



1. Access to Care Records Campaign Group is an association of individuals, organisations and adult care leavers working together to improve the rights of adult care leavers to have access to care records to enable them to have information about themselves and their family members held on in these records.
2. The current legal process enabling an adult care leaver to obtain their personal and other relevant data on their care records is to make a Subject Access Request under the Data Protection Act 2018. This process does not give sufficient weight to their rights under Article 8 of the Human Rights Act to find out about their family life and discriminates against the rights and needs of an identifiable group of persons.
3. We are asking the Law Commission to shape legislative proposals to replace the present legal route under the Data Protection Act 2018 with a dedicated and more empathetic legislative framework which addresses their unique lived experiences and establishes rights to knowledge about their family life recorded in care records.
4. We have made two proposals which are set out in more detail in our reply to Q.7. The first is to amend the Data Protection Act 2018 to provide a defence of 'reasonable justification' if the data controller of the care records is challenged when providing to the adult care leaver personal data of a third party without that person's consent. The second is legislation and regulations (akin to the framework for sharing information held in adoption records) which places the rights and needs of the adult care leaver at the centre of the process and decision making about what to share, together with support services which the adult care leaver may choose to use if they so wish.
5. A podcast – link below – made with Research in Practice in which two adult care leavers talk about what it means to find information in care records and why the present system is not 'fit for purpose' sets out more powerfully and persuasively than a thousand words why we believe an opportunity to review and amend the present process must be taken up now.

<https://www.researchinpractice.org.uk/children/content-pages/podcasts/reflections-on-accessing-care-records-and-supporting-good-recording/>

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Question 1

In general terms, what is the problem that requires reform?

Adult care leavers who want to find out about themselves and their birth family from their care records [also called case records] have to use the Subject Access Request process in the Data Protection Act 2018 [DPA18]. This process does not adequately address the rights and unique needs of people who have grown up 'in care'.

The State, which, whilst they were 'in care', was their 'corporate parent', should enable them to have as much information as practicable from their care records to assist them to join together and make sense of 'fragmented memories' of their time in care, to find out about their family connections, the reasons why they came into care and which people were responsible for these decisions.

Although 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 too frequently interpreted narrowly and exercised defensively, without clear reasons for the decision made. As a result, the adult care leaver receives 'a copy' of the care records held by the LA or VO that are significantly redacted with no narrative thread, thus reinforcing 'fragmented memories' and their experience of a 'care-less' system. This clearly impacts adversely on their Article 8 rights of respect for their family life.

Question 2

Can you give us an example of what happens in practice?

The LA, which held Parental Responsibility for the child/young person while in care, is required currently to retain for 75 years the adult care leaver's care records. Older care leavers will often learn that their care records cannot be located or may have been held by a residential care home which is no longer operating. In some cases, partial records may be held by a VO.

Although the tighter timeline for responding to a SAR in DPA18 is welcome, many LAs are still slow to respond. The process involves an officer retrieving and then going through the applicant's records, redacting personal data of any other person mentioned. Often, the applicant already knows this information and is actually seeking confirmation of their recollection or more detail.

Third party information can be shared with consent, but the LA may decide not to get consent of the third party for a range of reasons. Seeking the consent of a third party requires a sensitive judgement about the impact on the third party, gained through a reading of the records. It also requires the DC to have proper regard to the privacy of the person making the SAR as they may not wish the third party to know that they are asking to see the records, fearful of adverse repercussions. However, there are examples where the decision by the Data Controller not to share third party information seems more bureaucratic [for example no current address of the third party known and so steps taken to locate the individual] rather than constructive and thoughtful. For example, a decision not to provide the birth date, place of birth of a parent and/or any change of name of the parent before the SAR applicant's birth creates a barrier for the adult care leaver seeking more information about their parent. If a parent is born outside of the UK and this information is withheld, it will be very challenging for the adult care leaver to gain sufficient information to trace their parent.

Attempts to encourage and persuade the DC of the LA/VO to exercise its discretion to share relevant third-party personal data are emotionally challenging and exhausting for the adult care leaver to undertake alone and there are limited resources to guide and support them. Practice within the VO sector is more likely to be consistent, informed and supportive than in the local authority sector where resources allocated to this important work are very limited and often not given priority.

LAs can often be defensive about exercising discretion because of fears of fines for data breaches and/or litigation. As a result, adult care leavers may actually be forced to start litigation so the court rules in relation to disclosure of documents prevail. The Court has held that once proceedings are issued, the Civil Procedure Rules apply.

See, for example:

Durham County Council v Dunn (2012) EWCA Civ 1654.

