

# Care Experienced Information Rights and Organisational Practice

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## **Abstract**

This paper provides a commentary on how organisations can close the gap and build their capability to better meet the information rights of care experienced adults seeking access to records about their childhood in the care of the State. It provides an overview of requirements in respect of access to records by people with care experience, and of advocates who campaign for improvements to information rights. Looking beyond the legislative compliance aspects of how organisations meet those information rights, it highlights root cause issues in the broader holistic records access and information rights agenda. The paper discusses potential learning about care records from an organisational perspective, describing the complexities inherent with their identification, form, content and meaning. The paper concludes with possible solutions that could be applied to organisational practice today.

## **Keywords**

Care experience, information rights, corporate parenting, organisational practice, access to records

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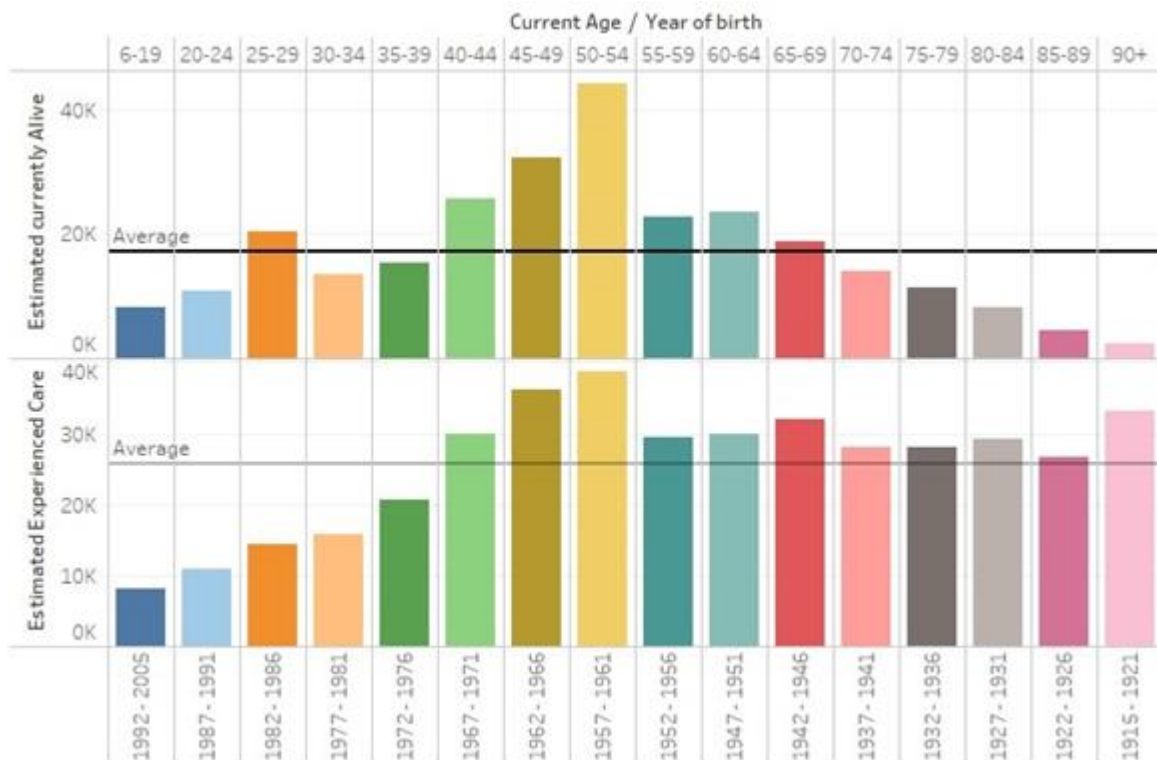
## **What are the issues with records?**

Our understanding of the issues facing our care experienced communities – individuals who have been cared for by the State as children - and their ability to access records about their time in care has been steadily growing over the past 20 years. The key recurring issues they face include getting access to those records, the number of redactions contained within those records, if and when they receive them, and the lack of support provided by the responding organisation to allow meaningful interpretation of the information those records contain (MacNeil, Duff, Dotiwalla, Zuchniak, 2018; Murray, 2017; Evans et al., 2015; Murray and Humphreys, 2014; O’Neil et al., 2012; Humphreys and Kertesz, 2012; Kendrick and Hawthorn, 2012; Goddard et al., 2010; Duncalf, 2010; Shaw, 2007; Horrocks and Goddard, 2006; Pugh and Schofield, 1999).

