

Meeting the needs of care experienced adults for information from their care records

Policy brief by The Care Leavers Association (CLA) and the Access to Care Records Campaign Group (ACRCG)



Introduction

The Care Leavers Association (CLA) and the Access to Care Records Campaign Group (ACRCG), informed by the voices of many care experienced adults, have long believed that all such adults should have a legal right to information held on their care records through specific legislation that addresses their unique rights and identity needs. Current data protection legislation is not suitable since it is designed primarily to protect personal data from misuse and commercial exploitation. It therefore restricts care experienced adults from obtaining a full account of their history of being cared for by the State. Adopted persons, in recognition of their identity needs, have a dedicated regulatory framework setting out their rights to information from their adoption records. Care experienced adults need a similarly 'fit for purpose' legal framework, setting out their rights and the duties of local authorities or other agencies which hold their case records.

Even within existing legislation, there is much that could be done, at the behest of the review, to quickly improve access and support rights for care leavers of all ages to information held about them by those who cared for them as children.

The identity needs of care experienced adults

Our sense of personal identity is usually established strongly in childhood, within one's birth family. Knowledge gaps have a profound impact on this process. For many well documented reasons, a care experienced adult may have fragmented memories of growing up in care and have few, or no, relationships from which to 'fill in' gaps. That is why, typically, care experienced adults are seeking as much information as possible from their care records, not a fragmented narrative with third party information redacted.

Why do care experienced adults seek information from their care records?

The impact of being 'in care' is lifelong. Hence the relevance of access to care file information is equally lifelong. The Care Review itself has already recognised the importance of this point ('The Case for Change, June 2021, p.71). However, there is no legal duty on local authorities to provide post-care support beyond the age of 25. (Volume 3 Transitions and Children & Family Act 2017 – reference below). For some, becoming a parent can be a trigger for seeking care records. For others, simply understanding the reasons they were placed in care is important. For many, it is a simple need to find some replacement, however bureaucratic and artificial, for the constant, flowing discussion of family history that is part of the warp and weft of family life.

'I started wondering about my history, then as I got much older it seemed to become more important...I just got to a certain stage in life' (Female, late 50's)

'I was about 34-35 when I applied, I felt like I was on just some crazy journey, going back round and round in circles.' (Male, early 50's)

Battling with a care-less process: A CLA Research report 2017

The problems with the current data protection framework for care experienced adults

Adult care leavers seeking information from their care records (also called case records) must use the Subject Access Request process of the Data Protection Act 2018 (DPA18). This process does not place the rights and needs of the care experienced adult at the centre of decision-making. Instead, it gives rights to the State, the 'corporate parent' of the person growing up in care, to withhold information about other persons that is often critical to building a coherent narrative of family connections, reasons for being in care and decisions made whilst in care.

While the Local Authority (LA) or Voluntary Organisation (VO), as Data Controller (DC), has discretion under DPA18 to decide what and how much 'third party' information to release without consent, this power is often interpreted narrowly and exercised defensively, without clear reasons for the decision made. As a result, adult care leavers frequently receive 'copies' of their care records that are significantly redacted and lacking a narrative thread. This clearly impacts adversely on their Article 8 rights of 'respect for [their] family life'. (Article 8, Human Rights Act 1998) Moreover, as the freedom of information enquiry conducted by the Access to Care Records Campaign Group in 2016 [see reference below] established, practice in responding to a SAR varies widely across England.

'I didn't think I would get them to be honest it took so long, but one morning months later I got three big files through the post with no warning.' (Female, late 40's)

'There were just blacked out pages some with just my name left on...did my head in because I was left with more questions than answers because of the redactions.' (Male, mid 20's)
Battling with a care-less process: A CLA Research report 2017

What currently happens when a care experienced adult makes a Subject Access Request under the Data Protection Act 2018?

The key process that takes place under the DPA is the redaction of third-party information. This is frequently information that the care experienced adult already knows. Consent can be gained for sharing such information, but the process can be complex and adds to delays. It also leaves discretionary power in the hands of local authorities. The Care Leavers Association and others have experience of cases where the decision by the Data Controller not to share third party information seems more bureaucratic and defensive, or risk-averse, rather than constructive and thoughtful. Challenging such decisions can add further delays in getting information. Adding to this is the lack of resources allocated by local authorities to this work (voluntary organisations tend to do better in this regard). The cumulative effect of this can be adult care leavers feeling the need to start litigation over the disclosure of documents See, for example *Durham County Council v Dunn* (2012) EWCA Civ 1654 and *In the matter of A (A Child)* (2012) UKSC 60 [references below].