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

The alternative is the SAR applicant to make a referral to the Information Commissioner's Office. Neither route is a sensible or cost-efficient way to achieve what the adult care leaver is entitled to have or a fair process.

Question 3

To which area(s) of the law does the problem relate?

The primary framework is the General Data Protection Regulation [GDPR] and the Data Protection Act 2018 [DPA18]. The GDPR and DPA18 intersect with Human Rights Act 1998 rights and family law principles and case law, especially duties on local authorities in the Children Act 1989 and the regulatory framework for children in the 'care system'.

Question 4

We will be looking into the existing law that relates to the problem you have described. Please tell us about any court/tribunal cases, legislation, books or journal articles that relate to this problem.

Legislation

Data Protection Act 2018

Case law

Durham County Council v Dunn (2012) EWCA Civ 1654 [referred to in Q2]

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

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 [2018]

[see summary of these documents in Appendix to this submission]

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

Please contact us for any additional articles or information sources.

Question 5

Can you give us information about how the problem is approached in other legal systems? You might have some information about how overseas legislatures have responded or how the court or tribunals approach the problem.

See Durham County Council v Dunn (2012) EWCA Civ 1654 [referred to in Q2]

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

If we can assist regarding other legal systems, please contact us.

Question 6

Within the United Kingdom, does the problem occur in any or all of England, Wales, Scotland or Northern Ireland?

Data Protection Act 2018 applies across the UK.

Question 7

What do you think needs to be done to resolve the problem?

We propose two options but would welcome discussing this issue with the Commission.

Option 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 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.

Outcome: less defensive and variable exercise of discretion by the Data Controller responsible for retaining care records.

Option 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.

Outcome: whilst aware this would require primary legislation, it would put the adult care leaver in an equivalent position to an adopted adult and place their rights and needs at the centre of the process and decision making.

Question 8

What is the scale of the problem?

This might include information about the number of people affected this year or the number of cases which were heard in a court or tribunal over a particular period.

There are no reliable data sources about the number of SAR applications made in any one year by adult care leavers. Many adult care leavers will not know about their right to make a SAR for their care records. When others know and attempt to access their care records via a SAR request, they often feel defeated and give up. It takes courage and resilience to stay the course as they are likely to experience many barriers and deterrents in the process. Some care leavers may have serious

health problems and lack access to resources to support them to make the SAR. Adult care leavers in prison experience difficulties under differing 'rules and practices' across the prison estate when seeking advice or making a SAR.

See ACRCG Summary of Response to FOI [summary in Appendix]

See Clarke and Kent op cit p8

Question 9

What would be the positive impacts of reform? Benefits derived from law reform can include:

- **Fairness** - the State taking responsibility for its parental role for children and young people who were in the care system, with common standards and approaches across all LAs.
- **Rights** - enabling the adult care leaver to exercise their Article 8 rights regarding knowledge of their family, who made decisions about them and why, to recover memories about their time in care and, if they wish, to begin to re-establish family connections.
- **Efficient and clear statement of the law** - DPA framework does not align positively with the rights and needs of adult care leavers. Clarity about the framework for decision making about sharing relevant personal data about other people/third parties would assist, not only adult care leavers but also, data governance decision makers.
- **Economic sense** - reduces physical, emotional and mental health costs and potential litigation. The impact of the current process on adult care leavers, some of whom may already have fragile mental health and emotional well-being, is not currently properly accounted for. The lack of a defined legal framework particularly impacts on the needs of adult care leavers in prisons and the cost to prison services is not currently accounted for.

Question 10

If this area of the law is reformed, can you identify what the costs or other negative impacts of reform might be?

Initially, there would be costs for LAs and any VO holding care records to set up/improve and resource, with skilled staff, the systems which would meet properly the needs of adult care leavers exercising their right to have information about their time in care. However, if considered from an 'invest to save' standpoint, these costs would reduce over time. LAs and VOs could collaborate in sharing systems and knowledge and reconfigure more efficiently archiving and retrieval systems through developing digital systems. If the rights of adult care leavers were to be placed at the centre of the process, support services should be provided throughout the process. Whilst this may appear an additional cost, savings would in the long term be made to the cost of adult care and mental health services.

Question 11

Does the problem adversely impact equality, diversity and inclusion by affecting certain groups in society, or particular areas of the country, more than others? If so, what are those groups or areas?

