drugs and Crime - UNICEF, *Manual for the Measurement of Juvenile Justice Indicators* (New York: UNODC, 2006), available at http://www.unodc.org/pdf/criminal_justice/Manual_for_the_Measurement_of_Juvenile_Justice_Indicators.pdf (last accessed 15 December 2014), section 1.3.C.

39 Council of Europe Children’s Rights Division and Youth Department, *Child Participation Assessment Tool: Indicators for Measuring Progress in Promoting the Rights of Children and Young People Under the Age of 18 to Participate in Matters of Concern to them*, available at http://www.coe.int/t/dg3/children/participation/Newdefault_en.asp (last accessed: 15 December 2014). See also Recommendation Cm/Rec(2012)2 of the Committee of Ministers to Member States on the Participation of Children and Young People under the Age of 18.

40 CRPD, Article 31(3).

41 CRPD, Article 36(4) and CRC, Article 44(6).

3.

Collecting Disability-Related Information about Individual Children with Mental Disabilities

3.1 Introduction

In order for justice system organisations to produce data on the presence and experience of children with mental (and other) disabilities in judicial proceedings, information systems must be developed to record age and disability-related details for individual children. The design of appropriate information systems requires careful consideration and input from a range of actors and raises challenging questions. These questions cannot be answered in this report. However, they can be asked.

This section will focus on two main types of question. The first concerns the recording of details about a child's disability or impairment-type. The second concerns the recording of details about the type of support or adjustment which a child will need in order to participate effectively in judicial proceedings, free from disability discrimination. These issues will now be addressed in turn before associated recommendations are set out.

3.2 Recording Details of Impairment Type

At the outset of this discussion, it is worth reflecting on the importance of collecting data in such a way that it is capable of being disaggregated on the basis of disability as well as age. Only if this occurs will the data throw light on the human rights situation of children with disabilities – children who are particularly at risk of being overlooked in implementation efforts. In the words of the CRC Committee:

“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.”⁴²

Similarly, a 2011 report of the UN Secretary General urged States to introduce measures to strengthen the collection of disaggregated data on children with disabilities in order to promote their visibility, enhance capacity for effective policy and planning, and enable more effective monitoring of their rights.⁴³

Insufficient disaggregation, based on overly broad categories, is unlikely to yield helpful information about the existence and nature of discrimination or disadvantage. Thus, data which places all people under the age of 18 into one category will result in information which conflates or averages out what might be significant variations between the experiences of younger children and teenagers. A more nuanced approach, which includes a greater degree of age disaggregation, is therefore required.

42 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, para. 15. See also Committee on the Rights of the Child, General Comment No. 5: General Measures of Implementation of the Convention on the Rights of the Child, 27 November 2003, CRC/C/GC/2003/5, para. 48.

43 United Nations, General Assembly, Status of the Convention on the Rights of the Child - Report of the Secretary-General, 3 August 2011, A/66/230, Part IV.

Similarly, data which simply categorises individuals as having or not having a disability will fail to reveal what might be significant differences in the situation of people who have different types of impairment. Article 31 of the CRPD, as explained above, requires States Parties to gather data which can be used to inform their efforts to implement the treaty. It also requires that this information shall be “disaggregated, as appropriate”. According to the Reporting Guidelines issued by the CRPD Committee, State reports should include “[s]tatistical data on the realization of each Convention right, disaggregated by sex, age, type of disability (physical, sensory, intellectual and mental)” as well as “ethnic origin, urban/rural population and other relevant categories”.⁴⁴ Thus, it seems clear that the Committee requires States to develop data collection and monitoring systems which will identify, not simply whether a person has any disability, but also the nature of that disability or impairment.

Systems of data collection which require people to be identified as being disabled or having a particular type of impairment are not uncontroversial. Traditionally data on disability has tended to focus on counting people with disabilities and their participation in various fields of life but overlooked the measurement of barriers to accessibility, which does not require identification of types of disability or impairment. Unsurprisingly, this has attracted criticism from disability studies scholars and activists.⁴⁵

Another potential problem associated with developing information systems which record whether a child has a particular impairment surfaced in a number of the country reports prepared for this study (e.g. Bulgaria and Lithuania) and concerns the potential negative impact on the child of being labelled as having that impairment. Once a child is diagnosed as having an intellectual or psycho-social disability, legal, policy or attitudinal mechanisms may well come into play which prevent them from accessing the full range of educational and employment opportunities which are open to people without disabilities. To use the language of the social model of disability, these forces operate to “disable” the child.

