



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

Written by the Access To Records Campaign Group



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Introduction and Key Recommendations

Improving Access to Care Records

This report has been written by the Access to Care Records Campaign Group (ACRCG), whose members are the Care Leavers' Association (CLA), CoramBAAF (formerly BAAF), Association of Child Abuse Lawyers (ACAL), The Post Care Forum and Barnardo's, supported by Baroness Lola Young of Hornsey, OBE. It is based on evidence collected through six roundtable events with care leavers and practitioners and managers which took place across England in mid-2015. It sets out some of the challenges and barriers to accessing care records and makes practical recommendations for Government, local authorities and other agencies to improve care leavers' access to records.

Access to Care Records Campaign Group

The ACRCG was formed in 2013 bringing together five organisations who have knowledge of the experience of care leavers seeking their care records to find out about their own and their family history and the decisions made about them while in care. The group believes that the current legal framework for accessing care files is not suitable and is working with care leavers to remedy this. A primary aim was to lobby with care leavers for a change in the law to make access to records easier and fairer, with more tailored support services for care leavers. This would be in line with the range of support services available to adopted adults, including intermediary services, when trying to locate and contact family members.

Lobbying by ACRCG in 2013 culminated in Baroness Lola Young tabling an amendment in the House of Lords on 9 December 2013 during the passage of the Children and Families Bill¹. This led to a debate about the barriers care leavers experienced when seeking their care files and in response the Department for Education (DfE) amended statutory guidance² in 2014 to require local authorities to support care leavers up to the age of 25 to access their care records. This includes having clear information available about how care leavers can access their records and the support available; suitably trained and supervised staff; and providing information that is legible, coherent and well-ordered.

The guidance also states that the principles and the support which should be offered to care leavers up to 25 should also apply to older care leavers who want to access their records.

Supported by Baroness Lola Young, ACRCG hosted the Children's Minister, Edward Timpson MP, at a Parliamentary event on 29 October 2014 to recognise the progress made in helping care leavers access their records. The event included a commitment to hold regional roundtables to help raise awareness of the new requirements placed on local authorities in the statutory guidance.

Acknowledgement of supporters of the roundtable events

ACRCG is grateful to the legal firms LeighDay, BondDickinson, Slater & Gordon and Irwin Mitchell and also the Father Hudson Society and Essex County Council for providing venues and refreshments for the roundtable events. We are grateful to the DfE for their commitment to improving care leavers' access to their records and for their support and to Ofsted and the Information Commissioner's Office (ICO) who contributed to these events.

We wish to thank all those care leavers who took part in the roundtables, those who facilitated roundtable events with us and those who contributed to the making of the film shown at the roundtables. Our grateful thanks also to Ken George, Director at KGB Productions for the support provided in making the film.

¹ Hansard, 9 December 2013, column 631 accessed at: <http://www.publications.parliament.uk/pa/ld201314/ldhansrd/text/131209-0002.htm>
² The Children Act 1989 guidance and Regulations, Volume 3: planning transition to adulthood for care leavers – see para 4.21 to 4.39

We also record our thanks to the participants at our roundtable events who shared with us their practice approaches about decision making and the barriers they found challenging when making decisions about sharing information from care records with care leavers.

What do we mean by care leavers?

The ACRCG works with care leavers (many of whom may have left care decades ago). This means that when using the word 'care leaver' we are talking about people of any age; they may be in their young, middle or senior adulthood. A common denominator they all share is that they have experienced living away from their family in a State care arrangement provided either by a local authority, a voluntary agency or other forms of State care. The DfE's remit is limited to the narrow definition of a care leaver under the Children (Leaving Care) Act 2000 and those who qualify as care leavers up to 25 years. The Care Leavers' Association says a care leaver is:

'anyone who has spent any time at any point in the care of the state, whether that be residential care (inclusive of secure settings), foster care or kinship care.'

The roundtables

Between June and September 2015, ACRCG held a series of six roundtable workshops across England to explore the issues and dilemmas in providing care leavers with their records. These were attended by data protection and information governance managers, social care and leaving care teams, legal advisers and care leaver support agencies. The aims of the roundtables were, firstly, to promote the statutory guidance on access to records for care leavers, and secondly to act as a forum for practitioners working on records access and their managers to share good practice and learn from each other.

