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30 September 2020

**Submission to the Special Rapporteur on the right to privacy examining the privacy rights of children and how this right interacts with the interests of other actors as the child develops the capacity for autonomy**

**With a focus on Alternate Care environments and issues:**

* **Governmental or other structures including regulatory arrangements, established to advance the human rights of the child;**
* **Children in vulnerable situations such as unaccompanied migration, violence, sexual exploitation, poverty and other economic, social, familial or physical circumstances;**
* **Programs, mechanisms and strategies that aid he positive development of the child by addressing their privacy needs and expectations**

## Privacy Rights in Alternative Care Systems

Much of the discussion about the rights of children in the digital environment in general, and privacy in particular, focuses on the *discretionary* use of digital systems by children and/or families. In this submission the emphasis is on the need to address the representation and enactment of children’s rights in *non-discretionary systems* and the particular complexities around how systems set up to protect children from harm do not themselves cause harm. These are systems in which children and their families have little choice over participation and so it is vital that they embed and embody children’s digital rights in their design and implementation. Central to this is ensuring that in acting in the best interests of the child, rights to privacy and the development of identity and connection to family, community and culture are also respected [1].

Children and young people in Alternative Care situations have little to no discretion around participation in the child protection and welfare systems that document the intimate, sensitive and personal details of their lives. A multitude of inquiries in Australia [2]–[7] and in other countries – Ireland, UK, Sweden, Canada, Norway, Iceland, Denmark, Germany, South Africa [8] have detailed the lifelong consequences of a lack of participation and agency in and over records of childhood Alternative Care experiences. A lack of agency in recordkeeping has been shown to deny children, young people and the adults they become their fundamental human rights to identity, memory, privacy and accountability [9], [10].

Many national standards for Alternative Care identify the rights of children and young people to have access to, and control over, a complete and accurate history of their time in Care, the plans for their future, their health, education and other important official records, their family and community connections, memories of key events, and other records which support and nurture their sense of identity, security, and connectedness with the world. They also emphasise the need for children and young people to participate in the decision-making that impacts on their lives, as part of their healthy development, which therefore must include the formation and use of this increasingly digital archive. Despite increasingly extensive policy layers reflecting the emphasis in Alternative Care standards on child-centred approaches, there is also continuing evidence of barriers to their translation into practice. For example surveys of Care experienced children and young people by CREATE Foundation, Australia’s national body representing the voices of children and young people with out-of-home care experiences, continue to show a lack of participation in case and cultural planning processes and access to information and records [11].

As Alternative Care systems move into the digital realm there is a real danger of encoding, enshrining and amplifying existing exclusions, biases and discrimination [12], without attending to the recordkeeping and information rights explicitly and implicitly embedded in children and other human rights charters [13]. Alternative Care recordkeeping systems can exemplify the ‘problematic tendency of existing frameworks to prioritize protection over participation, rather than finding better ways of resolving … [the] conflicts among rights … [that] inevitably arise’ [14, p. 490]. This is despite recognition that active participation and proactive provision of rights are a protective factor [15].

In Alternative Care environments the increased surveillance capabilities of both discretionary and non-discretionary systems have the potential to be utilised both for and against the best interests of the child. While increased abilities to monitor online activities and capacities for seamless sharing of digital data and information might help to identify risks to children and young people, they may also infringe on rights to privacy and confidentiality with consequent impacts on the development of self-identity, and connection to family and community. The ability to establish identity as an individual human being, as well as having agency and control over personal and sensitive information, goes to the core of fundamental human rights to autonomy and self-determination [16], [17].

It is vital that mechanisms to efficiently and effectively identify, protect and monitor these rights for children is incorporated into non-discretionary digital systems [18]. In Australia, governments are ploughing ahead with technological systems to join up the personal data that they hold about children for child safety and wellbeing ‘with significant privacy impacts’ [19]. There is a real danger that existing social and economic disadvantage will be amplified without fulsome and holistic exploration of these privacy challenges.

The potential for digital and networking technologies to address, rather than exacerbate, the current power asymmetries in information and recordkeeping systems for Alternative Care in particular could herald a new paradigm of rights-based practice in the sector, and achieve better development outcomes for children. However, there is a need to explicitly design these affordances into the technology and have similarly digital enabled mechanisms for their governance and oversight with regards to children and young people’s rights to privacy and knowledge about how their personal information is distributed and used.

## Archives and the Rights of the Child Research Program

Recordkeeping and its governance is a significant issue for the Alternative Care sector, which affects the social, emotional and psychological health and wellbeing of Care experienced children, young people and adults. Those with Care experiences often speak of having to fight for their rights, or of having strong advocates making sure that their best interests are at the forefront of decision-making, in a fractured, fragmented and under-resourced system. Quality recordkeeping is one of the rights they should be accorded as a matter of course. It should also be part of making Alternative Care systems more efficient and effective in safeguarding children and young people.