On the face of it, it might be anticipated that recent changes to Data Protection legislation in 2018 may have resulted in organisations improving the provision of access to records for care experienced communities exercising their information rights. However, underlying the provision of organisations complying with the legislation and meeting the needs of care experienced communities’ information rights is a complex set of additional issues that underpin a more holistic rights agenda. Unless the root cause issues are addressed, the active solutions available to organisations to improve those holistic underpinning practice issues, will not meet our care experienced communities’ information needs. This paper explores some of these issues in more detail to highlight possible solutions that could be applied in practice.

## **Who are Care Experienced communities?**

According to research by Kendrick and Hawthorn (2012), an estimated 480,000 children had experienced State intervention care in Scotland between 1915 and 2005. Two-thirds (320,000) were still alive at the time the research was conducted, with the oldest of that generation aged 98 years. Figure 1 shows the breakdown of these figures across the defined year range and age group.



**Figure 1 Estimates of children who have experienced care and those still alive (Kendrick and Hawthorn, 2012)**

The care experienced figures estimated here represent all communities of children who have experienced statutory care provided by the State as part of their duties to ensure the care, welfare and protection.

It is important to note that these figures are estimates, based on census data, and may not provide the accuracy levels we would expect now. Given the historic nature and duration represented here, they do however provide an indication of the significant number of children, now adults, who may want to exercise their information rights to access records.

Mapping the type of care interventions, provided for children by the State, or on their behalf, now commonly referred to as 'corporate parenting', has been in place for decades, in different guises (Norrie, 2018; Shaw, 2007). The records created by organisations over this period have changed as dictated by the legislative and regulatory environment over that time (Norrie, 2018). Whatever form the records created takes within this time period, this is the child's personal family album, charting their childhood from their time in care. However, given the extensive historic time period in scope, in many instances, if the applicant is

successful in their request, the records received are far from what traditional family albums would contain, or could be discerned from family networks.

## **What are care experienced communities' records needs?**

It is now recognised that care experienced communities' records needs are complex because they do not have the same access to a family album, through traditional family relationships and networks, but are instead reliant on the organisational recordkeeping of those providing that care. The impact of records on any care experienced individual's sense of identity, providing them with an understanding of what happened to them, when it happened, and why, is something that might only be available through records, if they exist (MacNeil et al., 2018; Murray, 2017; Evans et al., 2015; Murray and Humphreys, 2014; O'Neil et al., 2012; Humphreys and Kertesz, 2012; Kendrick and Hawthorn, 2012; Duncalf, 2010; Shaw, 2007, Horrocks and Goddard, 2006; Pugh and Schofield, 1999).

The main issues cited by care experienced communities about access to records are the difficulties in getting access and, if successful, making sense of what those records contain. If unsuccessful, the key issue is coping with the prospect of never finding out specific details of when they were in care, why they were in care, and what happened while they were in care. Records often do not contain any meaningful descriptions of the child and their personality, likes and dislikes, developmental milestones: all things that within a birth family would be more easily known and accessible through family photos and recalled memories. These records, if received, usually consist of reports produced as an organisational account and justification for actions taken. Reports, when they are made accessible, are often heavily redacted, with any sense of the child, who may be reading these reports as an adult, and seeking a more meaningful understanding about what happened, and why, being lost.

The childhood memories care experienced individuals have shaped their sense of self and their ability to reflect on their childhood as adults. These often trigger a need to clarify or re-create those memories and understanding. Care experienced individuals may seek knowledge that can encompass a spectrum of

unanswered questions they may have, including what happened to their birth parents, their siblings and other family members, to what sort of child they were, and in some cases whether there were any known hereditary health conditions.