The workshops started with brief presentations from a range of stakeholders, including the Care Leavers' Association, Ofsted, the ICO, the DfE, local authorities and various legal firms. A video, made by care leavers about their experiences of accessing their records, was shown at each roundtable. Delegates were then invited to discuss different aspects of access to records and generate some solutions.

Key areas discussed at the roundtables

The roundtable discussions considered a number of key areas identified through a wider body of work within the CLA directly with care leavers and by the ACRCG partner organisations.

Legal parameters

- Differing interpretations of the law
- Consequences of litigation

Working together

- How the Data Controller works with social care
- How the Local Authority/Agency supports care leavers

Identification of need

- Local Authority/Agency strategy to inform care leavers of rights
- Supports in place to ensure it is less bureaucratic and more person-centred

Training and Awareness

- Development of joint training between Local Authorities and Agencies
- Developing training involving Data Protection Teams and Social Care Teams

Redaction

- Meeting the requirements of the Data Protection Act 1998, whilst being flexible and enabling
- Best practice when making redactions

Key issues highlighted

There were wide ranging discussions and information sharing both in general points raised during questions to presenters and during themed roundtable work which was shared in a plenary session. This summary of the key issues is based on notes made by participants during the group discussions.

- The wide range of reasons why care leavers want to find out about their time in care and their experiences, when asking to see their care records, which at times did not appreciate their individual circumstances, was not sufficiently understood and recognized by agencies when providing the service and identifying support and developing staff training.
- Participants generally agreed that the current data protection framework and the purpose and structure of the Data Protection Act 1998 was not suitable for meeting the rights and needs of a care leaver wanting information from their social care record.
- There appeared to be a lack of joint protocols between data governance officers and social care practitioners to secure and develop professional expertise across both sectors and to ensure sound and consistent decision making about sharing information with a care leaver accessing their care file.
- There is currently no requirement on Data Controllers to provide:[a] information about a care leaver's right to have information from their care file [b] support or signposting to assist a care leaver who asks for support during the access to care records process and afterwards.
- There were indications that care leavers as a group experienced inconsistent responses to a Subject Access Request and were a neglected group in terms of support services available. Redaction of information in the care leaver's records appeared to be made on a case by case basis, in a context where decisions about what to share were influenced by anxiety about breaching data protection legislation and its consequences and also possible future legal action against the local authority or care agency.

Key recommendations

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.

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: <ul style="list-style-type: none"> - 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.

Chapter 1: The Voice and Experience of Care Leavers

The Care Leavers' Association supported care leavers who had experienced seeking their care records to be involved in the roundtable discussion groups and enabled them to make a film about their experience which was shown to participants. The film **'My Journey; My Life!'** is available on the website of the Care Leavers' Association. Participants valued the care leavers' contributions to the discussions about practice and issues when responding to a request by a care leaver of any age to see their care records. Improving practice and seeking changes to the current legal framework must be informed by the knowledge and experiences of care leavers and those working to support care leavers access their files.

Why do care leavers want to see their care records?

Knowing where we have come from and what has happened in our past is an important part of making sense of ourselves and our lives. For many people who have been in care, however, the collective family memory of events is often not available and there can be gaps in information or confusion about what actually happened. Some care leavers may be seeking to understand the reasons why they were brought into care, which may have taken place when they were very young, and as a result of their family circumstances at the time. They may want to know the placements they had and the carers who looked after them at a formative stage of their lives. They want to piece together fragmented memories and also have a sense of ownership of their life and history.

Others may want to trace family members they have lost touch with as a result of being in care or find out about their health history or access copies of certificates relating to their achievements during their childhood and adolescence.

Growing up in care for some people is an experience covering their whole childhood. For others they may have moved between care placements and their own family, whilst others may have spent time in care for a specific period. In all these situations, there will be questions to be answered. However, it is often not until the care leaver reaches adulthood and is settled with a family of their own, that they begin to reflect on their past and think about their own childhood experiences.

Care leavers give a wide range of reasons and/or triggers about why they want to access their care records; these include curiosity; fragmented memories; wanting photos to show their own children; reminiscing; making sense of difficult memories and life events; seeking answers about why they went into care as families often have disparate explanations; trying to trace family members which redaction impedes; and seeking medical information in reference to hereditary illness/disease. These are just some of the reasons why care leavers want to access their files.