Plainly, the design and operation of any information system must always be guided by considerations of the best interests of the child – as required by the CRC and also Article 7 of the CRPD. The fact that there are potential risks associated with developing an information system capable of disaggregating data on the basis of disability, however, does not mean that the enterprise should be altogether abandoned. Failure to do anything also carries risks. The absence of data on the number of child victims of crimes who have intellectual disabilities, for instance, may mean that factors that expose such children to particular risks of harm are not identified and tackled. Potential types of harm that might be caused to a child, because of being recorded as having a disability in the course of judicial proceedings, must be anticipated and used to inform the design and operation of information systems. The incorporation of considerations of data protection and autonomy into such systems is clearly important.

A further important question arises in connection with the design of information systems capable of producing disaggregated data on the basis of disability, and this concerns the further level of disaggregation according to impairment type. Which categories of impairment should be used for these purposes? Those suggested by the CRPD Committee, as mentioned above, are “physical, sensory, intellectual and mental”. However, “mental”, for these purposes, is not likely to be regarded with favour by the people to whom it may be intended to apply and would in any event present definitional challenges, particularly in connection with distinguishing it from “intellectual”. In addition, although outside the scope of this report, “sensory” is also overly broad in that relying on it would not permit the identification of important differences in the experiences of people with visual and hearing impairments. Further guidance on this question is urgently needed. Given the need for this guidance to be used in the implementation of the CRPD by all States who have ratified it, the Washington City Group on Disability Measurement⁴⁶ (which reports to the UN Statistical Commission) would seem to be best placed to provide it. However, European-level initiatives are also important.⁴⁷ The full involvement (and ideally the leadership) of disabled people’s organisations (DPOs) is pivotal to the success of any such venture – as well as being required by Article 4(3) of the CRPD.



44 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).

45 See, for example, Paul Abberley, “Counting us Out: A Discussion of the OPCS Disability Survey”, *Disability, Handicap and Society* 71 (1992): 39; Michael Oliver, *The Politics of Disablement* (Basingstoke: Palgrave Macmillan, 1990), 7-8; and Paula C. Pinto, “Monitoring Human Rights: A Holistic Approach” in Marcia H. Rioux, Lee Ann Bassler and Melinda Jones (eds.), *Critical Perspectives on Human Rights and Disability Law* (Leiden and Boston: Martinus Nijhoff Publishers / Brill Academic, 2011).

46 http://www.cdc.gov/nchs/washington_group.htm (last accessed: 15 December 2014).

47 See the recognition of this in, for example, 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, para. 3.14.3(v).

3.3 Recording Details of Adjustments and Supports Needed

As is explained more fully in the report produced as part of Workstream 2 of this project, *Access to Justice for Children with Mental Disabilities. International Standards and Findings across Ten EU Member States* (forthcoming), when it becomes clear that a child with mental (or other) disabilities is likely to be involved in legal proceedings, human rights law requires efforts to be made to gather information about any particular adjustment or support which they will need in order to participate in the justice system on an equal basis with others.⁴⁸ Assessments of the adjustments and support which a person with a disability needs in order to participate equally in a particular type of activity (e.g. legal proceedings, employment, education or transport) are different in nature from assessments of whether they have a medical condition or impairment. Medical professionals are not therefore necessarily the most appropriate people to carry out such assessments. As is recognised in General Comment No. 2 of the CRPD Committee in 2014, ascertaining what reasonable accommodations are required in any particular case demands that the individual's "dignity, autonomy and choices" are taken into account. Such assessments therefore necessarily entail processes of engagement and consultation with individual children to identify the types of support or adjustment with which they feel most comfortable and by which they are enabled to participate in legal proceedings most effectively. This will be affected by differences in personality and experience as well as by differences in diagnosis.

Once information has been gathered about the adjustments and supports needed by a particular child with a mental disability, it is important that it should be recorded appropriately so that relevant information can be shared with key actors in the justice system who will be interacting or otherwise dealing with him or her. This requires the development of systems for recording relevant adjustments and supports (particularly those relating to communication) in a manner that ensures it will be apparent to relevant staff whilst respecting data protection requirements.