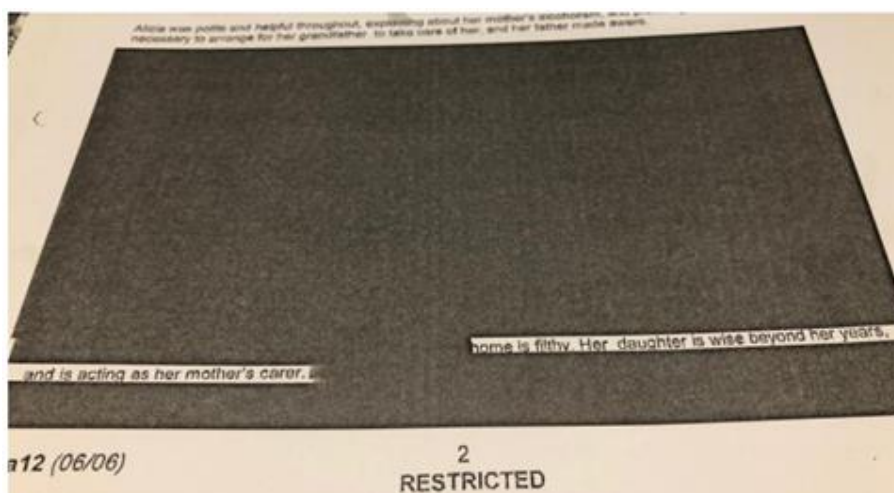
The existence of records for an individual's care experience is dependent on a number of factors, including: the type of care they received; when historically that care was provided; by whom and for how long; and the legislative and regulatory framework governing that type of care at that time.

Records can help clarify or validate specific childhood events and memories:

[I] wanted to know where I came from.....because I thought I had been lied to and not told the whole truth about what happened to me (Who Cares? Scotland, 2019, p. 3).

Adults with care experience may experience feelings of confusion or frustration when reading records of their childhood journey:

I sat up in my bed until 3am reading details of my life on these pieces of paper that summarised my childhood. I read countless police reports that I was a part of because of my mum, but they would refer to me as 'the subject': I am not a subject or an object. Care Experienced people are not 'subjects' or 'objects', we are human beings with feelings that are valid... A lot of my file was heavily redacted too ...There are hundreds of pages that look like this (Who Cares? Scotland, 2019, p. 6):



This example of a record in redacted form provides a stark illustration of a Care experienced individual's reaction to the records they received. However, it can be devastating for Care experienced individuals when they are unable to access records because they cannot be found or because they no longer exist.

I just want to fill in the blanks. I want to make sense of the worst time in my life, however, I cannot do this with the little information I remember (Who Cares? Scotland, 2019, p. 13).

For some individuals, the duration of their care experience was short, for example, if a parent was ill. For others, the experience of care could span their entire childhood. Records created about the individual's time in care will be dictated to some extent by the historic time period, and duration of care, but, as is now more commonly understood, the further back in time we go, the more difficulties there can be with identifying records.

## **Advocates for care experienced communities**

Several care experienced communities have set up groups to provide mutual support and campaign collectively for their rights. In Scotland, there are a number of these groups such as In Care Abuse Survivors (INCAS), Former Boys and Girls Abused of Quarrier's Homes (FBGA), and Who Cares? Scotland. One specific campaign issue they all have in common concerns care experienced individuals' information rights and access to records.

Research into the needs of care experienced communities worldwide spanning 20 years highlights recurring issues of access to records. More recent examples include: 'Setting the Records Straight for the Rights of the Child' in Australia (Evans, 2017); 'MIRRA: Memory-Identity-Rights in Records – Access' (University College London, 2019); and 'Our Lives, Our Stories, Our Records' (Who Cares? Scotland, 2019). Projects like these are trying to move the debate on access to records towards practice solutions, but progress is slow with few active solutions being deployed in organisational practice. Despite these efforts, the impact on those who are able to access their records today cannot be minimised, as exemplified in this example:

Fairly straightforward but ultimately left more questions unanswered. There was little in my Care File. I was in care for 7 years but there was not one photo, no parental letters, not one school report, no mention of how I was doing at school, nothing insightful. My Care File had all the use and interest of an old shopping list. It seems to have been written by complete strangers about a complete stranger. Some of the remarks were about someone else, they must have been (Male, 58, Hull). (Duncalf, 2010, p.39).

It would appear that despite current research, advocacy group campaigns, and care experienced communities' records needs being better understood, there is a gap between improvements at the organisational practice level and the ability to meet expectations of care experienced communities.

## **Possible solutions versus organisational practice**

The Who Cares? Scotland (2019) access to records campaign, driving improvements to practice at national level, is starting to establish ways in which these improvements can be shaped at the organisational practice level. A recent collaboration with Aberdeen City Council to co-design improvements with care experienced communities to create national good practice standards that promote openness (minimal redactions) and care (support and ease of access) (2019), commenced in early 2019.