The experience of care leavers

Often care leavers feel that they are a largely invisible group, especially people who come back to ask for their care records many years after they were in care and they struggle to get the service and support they need. As individuals and as a collective group of people they frequently experience varying forms of discrimination. A consistent thread experienced by many care leavers is trying to make sense of past experiences which profoundly impact on their emotional well-being. The State's intervention in their family life has often created a legacy of unresolved issues and fractured memories. It is challenging to build resilience and emotional well-being and move forward into the future if the past remains unresolved.

ACRCG is made up of several organisations which work directly with many care leavers for whom the residual issues of their care experience and transition to independence, often negative and unsupported, follows them into their later adult life. A care leaver may at any age arrive at a stage in their life journey when they are seeking knowledge about past events and decisions made for them during their time in care to enable them to reflect on its impact on their current life. That information may or may not be in their care records.

It is important to recognise and acknowledge that care leavers of any age are entitled to have access to their personal information and relevant third party information to make sense of the narrative of their lives. Furthermore, it should be noted that the State took on 'corporate parental responsibility' for them and, especially for older care leavers, being in the State's care was often arranged without court intervention and scrutiny. They should have the opportunity to access a range of appropriate supports provided by agencies on behalf of the State throughout the process of getting access to their care records, including help with tracing members of their family with whom they have lost touch.

Care leavers' experiences of accessing records

Making the decision to access their records can be emotionally challenging for someone who has been in care. Having taken the step to request access, many care leavers have then struggled to navigate the local authority's processes and even faced barriers to accessing information about their own history. Care leavers explained to participants at the roundtables how the Data Protection Act 1998 and Subject Access Request process did not take into account, in its legal requirements, their needs and emotional well-being. They were clear that the Data Protection Act 1998 meant that agencies were required to give them their personal information and it was distressing to find that their own care records were either destroyed, not complete or not properly made available to them. This seemed to them to run counter to the purpose of the Data Protection Act 1998 – to make personal information available to the subject of the information. This reinforced their sense of being different from other people who had not been in care.

As far as care leavers are concerned their case record belongs to the care leaver, yet they experience the local authority determining access to the contents of their file. This, for a care leaver, is very similar to the relationship they will have experienced growing up in the care system with the local authority 'in loco parentis'.

The Care Leavers' Association, which supports care leavers of any age to access their records, has identified a number of common barriers:

- No response to requests to access care records.
- No files found, as they had been lost, destroyed or filed incorrectly.
- Refusal of access to their files because officials considered it was too damaging to the individual to release.
- Assumptions by officials that care leavers should not want to access the information because it was all in the past.
- Files provided with unnecessary redactions, even removing information that the care leaver already knew.

The findings from the workshops about access to care records

It is clear from the experience of ACRCG and the discussions in the roundtable events that current practice in providing access to care records is inconsistent. Although some local authorities provide an effective, supportive service to care leavers, the approach in others is led more by a defensive response and over redaction to 'protect' the local authority as opposed to an enabling and empowering approach which seeks to provide as much information as possible to help the individual. The Data Protection Act 1998 is cited as a barrier for releasing information from care records, often with misunderstandings about the Data Controller's power to exercise discretion to share relevant third party information with the care leaver. This is a perverse use of the Data Protection Act 1998 which is an enabling statute.

The roundtables also evidenced the limited awareness of the change to statutory guidance, with less than 20% of participants aware of the new guidance from the Department for Education. Frequently, participants from data governance did not know of this guidance. Ofsted's single inspections of local authorities requires inspectors to report on care leavers' awareness of, and access to, their legal entitlements (such as access to their case records). While the inspection framework uses access to records as an example of those entitlements, there is no requirement on inspectors to report on access to records in all published reports.

What is an effective approach to access to care records?

In 2008, the Care Leavers' Association launched CLEARmark, a quality mark for access to records. CLEARmark is made up of seven criteria, which were identified by care leavers, and can be awarded to local authorities and voluntary agencies that demonstrate good practice. The organisation should:

- Advertise the right for care leavers to access their records in at least one type of media, which might be: a webpage; a flyer; a poster or an advertisement in a local newspaper.
- Have a statement of recognition that care leavers have a right to this information.
- Recognise the positive importance of accessing files.
- Have an Access to Records policy that is publicly available.
- Have a monitoring system on requests received and responses made (or to be demonstrably working towards such a system).
- Provide a brief and accessible response letter and leaflet to encourage care leavers to see the process through.
- Monitor the effectiveness of the service through use of an evaluation form.

