

# Introduction

This practice guide has been written for social workers and Access to Records Officers (AROs) in England, and will, we hope, be of assistance to practitioners in Northern Ireland, Scotland and Wales. Other professionals, including lawyers, may also find it useful. Its purpose is to offer guidance and practice examples to assist decision-making about providing information to an adult care leaver who makes a Subject Access Request (SAR) under the Data Protection Act 2018 (DPA). The DPA is sometimes misunderstood as legislation that limits an individual's right to see their personal information held about them, rather than enabling legislation that gives a person the right to find out what data is held about them and the lawful basis for holding any personal data.

The Information Commissioner's Office (ICO) is responsible for overseeing that organisations holding personal data deal with such data lawfully, securely and fairly. The Office has recently issued guidance to organisations setting the standards for responding to requests to organisations to share with an individual their personal data.<sup>1</sup> Whilst this is in general terms, it is a helpful starting point for what is expected when a SAR is made. The guidance provides an important reminder that it is a fundamental right of everyone to know what personal data an organisation holds about them.

The former Information Commissioner, Elizabeth Denham CBE, made a commitment to enhance the trust that people can place in organisations holding their data by ensuring greater transparency and accountability. At a symposium in July 2019, organised by the MIRRA Project (Memory – Identity – Rights in Records – Access) at University College London, she said: 'Records of people's past don't just help to shape their memories, but help to shape how people see themselves today. This is too important an issue not to get right.'

The DPA is the UK-wide vehicle for implementing the requirements of the General Data Protection Regulation 2016 (GDPR) (which came into effect in 2018), a Europe-wide legal framework imposing legal and enforceable requirements on any organisation holding and processing personal data. The GDPR continues, at the time of writing, to apply to the UK, although the UK is no longer a member of the European Economic Union.

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<sup>1</sup> <https://bit.ly/3dEwlcD>

The DPA dictates that each SAR is dealt with on a case-by-case basis, and decisions about sharing with the individual seeking their personal data take into account the reason for their request and the reasons why the organisation is holding their data. Inevitably, this results in differing responses to each request, with varying standards of practice across the UK.

This guide is informed by the day-to-day experiences of social workers and AROs tasked with making decisions and judgements about providing information to adult care leavers. It is also informed by adult care leavers themselves and their experiences of asking local authorities and other agencies for information about their time in care. It is intended to help workers make empathetic and constructive decisions about information sharing to enable adult care leavers to have sufficient information about:

- their family, their background and their time in care to enable them to have an understanding of their past;
- decisions made while they were in care; and
- how this may have affected their journey throughout their childhood and into adulthood.

The guide refers to guidance issued by the ICO about responding to a SAR (see footnote 1) and the statutory guidance applicable to England, issued by the Government through the Department for Education (DfE) in May 2014. Many groups are asking for this statutory guidance to be updated to reflect properly the principles and requirements of the current DPA and GDPR. At the time of writing, this has not been done. Many local authorities and voluntary agencies have procedures to support workers responding to requests from adult care leavers to access their care files; however, many do not.

There is still a lot to learn in this area. The intention of this guide (now in its third edition) is to build on the good practice already in place, informed by what adult care leavers tell us, alongside recent research findings, so that the quality of decision-making by professionals and agencies is enhanced and policy and practice are continuously refined and focused on the rights of adult care leavers.

## A NOTE ON TERMINOLOGY

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The term “adult care leaver” is used in this guide, but some people who grew up in care may refer to themselves as “post-care adults”, “care-experienced adults”, or simply as “a person who grew up in the care system”. The term is used to include anyone who has spent all or part of

their childhood in the care of a local authority – either living with foster carers or in residential care – or living in the care of a voluntary agency.

We refer to all agencies, local authorities, health trusts and voluntary agencies as “organisations”. The term “worker” or “case worker” is used to describe social workers, AROs and data governance officers or any other person working in an organisation and dealing with an adult care leaver’s request to see their case records.

Personal data terminology is considered later in Chapter 1.

## WHY ADULT CARE LEAVERS WANT TO FIND OUT INFORMATION FROM THEIR CARE FILES

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Sharing memories and photos, recounting family stories and significant events are integral to normal family life, helping to build children’s sense of belonging, identity and security. However, for people brought up in care outside their family network, this may not have happened. As a result, they may lack the basic information that people who grow up in their own families take for granted. Finding out about such information can be a challenge for those raised in care with no contact with the family into which they were born.

There is a range of reasons why people seek information from care records held by local authorities and voluntary agencies. For many, it is often to rebuild fractured identities and resolve personal questions about their origins and histories. For some, it is to confirm significant events in their lives, for example, when and why they came into care, where they lived at various ages and the decisions that were made about them. Some people want information to help them seek the relatives with whom they have lost touch. For others, it is to try and make contact with significant people from their lives in care, for example, particular friends, foster carers or residential staff, as these people may be as important to them as birth family members. For others, it is curiosity and just wanting to know where they lived, why they were moved and what records have been kept. Some adult care leavers seek photos to show their partners or their own children. Others, as they become older, may want to find medical information about family illnesses.