Human rights standards concerning recordkeeping within elements of the justice system exist but, regrettably, do not explicitly require information about the adjustments and supports needed by a particular individual to be included. In the context of children in detention, the UN Havana Rules⁴⁹ specify that a record must be kept for every child who is deprived of their liberty (e.g. whilst in police custody) and that this must contain the following information:

- "(a) Information on the identity of the juvenile;
- (b) The fact of and reasons for commitment and the authority therefor;
- (c) The day and hour of admission, transfer and release;
- (d) Details of the notifications to parents and guardians on every admission, transfer or release of the juvenile in their care at the time of commitment;
- (e) Details of known physical and mental health problems, including drug and alcohol abuse."⁵⁰

Thus, details of any adjustments or supports which would enable the child to interact or communicate effectively with others or to participate in available activities (e.g. recreational or educational) are noticeably absent from this list.

In the context of people suspected or accused of criminal offences, the EU Interpretation and Translation Directive requires that records should be kept of the fact that adjustments and support (in the form of translation) have been used.⁵¹ This, however, is a retrospective record of what has happened and not a record designed to notify relevant professionals more proactively of what they should do to ensure equal participation. In relation to victims, the European Commission has recommended that Member States should develop "appropriate models, templates, IT tools, etc." to ensure that appropriate information is given to crime victims at different stages of the trial process in a manner adapted to their particular circumstances. Although this does not explicitly recommend that such tools or systems should record information about a person's adjustment needs (so that these can be shared with other justice professionals who need to interact and communicate with the person in question) it may well be regarded as doing so implicitly.⁵²

No examples of initiatives to develop comprehensive systems for collecting and sharing information about adjustments and supports emerged from the country reports. However, useful guidance may be derived from developments taking place in other types of public service. Particularly noteworthy in this regard is the "Accessible Information Standard" currently in the process of being developed in the United Kingdom by NHS England. A draft version of this standard was open to public consultation between August and November 2014. The plan is to finalise it with a view to adopting and implementing it across

48 See, for example, CRPD, Article 13 (which requires "age appropriate accommodations") and Article 5 (which requires "reasonable accommodation").

49 United Nations, General Assembly, Resolution No. 45/113: United Nations Rules for the Protection of Juveniles Deprived of their Liberty, 14 December 1990, A/RES/45/113.

50 Ibid, para 21.

51 Directive 2010/64/EU of the European Parliament and of the Council of 20 October 2010 on the right to interpretation and translation in criminal proceedings, OJ L 280/2, Article 7.

52 European Commission, DG Justice guidance document related to the transposition and implementation of Directive 2012/29/EU of the European Parliament and 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, 19 December 2013, Ref. Ares(2013)3763804, available at http://ec.europa.eu/justice/criminal/files/victims/guidance_victims_rights_directive_en.pdf (last accessed: 15 December 2014), para./recommendation 12-13.

all health and adult social care services in England in 2016.⁵³ NHS England's draft "Accessible Information Standard" addresses the ways in which the information and communication needs of individual patients with disabilities or carers should be identified and recorded as well as how they should be met (by the provision of information in formats appropriate to that individual and by the provision of appropriate adjustments and support to enable that individual to engage in effective communication with health professionals).

It has been drawn up after thorough consultation and engagement with disabled people's organisations and those likely to require information in non-standard formats and support or adjustments when communicating with medical practitioners. These include, in particular, people with intellectual disabilities and people with psycho-social disabilities. One of the great strengths of this emerging standard is that it would embed, as standard practice across all health services (and some social services) in England, a standardised means by which to identify and record information and communication needs. The result should be that all communications with the individual in question would be accessible to them, as they would be in accordance with the requirements specified on the individual's health record. Another strength is that, in specifying how needs should be met, the standard would incorporate minimum quality standards (e.g. on easy read, Braille, sign language or electronic formats). There would seem to be much value in investigating the possibility of developing similar systems for recording information about adjustments and supports in the context of the justice system.

Finally, it is important to stress the relationship between recording information about an individual's adjustment and support needs on the one hand, and the monitoring of service delivery and human rights on the other. The connection between them is noted in the CoE's Disability Action Plan 2006-2015 which includes the following as one of its actions:

"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".⁵⁴

This action depends on the development of information systems which allow details of adjustments and supports required by a particular child to be entered in a manner that will support the gathering of collective anonymised data (e.g. about the number of children requiring the services of a professional communicator or registered intermediary). However, the country reports reveal that, even where assessments of adjustment and support needs are carried out, relevant details are rarely recorded in information systems in a way that could support processes of service delivery and human rights evaluation and monitoring. Consequently, an important opportunity is missed.



3.4 Recommendations

D. Justice organisations should develop information systems which will permit them to record whether a child has a disability (and type of impairment) alongside other personal characteristics. These systems should also be capable of recording information (in a systematic way) about the nature of the adjustments or supports required by individual children with disabilities. These information systems must honour the principle of the best interests of the child and comply with data protection requirements.