<http://www.careleavers.com/clearmark>

Unless care leavers are involved in developing with government a 'fit for purpose' legal framework and properly funded support services, care leavers will continue to experience variable responses to their request to see their files. Those agencies striving to deliver a supportive service are frequently dependent on individual case workers in the absence of policy, resources and supervision. In other agencies, bureaucratic and defensive responses are yet another indirect form of discrimination against care leavers.

The Care Leavers' Association, through its many years of campaign work 'It's Our History, It's Our Right; Reclaiming Our Past' believes we should work collaboratively to:

- Promote engagement across key agencies concerned with the recording, retention and access to the social care files of Looked After Children and Care Leavers.
- Develop and promote innovative approaches to national partnership working with Looked After Children/Care Leavers in the development of services that address their individual needs.
- Promote transparency, openness and accountability of public services to Looked After Children and Care Leavers, in view of the overwhelming impact of public services on their life chances and quality of life.
- Provide training and information on the needs of Looked After Children/Care Leavers, their emotional well-being and how this is impacted by the process of accessing their file(s).
- Ensure user led perspectives are central to policy developments and implementation.

Chapter 2: Legal Barriers to Accessing Social Care Records

The right of an individual to access records held about them is set out in the Data Protection Act 1998. The Act imposes a range of responsibilities on agencies, including local authorities and voluntary organisations, who are concerned about failure to meet the legal requirements, especially in relation to breaching the rights of third parties to confidentiality and the risk of censure. In addition, having failed to access records through the more usual route, some care leavers have engaged a lawyer to gain access, which might be related to court proceedings around abuse or other issues. As a result, one of the most significant barriers to local authorities providing care records appropriately is the concern about either legal challenge by third parties or a negligence action.

Local authorities managed Subject Access Requests in varying ways, with some requests handled by data governance officers and others by social work staff. In some authorities, data governance officers dealt with closed care files, with social care teams responsible for files still open. In other authorities, this distinction was not necessarily made. This can result in substantial variation between authorities in how care leavers' access to records requests are dealt with. There were some indications that requests handled by data governance staff tended to take a different approach to redaction, applying data protection principles, whilst those processed by social care teams took a welfare based approach. This varying but essentially risk averse attitude was perceived to be encouraged both by regulation by the Information Commissioner's Office and the consequences of a breach of the Data Protection Act 1998 and risks around litigation.

Subject Access Requests made under the Data Protection Act 1998 are required to be processed within 40 calendar days of the request being made. Failure to meet the time limit can lead to sanctions by the Information Commissioner. Care records should also be provided in a clear format that will enable the care leaver to make sense of what has happened during their time in care. Data governance officers and social care case workers explained that meeting the time limit for Subject Access Requests from care leavers can be very challenging as care files may be long and complex; individual files will often be within family files; they may be held by multiple parts of the local authority; third parties may need to be consulted about releasing information about them or a report they made; and some redaction may be needed. The EU rules currently under consideration will reduce the time limit for responding and this will pose challenges for local authorities.

Some agencies had in place a process for releasing information to the care leaver in batches as data became available. This needed to be done in a logical order to help the care leaver make sense of the records. It was important to keep the care leaver informed of progress and for the local authority to develop a relationship with the care leaver. Some agencies asked at the outset what the care leaver wanted to know immediately and started with releasing that information first.

A significant concern for agencies in providing care records is the exposure of information about third parties. Often, this is the information that care leavers want to access, such as finding out about the reasons why their parents were unable to care for them, to trace family members, or to find out about previous foster carers or social workers.

Some agencies had in place clear protocols to assess any risks associated with sharing the details of former foster carers or siblings. It was seen as important to find out from the care leaver what they already knew about those contacts, so that information was not withheld unnecessarily. In addition, it was seen as good practice to secure permission to release information from individuals such as foster carers or birth parents at the time of recording the data when a child was in care. Inevitably, this was not a practice in place in historic care records. Where there was no policy to support staff or explicit permission from a third party, it left individual staff having to make decisions which were likely to be risk adverse and resulted in more information being redacted or decisions being delayed.

