Project AEGIS briefing: data visibility and gaps

Background

- Rigorous data collection and analysis allows unmet need, emerging trends, outcomes and impact of interventions to be identified. This is essential to inform the development of meaningful and appropriately resourced care, and to impact policy and practice.
- National-level datasets, comprising data across various sectors, are important to allow visibility of populations and their needs. The Education and Child Health Insights from Linked Data (ECHILD) database links health, education and social care data from over 15 million children in England.
- Local-level data are also an important source of insight. For example, service records can help to understand individuals' interactions with community care as well as their health outcomes. This could suggest where practise is working well and where unmet need remains.

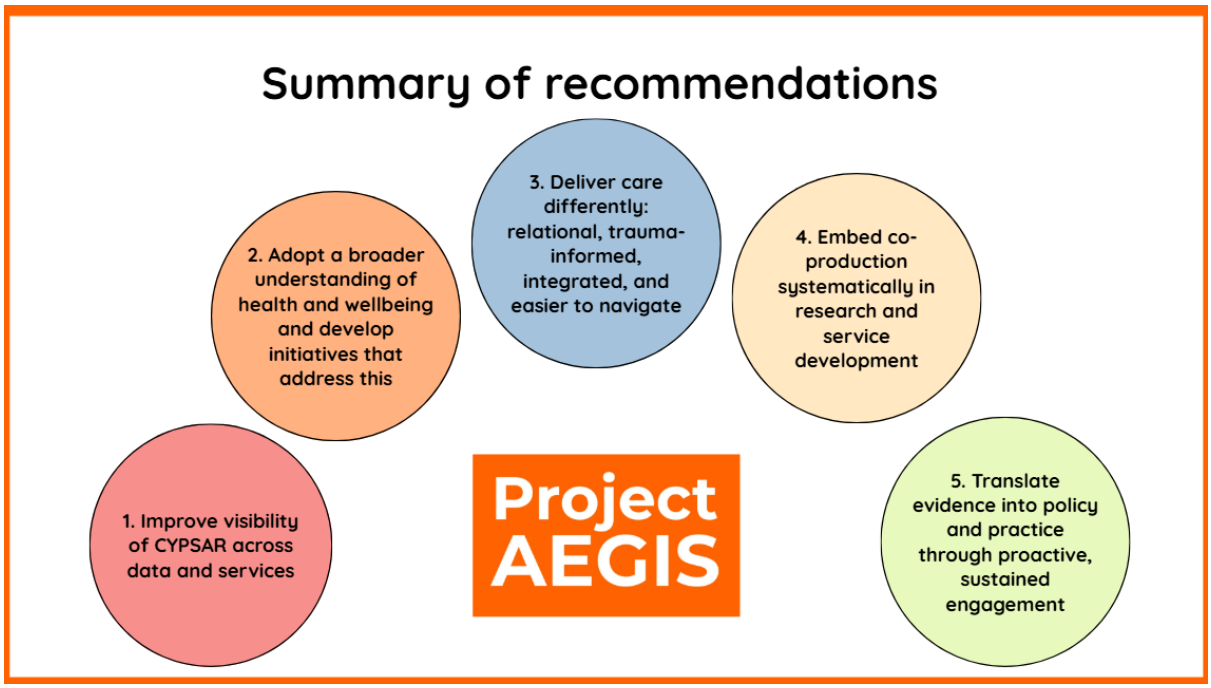
Our findings

- Project AEGIS examined whether children and young people seeking asylum and refugees (CYPSAR) can be identified within the ECHILD dataset. We found that some CYPSAR groups are better represented than others. For example, unaccompanied CYPSAR (CYPSAR-U) are more visible as a cohort compared to accompanied CYPSAR (CYPSAR-A).
- This difference is because CYPSAR-U are automatically recognised as looked after children when they arrive in the UK. As such they become part of the health and social care systems upon which ECHILD data are based. Contrarily, CYPSAR-A, who don't have this interaction with social care systems, are largely invisible as a cohort in ECHILD.
- Project AEGIS also examined routinely collected Initial Health Assessment (IHA) data from three NHS Trusts over one year. We found that this data has the potential to be a rich source of information on the health needs of CYPSAR-U, but that its utility is limited by inconsistency of data collection between services and barriers to information sharing across agencies and areas.
- Project AEGIS spoke to CYPSAR to understand their views on data. They expressed concern that the information they disclosed could be used against them; for example, that discussion of a pre-existing health condition could impact their application for asylum. Their experiences also suggested a need to interrogate the meaning behind trends in the data. For example, low recorded uptake of services may reflect system barriers, mobility or mistrust rather than a lack of need or disengagement by young people.

Recommendations

- Building trust with CYPSAR and helping them to understand how their information will be used is crucial.
- Improving data collection, digitalisation, linkage and accessibility at national and local levels is key to reliably flagging CYPSAR cohorts, their outcomes and, consequently, to informing service improvement recommendations.

Project AEGIS: overall recommendations



We have found that: CYPSAR are often invisible in data; health is broader than healthcare; what good care looks like in practice is able to be described; CYP must shape services; and it is essential research findings are translated into policy and practice.

Find out more:

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