The *Archives and the Rights of the Child Research Program* is a transdisciplinary research agenda to investigate how multiple and lifelong rights in records and recordkeeping can be recognised, respected and enacted in Alternative Care systems utilising digital and networking technologies [20]. It brings together researcher from a range of academic, community and organisational contexts, and from a variety of disciplinary perspectives to tackle this complex problem using participatory research and design methodologies (see <https://rights-records.it.monash.edu/research-development-agenda/>). It is an example of giving voice and agency to those with Care experiences in research to address their recordkeeping needs.

The program incorporates a range of interconnected and complementary research projects, including

* Australian Research Council (ARC) Future Fellowship*, Connecting the Disconnected: Co-Designing Integrated and Inclusive Recordkeeping and Archival Networks* (2015-2018),
* ARC Discovery Project, *Rights in Records by Design: Transforming Recordkeeping Systems for Children in Out-of-home Care* (2017-2020) and
* ARC Discovery Project, *Real-time Rights-based Recordkeeping Governance for Childhood Out-of-Home Care* (2021-2023).

The research agenda embodied in these projects is linked to the 2017 *Setting the Record Straight for the Rights of the Child National Summit* that brought together stakeholder communities to develop a ten-year research, development and action agenda to transform recordkeeping and archiving for childhood Alternate Care around recognizing, respecting and enacting multiple rights in records [21], [22].

In the *Rights in Record by Design Project,* we are currently researching a world first Charter of Recordkeeping Rights for Childhood Alternative Care and its translation into a recordkeeping rights engine – a technical demonstrator of how recordkeeping rights in Alternative Care systems can be dynamically enacted, negotiated and monitored. This research is part of imagining future digital systems for Alternative Care capable of real-time, proactive and transparent accountability to the principles of provision, protection and participation in the best interests of the child enshrined in the Convention on the Rights of the Child.

Working with a co-design team of young adults with Alternate Care experiences [23] we have built a prototype of a system in which they can manage their personal information – choosing what, when, how and who they share it with – as well as having access to, and potentially appropriate control over, their Care records [24]. While for these and other Care leavers the focus is about gaining retrospective control, particularly in transitioning out of the Care system into independent living, their involvement in this research is also motivated by a strong desire to see the systems for children and young people currently in Care designed to better respect rights to privacy in such complex situations. Whether that be having an appropriate say over who has access to their personal and sensitive information and/or mechanisms to detect and prevent inappropriate use, there is great potential in re-imagining through digital technologies how better enablement of privacy rights can support the development of their sense of self and worth.

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Note the publication repository for the *Rights in Records by Design* project is available at <https://rightsinrecordsbydesign.github.io/publications/> with open access copies of research papers as allowed by publishers.

**Recommendation**

State and member bodies shall require the design and implementation of rights-based recordkeeping systems to support the human rights of all children, but particularly those in alternative care and forced migration environments, to enable life-long accountability to the child for all deliberations and decisions impacting on the autonomy, identity, privacy, safety and well-being of a child.

**Recordkeeping and Rights in Records**

Records made and kept by governments, institutions, service providers and other organisations about children for their administrative purposes often fail to meet their information, evidence and accountability needs. Without rights to know what records are maintained or where they are, or to exercise any control over how such records are created, managed and accessed, children are caught up in a disenfranchising power imbalance and are at risk of records being weaponised against their best interests.

Activating, asserting, enforcing or rectifying issues impacting on children’s right to autonomy and privacy is fundamentally dependent on there being authoritative records that document actions. Yet contemporary analysis of the information environment routinely focusses not on this foundational issue but rather on commercial data access and privacy, or the bias and unfairness of algorithmic uses of data. These issues, while important, sidestep the importance of authoritative records – persistent representation of events that shape human activity as instruments integral to identity, memory and cultural heritage as well as safety, security, wellbeing and accountability. When individuals or collectives cannot control or access records by or about themselves, it is impossible to actualise or assert inalienable human rights including the right to privacy.

Records come in all forms. They can encompass data, photos, CTV video footage or identity data, and multiple forms of inscription on media. They can be passed down orally as part of dance, ceremony and story. In the case of refugee children, a potent example is DNA-as-record. Increasingly used as a key identity document, DNA is inherently unique to the individual, but also implicates other relatives in its remit. When linked to biometric identification systems, DNA can be shared without explicit consent to transnational systems in ways that are beyond an individual’s, or community’s, capacity to control. For children enmeshed in systems of heightened surveillance, the consequences of such non-consensual sharing of such records mean that inherently personal identity information spirals into potential nightmarish scenarios of social control.