In some situations, access to records requests are made by lawyers acting on behalf of a care leaver.

County Council v Dunn [2012] EWCA Civ. 1654 that the Data Protection Act 1998 did not apply in this situation and the correct approach was a balancing exercise, weighing the duties of disclosure in civil litigation under the Civil Procedures Rules and the European Convention of Human Rights, Article 8 privacy rights of the third party enacted in the Human Rights Act 1998, together with the litigant's Article 6 right to a fair trial. Despite this judgement, there is still evidence of redaction taking place. The roundtables indicated that many officers involved in access to records were unaware of the courts' powers to order the disclosure of social care records in the context of litigation.

Data governance and social care staff need to have greater awareness of the case law and rules and the rights of the care leaver in civil litigation.

Detailed recommendations on legal issues:

Local authorities should:

- Put in place clear protocols, based on assessed risk, for providing third party information as part of a Subject Access Request.
- Seek permission from third parties at the time of making records during a child's stay in care to create a more robust process for providing information to care leavers.
- Keep a documented record of the reasons for decisions relating to releasing third party information to protect against any future legal challenge.
- Train data governance and social care staff on the role of legal proceedings in Subject Access Requests.
- Provide training for staff about the process and case law relevant to civil litigation decisions and the interface between the Civil Procedure Rules and the Data Protection Act 1998 and Subject Access Requests.
- Ensure that statutory guidance to provide for looked after children and young people's 'life story' work is complied with.

The Information Commissioner's Office should:

- Provide more guidance on and examples of how to deal with releasing third party information in cases of care leavers' Subject Access Requests.

Government should:

- Enact legislation which specifically provides the legal framework and process for accessing care records regardless of the age of the care leaver or the agency holding the care files.
And meanwhile,
- Amend the Data Protection Act 1998 so that while this Act continues to be the legal framework for responding to a care leaver's request to see their care records, the Data Protection Act 1998 should be amended to provide a defence of 'reasonable judgement' when the release of third party information is challenged by the third party. This would enhance more balanced and reasoned decision making and reduce defensive decision-making to redact, which has significant adverse consequences for the care leaver.

Chapter 3: Effective Joint Working in Local Authorities and Voluntary Agencies

Access to care records may be handled by different departments, depending on the local authority or voluntary agency. In some, the process is managed by leaving care or social work teams who have a detailed knowledge of the care system, but often limited time to work on Subject Access Requests, with limited understanding of the Data Protection Act 1998. In others, access requests are handled by data governance teams, who have wide experience of providing access to information but usually limited knowledge of the care system or its impact on people who have been through it. Where the expertise was combined in a dedicated team, the care leaver was likely to receive a high standard of decision making about information sharing and support. Voluntary agencies where staff had experience of providing intermediary services to adopted persons or their relatives may have additional skills to support care leavers and to make decisions about third party information. It is essential that the learning from all groups is brought together to provide for care leavers a sensitive and individual service that understands and supports their needs but also meets data protection requirements.

Several local authorities and voluntary agencies explained the importance of developing good relationships with the care leaver requesting access to their care records. Redacting information that care leavers already know is unnecessary and disrespectful of the care leaver's needs and rights. Taking the time to speak with the care leaver is key, which should involve having a thorough discussion about what they want to find out, what they already know and their expectations of the access process. Good practice included having a dedicated officer assigned to each individual Subject Access Request to enable consistency of relationships, and also meeting with the care leaver face-to-face to find out what they know and their expectations of the process. If the care leaver was still accessing services through the local authority, their personal adviser or social worker should also be involved.

A concern for many local authorities was sharing third party information with care leavers, particularly when these individuals were not available to be asked for their permission. Some local authorities have in place multi-agency data sharing agreements to help manage third party information. This means, for example, that any information that would not be appropriate to share without prior consent, such as medical records of a third party from a GP, can be flagged on the care records. Other local authorities, such as Essex County Council, had protocols in place to secure parent, carer or other third party consent to sharing information in the future. However, this is unlikely to apply in the case of care records made several decades ago. Several local authorities indicated that clearer guidance with case examples from the Information Commissioner's Office would be useful to clarify good practice regarding third party information when providing access to care records.