As an example, if the law relates to criminal justice, existing problems might be more likely to have a disproportionate impact on BAME communities. Or, if the law relates to agricultural land, it might affect farmers and their families more than the general population

Adult care leavers are among one of the most marginalised groups in society. Compared with adopted adults, where there is an acknowledgement that adoption is a lifelong experience, there is no legal duty on the LA to provide post care support beyond the age of 25 years. [See Volume 3 Transitions and Children & Family Act 2017.]

Many adult care leavers will have experienced a disrupted and often uncaring 'parenting' by the State. Many care leavers are in the prison system, partly connected to the adversity they experienced growing up in care. It is not easy to quantify but there are presently more children from minority ethnic groups in the care system. For older adult care leavers, many came into the system because of discrimination, and poverty that their parent may have experienced, which may have impacted on their ability to care for their child. Others will be marginalised because of mental health and limited economic opportunities reflecting a disrupted education experience. All these factors undermine building cohesive and caring communities.

For some care leavers, becoming a parent or when their children or grandchildren are asking questions, this can act as a trigger to seek records relating to their time in care. The other problem which organisations such as Care Leavers Association know too well and which the FOI enquiry done by Access to Care Records Campaign Group in 2016 established is that practice - good and poor - about responding to a SAR varies widely and erratically across, for example, England and likely elsewhere in the UK.

Question 12

In your view, why is the independent, non-political, Law Commission the appropriate body to undertake this work, as opposed to, for example, a Government department, Parliamentary committee, or a non-Governmental organisation?

The issue of a transparent and fair legal framework for accessing care records extends across a number of government departments and Ministers. The DfE has been helpful in issuing statutory guidance, but its remit is constrained to care leavers up to the age of 25 years. To review and either amend DPA18 or to scope out and shape for Parliament a Bill to consider alternative legislation is not something a Parliamentary Committee is set up for or equipped to do. There is little scope for 'direction' from the judicial system and there is no relevant NGO which represents the interests and needs of adult care leavers. Adult care leavers make little impact in the political arena. The Law Commission has both the knowledge and the analytical skills - similar to the way in which the Law Commission shaped the private law sections of the Children Act 1989 - to take into account sectional interests across government and potential conflicts to present a cogent and persuasive case for legal change.

Question 13

Have you been in touch with any part of the Government (either central or local) about this problem? What did they say?

DfE says it recognises the issue, but their remit is up to the age of 25 and they have done their best by issuing guidance – see reference above. We agree civil servants in DfE have been most helpful, but the guidance does not seem to be widely known in the sector.

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.

Question 14

Is any other organisation such as the Government or a non-Governmental group currently considering this problem? Have they considered it recently? If so, please give us the details of their investigation on this issue, and why you think the Law Commission should also look into the problem.

MIRRA Project at UCL has done work in the field with adult care leavers leading to recommendations but no government department or non-government group are either willing or able to take this issue on board, reflecting the extent to which the rights of adult care leavers are consistently marginalised at the political and social interface in civil society.

APPENDIX

Summary of three Reports referred to in Response from ACRCG

It's My Journey: It's My Life!

Care leavers and access to social care files

A report on a series of multi agency roundtable discussions on Data Protection, Subject Access Requests and Support, 2016

Summary

An effective response to meet the needs of children currently looked after and care leavers regardless of their age or when they were in care, who wish to exercise their right to access their social care files, will require a comprehensive revision of legislation and associated guidance. These recommendations and associated actions should not be taken to apply only to the rights or entitlements of those who are currently defined as looked after or who qualify as care leavers under the Children Act 1989 and the Children (Leaving Care) Act 2000. This report acknowledges there is increasing attention on the needs and rights of care leavers at a central policy level. In October 2013, the government produced a Cross Departmental Strategy for care leavers, updated in October 2014, which accepts "central and local government have a unique relationship with children in care and care leavers as their 'corporate parents. This strategy makes clear the government's responsibilities as the 'corporate parent' to establish a joined up approach ensuring that government departments across Whitehall work closely to develop a more coherent approach to how looked after children and care leavers are supported. There also needs to be recognition of the needs of care leavers across the life course. We call upon the government to take note of the evidence which shows that older care leavers seek access to records across the life course in search of their history.

Six Key Recommendations

1. Develop effective processes for gaining permission from third parties, both family members and professionals, to share information with care leavers at the time of engagement with them, whilst understanding that third party consent is not determinative of a decision by the Data Controller to share information with the care leaver.

Action Required

Ofsted inspections should consider the extent to which local authorities' case recording policy and guidance addresses the issue of third party permission and whether effective training on this issue is given to practitioners.

