

# Briefing note: aligning data protection rules with international standards

## **Introduction**

'Who am I?', Oedipus asked, but nobody had the courage to give him a truthful answer, except for a seer who knew what tragedies were to follow.

The question of who we are has been with us since mythical times. It is a question that relates not only to the past but also to the present. For many—children or adults—it is also an ever-present, existential question that spans over decades. Not knowing where you come from affects one's physical as well as mental well-being, and has critical repercussions for the next generations. Knowing who you are is a human right.

Technological and scientific advances should enable States to fulfil their duties to preserve and restore the data on every person's identity. Yet tens of thousands of people are, to this day, denied access to unredacted birth information as well as other information, including care placements, adoption and assisted reproductive technology. Despite obligations embedded in international standards, roadblocks of an impermeable bureaucracy exist, which often starts by denying access to records.

This document presents an evidenced-based plea for States to ensure data protection rules comply with international obligations. This briefing note targets all professionals mandated to preserve identity information and/or provide access. Below follows an explanation of the legal rights of all to have their identity respected, divulged, and restored, as well as recommendations to ensure full alignment.

#### **Background**

Every child has a unique identity, including birth registration, name, nationality and family relations. Without society's formal recognition of this reality through registration, the child becomes invisible. The child's capacity to access other rights is compromised (such as education, health and social security) as well as greater risks of exploitation. The consequences can be dire and long-lasting for children's harmonious development, the deployment of their evolving capacities, sense of self-worth and well-being. There is a plethora of research indicating that identity is central to human development.

The violation of the right to identity impacts millions of children, including the 237 million children without a birth certificate, those who are in alternative care and/or adopted, those born through assisted reproductive technology (including surrogacy), those who are displaced, migrating and/or are refugees, those who are living on the street, those who are subject to child marriage, armed conflict, and many other situations. This contravention impacts adversely also on the millions of children, now adults, whose identity rights have historically not been respected and who continue to suffer as a result.

## International standards on the right to identity: preservation, access and restoration

Each person has the **right to identity including birth registration, name and nationality** (Article 24 of the <u>International Covenant on Civil and Political Rights 1976</u> (ICCPR)). Article 8(1) of the <u>Convention on the Rights</u> <u>of the Child</u> 1989 (CRC) adds **family relations** to this right to identity. The fulfilment of the right to identity requires that, at a minimum, information about birth facts, name, nationality and family relations, be preserved into perpetuity and be fully accessible.

Article 19(2) of the ICCPR provides that the right to **freedom of expression** includes the freedom to seek, receive and impart information 'without distinction of any kind, such as (...) birth' (Art. 2). The United Nations Special Rapporteur on Freedom of Opinion and Expression 'has consistently stated that the right to seek and receive information is not simply a converse of the right to freedom of opinion and expression but a freedom on its own'.<sup>i</sup> Accordingly, 'the right to seek, receive and impart information imposes a positive obligation on States to ensure access to information, particularly with regard to information held by Government'.<sup>ii</sup>

Similarly, in their 2004 Joint Declaration, the three special mandates on freedom of expression at the United Nations, the Organisation for Security and Co-operation in Europe and the Organization of American States declared that '[t]he right to access information held by public authorities is a fundamental human right'.<sup>III</sup>

Consequently, **the right to access personal information held by a public authority is extrinsically linked to the person's right to identity**. Given the scope of Article 8(1) CRC and the child's right to identity in family relations, the achievement of this right entails **preserving information** concerning the identity of [the child's] biological family and all the events of their life story before alternative care placement and/or adoption.<sup>iv</sup> The fulfilment of this right also encompasses the ability to **access this information**. The UN Special Rapporteur's 2020 report on the promotion of truth, justice, reparation and guarantees of non-recurrence outlined the importance of archives and ensuring access.<sup>v</sup> In cases where the child has been separated from their parents, the State should respect, according to the <u>UN Guidelines for the Alternative Care of Children</u>, child's rights to access information on his or her origins where appropriate as well as facilitate the maintenance of contact with parents when separated. In addition, the Special Commission on the Practical Operation of the <u>1993 Hague Intercountry Adoption Convention</u> recommended that adoption records should be preserved in perpetuity, which allows for compliance with Article 30 on States' responsibility to ensure access to information.<sup>vi</sup>