In some authorities, care leavers' Subject Access Requests were handled by leaving care or social work teams within Children's Services, whereas in others it was carried out by data governance officers in a central team. Whilst handling requests was seen as time-consuming, albeit important, by frontline social care staff, there was some concern that processing by data governance officers could lead to disjointed approaches as they would not know the care context as well and may be more likely to recommend redactions. Data governance officers, however, commented that they considered they were sometimes less restrictive in sharing information operating within Data Protection Act 1998 principles. There were also examples of data governance officers unknowingly failing to provide full records to a care leaver as they did not have full electronic access to sensitive case files.

Joint training was seen as a key element for successfully managing data requests from care leavers. Participants at the round tables welcomed the opportunity to discuss practice issues with colleagues from different practice backgrounds. The training could involve both leaving care staff and data governance officers sharing their ways of working and explaining and resolving the risks and opportunities that each identified in providing access to records. It would be constructive to involve care leavers who could describe their own motivations for and experiences of accessing their care records.

There needs to be a culture of openness and joint working between Children's Services and data governance departments, with clear channels of communication and the ability to raise concerns or suggest improvements in the process. A number of local authorities carried out this joint working to improve the service that they were able to offer care leavers. It was seen as important that not only front line staff but also managers needed to be trained and made aware of good practice, given their role in decision-making on the release of records.

Having good records in place makes responding to Subject Access Requests much easier, so it was seen as important that social workers and leaving care staff received training in how to record information appropriately. Essex County Council, for example, had a series of online modules for new social work staff as part of their mandatory e-learning programme to make clear to staff the importance of good record keeping. CoramBAAF (previously BAAF) published a good Practice Guide on Access to information for post-care adults for Social Workers and Access to Record Officers in 2009, but seemingly there were many local authorities who were not aware of this resource. The Care Leavers' Association has produced a user guide to Subject Access Requests, available FREE of charge to care leavers through their website, which is aimed at supporting care leavers through the process. This guide is complimented by a full FREE advice, guidance and support service to care leavers seeking to access their social care files. Whilst significant numbers of care leavers do use this guide and support service, many local authorities are not aware of it and as such are not able to make care leavers aware of it. We would re-emphasise that the opportunity to work side by side with care leavers through the process of the roundtables was seen as invaluable to practitioners and their managers and demonstrates the need to ensure any good practice development must have care leavers central to it.

Detailed recommendations on joint working:

Local authorities and voluntary organisations should:

- Put in place protocols for combining the expertise of data governance officers and social work or leaving care staff in making decisions about access to records.
- Assign a nominated officer to each care leaver's Subject Access Request to help understand what the individual already knows and their expectations of the process.
- Ensure that staff handling records have full access to the records to remove the risk of any inadvertent omissions, such as around sensitive information.
- Provide joint training on access to records for leaving care and social work staff and data governance officers, which should include significant input from care leavers themselves.

The Information Commissioner's Office should:

- Provide clearer guidance on what constitutes good practice in access to care records by local authorities and voluntary agencies.

Ofsted should:

- Ascertain, where relevant to any inspection, good practice and compliance with statutory guidance and Information Commissioner's Office standards when responding to access to records requests and evaluate the effectiveness of training for staff.

Chapter 4: Supporting Care Leavers

Deciding to access your records is an emotional experience for a care leaver, and may be something that they have been considering for months or even years. It is very important, therefore, that local authorities are able to understand the experience from a care leaver's point of view and provide support, if the care leaver wants this, and information that is appropriate and sensitive to their needs.

Central to supporting care leavers is the need to make them aware of their rights and entitlements to access their care records. For young people who are currently in care or who have recently left, local authorities need to provide information about how and when they can access their records, including the process that they would go through. One approach would be to build this information into the young person's Pathway Plan, or to provide a leaflet or website for them to know how to access their records if they choose to do so in the future. It is also essential that social workers and leaving care staff do life story work with young people whilst they are in care, which can help them understand better what has happened to them and raise any concerns or gaps at an earlier stage.