2. Work more effectively across local authority departments to share the knowledge and expertise of data governance officers and social work or leaving care staff in making decisions about access to records. Any government guidance about access to care records should be addressed to both Data Controllers and Directors of Children's Services.

Action Required

The Local Authority and CEO, Director of Children Services and Data Controller should create structures for information sharing between departments and joint training for staff. Any revised government guidance about access to care records should be directed to both social care staff and data governance officers.

3. Offer support to all care leavers of any age across their life-span through the access to records process, and keep open communication with them throughout.

Action Required

Ofsted should inspect the delivery of support services for care leavers accessing their files until 25 The Data Controller should be specifically tasked with developing support services in partnership with social care services for older care leavers.

4. Avoid redaction wherever possible, keeping a clear record of any redaction decisions made

and giving an explanation to the care leaver of the reasons.

Action Required

Staff should be given training about decision making under the Data Protection Act 1998 which enables them to hear directly from looked after children and care leavers about their experiences. Decision making about redaction should be audited for consistency and empathy for the needs of care leavers

5. Provide detailed guidance for data governance officers in relation to access to care records.

Action Required

Information Commissioner's Office supported by the Department for Culture, Media and Sport (jointly with the Department for Business, Innovation and Skills) where Ministerial responsibility for Intellectual Property sits should review this recommendation and report proposals to the government's Cross Party Care Leaver Strategy group and to Parliament. Ofsted should be asked to make proposals for incorporating into inspections a review of compliance with statutory guidance, including:

- the extent to which local authorities' case recording policy and guidance addresses the issue of third party permission and whether effective training on this issue is given to practitioners
- the delivery of support services for care leavers accessing their files until 25.

6. There needs to be a new legal framework that addresses the particular rights and information needs of care leavers to access care records and the necessary support available to them to do so. The Data Protection Act 1998 was not designed to deal with requests for family history and information and decisions relating to a person's time in care and amendments are needed.

Action Required

Government should review and consult to develop new draft legislation about care leavers' rights to access their care records which is fit for purpose.

Government should, whilst Data Protection Act 1998 continues to be, for the present time, the frame-work for access to care records, amend the Act to include a defence of 'reasonable judgement' about a decision to release third party information to a care leaver.

Battling with a 'care-less' process: Adult care leaver experiences of accessing records of time in care

Clarke B and Kent K, Manchester Metropolitan University 2017

Summary of recommendations from MMU report

These are the demands of adult care leavers interviewed in the study based on their own experience of asking to get their care records.

1. Need to increase awareness ...

Government must:

Require local authorities and any agency which has been responsible for providing care for children and young people at any time to

- [a] publicise through a wide range of media options information for adult care leavers about their rights to access their care files
- [b] set up systems which are accessible for all adult care leavers to enable them to make a request for their care records
- [c] provide suitable support based on the individual's circumstances and wishes when responding to the request to see their care file.

2. Need for consistency....

Government must:

- [a] establish a protocol of good practice for Data Controllers dealing with requests by adult care leavers or person nominated on their behalf for social care records
- [b] set minimum standards of good practice under the remit of the Information

Commissioner's Office which will provide the base line for responding to requests for care records.

3. Need for swifter responses...

Government must:

- [a] set up systems to ensure compliance with statutory guidance and minimum standards are monitored and reviewed
- [b] enable adult care leavers to be compensated for delays in dealing with requests
- [c] ensure that the Local Government Ombudsman is aware of these requirements.

4. Need for support ...

Government must:

- [a] include the requirement for suitable support services in minimum standards
- [b] assist local authorities to identify funding streams to support adult care leavers
- [c] ensure that health, education and prison services are required to work in collaboration with local authorities and voluntary care providers in developing a range of support services.

5. Need for investment...

Government must:

- [a] properly address the needs of all adult care leavers and not confine itself to current care leavers up to the age of 25 years
- [b] ensure that the additional needs of adult care leavers for a range of services including health services are properly identified and resourced
- [c] provide for the needs of adult care leavers who seek access to their care files when in prison are addressed within the prison system and that systems are in place which respect privacy and skilled support is identified throughout the process.

Conclusion of the report

We trust that these research findings, alongside the growing tide of critical evidence demonstrating the impact of the current 'careless' system, will spark action from the state which results in those who have been looked after as children by the state receiving the justice they are battling for.