The alternative for care experienced adults is to make a referral to the Information Commissioner's Office. This can be helpful, but neither route is a sensible or cost-efficient way to achieve what should be an uncomplicated result.

'I heard nothing for months, I had to keep ringing social services and I was just fobbed off with excuses. It was like they had better things to do and I was taking up their time or something. It was like a battle trying to get it.' (Male, early 50's)

'They replied saying so many days but a couple of months later I had heard nothing. I emailed and rang and was then directed to one person.' (Female, late 20's) *Battling with a care-less process: A CLA Research report 2017*

What action has the Department of Education and the Information Commissioner's Office taken so far?

The DfE recognises the issue of providing greater support for care experienced adults in this process but notes that their remit is up to the age of 25 and that they have done their best by issuing guidance – see reference below. Regrettably, this guidance does not seem to be widely known in the sector. The ICO says it is not appropriate for them to issue sector-specific guidance addressing the unique rights and needs of adult care leavers making a SAR.

The issue of a transparent and fair legal framework for accessing care records extends across a number of government departments. To review and either amend DPA18 or provide a Bill to produce alternative legislation is currently on no official agenda. The Care Review provides a powerful opportunity to make a persuasive recommendation for change.

What do we want to achieve?

- **Care experienced adults being at the centre of decision making**, enabling local authorities and voluntary organisations to make empathetic and reparative decisions about sharing information from care records
- **Respecting rights** to knowledge about one's time in care, thus helping improve physical, emotional and mental well-being and enhancing life opportunities
- Opportunities for care experienced adults to **re-establish family and other personal connections**
- Less variable and **less adverse experiences** when seeking one's care records
- **Sufficiently skilled and supported case workers** to undertake this work
- Ensure that care experienced adults have the option to access **a range of support options** to help deal with issues raised because of accessing files

What is required to achieve these goals?

The Care Leavers Association and ACRCG urge the Care Review to demand that the government:

- 1) implements immediate reforms to the process for care experienced adults accessing care records
- 2) legislates for a unique framework for accessing care records outside of current data protection laws. This new framework would make the rights, well-being and welfare of the care experienced adult the 'paramount consideration' in decisions about sharing all information on their care records.

We propose two stages: the first is an immediate interim measure, the second is a necessary longer-term measure.

Stage 1

Amend DPA18 to provide a defence of 'justifiable reason[s]' in relation to the exercise of discretion by the Data Controller (DC) to share personal data of a third party without consent: the DC would set out their reasons when making the decision to exercise discretion, taking into account the individual circumstances of the SAR applicant and the content of the information to be shared and any consequences for a third party. The approach would balance HRA98/Article 8 rights of privacy of the individual whose data is under consideration and the 'respect for family life' rights of the adult care leaver within a context in which the DC has usually been the 'corporate parent' of the applicant making the SAR. The amendment to DPA18 could be supported by guidance issued either by government or through the Information Commissioner's Office.

Improve the current Statutory Guidance and extend it to those care experienced people over 25, with amendments as appropriate for older age groups. Any revised guidance should be directed both to local authority children's services and data controllers/information governance teams and should include:

- Children's Services and Information Governance should develop closer links, information sharing protocols and training and support mechanisms.
- All data caseworkers to receive trauma-focused training on social care files.
- The local authority must clearly publicise, through a wide range of media, the rights and process for care experienced people accessing their social care file.
- Good practice protocols in terms of improving the process of accessing and receiving files. Data case workers should be encouraged to build a relationship with the care experienced person, keep them regularly updated on the process, and agree how the files will be collated and given to the care experienced person.
- Local authorities should provide an offer of independent support to the care experienced person to help them deal with the issues generated by accessing their care records. By independent, we mean unrelated to the local authority providing access to the files. Support could be provided by specialist organisations, local advocacy or support organisations or other local authority social workers. Attempts should also be made to establish local peer support networks.
- Provide guidance to data caseworker to avoid redaction, keeping a clear record of any redaction decisions made and giving explanations for the redaction.