The motivation for Aberdeen City Council to embark on this collaboration stems from organisational research conducted into how the Council prepared for responding to the Scottish Child Abuse Inquiry in 2017: 'Making Records Ready: Responding to the Scottish Child Abuse Inquiry' (Anderson, 2018). Some of the insights revealed from this research highlighted specific challenges for the organisation in the identification of, and access to, historic organisational records – its corporate memory – in its capacity as corporate parent.

Pulling the care experience and organisational parts of the access to records issues together, what we are now beginning to understand is that these issues are multifaceted and extend much further than previously known. They also

suggest that any solutions adopted will be dependent on the organisations that provided care engaging with these issues and the relevant communities. Knowledge of exactly what organisational records are held in relation to their historic corporate parenting role and responsibilities, what information those records contain, and a willingness to invest in that approach is key to the organisation's ability in practice to relate to care experienced individuals' information rights in a compassionate and meaningful way.

The recommendations from this research revealed the multifaceted challenges facing the organisation regarding their own access to, and understanding of, records they hold in relation to their role and responsibility as corporate parent. As organisational records identified and accessed increased, in different forms, often containing handwritten text, spanning considerable time periods, they became voluminous. The ability to analyse, understand and interpret these records requires specialist roles and skillsets and the time to do this work. Skills required include determining meaning from what was expressed in records using dated language about a child and their care journey, and the organisational decision-making process within that journey that were reflective of the legislative and regulatory environment of the time.

The complexity of information held within records about a child's care journey and experience often includes many references to third parties. Under data protection law, strict considerations must be made about what personal information can be released about an individual, to that individual. The challenges this poses for an organisation, and the decision-making processes required, can be immense when the records contain an array of personal detail about other parties, including siblings, extended family, friends, practitioners and other contacts.

Each request received from a care experienced individual relates to a unique person with a unique care journey and can contain a variety of records about when, why and how that care was provided. It is perhaps not surprising that the attention and specialist skills required to go through records means that considerable time is required to analyse and contextualise such a request on behalf of the organisation. It also goes some way to explaining why many Care



Experienced individuals receiving information report difficulties, frustrations and upset when trying to absorb and translate the information in redacted form about their lives in a meaningful way (Who Cares? Scotland, 2019).

## **Concluding comments**

Marrying the knowledge and understanding available to us from care experienced communities, advocacy groups and research introduces a complex set of additional issues that underpin a more holistic rights agenda. This paper explored some of these issues in more detail to highlight possible solutions that could be applied in practice today.

This paper has explored some of the issues facing organisations and how they could develop their capability to comply with legislation and respond meaningfully when meeting the information rights and access to records needs of our care experienced communities. It has described from an organisational practice perspective some of the root cause challenges in organisational practice in identifying whether records exist, as well as interpreting and analysing records with an understanding of the historic landscape in which that care was provided. These practice issues are fundamental to an organisation's ability to exercise its duty as corporate parent and meet the broader holistic information rights of care experienced adults seeking access to their family album.

The collaboration between Who Cares? Scotland and Aberdeen City Council could be the start of a national collective across Scotland to improve access to records at policy and practice level. If, collectively, we have that better understanding of the historic landscape and the records that exist, we can better articulate this publicly and manage the sensitivities and fragility around care experienced communities' information needs and rights. It would also enable us to better manage our role as corporate parent, to articulate the personal aspects and events of someone's care experience journey where, in some circumstances, no records of their personal journey have survived.

Our understanding of the landscape in which care for children was practised could enable organisations to learn and make the improvements to root cause issues now. If we accept the moral and ethical requirements in which historic

State interventions have been applied to ensure the care, welfare and protection of our children, we must do all we can to provide that holistic, national narrative; and do this with a care that constitutes our responsibility as corporate parents, producing a family album for those seeking to reclaim any part of their childhood at any time in their adult lives; past, present and future.

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### **About the author**

Dr Caroline Anderson works at Aberdeen City Council as Information and Data Manager and has recently completed a Professional Doctorate at Robert Gordon University. Caroline has a longstanding interest in the moral and legal aspects of recordkeeping for Care experienced communities.