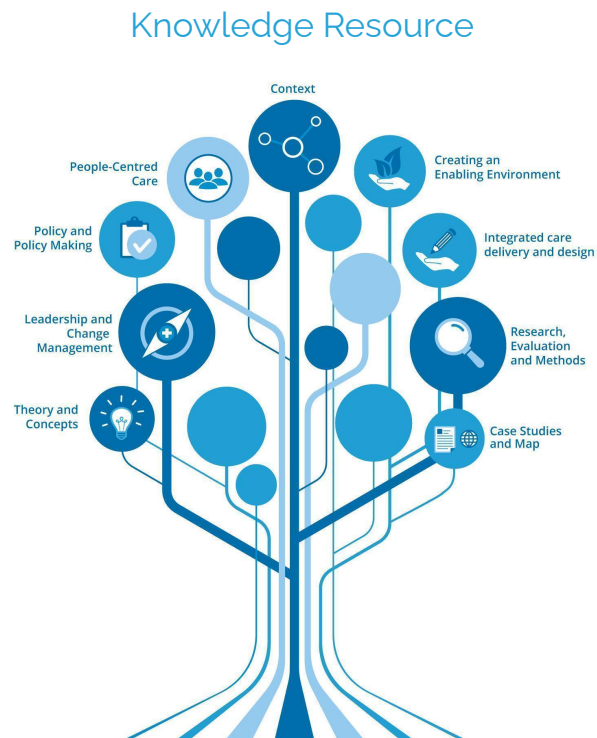


Integrated Care Matters

Child and Family Centred Integrated Care



About the information

The information provided in this document is intended to support the Integrated Care Matters webinar series.

Where possible, we select evidence that is published open access, and provided links to the materials referenced. Some are identified as author repository copies, manuscripts, or other copies, which means the author has made a version of the otherwise paywalled publication available to the public. Other referenced sources are pdfs and websites that are available publicly.

Developed in partnership



Out of school Additional

Adams, S, Nicholas, D, Mahant, S, et al. Care maps and care plans for children with medical complexity<https://onlinelibrary-wiley-com.knowledge.idm.oclc.org/doi/full/10.1111/cch.12632>. *Child Care Health Dev.* 2019; 45: 104– 110

Care plans and care maps were identified as valuable complementary documents. Their integration offers context about family experience and respects the parents' experiential wisdom in a standard patient care document, thus promoting improved understanding and integration of the family experience into care decision making.

Allen D, Scarinci N, Hickson L. [The Nature of Patient- and Family-Centred Care for Young Adults Living with Chronic Disease and their Family Members: A Systematic Review](#). *Int J Integr Care.* 2018 May 18;18(2):14.

The published literature addressing the nature of patient- and family-centred care (PFCC) among young adults (16–25 years old) living with chronic disease and their family members is diverse. The aim of this systematic review was to collect and interpretatively synthesise this literature to generate a conceptual understanding of PFCC in this age group.

ALLIANCE (2022) [Support Needs \(ASN\) services in East Ayrshire: families' experiences and recommendations for improved access and support](#)

Outlines the findings from a research project commissioned by East Ayrshire Council to understand families' experiences of accessing out of school (or recreational) additional support needs services in

the local area. The research aims were to gather evidence of disabled children's, young people's, and their families' lived experience in terms of accessing out of school ASN services, over the summer holidays as well as during term time; to identify what children and young people with high levels of need, and their families, would like to see change about the out of school support they can access; to inform East Ayrshire Council's services commissioning plan to support children and young people with high levels of need, and their families; for East Ayrshire Council to work in partnership with children, young people, and families/carers in deciding what are the priorities to improve out of school ASN service provision.

