

Children at the heart of data: insights from young people on the Data Standards project

Coram, Open Data Institute and Social Finance

Social Finance, the Open Data Institute and Coram are working in partnership to develop data and interoperability standards for social care.

This work is jointly funded by the Department for Education (DfE) and the Department of Health and Social Care (DHSC) seeking to benefit children, young people and adults supported by social care. The programme is under the direction of a steering board which brings together a range of stakeholders from across the sector.

This programme aims to tackle one of the most persistent challenges across children's services: how to share the right information, with the right people, at the right time. Fragmented systems, inconsistent data, and siloed working mean that crucial details about a child's life often sit in separate databases that don't speak to one another. As Coram and Social Finance emphasised at the workshop, the vision is clear: better technology and shared data standards should support better decisions, safer practice, and more meaningful participation for children and young people.

But transforming how personal information is recorded and shared cannot happen without the insight of those whose lives are most affected. That is why young people with lived experience of care were central to a workshop held in November 2025, and why their voices will continue to shape this national programme.

Why young people's voices matter

A recurring theme from the discussion was agency. Young people described the frustration of having little involvement in what is written about them, how it is shared, or how it shapes their care journey. Many highlighted the emotional burden of repeatedly retelling traumatic histories to new professionals, especially during placement moves or when accessing support. They stressed that good informationsharing can prevent re-traumatisation and help professionals understand their needs more quickly and sensitively.

At the same time, young people were clear about their expectations for privacy, autonomy, and control. They raised thoughtful questions: *Who really* needs access to my information? What counts as "too much"? How do we stop sensitive details being shared unnecessarily, or used in ways that limit my opportunities?

Their insights highlight a vital balancing act: safeguarding and support must improve, but not at the expense of dignity, trust, and the right to keep aspects of their lives private.

What young people told us

1. Safety and safeguarding come first.

Participants strongly supported sharing information that protects them from harm – such as risks relating to going missing, exploitation, or mental health crises – provided this information is accurate, up-to-date, and clearly contextualised. They also emphasised the importance of correcting or removing outdated labels that can negatively shape professional attitudes.

2. Mental health and additional needs should be visible, when helpful.

Several young people wanted key diagnoses included, particularly when they affect how they communicate or respond to stress. This could prevent constant self-explanation and help staff prepare appropriately. But they were equally clear that not every professional should access this level of detail.

3. Not everyone should have access.

Young people supported access for social workers, key workers, personal advisors, and mental health or education professionals. They were firm that some groups, such as GPs, housing officers, or parents where restricted by court order, should *not* have access.

4. Records must reflect progress and lived experience.

Young people want systems that recognise growth, show updated risk levels, and allow them to challenge inaccuracies. Several described gaps or redactions in their own records that left them without a coherent understanding of their early life.

5. A system that supports better placements.

Feedback extended beyond information sharing into placement standards. Young people advocated for transparent Ofsted ratings, data on intrusive measures in residential homes, clearer terminology across regions, and recognition of the value of standalone placements for some.

A future built with young people, not just for them

Perhaps the strongest message was that involvement must be ongoing. Young people said they prefer regular, focused conversations rather than one-off engagement sessions. They want to see their input shaping the programme in real time, not disappearing into a black box.

Their insights reinforce a simple but powerful truth: data systems in social care will only succeed when they reflect the lived realities, aspirations, and rights of the young people they exist to serve.

[Learn more about the project here.](#)