Other immediate measures to consider include:

- Care experienced adults who might find it particularly difficult to access their records in person should also be entitled to support. For example, the work of the CLA has already shown that files access can be particularly valuable for care leavers in the secure estate.
- The review should consider developing and extending the 'Always Here' policy of North Yorkshire Children's Services across the sector as a whole. This new initiative offers a model for post-25 advice and guidance, challenging the cliff-edge loss of support for care leavers in their mid-twenties. A specific remit for such services could extend their work beyond advice and guidance to support with care files access. Research has consistently shown that adults with care experience return for help with files access at all ages, often in their fifties and beyond. Hence this offers local authorities and others the opportunity to demonstrate a meaningful commitment to a lifelong supportive relationship.
- Extend the period of time for keeping care records. Currently, local authorities in England must retain care records securely and confidentially for 75 years from the date of birth of the person who was 'in care' or if that person dies before reaching adulthood, 15 years from the date of their death. [Regulation 50, The Care Planning, Placement and Case Review (England) Regulations 2010]. Adoption records must be kept for at least 100 years after the date of the adoption order. Care experienced adults should have parity with adopted persons. Local authorities are under pressure not to retain files beyond the minimum period for various reasons, including costs of maintaining archival material. Hence, the importance of this measure. This 'gain' could be achieved through a simple amendment to existing Regulations.
- Records should hold not only reports but can, and should, hold memorabilia (photographs, for example). This can be of great personal significance for care experienced adults and their relatives. Foster carers and residential care staff are key to these personal artefacts being retained and need to be supported to do so. Archival policies, procedures and contractual arrangements need to take this into account.
- For care experienced adults trying to locate social care records can be hugely challenging as it is not always easy to identify where social care records are held. A positive solution to this difficulty would be to provide funding and resources to create a records locating data-base that would help care experienced adults find the

- information they are looking for. Examples of this already exist, such as CoramBAAF's locating adoption records database which can be found on the Adoption Search & Reunion Website: <http://www.adoptionsearchreunion.org.uk/search/adoptionrecords/> and also Australia's Find and Connect website: <https://www.findandconnect.gov.au/about/>
- Currently, descendants of care experienced adults do not have a right to information from the records of their deceased relatives. This restriction does not apply to descendants of an adopted person. Impediments need to be removed (this may require legislative action) to direct descendants of care experienced adults accessing the files of their parents and grandparents and close relatives. The care experienced aspect of family history can be of enormous value to such individuals. We see no good reason why they should be denied access to such information.

Stage 2

Similar to adoption legislation, create a unique and specific regulatory framework for sharing care records with the adult care leaver. The framework would place the rights of the adult care leaver asking for their care records to have full information from their records central to decision making, whilst enabling the privacy rights and any risk to others to be taken into account. It would create a workable framework for decision making, assisting the adult care leaver to have more information about their family connections, whilst also providing a more coherent and transparent framework for decision making about what to share.

Summary

Care experienced adults are marginalised by government and society. They must have legally secured rights to establish a coherent narrative of their time in the care of the State. The current personal data protection legislation and current policy and practice do not enable or support them to achieve this. The Care Review can address this by using the two stage steps proposed above.

Background information and references

Legislation and Guidance

Data Protection Act 2018

<https://www.legislation.gov.uk/ukpga/2018/12/contents/enacted>

Volume 3 Transitions and Children & Family Act 2017

<https://www.gov.uk/government/publications/children-act-1989-transition-to-adulthood-for-care-leavers>

Case law

Durham County Council v Dunn (2012) EWCA Civ 1654

<https://www.bailii.org/ew/cases/EWCA/Civ/2012/1654.html>

In the matter of A (A Child) (2012) UKSC 60

<https://www.bailii.org/uk/cases/UKSC/2012/60.html>

Reports at the link below:

<https://www.accesstocarerecords.org.uk/about-us/resourcesdocuments/>

Report on Roundtables, ACRCG [2016]

Battling with a 'care-less' process Clarke, B and Kent, K [2017]

Summary of FOI Responses – ACRCG and Barnardos

Articles published by the MIRRA Project, University College London

Hoyle V, Shepherd E, Flinn A and Lomas E (2019) 'Child social-care recording and the information rights of care-experienced people: a record keeping perspective', British Journal of Social Work, 49:7, pp 1856–1874

Hoyle V, Shepherd E, Lomas E and Flinn A (2020) 'Record keeping and the life-long memory and identity needs of care-experienced children and young people', Child & Family Social Work, pp 1–11

Kirton, D., Peltier, E., Webb, E. After all these years (2001) Accessing care records, Adoption & Fostering, 25(4), 39-49

Information Commissioner's Office

ICO Guidance on Subject Access Requests