Brenner, M et al (2019), "[Services and Boundary Negotiations for Children with Complex Care Needs in Europe](#)", Blair, M., Rigby, M. and Alexander, D. (Ed.) *Issues and Opportunities in Primary Health Care for Children in Europe*, Emerald Publishing Limited, Bingley, pp. 199-218

The project explored the interface between primary care and specialised health services and found that it is not easily navigated by children with CCNs and their families across the European Union and the European Economic Area countries. For all children with CCNs, we found wide variation in access to, and governance of, care. Effective communication between the child, family and health services remains challenging, often with fragmentation of care delivery across the health and social care sector and limited service availability.

Brigden, A, Shaw, A, Barnes, R, Anderson, E, Crawley, E. “[The child’s got a complete circle around him”](#). [The care of younger children \(5–11 years\) with CFS/ME. A qualitative study comparing families’, teachers’ and clinicians’ perspectives’](#). *Health Soc Care Community*. 2020; 28: 2179– 2189.

There is opportunity to support a child with complex health needs by targeting the systems around the child; parents, teachers and clinicians, as well as education and health policy that can enable shared-care. Involving schools in assessment, communicating diagnosis across settings and using a stepped-care approach to integrated care may be beneficial.

Cassidy L, Quirke MB, Alexander D, Greene J, Hill K, Connolly M, Brenner M. [Integrated care for children living with complex care needs: an evolutionary concept analysis](#). *Eur J Pediatr*. 2023 Feb 13:1–16.

Children with complex care needs require long-term care, and are in need of improved services, communication, and information from healthcare professionals to provide them with the ongoing support they need to manage their condition; integrated care is a key component in healthcare delivery for children with complex care needs as it has the potential to improve access to family-centred care across the entire health spectrum. Integrated care for children with CCNs refers to highly specialised individualised care within or across services, that is co-produced by interdisciplinary teams, families, and children, supported by digital health technologies; there is a need for the development of measurement tools to effectively assess integrated care within practice.

Fazel, M., Townsend, A., Stewart, H., Pao, M., Paz, I., Walker, J., Sawyer, S. M., & Sharpe, M. (2021). [Integrated care to address child and adolescent health in the 21st century: A clinical review](#). *JCPP Advances*, 1(4), e12045.

As the science of medicine improves, children and adolescents with increasingly complex needs are being managed by paediatric teams; better integration of somatic and psychological care is needed with models of collaborative care in children’s hospital settings being developed; the range of disorders that benefit from integrated care include cancer care, disorders involving the brain, common chronic conditions, psychiatric emergencies and chronic pain and eating disorder treatment; incorporating the preferences of children and adolescents, as well as their families, into these models of care remains important.

Ford, K et al (2018) [Child Centred Care: Challenging Assumptions and Repositioning Children and Young People](#) *Journal of Pediatric Nursing Volume 43, November–December 2018, Pages e39-e43*

Explores the concept of CCC and its potential theoretical alignment with an ecological approach to health care. Highlights: challenges and continues the debate in regard to the provision of family-centred care; child-centred orientates children to a more central position in health care; an ecological model allows exploration of relational, contextual and environmental influences on the delivery of care.

García-Ventura, S, Mas, JM, Balcells-Balcells, A, Giné, C.
[Family-centred early intervention: Comparing practitioners' actual and desired practices](#). *Child Care Health Dev.* 2021; 47: 218– 227.

Key messages: Recommendation–implementation gap still exists despite the evidence supporting family-centred practices; Spanish early intervention practitioners are moderately in line with family-centred practices but oriented towards implementation; training and intervention seem to be the key to bridge the recommendation–implementation gap.

The Health Foundation [Patient and Family-centred Care](#)

Run in partnership with The King's Fund, this programme aimed to improve the experience of hospital care for patients and their families, and the working lives of staff.

IFIC (2023) [Integrated Care Perspective for Children with Cancer](#)

The needs of children and families with cancer and the importance of providing an integrated care response.