Adult Care Leavers: Freedom of Information analysis, findings and recommendation September 2018

Key findings of the Freedom of Information request to all local authorities in England

1. Three fifths of councils had no records of the number of Subject Access Requests [SARs] made in a 12 month period by adult care leavers.
2. Where councils did have records, there was wide variation as to the percentage of SARs made in any one year. The average was a fifth of all SARs received were from care leavers, although three councils reported SARs from care leavers were over 50% of the total number of applications.
3. The pattern of significant variation across England resonates with findings from other enquiries by the Access to Care Records Campaign Group [ACRCG] that despite statutory guidance on the need to have skilled staff to deal with these SARs and supports tailored to the individual's needs, this is not evident.

Recommendation to Government

There is an urgent need to establish National Standards for care records retention and processes to support adult care leavers making a Subject Access Request under the Data Protection Act 2018.

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- Where councils did have records, there was wide variation as to the percentage of SARs made in any one year. The average was a fifth of all SARs received were from care leavers, although three councils reported SARs from care leavers were over 50% of the total number of applications.
- The pattern of significant variation across England resonates with findings from other enquiries by the Access to Care Records Campaign Group [ACRCG] that despite statutory guidance on the need to have skilled staff to deal with these SARs and supports tailored to the individual's needs, this is not evident.

Recommendation to Government

There is an urgent need to establish National Standards for care records retention and processes to support adult care leavers making a Subject Access Request under the Data Protection Act 2018.

FOI questions to 153 councils in England

In 2017, Barnardo's carried out, at the request of the Access for Care Records Campaign Group [ACRCG], a Freedom of Information (FOI) request to 153 councils across England. The two questions asked were:

1. How many Subject Access Requests (SARs) under the Data Protection Act 1998 did your Local Authority / Data Controller receive in the following years? 2014, 2015, 2016.
2. How many Subject Access Requests under the Data Protection Act 1998 did your Local Authority / Data Controller receive from adult care leavers for their own social care records in the following years? 2014, 2015, 2016.

Response rate to the FOI

- Out of 153 councils, 11 did not respond to the request.
- Out of the 142 who did respond, 5 had no records available for both questions asked.

Purpose of the FOI

The purpose was to understand the number of adult care leavers accessing their records, and what percentage of the total numbers of SARs to each individual council were made by adult care leavers. We believed that

the data gathered would assist us to inform the Campaign's strategy to support our work with Local Authorities and the Government to improve every adult care leaver's experience of accessing their social care records.

Data analysis

Of the **142 councils who responded, 85 had no record of whether Subject Access Requests were being made by adult care leavers in their area. This equates to three fifths of councils who responded (59.8%) having no records of when or how often adult care leavers were making subject access responses.** This is likely to make planning for support services for care leavers who are accessing records very difficult in the majority of councils.

This is consistent with the reality that we have discovered through other work of the ACRCG with adult care leavers who have asked to see their care records. The duty on councils to provide adult care leavers with their personal information about their time in care is often not seen as a dedicated need within the local authority with little monitoring on how the service is being used or how it could be improved.

There were some signs of improvement with a very small number of councils who had begun to hold records of SARs by adult care leavers from 2016. While it is not within the remit of the FOI to understand the reasons for this development, the data will enable ACRCG to return to those councils to find out more about how practice has changed on the ground and the reasons they have begun to collect this data.

For those councils which did have records, adult care leavers accounted for an average of around a **fifth of all SARs received.** However, the averages varied significantly across different councils (ranging from 0-92%). The percentages were typically towards the lower end, with **only three councils having an average of over 50%.** We cannot deduce much from this information, as the data does not provide us with an explanation as to why these councils had such a high volume of requests. For example, is this down to any specific work by the particular council to raise awareness among care leavers of their rights to access records? Further follow up with the councils which have a very high percentage of SARs coming from adult care leavers may therefore provide some constructive lessons for practice. In particular, how councils can work to build successfully awareness amongst their own adult care leaver population of their rights to access information and how to do this.

Conclusion

Although we got a disappointing level of data from across England as to the number of SAR requests that are being made by adult care leavers, it reflects much of what is known through our Round Table sessions. It resonates with the experience of adult care leavers written up in the research report commissioned from Manchester Metropolitan University by the Care Leavers Association that many care leavers struggle to access records, and do not get the necessary support to do so from their local authority. [Battling with a Careless Process: Adult care leaver experiences of accessing records of time in care. MMU & CLA, November 2017].

The lack of data clearly indicates that councils do not always have an understanding of the provision and service necessary to support adult care leavers to access their case records. This includes keeping accurate records of the level of need for the service in their area. It suggests that the current state of affairs remains unsatisfactory and inconsistent across authorities.

The ACRCG believes this demonstrates further the urgent need to set in place National Standards for care records retention and processes to support adult care leavers making a Subject Access Request under the Data Protection Act 2018.