For children and young people in care or “looked after” today, there is a clear expectation that they should be provided with comprehensive information about their family background and time in care. As part of their care plan, they should have a life story book and “memory box”, containing information to help them understand the reasons why they are in care and to learn about their personal histories and their family’s circumstances. Children and young people should be involved in the

decisions made about them and when care plans are made at looked after reviews. Gathering and recording of information are undertaken in the knowledge that an adult care leaver may at any stage in their adult life request access to information on their care records. Hence, files are organised in such a way as to address third-party information (information about another person), for example, each child in the family has their own record.

Foster carers are now supported to understand the need for and the importance of collecting and retaining information about the child, such as photos, school reports and certificates and other memorabilia. In this way, the child's experiences and memories can be preserved materially should they move to another foster home or want to see these items in later life.

Whilst adult care leavers today may have more information about their time in care, older care leavers experience considerable barriers to getting information about their time in care. Well into their adult life and perhaps with their own families, they may begin to reflect on their past and want to have details about their childhood and adolescent years. It was not uncommon for children who had spent all their lives in care to grow up without knowing basic facts about their family connections and history and why they were separated from their parents and family.

For people who grew up in care prior to the 1980s, information was not made accessible in the same way as would be expected today. A number of these children had no contact with any family members and, for those who did, that contact was not always encouraged. For example, it was not unusual for a parent to be refused permission to have their child home for Christmas or other important festivals, or to see them on their birthday. This was sometimes for fear that it might unsettle the child or be unfair to the other children, either in the foster home or in a children's home, for whom such contact was not possible. Children were often placed in homes far away from their families, making direct contact very difficult. Children in these circumstances lacked the opportunity to know about their birth parents and other relatives.

Each year, an estimated 4,000 requests for access to files are made by adults, formerly in care, to a local authority, health and social care trust or voluntary agency (Goddard *et al*, 2005, 2013). This figure may well be higher now, some years after the latest research on this was published. However, in the absence of any duty on organisations to hold this data, the number of requests and therefore the planning to respond to such SARs varies UK-wide, much to the detriment of adult care leavers.

A survey of local authorities (Goddard *et al*, 2005) showed that the procedures and practice for providing access to information services for adult care leavers vary enormously. It also revealed the dearth of other support services that may be required as a result of an adult care leaver

accessing information about their background and time in care, such as tracing and intermediary services. In addition, unlike adoption, there has been no specific legislation to govern the particular information needs of adult care leavers and the services they may require.

The Access to Care Records Campaign Group (ACRCG), with the assistance of Barnardo's, made a Freedom of Information (FOI) request to all local authorities in England in 2016. Key findings from local authorities that responded established that:

- Of the 142 councils that responded, 85 had no record of whether SARs were being made by adult care leavers in their area.
- Three-fifths of councils had no records of the number of SARs made by adult care leavers in a 12-month period.
- Where councils did have records, there was wide variation as to the percentage of SARs made in any one year. On average, one-fifth of all SARs received were requests from care leavers, although three councils reported that SARs from care leavers were over 50 per cent 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 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.

As a result, recommendations have been made to the Government and Ofsted about the need for local authorities to have much improved data and information for adult care leavers about their right to make a SAR. As yet, the Government has not made the rights of adult care leavers a priority action.

A summary of the analysis of the responses from the FOI can be found on the Access to Care Records Campaign Group website.<sup>2</sup>

## EXPERIENCES OF ADULT CARE LEAVERS ASKING FOR ACCESS TO CARE RECORDS

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It is generally agreed by many adult care leavers, those representing them and those professionals working in the area of providing information, that the DPA is not an effective way to meet their information needs. This is primarily the effect of the legislation's restrictions on sharing personal information about another person

<sup>2</sup> <https://bit.ly/3dDQ4cG>

without consent, which can result in the person making the SAR not being able to access significant family history information, including details of their parents, siblings and extended family. Sometimes, they are not given identifying information about their family members, even though it is known to them or available in public records. Providing comprehensive information from childhood records to enable the adult care leaver to piece together a narrative about their time in care is a challenge for those tasked with responding to SAR requests, but is not insurmountable, as the organisation does have discretion to share third party information without consent, as is discussed below.