The lifelong impacts of lack of rights in records are most clearly demonstrated in extreme cases. Illustrated dramatically by children who are placed in alternative care and situations of forced migration as refugees, the lack of records can be demonstrated to have a lifelong effect an individual’s identity, autonomy, wellbeing and safety. In these situations, children are subjected to heightened surveillance of their life by third parties. The records about them accumulate in multiple systems, often without their knowledge, let alone informed (age-appropriate) consent. Options to opt out are impossible to assert. All children, and all individuals, are affected by the existence or non-existence of records. While in the control of multiple agencies involved with administering their particular activities, the child is rendered powerless to know what is recorded about them, where it is, to challenge assumptions or to access them to seek redress for actions, particularly when the record is controlled by the perpetrator. The privacy rights of third parties are commonly privileged by default over the identity and accountability rights of the ‘subject’ of the record when access is sought through multiple relevant systems needing to be navigated to even know what records exist to support the exercise of lifelong, inalienable, human rights.

Complaint mechanisms are essential to rectify actions, however complaint mechanisms are dependent upon authoritative records. With no rights to ensure that authoritative records exist and no control in mechanisms that ensure the appropriate management and control of records, complaint mechanisms are inherently biased towards those that possess the record. Reporting approaches as monitoring techniques are similarly not sufficient to enable instantiation of rights. Reporting focusses on data, disaggregated from the context of its creation, often focussed on specific problem areas. Such data-oriented approaches, even where nominally deidentified, is specifically linked to a point in time, and does not provide appropriate accountability for authoritative information about individuals across time. At the same time, accurate reporting itself is dependent on evidence provided by authoritative records. Complaints mechanisms and reporting strategies do not replace or adequately address needs for authoritative records.

Establishing a rights framework for records based in broader human rights is an emerging mechanism to reposition recordkeeping to empower individuals to instantiate their human rights. Rights frameworks for records seek to empower individuals to know about and exercise their right to participate, access and control records relating to themselves. Current projects are defining Charters of Rights to Records to assert the relationships of records to broader human rights for specific communities and realign organisational recordkeeping. A shift away from organisation-centric records of control and surveillance towards child-centred recordkeeping would enable children to exercise their rights under the *United Nations Convention on the Rights of the Child* 1990. For children in alternative care, child-centred rights-based recordkeeping systems would enable age-appropriate participation of children in both organisational and personal recordkeeping which documents their lives, develops their sense of identity and belonging, keeps them connected with family and community, address their questions about who they are, where they come from, and why they are in care.

The Rights to Records Charters are based on rigorous analysis of instrumental and testimonial warrant. Developed in conjunction with members of affected communities, the Charters specifically address the lifelong records requirements for children who experience alternative care environments[[1]](#footnote-1), and for refugees[[2]](#footnote-2). These frameworks are fundamentally based in the notion of enabling autonomy for children. Adoption of such frameworks will impact systems of business, government and not for profit organisations and will involve fundamental reconfiguring of the design, implementation and access to systems which record personal information. Such reconceptualised systems and approaches place the individual and authorised communities at the centre of actions, as active empowered participants rather than passive ‘subjects’ of systems of data collection. Such mechanisms will enable individuals to assume controls, exercise autonomy and assert rights over information at present stored in multiple, disconnected, distributed and closed systems.

**CHARTER OF LIFELONG RIGHTS IN CHILDHOOD RECORDKEEPING IN OUT-OF-HOME CARE**

**FRAMING RIGHTS**

**Participation**

* Rights to participate in decision making/have a voice in all matters that impact on you
* Collective community right to participate in developing frameworks, legislation, policies and processes that impact them

**Memory**

* Individual and collective memory rights
* Rights to remember/forget
* To be remembered/be forgotten

**Identity**

* Rights to cultural, family and self-identity; to know who you are, where you belong and to practice your culture

**Accountability**

* Rights relating to holding society, governments and service providers to account for actions that impact on you as an individual or community

**RECORDKEEPING RIGHTS**

**Participatory Rights in Recordkeeping, including:**

* Acknowledging the importance of childhood records into the future, all agencies and organisations that take children into their custody from this time forward must create a full and accurate record of actions affecting the child
* Setting recordkeeping and archival frameworks (metadata, classification, categorisation, description), making policies (appraisal, access, disclosure, keeping places) and participation in decision making about legal and administrative processes (note: a collective and individual right).
* Creating records about you in organisational settings; and your own personal records
* Deciding or consenting to what is recorded in organisational and archival systems about you, how your records and used, and who has access to your records
* Intervening in the record (right of reply/setting the record straight/truth telling)
* Deciding how long to keep records, and in what form

**Disclosure and Access Rights to:**

* Lifelong access to your records (including rights to receive copies, timely and low cost access, and special accelerated access where circumstances require this
* Have a say in intergenerational access
* Know and be informed of where your records are held
* Understand the type(s) of records held about you
* Be informed of when and why others are given access to your records
* Consent to use of your records by others
* Know when and why records about you are destroyed

**Privacy and Safe Recordkeeping Rights to:**

* Individual and collective privacy as understood in your culture and worldviews
* Not to have your records used for other than their original agreed purpose without consent
* Safe and secure recordkeeping infrastructure, processes and systems
* Safe and secure keeping places for archival records.

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