Some care leavers may decide to access their records many years or decades after they leave care. Local authorities need to make information available to them about their rights to access their records. This could be through posters or advertisements in community health centres, libraries, council offices or through social media channels. Another approach would be to run periodic local advertising campaigns to raise awareness of care leavers' access rights. Having a nominated individual for care leavers to speak to was also seen as good practice.

For some care leavers, having dedicated support in place can make a significant difference to their experience of accessing their care records. Care leavers accessing files written decades ago may find language and opinions which would not be in current case records or used today. Such opinions recorded by social workers and other professionals may not fit with the care leaver's opinion of themselves and it is essential that support is offered. Having a link worker or nominated officer to support them, who knows their case, can be very helpful. One approach would be to offer care leavers the option of requesting additional support as part of their Subject Access Request. The option for requesting support should also be available at any time throughout the access process. Other options would be offering counselling to care leavers during and after the process, which may be through signposting to other local or national agencies. It is essential when the social care files do not exist or are not complete that clear signposting and support is offered to the care leavers to make them aware of other Subject Access Requests that can be made to retrieve information, for example education records, hospital records and records that may be held by voluntary organisations.

Good communication with a care leaver is a central element of providing a good service. It was seen as important to have a face-to-face meeting wherever possible, to find out from the care leaver what they knew and wanted to find out, as well as their expectations of the process. This would also be an opportunity to explain the process of requesting records within that local authority or agency, as well as giving some information about what care records tend to include and what may be excluded and why. For those care leavers who left care many years ago, it would also be useful to explain some of the language that may have been used in their care records that may not be seen as appropriate to a modern reader. A number of local authorities described the importance of recruiting data governance staff who were approachable and able to empathise with care leavers trying to access their records.

Some care leavers have described being left uninformed about the progress of their Subject Access Request for many weeks or even months. It is critical that local authorities keep care leavers updated on progress with their request, including the reasons for any delays or problems in accessing information. They should also be kept informed about what happens next and the stages involved in the process.

Detailed recommendations on support for care leavers:

Local authorities should:

- Provide up-to-date information to care leavers about their rights and how to access their care records, with a nominated officer to contact.
- Offer support to care leavers through the access to records process, either directly through a nominated officer or by signposting to relevant services.
- Maintain open communication with the care leaver throughout the access to records process, keeping them informed of any delays or problems.

Chapter 5: Redaction

A key issue raised consistently by care leavers, social care staff, data governance officers and legal advisers was redaction. Care leavers described being handed records that were overly edited, removing information that they already knew or names of people of whom they were already aware. For care leavers, this level of editing was seen as intrusive in that they felt their own history was being deleted, and in some cases led to a greater feeling of suspicion that there must be “something to hide”. This, in some cases, was a trigger for a care leaver seeking legal advice about how to access their file, leading to a legal challenge and associated financial costs.

Local authority staff described the challenges they faced in providing open and honest access to records whilst protecting the interests of third parties who had not consented to having their data shared, as well as the difficult decisions that took place over redaction, especially about perceived risk to the care leaver or third parties. Some local authorities indicated that social work officers tended to approach access to records through their experiences of child protection and a perception of concern. They were anxious about what impact the information in the case records could have on care leavers’ emotional and mental health, particularly the information on historic files. Hence they were less likely to approach it through care leavers’ rights to see their information, which could result in greater amounts of redaction.

There were differing views about the role and use of redaction. Some local authorities took an approach that care leavers have the right to know about what happened whilst they were in care, and so assumed little or no redaction would be needed. Others were concerned about third party interests, or potentially the local authority’s own interests and the risk of legal challenge, and so took a more cautious approach to releasing information.

In many situations, redaction can be avoided, or at least limited, by having a good understanding of what the care leaver already knows about their care history and the people involved. Some local authorities described the importance of developing, through face-to-face meetings, a clear chronology of what the care leaver already knew, and where they had gaps in their memory or experiences that they wanted to try and fill. The point was made strongly by care leavers that for many care leavers the reason they want to see all of their file is because they do not have knowledge about their time in care and it is difficult to ‘know what you do not know’. Others described being aware of what information was already in the public domain – for example, a parents’ criminal conviction may not already be known by the care leaver but may be publicly available information. Some local authorities described having a risk assessment process in place to weigh up the balance of the risk of redacting or of not redacting information.

