### **Subject Access Requests Are Not a Replacement for Life Story Work:**

### Why Access to Records and Access to Meaning Must Work Together

#### Abstract

This essay examines whether **Subject Access Requests (SARs)**—the legal right to obtain a copy of one's personal data—can replace **Life Story Work (LSW)**—a person-centred practice that helps care-experienced children and young people (and adults, including people living with dementia) make sense of their past, present, and future. I argue that SARs and LSW serve different, complementary purposes: **SARs provide access to records; LSW provides access to meaning.** The discussion sets out their legal frameworks, practice guidance, empirical evidence, areas of overlap, typical pitfalls, and a pragmatic operating model for using SARs to *assist* LSW, not replace it. Examples and actionable steps are provided, and the essay concludes with recommendations for practitioners, carers and commissioners. (*Key sources include the UK Information Commissioner's Office (ICO) on the right of access; NICE guideline NG205 on looked-after children and young people; Research in Practice; a BMJ Open realist review on adolescent low-intensity LSW; and a British <i>Journal of Social Work realist evaluation of Digital LSW*). ICO, 2025; NICE NG205, 2021; Research in Practice, 2022; BMJ Open, 2023; BJSW, 2025

# 1) Two Very Different Aims

Subject Access Requests (SARs) exist to uphold the right of access under UK GDPR Article 15 and the Data Protection Act 2018. Controllers (e.g., local authorities, NHS bodies) must respond without undue delay and within **one month** (extendable for complex requests), verify identity, conduct a reasonable search, and disclose information securely in an intelligible form; fees are typically not permitted. SARs promote transparency and accountability by letting people see what information is held about them. ICO, 2025; BMA, 2024

**Life Story Work (LSW)** is not a statutory right; it is a **practice approach** recommended by NICE for looked-after children and young people to build a coherent narrative starting **in the present**, and to explain reasons for care, changes of placement, and hopes for the future. It aims at **identity formation**, **belonging**, **and emotional regulation**— outcomes that are fundamentally different from a *data disclosure*. NICE NG205, 2021; Research in Practice, 2022

**Conclusion for this section:** SARs and LSW point in the same *direction*—toward understanding and empowerment—but they are not the same *vehicle*. One is legal-procedural; the other is relational-developmental. SARs should not replace LSW.

### 2) What the Evidence Says About "Good" LSW

Recent evidence has clarified **how** LSW should be done to benefit adolescents—who are the fastest growing cohort entering care and at particular risk of mental ill-health. A realist review (BMJ Open) recommends **low-intensity, adolescent-focused LSW** that begins "in the now", is **co-constructed**, records **everyday positives**, and is supported by **trained carers** rather than relying exclusively on specialist, long-form therapy. <u>BMJ Open</u>, 2023; Research in Practice, 2022

There is also growing interest in **Digital LSW** platforms. A mixed-methods realist evaluation (BJSW, 2025) found effectiveness was likeliest when platforms are **flexible** and person-centred, start early in the care journey, begin with the present, offer participation choices, and record everyday experiences; crucially, training and implementation support are required for success. <u>BJSW</u>, 2025; <u>UEA News</u>, 2025

### 3) Why SARs Cannot Replace LSW

SAR outputs are **record bundles** compiled for compliance; they reflect the priorities and idiom of professional recording at the time. Empirical work shows that social-care records can be **fragmentary**, **deficit-framed**, **and organised for organisational—not personal—audiences**; they require translation and contextualisation for identity work. Hoyle et al., BJSW 2019; Research in Practice, 2022

Disclosures are also subject to **redactions** to protect third-party privacy or where disclosure would be likely to cause **serious harm** in social-work or health contexts. As a result, the "story" visible through SARs may have **missing names, occluded relationships, or distressing details without supportive framing**, which makes it unsuitable as a standalone vehicle for meaning-making. ICO, 2025; BMA, 2024

By contrast, **LSW** is a paced, relational process—it starts with the person's *present* context, uses plain, age-appropriate language, and integrates facts (including those discovered via SARs) into a coherent, identity-affirming narrative. <u>NICE NG205, 2021</u>; <u>BMJ Open, 2023</u>

### 4) How SARs Can Assist LSW (and Where They Fall Short)

# Where SARs help

 Factual anchors: dates of moves, reasons for decisions, meeting minutes, letters, photographs—materials that can be curated into LSW books, boxes or digital artefacts. <u>Hampshire CC</u>, 2025; <u>Social Work England</u>, 2022  Transparency and trust: done well, SARs can demonstrate openness and help counter myths or self-blame when facts are clarified and explained sensitively. ICO, 2025; Research in Practice, 2022

#### Where SARs fall short

- Redaction/omissions: names and relational context may be removed;
   distressing details may surface without preparation. ICO, 2025; BMA, 2024
- Language/register: notes written for professional audiences may be technical or deficit-focused; they require transformation into plain, child-centred explanations. <u>Hoyle et al., 2019</u>; <u>Research in Practice, 2022</u>