One applicant described the outcome in this way:

*I had been in care for 15 years and found out I could apply for my records, but all I got were ten sheets of paper with lots of information tippexed out. I wondered why I had bothered to access the information as what I got did not make a lot of sense.*

(Feast, 2006, p 34)

## ISSUES WITH THE DATA PROTECTION ACT

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For more than two decades, there has been increasing concern about how difficult it is to work within the various versions of data protection legislation as the legal framework to provide an access to records service for adult care leavers. There is a tension between the duty of the Data Controller (the organisation that holds the information) to be mindful of confidentiality of information regarding identifiable third parties and the entitlement of the adult care leaver to have knowledge of their family to establish their “family life”, an understanding of why they came into care and decisions made about them while in care.

In June 2005, a landmark debate about the lifelong needs of people who grew up in care took place in the House of Lords. The debate, led by Baroness Barker, brought to the fore the importance of the Government and local authorities redressing the balance to ensure that the needs of all adult care leavers are placed on the same footing as those of adopted people, especially regarding access to information, support and intermediary services. It was acknowledged that the gulf between the services that adopted people and their families receive, compared to those for people brought up in care, should be bridged:

*The concerns and preoccupations of adults who were formerly in the care system about who they are and from where they came are natural, human concerns. They are every bit as strong and every bit as valid as the desire of adults who were once adopted to discover information about*

*their birth parents and perhaps even to seek contact with them and with their wider birth families.*

[Earl Howe, House of Lords, 14 June 2005]

A further opportunity arose when the Children and Families Bill was debated in Parliament during 2013, and the Access to Care Records Campaign Group came together to seek legal changes. Baroness Lola Young of Hornsey OBE tabled an amendment to the Bill that led to a second debate in the House of Lords on 9 December 2013:

*Some of the key issues that this amendment seeks to address are the lack of consistency across the country's local authorities in the way they deal with giving access to records to care leavers, and also, importantly, how they deal with the issue of redaction of those records. A number of care leavers gave us evidence of how they received notes from their past which were essentially incomprehensible because of the amount of redaction that had taken place. Again, that seems to depend on whereabouts you live in the country. That should obviously not be the case. In the amendment, we call for clear, effective statutory guidance and the opportunity for care leavers to access support once they have accessed their records.*

Whilst the Government was unwilling to amend primary legislation, it committed to revising statutory guidance to require local authorities to have policies and provide services to support adult care leavers up to the age of 25 to access their care records. This guidance applies only to England and is limited to current and recent adult care leavers. However, it is a useful resource for organisations developing service standards and clearly states that principles and service requirements should apply to all care leavers of any age who want to access their care records. Baroness Young again raised the needs and rights of adult care leavers in a debate on the Children and Social Work Act 2017, citing the report of the Access to Care Records Campaign Group (2016). This did not result in a further change in the Government's position (Hansard, 14 June 2016). As a result, the legal framework for adult care leavers accessing care records in the UK remains the DPA. The Access to Care Records Campaign Group continues to work with adult care leavers to achieve legislative change alongside improved services.

The Government has emphasised that information relating to third parties must be handled in accordance with the principles of the DPA. However, it also accepts that there is scope for the Data Controller (DC) to exercise discretion and disclose information that is already accessible and/or relevant to the individual's understanding of the issues they face from having been in care.

This approach is reinforced by the Information Commissioner's Office in their *Guide to Data Protection*,<sup>3</sup> and more detailed guidance. Whilst this does not specifically refer to responding to an adult care leaver's request to see their records, it provides a helpful framework to inform decision-making and confirms again that obtaining this personal data is an individual's fundamental right.

However, research findings (Goddard *et al*, 2005) and those from a series of seminars with frontline practitioners and managers led by the Access to Care Records Campaign Group in England during 2015, show that practice varies in local authorities and voluntary agencies, and that there is no common understanding of when and how much information, particularly third-party information, it is reasonable to share.

In November 2018, the Access to Care Records Campaign Group organised a seminar attended by adult care leavers, practitioners, lawyers and policy makers, and Baroness Hamwee, chaired by Baroness Lola Young of Hornsey. The overwhelming view, based on shared experiences, underlined yet again that current data protection legislation, whilst allowing adult care leavers to access their personal information on their care records, is not designed to deal with requests for family history, information and decisions relating to a person's time in care. During the passage through Parliament of the Data Protection Act 2018, the Government did not address the disadvantages adult care leavers experience. Current legislation remains not "fit for purpose" when adult care leavers are seeking information about themselves and their family life. The Campaign Group and its supporters continue to press for dedicated legislation to establish a legal framework that properly recognises the rights of all those who grew up in the State's care to have complete knowledge of their family history and to know what decisions and events have shaped their adult life.

Meanwhile, the Group is working to persuade Parliament to introduce standardised and accountable measures to ensure that those who ask for their care records under the DPA are given a proper service and sufficient support as they process their contents. It is also supporting National Standards to apply across all sectors to support those adult care leavers making a SAR under the DPA.

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3 <https://bit.ly/3nd4Nyn>