E. Future guidance issued by the European Commission to accompany justice-related directives should explicitly state that data should be disaggregated on the basis of disability as well as age and gender. In addition, it should specify that

data should be capable of further disaggregation so as to reveal differences experienced by people with different types of impairment.

F. Efforts should be made (at international but also European and national levels) to develop, with the full involvement of disabled people's organisations, clear guidelines on broad types of impairment category to be used for purposes of human rights monitoring.

G. Where there is evidence that a person's life opportunities are expressly restricted simply because they are labelled as having a disability, urgent action should be taken by States to amend the relevant laws or policies so that the restrictions can

53 www.england.nhs.uk/accessibleinfo (last accessed: 15 December 2014).

54 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, para. 3.14.3(ii).

be removed. Such restrictions are discriminatory and contrary to the CRPD (in particular, Articles 4 and 5). They are relevant to data collection because they put individuals identified as having a disability at risk of disadvantage.

H. Guidance (drawn up by the European Commission⁵⁵ and by national governmental bodies) accompanying legislation relating to children’s rights in the justice system should clearly articulate the importance of carrying out assessments to identify any disability-related adjustment or support which a child will need in order to participate in judicial proceedings on an equal basis with non-disabled children. Such guidance should also specify that these assessments must be carried out as soon as possible after the child comes into contact with the justice system. In addition, it should explain how these assessments differ from medical assessments and stress the importance of taking account, as far as possible, the child’s own views and preferences.

I. Any new guidance (by EU or national bodies) on information to be included on the records of children in judicial proceedings should include details of disability-related adjustments and supports they may need.

J. Efforts should be made within justice systems to develop electronic tools and systems which facilitate the sharing of relevant information about the disability-related adjustments and supports needed by children in judicial proceedings with key professionals who will be interacting with them on a multi-disciplinary basis. The NHS England’s “Accessible Information Standard” provides an example of how this might be done.



55 Building on the guidance provided in European Commission (DG Justice) guidance document related to the transposition and implementation of Directive 2012/29/EU of the European Parliament and 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, 19 December 2013, Ref. Ares(2013)3763804, Recommendation 8, but more clearly differentiating assessments of adjustments and supports from medical assessments.

4. Facilitating and Conducting Independent Research on Access to Justice for Children with Mental Disabilities

4.1 The Importance of Independent Research

The discussion above has focused on the collection of data through mechanisms within the justice system itself. However, there is also an important role for independent research in the collection of data relevant to human rights monitoring. This has been recognised by the CRC Committee, according to which:

“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.”⁵⁶

Such independent research is particularly important in contexts, such as those revealed by the country reports for this project, in which there is currently minimal official data. In addition, it should be recognised that statistical data, while being extremely important, necessarily has limitations and that qualitative or narrative-based data might well be required to identify the nature and extent of disadvantage or marginalisation experienced by children with mental disabilities. In recognition of this, governments and publicly-funded research bodies should be encouraged to commission further research into the hitherto relatively neglected topic of children with disabilities and the justice system.⁵⁷

The problem of lack of data, identified by the country researchers and explained in detail in the accompanying report, *Access to Justice for Children with Mental Disabilities. Data Collection and Dissemination: Synthesis of Findings (forthcoming)*, concerns data of a type that could be used to populate indicators of outcome. Gathering information about laws, policies and relevant structures and processes (that could be used to populate indicators of structure and process) was less problematic. At present, however, in all project countries, there is a serious dearth of official evidence about the presence and experience of children with mental disabilities in the justice system. The extent to which this gap was filled by independent research varied from country to country but clearly there is a need in all countries for more data on this subject and thus for more independent research.

As explained in the accompanying Data Synthesis report, researchers in this study encountered a range of obstacles in their efforts to gather data about the presence and experience of children with mental disabilities in the justice system. While these problems will not be revisited in depth here, they will inform the discussion in this section. An attempt will be made here to reflect on ways in which States might help to promote and facilitate independent research in this area by tackling these difficulties.

⁵⁶ Committee on the Rights of the Child, General Comment No. 5: General measures of implementation of Convention on the Rights of the Child, 27 November 2003, CRC/C/GC/2003/5 – especially para. 48.

⁵⁷ 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, paragraph 3.14.3(xii) urges States to “commission relevant research and innovative pilot projects to support policy development which covers all the relevant areas of this Action Plan”.