In Control (2014) [Creating an integrated, outcome-focused and family-centred offer](#)

This paper sets out a theoretical understanding of integrated children's services across education, social care and health, discusses the challenges of implementing such an approach, and provides practical guidance around funding. It aims to develop an efficient and child-centred approach to the allocation of personal budgets set alongside mainstream, targeted and

informal/community based support. It identifies the two key values underpinning any co-productive approach to resource allocation: transparency, whereby everyone understands how and why decisions are made and participation, whereby everyone who needs to take part is supported to do so and their contribution is valued and informs any decision taken.

Johnson, H., Newcomb, D., Borkoles, E. and Thompson, S., 2020. [A study of healthcare providers' perceptions and experiences of integrated care](#). *International Journal of Integrated Care*, 20(S1), p.53.

There is limited literature that explores the experiences of healthcare providers who try to deliver integrated care to children with chronic and complex conditions, and this research aims to address this gap. It describes some of the barriers and enablers to delivering integrated care by exploring the experiences and perspectives of six healthcare providers.

Johnson H, Simons M, Newcomb D, Borkoles E.
[Understanding Young People and Their Care Providers' Perceptions and Experiences of Integrated Care Within a Tertiary Paediatric Hospital Setting, Using Interpretive Phenomenological Analysis](#). *Int J Integr Care*. 2020 Oct 27;20(4):7

Stakeholders' experiences of integrated care highlighted the need to examine the discrepancies between healthcare strategies, policies and service delivery within a complex, and often inflexible organisational structure. Power imbalance and family agency

(including directly with children and young people) needs to be addressed to support the implementation of integrated care.

Kanste, O et al 2019 [Promising models of multi-disciplinary integrated peoplecentred family services in six OECD countries](#) *International Journal of Integrated Care*, 19(S1): A581, pp. 1-8,

Several countries have developed children and family services towards more integrated people-centred care based on involvement of families as partners in care and early intervention strategy. The aim was to find out what kind of integrated family services are in those selected OECD countries where integrated services have been developed (England, Netherlands, Norway, Sweden, Denmark, Finland) and what kind of benefits have been found from these services.

Liersch et al. (2020) [Evaluation of the pediatric-centered integrated care AOK Junior: protocol for a mixed-method study](#) *BMC Health Services Research* (2020) 20:217

The focus of this program is on prevention and early detection of illness on C&A. Furthermore, the aim is to maintain the health of C&A and to prevent, detect and treat illness on time. Elements of the program are not only the integrated care of C&A, but also, for example, weight reduction and additional medical checkups. The evaluation of the complex intervention should provide information about the effectiveness of early disease detection and costs-effectiveness as well as of other parameters like satisfaction

Maile, EJ et al (2022) [Back to the future? Lessons from the history of integrated child health services in England](#) *Future Healthc J* Jul 2022, 9 (2) 183-187

Suggests lessons for future integration initiatives: integration may support the quadruple aim; integration depends on addressing divides between primary and secondary care; workforce and funding challenges need to be resolved before integration can thrive; high-quality research and evaluation of integrated interventions is required; strong relationships between professional groups are key to integration; and integration can help address health inequalities.

McCarthy, E., & Guerin, S. (2022). [Family-centred care in early intervention: A systematic review of the processes and outcomes of family-centred care and impacting factors](#). *Child: Care, Health and Development*, 48(1), 1– 32

Key messages: The translation of FCC from theory to practice has been challenging, despite a robust theoretical base and evidence for the efficacy and effectiveness of family-centred practices. In the absence of a universal model of FCC, further empirical support is required to examine the operationalization of this model in EI; family-centred processes extracted included both qualitative data and/or the subscales of the MPOC. These data were collated due to similarities in content; review findings are synthesized and presented as a visual overview of the processes and outcomes of FCC in EI and factors that promote or hinder service delivery; FCC was primarily conceptualized in the literature as the application of care with corresponding outcomes and confounding variables.