Only when information is preserved in its entirety, with integrity, and fully accessible, can the affected person's **identity be speedily re-established when elements are missing and/or falsified**, as required by Article 8(2) CRC. The Special Rapporteur on the sale and sexual exploitation of children in her 2017 report recommended to States to '[e]nsure the right to information about one's origins and access to information about the rights of victims of illegal adoptions'.<sup>vii</sup> In cases of systematic and ongoing abuses, the UN SR on transitional justice has recommended actions for the design and implementation of effective apologies.<sup>viii</sup> Respecting the above rights also contributes to the achievement of Sustainable Development Goals (SDG) 16.3 in terms of wide access to justice and SDG 16.9, ensuring a legal identity for all. The **CRC Committee**, through its Concluding Observations, often reminds States to guarantee full access to information on children's origins, with appropriate support from all concerned.<sup>ix</sup>

For all of the above compelling reasons, current Data Protection Regulations should not be interpreted contrary to the rights of children when 'mixed information' is concerned.<sup>x</sup> Article 15(1) <u>General Data</u> <u>Protection Regulation</u> is the general rule which gives broad access to all information. Article 15(4) should, however, not be interpreted in a way that deprives children of fundamental information about their identity, including when illicit practices may be involved. Even when other interests should be considered, information about genetic and gestational origins enables children including those who are adopted, donor-conceived, born through surrogacy, etc., to have complete histories and information about their genealogy.<sup>xi</sup>

- 1. Based on this international framework, CHIP and its partners\* are advocating for:
- Collection and preservation of all accurate identity information within a central repository, in perpetuity, related to:
  - birth facts (e.g., name, nationality and family relations)
  - family relations including all biological, gestational, social and legal information that has contributed to the child's birth.
  - any potential modification (e.g. foster care, adoption, surrogacy) including proofs that such a decision was in the child's best interests
- Central repository should include all identity information within the mandate of relevant of State authorities, and kept by all private organisations and actors
- When new information becomes available, this should be added to the central repository
  - authorities should immediately inform the affected person(s) that new information is available, to comply with the obligation to speedily re-establish missing elements

- support including the appointment of an independent professional to represent the rights of the child and recourse to mediation should be encouraged, but should not be mandatory
- **Records should be electronically safeguarded** in a way that facilitates future searches and can be safeguarded against any potential loss (e.g. multiple back-ups in different locations and under the responsibility of a public authority)
- Access to all identity information should in principle be:
  - unlimited and free of charge
  - supported by competent professionals, if requested by the children/affected persons, but not mandatory and available even if there is challenging content.
  - a promising practice in this respect can be found in the work of the Stasi Records Archive in Germany, where every individual has the right to view the records that the Ministry for State Security collected about him or her.<sup>xii</sup>
- Access to identity information may exceptionally be limited when the rights of other affected persons may significantly be jeopardised
  - non-identifiable information should be made available, especially when of a medical nature
  - identifiable information may be requested through an independent organisation, which should have the capacity to contact the other affected person
  - recourse to mediation may be useful in this context
- Capacity building of all actors, including civil registrars, involved in preservation and access

# \*Partners include

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Transracial Adoptee Community

vii <u>Report of the Special Rapporteur</u> para 95 (j).

viii United Nations General Assembly, <u>Report of the Special Rapporteur on the promotion of truth, justice, reparation and guarantees of non-recurrence (</u>2019), para 48-60.

Committee on Social Affairs, Health and Sustainable Development, Parliamentary Assembly.

x<sup>ii</sup> See <u>Federal Commissioner for the Archives of the Ministry of State Security of the German Democratic Republic</u>.

<sup>&</sup>lt;sup>i</sup> Report of the Special Rapporteur, Mr. Abid Hussain E/CN.4/1998/40 (28 January 1998), para 11.