4.2 Facilitating Independent Research on the Experiences of Children with Mental Disabilities in the Justice System

A barrier to research which several country researchers encountered seemed to be linked to data protection laws and the ways in which they were interpreted and applied. Researchers in Ireland and Latvia reported that, in the interests of data protection, cases involving children were frequently not made publicly available, even in an anonymised form. In Latvia, anonymised statistical information about such cases is not publicly available in part, it seems, because of data protection concerns.

Whilst it is clearly of utmost importance to protect the identities of the children involved, it may sometimes be easier to respond to data protection concerns by keeping all information out of the public gaze instead of investing the care and resources required to ensure that it is made available after being carefully anonymised. However, caution about recording disability and impairment status also results from the categorisation of health information as sensitive data for purposes of data protection law.

It is important therefore that effort is invested in developing systems for gathering data, relevant to human rights monitoring, in a way that protects the identities and privacy of the individuals concerned. The European Commission's 2012 proposal for a "package" of reforms for the European data protection framework has the potential to assist. It aims to modernise the EU legal system for the protection of personal data - strengthening the protection for individuals and improving the clarity and coherence of the rules. The Proposal for a Regulation on the protection of individuals with regard to the processing of personal data and on the free movement of such data,⁵⁸ included in this package, is a new exception to restrictions on processing personal data. Subject

to certain protections,⁵⁹ this would enable the collection of sensitive data (including health) where necessary for purposes of historical, statistical or scientific research. The FRA has recommended (citing Article 31 of the CRPD) that collecting data for purposes of combating discrimination based on grounds including disability should be added to this provision.⁶⁰ Such an amendment would indeed be helpful, particularly if accompanied by explicit encouragement and guidance relating to the development of appropriate data collection system – encouragement and guidance which appear to be envisaged by the CoE Disability Action Plan which urges States:

"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".⁶¹

A second factor which, whilst of great value in many respects was felt by some of the researchers to be an obstacle to gathering relevant data, was research ethics procedures which were lengthy or burdensome. This is particularly problematic for research projects in which less than a year is available before empirical research must be completed. The FRA is currently in the process of compiling information about the ethics procedures applicable to conducting empirical research on the experiences of children and judicial proceedings in different EU countries. It would be helpful to researchers and possibly also to funders if this were to include information about the length of time generally taken by these bodies to grant or withhold approval and on other factors (such as expense or levels of bureaucracy) that might be significant considerations for those involved in designing and funding research projects.



58 European Commission, Proposal for a regulation of the European Parliament and of the Council on the protection of individuals with regard to the processing of personal data and on the free movement of such data (General Data Protection Regulation), 25 January 2012, COM(2012) 11 final.

59 Set out in Article 83.

60 Opinion of the European Union Agency for Fundamental Rights No. 2/2012 on the proposed data protection reform package, 1 October 2012, available at: <http://fra.europa.eu/sites/default/files/fra-opinion-data-protection-oct-2012.pdf> (last accessed 15 December 2014), p. 5.

61 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, paragraph 3.14.3(i).

4.3 Recommendations

K. Governmental and other bodies with the capacity to fund relevant research, particularly in countries where little independent research has been carried out into this topic, should take steps to encourage and support relevant independent research, including qualitative research which aims to make visible the stories of children with mental disabilities about their experiences in judicial proceedings. There is a need for the European Commission to build on the large-scale research into children in judicial proceedings which it is currently funding so as to ensure that data can be appropriately disaggregated and that children with disabilities are rendered visible in the emerging indicator system.

L. The Commission should produce clear guidance to accompany EU data protection legislation, on the processing of information related to health and disability for purposes of human rights monitoring.

M. The proposed FRA resource on research ethics bodies in EU countries, including on children in judicial proceedings, should include information about average lengths of time for processing applications, costs and the length and complexity of any forms or other procedures that must be completed. This resource might also helpfully draw attention to the value of undertaking research with (and not simply on) children, including children with disabilities.⁶²



⁶² Reference could be made to relevant resources such as Priscilla Alderson and Virginia Morrow, *The ethics of research with children and young people: a practical handbook* (London: Sage Publications, 2011).

5. Conclusion

It is clear from the accompanying report, *Access to Justice for Children with Mental Disabilities. Data Collection and Dissemination: Synthesis of Findings (forthcoming)*, that there is currently a worrying lack of data about the existence and situation of children with mental disabilities in judicial proceedings. Without data, outcome indicators for monitoring the rights of such children to access justice cannot be populated. The invisibility of these children from the data renders any marginalisation, discrimination or neglect they experience invisible.