NDTi [Community Led Support Evidence & Learning](#)

A series of six briefings and several blogs, podcasts and case studies, to share findings and lessons from the second major round up of data, stories, evaluation findings and programme lessons exploring the impacts of community led support across the UK.

NDTi (2023) [Valuing Community Led Support \(CLS\): The economic case for strengths based, community led support](#)

Report about the economic case for strengths based Community Led Support. Over a period of eight years, NDTi has collected a growing body of evidence that shows the value of Community Led Support. Community Led Support (CLS) is based on a set of values and principles that are based on the simple ambition to 'do the right thing' for those of us who need support at any time in our lives to live well, as independently as possible with purpose and connection.

NHS England (2019) [Understanding how integrated care systems are supporting children and young people](#)

Case study.

NICE (2018) [Delivering family-focused multi-disciplinary care for children with spasticity](#)

Children with CP have large numbers of health professionals involved in their care, with multiple appointments. The impact of their condition has far reaching implications for them, their family, education and care services. They have established a local neurodisability network with professionals and service users to

improve communication, share good practice and ensure equitable local care across providers.

Nooteboom LA, et al. [What Do Parents Expect in the 21st Century? A Qualitative Analysis of Integrated Youth Care](#). *International Journal of Integrated Care*, 2020;20(3): 8, 1–13.

The aim of this study is to advance our understanding of key components of integrated Youth Care from a parental perspective.

O'Connor, S, Brenner, M, Coyne, I. [Family-centred care of children and young people in the acute hospital setting: A concept analysis](#). *J Clin Nurs*. 2019; 28: 3353– 3367

Aims and objectives: To provide an operational definition of family-centred care as it applies to hospitalised children. There is a lack of attention to cultural and societal changes, which impact on those receiving and delivering care. While we know that family-centred care is widely endorsed and enhances well-being, there is a lack of empirical evidence about the impact on health outcomes for children. While children's nurses have been applying some elements of family-centred care to their clinical practice for decades, the concept continues to evolve.

The Point of Care Foundation [PFCC: Patient and Family-Centred Care toolkit](#)

This toolkit is a step-by-step guide to improving processes of care and staff–patient interactions. It offers a simple way for organisations to show their commitment to patients' experience while also motivating the staff who deliver that care.

The Promise (2021) [Plan 21-24](#)

Focuses on the period from 1 April 2021 until 31 March 2024. It outlines a set of outcomes that should be concluded by 2024.

RCPCH [Integrated Care](#)

The NHS Long Term Plan has emphasised the importance of integrated care to the future of the health service. This section looks at case examples and resources for delivering integrated care in paediatrics and child health.

Scottish Government (2022) [Getting it right for every child \(GIRFEC\)](#)

GIRFEC provides Scotland with a consistent framework and shared language for promoting, supporting, and safeguarding the wellbeing of children and young people. It is locally embedded and positively embraced by organisations, services and practitioners across Children's Services Planning Partnerships, with a focus on changing culture, systems and practice for the benefit of babies, infants, children, young people and their families.

Together For Short Lives (2018) [A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions](#)

The pathway aims to ensure that families experience a coordinated approach to family-centered care throughout their child's life. There should be clear and open communication and support to enable the family to build up and maintain access to an appropriate network of support, regardless of where they are cared for, whether in hospital, at home, or in a children's hospice. A key feature of the Care Pathway approach is that there is parallel planning for achieving the

best quality of life for the child, alongside planning for end-of-life care. The pathway proposes a core framework for professionals working with children and young people to support the local development of an integrated care pathway for children diagnosed or recognised as having a life-threatening or life-limiting condition and following the child and family's unique care journey. The pathway puts children and families at the centre of a planning process, with the aim of delivering integrated services in response to individual needs.

Wolfe, I et al 2019 [New integrated care models to improve health, healthcare quality, and patterns of service use among children and young people](#). *International Journal of Integrated Care*, 19(S1): A543,pp. 1-8, Poster abstract.