**Bottom line: Use SARs as the archive; use LSW as the atelier**. Records supply raw material; LSW crafts meaning.

## 5) Ethics, Consent and Children's Rights

**Children's data rights** mirror adults'. Organisations should use **plain, clear language** in disclosures to children and consider maturity and capacity when handling requests via parents or carers. <u>ICO—Children and UK GDPR, 2025</u>

In **dementia settings**, LSW raises consent/confidentiality questions. Practice guidance shows LSW can be used without violating consent/confidentiality when proportionate and appropriately governed (e.g., clear ownership, sharing rules, and integration with clinical records where relevant). Pouchly et al., 2013; NICE NG205, 2021

When disclosing SAR material, **trauma-informed practice** is essential: prepare the person, allow **pace and choice**, and schedule **follow-up**. Consider staged disclosure and support for carers; use reflective supervision to manage vicarious trauma.

Research in Practice, 2022; BMJ Open, 2023

#### 6) Practical Guidance: A Tiered Operating Model

# 6.1 Start with universal, low-intensity LSW

For all children in care, offer present-first, co-constructed LSW that records everyday positives (photos of achievements, notes about friendships, favourite activities). This builds identity and belonging **now**, while creating a scaffold for integrating past material safely later. <u>BMJ Open</u>, 2023; <u>NICE NG205</u>, 2021

#### 6.2 Use SARs strategically

Make SARs **question-led** (e.g., "Why did I move schools twice?") with date ranges and explicit requests for **artefacts** like photographs. Prepare the person for **redactions** and privacy rules; agree how to handle sensitive content. ICO, 2025; Hampshire CC, 2025

### 6.3 Integrate with Therapeutic LSW where indicated

For complex trauma or significant distress, escalate to therapist-led LSW. Integrate SAR-derived facts into **plain-language** narratives; document questions that remain unanswered and agree next steps. Research in Practice, 2022; NICE NG205, 2021

## 6.4 Consider Digital LSW with robust governance

Where appropriate, adopt secure Digital LSW platforms with **role-based access**, **consent life-cycle** controls, **training**, and **ongoing support**. Align implementation with person-centred principles, early start, and everyday recording—not just landmark events. <u>BJSW</u>, 2025; <u>UEAHSCP Seminar</u>, 2025

## 7) Case Vignettes

**A. Jay (15, foster care):** Jay wants to know why he moved schools twice. The practitioner scopes a SAR for the relevant 18 months (meeting minutes, emails, placement records) and prepares Jay for possible redactions. The response is summarised in plain English and added to Jay's timeline ("what happened / how I felt / what I learned"), alongside fresh low-intensity material capturing present wins (football team selection, music interests). Jay reports reduced rumination and stronger sense of control. Hampshire CC, 2025; BMJ Open, 2023

**B. Leila (28, adult care leaver):** Leila requests her files; the bundle is extensive and redacted. With practitioner support, key decisions are translated into a "then–now" life book. Where names are redacted, placeholders and feelings are captured, with a small follow-up SAR for specific photographs cited in logs. Leila reports a more coherent self-story and reduced self-blame. Social Work England, 2022; ICO, 2025

**C. Noor (76, living with dementia):** LSW is used on a ward to help staff understand Noor's preferences, relationships and biography. With consent, curated excerpts from historic records are integrated with family photos to support communication and a calmer ward routine; staff feel better equipped to offer person-centred care. Pouchly et al., 2013; NICE NG205, 2021

## 8) Common Pitfalls (and How to Avoid Them)

- Starting with the most painful past: Begin with the *present* to build safety; integrate the past once strengths and relationships are established. <u>BMJ Open</u>, 2023; NICE NG205, 2021
- Treating SAR bundles as "the story": Translate, contextualise, and co-construct; don't hand over PDFs and hope for the best. <u>Hoyle et al., 2019</u>; Research in Practice. 2022
- **Weak governance for digital**: Implement privacy-by-default, permissions, training, and sustained support. <u>BJSW</u>, 2025; <u>UEA News</u>, 2025

# 9) Policy and Commissioning Implications

Commissioners should avoid the false economy of **records-only solutions**. The evidence suggests that consistent, **low-intensity LSW** across placements, with escalation to **Therapeutic LSW** where needed, is more likely to improve identity, belonging and placement stability than episodic, high-intensity interventions alone. SARs should be resourced as **assistive**, not substitutive, tools—invest in **LSW capacity**, **carer training**, and **implementation support** for digital. BMJ Open, 2023; BJSW, 2025

#### Conclusion

Subject Access Requests are not a replacement for Life Story Work. SARs uphold people's information rights; LSW upholds people's identity needs. Where SARs can provide raw material, LSW provides meaning. Effective practice treats them as partners: use SARs strategically and sensitively, but invest in present-first, co-constructed, relationship-based LSW—supported, where appropriate, by well-governed digital tools. That is how we move from what happened to who I am and where I'm going. ICO, 2025; NICE NG205, 2021

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