This report has demonstrated that, despite the insistence of international and European standards on disaggregated data, as yet systems for disaggregating justice-related data on the basis of childhood and disability combined appear to be lacking. At EU level, important initiatives (both legislative and research-based) are taking place to generate and present reliable data on children in judicial proceedings. The opportunity to capture the particular experiences of children with different types of impairment or disability, however, has been largely missed to date. This is a trend that needs to be acknowledged and brought to an end. Children with disabilities need to be noticed so that their experiences can feed into processes of policy and practice reform. This will require attention to be given to difficult questions concerning classifications of types of impairment or disability and data protection – questions that require the input of disabled people’s organisations and which would benefit from multi-national and multi-sector dialogue.



Appendix:

Consolidated Recommendations

- A.** In systems for monitoring disability rights, such as DOTCOM, efforts should be made to give access to justice rights a higher profile. In addition, disability rights monitoring systems should provide data disaggregated on the basis of age wherever possible.
- B.** Systems for monitoring the access to justice rights of children should include structural, process and outcome indicators particularly relevant to children with disabilities.
- C.** Anonymised data relating to children with disabilities in judicial proceedings should regularly be made publicly available in formats which are accessible to people with disabilities.
- D.** Justice organisations should develop information systems which will permit them to record whether a child has a disability (and type of impairment) alongside other personal characteristics. These systems should also be capable of recording information (in a systematic way) about the nature of the adjustments or supports required by individual children with disabilities. These information systems must honour the principle of the best interests of the child and comply with data protection requirements.
- E.** Future guidance issued by the European Commission to accompany justice-related directives should explicitly state that data should be disaggregated on the basis of disability as well as age and gender. In addition, it should specify that data should be capable of further disaggregation so as to reveal differences experienced by people with different types of impairment.
- F.** Efforts should be made (at international but also European and national levels) to develop, with the full involvement of disabled people's organisations, clear guidelines on broad types of impairment category to be used for purposes of human rights monitoring.
- G.** Where there is evidence that a person's life opportunities are expressly restricted simply because they are labelled as having a disability, urgent action should be taken by States to amend the relevant laws or policies so that the restrictions can be removed. Such restrictions are discriminatory and contrary to the CRPD (in particular, Articles 4 and 5). They are relevant to data collection because they put individuals identified as having a disability at risk of disadvantage.
- H.** Guidance (drawn up by the European Commission⁶³ and by national governmental bodies) accompanying legislation relating to children's rights in the justice system should clearly articulate the importance of carrying out assessments to identify any disability-related adjustment or support which a child will need in order to participate in judicial proceedings on an equal basis with non-disabled children. Such guidance should also specify that these assessments must be carried out as soon as possible after the child comes into contact with the justice system. In addition, it should explain how these assessments differ from medical assessments and stress the importance of taking account, as far as possible, the child's own views and preferences.
- I.** Any new guidance (by EU or national bodies) on information to be included on the records of children in judicial proceedings should include details of disability-related adjustments and supports they may need.
- J.** Efforts should be made within justice systems to develop electronic tools and systems which facilitate the sharing of relevant information about the disability-related adjustments and supports needed by children in judicial proceedings with key professionals who will be interacting with them on a multi-disciplinary basis. The NHS England's 'Accessible Information Standard' provides an example of how this might be done.
- K.** Governmental and other bodies with the capacity to fund relevant research, particularly in countries where little independent research has been carried out into this topic, should take steps to encourage and support relevant independent research, including qualitative research which aims to make visible the stories of children with mental disabilities about their experiences in judicial proceedings. There is a need for the European Commission to build on the large-scale research into children in judicial proceedings which it is currently funding so as to ensure that data can be appropriately disaggregated and that children with disabilities are rendered visible in the emerging indicator system.
- L.** The Commission should produce clear guidance to accompany EU data protection legislation, on the processing of information related to health and disability for purposes of human rights monitoring.

63 Building on the guidance provided in Recommendation 8 of the European Commission [DG Justice] guidance document related to the transposition and implementation of Directive 2012/29/EU of the European Parliament and 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, 19 December 2013, Ref. Ares(2013)3763804, but more clearly differentiating assessments of adjustments and supports from medical assessments.

M. The proposed FRA resource on research ethics bodies in EU countries, including on children in judicial proceedings, should include information about average lengths of time for processing applications, costs and the length and complexity of any forms or other procedures that must be completed. This resource might also helpfully draw attention to the value of undertaking research with (and not simply on) children, including children with disabilities.



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