<sup>&</sup>quot; Ibid., para 14.

<sup>&</sup>lt;sup>III</sup> Joint Declaration by the UN Special Rapporteur on Freedom of Opinion and Expression, the OSCE Representative on Freedom of the Media and the OAS Special Rapporteur on Freedom of Expression (6 December 2004) p. 2. See other relevant international standards promoting maximum disclosure in Maeve McDonagh (2013), 'The Right to Information in International Human Rights Law', *Human Rights Law Review* at https://www.corteidh.or.cr/tablas/r30698.pdf

<sup>&</sup>lt;sup>1v</sup> Cécile Jeannin and Mia Dambach, <u>Policy Brief 1: Child's right to identity in intercountry adoption</u>, Geneva, Switzerland: Child Identity Protection, p. 12. The addition of "family relations" in Article 8 has its origins in Argentina's history and request to restore the identities of the children, who had been illegally removed from families linked to the opposition of the Dictatorship. Noting the advocacy efforts in this context, particularly by the grandmothers, the term "family relations" arguably goes beyond nuclear ties.

<sup>&</sup>lt;sup>v</sup> Human Rights Council, <u>Report of the Special Rapporteur on the promotion of truth, justice, reparation and guarantees of non-recurrence</u> (2020), paras 70-73.

<sup>&</sup>lt;sup>vi</sup> <u>HCCH, Conclusions and Recommendations and Report of the Special Commission on the Practical Operation of the 1993 Hague Intercountry</u> <u>Adoption Convention</u> (2010), recommendation 28.

<sup>&</sup>lt;sup>1x</sup> See, for example, UN Committee on the Rights of the Child, *Concluding Observations* to *Australia*, 1 November 2019, CRC/C/AUS/CO/5-6; UN Committee on the Rights of the Child, *Concluding Observations* to *Belgium*, 1 February 2019, CRC/C/BEL/CO/5-6; UN Committee on the Rights of the Child, *Concluding Observations* to *Belgium*, 1 February 2019, CRC/C/BEL/CO/5-6; UN Committee on the Rights of the Child, *Concluding Observations* to *Belgium*, 1 February 2019, CRC/C/BEL/CO/5-6; UN Committee on the Rights of the Child, *Concluding Observations* to *Belgium*, 1 February 2019, CRC/C/BEL/CO/5-6; UN Committee on the Rights of the Child, *Concluding Observations* to *Belgium*, 1 February 2019, CRC/C/BEL/CO/5-6; UN Committee on the Rights of the Child, *Concluding Observations* to *Ireland*, 1 March 2016, CRC/C/IRL/CO/3-4; UN Committee on the Rights of the Child, *Concluding Observations* to *Israel*, 4 July 2013, CRC/C/ISR/CO/2-4; and UN Committee on the Rights of the Child, *Concluding Observations* to *Switzerland*, CRC/C/CHE/CO/2-4, 26 February 2015.

 <sup>\*</sup> See <a href="http://ifmresearch.com/wp-content/uploads/2021/03/Submission-to-Oireachtas-Justice-Committee-Re-GDPR-MOR-CMG-LON-26.3.21.pdf">http://ifmresearch.com/wp-content/uploads/2021/03/Submission-to-Oireachtas-Justice-Committee-Re-GDPR-MOR-CMG-LON-26.3.21.pdf</a> and here <a href="https://datasubject.ie/mbh/">https://datasubject.ie/mbh/</a> and CHIP submission to the DGD on alternative care on 16 and 17 September 2021 <a href="https://www.child-identity.org/index.php/en/resources/advocacy-and-policy/201-submission-to-the-crc-committee-s-dgd-on-16-and-17-september-2022.html">https://www.child-identity.org/index.php/en/resources/advocacy-and-policy/201-submission-to-the-crc-committee-s-dgd-on-16-and-17-september-2022.html</a>.
\*\* See Petra De Sutter (2019), Anonymous donation of sperm and oocytes: Balancing the rights of parents, donors and children (Doc. 14835).