Local authorities explained that concern about censure from the Information Commissioner drove a significant proportion of redaction decisions. It was noted that clearer guidance from the Information Commissioner, including relevant case examples, would be very helpful to improve decision-making. Where redaction was needed, local authorities explained the importance of keeping a clear record of the decision-making process. This could document, for example, what the care leaver already knew about their care experience, the situation of gaining consent from various third parties, the risks of not redacting, and the ultimate reasons for the decision. Recording decisions in this way would also be helpful if, later, the decisions were subject to a challenge by the Information Commissioner.

In situations where substantial redactions had been made, some participants explained that they would offer to meet face-to-face with the care leaver and explain to them why there were redactions. This could help the individual come to terms with any omissions in their care records and help them understand why redaction was needed. It was also explained that a summary to give context and narrative may be helpful.

There were mixed views about redacting archaic language from care files. Some local authorities considered that the way in which files were written in the past, particularly if it were by people whom the care leaver knew and trusted, could be damaging to read years later. Others, however, took an approach of explaining in advance about the language used and supporting the care leaver through the process of receiving and reading their records. The Care Leavers' Association's experience of working with care leavers is that removing archaic language is not helpful and is not necessary if proper supports are available to the care leaver. There was also discussion about the appearance of a heavily redacted file and the impact this can have on the care leaver. It was considered that we need to improve the way redactions are made and have the supporting software to do this.

Detailed recommendations on redaction:

Local authorities and voluntary agencies should:

- Avoid redaction wherever possible, through understanding what the care leaver already knows and taking an attitude of openness and transparency, recognising the Data Protection Act 1998 as an enabling statute.
- Document and explain to the care leaver the reasons for any redactions made.

The Information Commissioner's Office should:

- Provide more detailed guidance about redaction in care records to help local authorities make fair decisions that are not based on the fear of censure.

Conclusions

In the evaluations and feedback from the roundtables, the consistent message from delegates was how much they welcomed the opportunity to meet care leavers and work alongside them as well as sharing good practice with case workers and managers from other local authorities and agencies to consider together the practice dilemmas and issues about making decisions to share information with a care leaver who asks to see their file. It is evident that many of the delegates worked alone or in small teams and in most authorities there appeared to be limited or no interaction between data governance teams and social care teams. They also welcomed the opportunity to hear from representatives from the Department for Education, Information Commissioner's Office and Ofsted on the occasions these agencies were able to join delegates in the discussion after their presentations. There is a demonstrated need to provide further seminars, training and workshops.

It was disturbing to find that the Department for Education guidance issued in 2014 was not widely known as this provides for agencies and authorities a helpful framework from which to shape good practice policies for all care leavers, regardless of their age. Data governance officers need to be informed of the guidance and the Department for Education needs to lead on this. Equally of concern was that the Care Leavers' Association guidance accessible for FREE through their website and the CoramBAAF Practice Guidance were not widely known and thus these resources were not being utilised by practitioners.

The information provided by lawyers about the rules and process for disclosure of care files when an application is made for the file pending or during litigation was, for most delegates, new information. This case law has significant implications for care leavers and those dealing with requests to see a care file. It was evident that the Data Protection Act 1998 and its serious consequences for an agency if breached created, in some agencies, a risk adverse culture when it came to information sharing, which resulted in redactions which in some cases gave no context at all to the limited care records eventually disclosed.

We were struck by the variation in practice across agencies which clearly results in differing outcomes for a care leaver, but we were also impressed by examples of thoughtful and empathetic practice and a range of supports provided, although at times, in the absence of any clear procedures. For a care leaver, variation and unpredictability are unacceptable. It creates forms of institutional discrimination against people who, through no fault on their part, were parented by the State. This 'corporate parent' cannot in the care leaver's later life continue to retain the power of withholding information about decisions and actions which have so profoundly impacted on their life journey, without recognising the continuing responsibility to offer clear explanations and full support throughout the process.

The discussions, comments and exchange of knowledge the six roundtables engendered has reinforced the view of the Access to Care Records Campaign Group that the Data Protection Act 1998 is not suitable for dealing with requests made by care leavers to see their records. Care leavers need a dedicated legal framework which is premised on the rights and needs of the care leaver and this should be developed in consultation with care leavers and those agencies that provide access to social care records services.



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