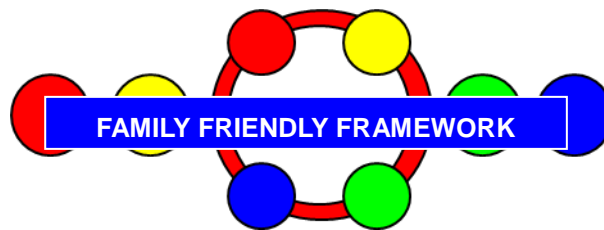




Introducing the “Family Friendly Framework”



**A whole systems approach for the
planning, delivery and improvement of
services for children and families**

September 2014

Introduction to BACCH

The British Association for Community Child Health (BACCH) aims to promote and protect the health and well being of children and their families. We aim to achieve our mission through:

- Enhancing training and practice of all those working with children and their families;
- Encouraging active collaboration with other disciplines, agencies and professional bodies concerned with the health of children and their families;
- Promoting research related to the health of children and their families and disseminating the results; and
- Serving as an advocate for children and their families through professional, academic and other channels.

More information is available from the BACCH website.

www.bacch.org.uk

Introduction to BACAPH

British Association for Child and Adolescent Public Health (BACAPH) is a multi-disciplinary, four nation organisation, working on the following strategic goals:

- *Policy*: To promote the development and implementation of evidence-based child public health programmes nationally and locally.
- *Advocacy*: To act as advocates in partnership with others on significant issues requiring multi-disciplinary co-ordinated responses, such as health inequality and child poverty.
- *Knowledge*: To promote research that brings new science to long standing questions, and provide training to help provide the skills and knowledge needed to tackle the diverse and growing challenges in child public health.

Please feel free to download then adopt and adapt for local use:

The Family Friendly Framework (for colour printers)

The Family Friendly Framework (for mono printers) [to follow]

A PowerPoint presentation about the Family Friendly Framework

Frequently asked questions (FAQs) for the Family Friendly Framework

CYP version [to follow]

Animation [to follow]

Precis [to follow]

Please reference this document to BACCH/BACAPH when adapting it locally.

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Executive summary – the key points

The "Family Friendly Framework" (FFF) has been written in response to concerns about the increasing fragmentation and discontinuity of services for children and families resulting from the introduction of competition and market principles into health service provision. BACCH/BACAPH do not believe that creating a market economy within healthcare is the best way of allocating resources and driving improvement, but do recognise that professionals have to work within the current system to achieve the best they can for children and young people with the resources that are available.

The Family Friendly Framework brings together four different concepts into a practical whole systems approach to improve outcomes for children, young people and their families. They are:

- the **values** contained within the UN Convention on the Rights of the Child, with
- application of the best possible **evidence** and
- the World Health Organisation (WHO) **systems approach** to service delivery, followed by
- **learning** through the delivery of services from innovation, evaluation and quality improvement.

The framework is not intended to be prescriptive, rather it is an approach which should be adopted and adapted depending on local circumstances. The framework is applicable to all agencies, organisations and professional groups who work with children and families.

In times of austerity and major systems reform, it is particularly important that all the relevant stakeholders, namely, policy-makers, commissioners, providers and regulators; those in the public, private and community provider sectors; and families, practitioners and community members, all share a similar approach to improve quality, safety and outcomes. In turn, this creates an alignment and synergy between their collective efforts to improve not only the health of this generation of children and young people, but also the next generation.

This paper therefore:

- considers the current context of services for children and families in the UK,
- proposes a 4x4 structure for the Family Friendly Framework, with examples,
- considers its application for service and life-course pathways, then
- outlines the benefits of this approach and
- discusses the practical implications of adopting this approach.

Stated simply, the intention of the Family Friendly Framework is to create a system that ensures the right things happen, to the right children, in the right way, at the right time, in the right place coupled within a system that guarantees all parts are in place and working well together. This is complemented by a process to detect the weakest links, create appropriate feedback loops and then innovate and evaluate to create continuous improvement through evaluation and learning at every level.

The Family Friendly Framework is structured as a 4x4 framework, starting with the basics, proceeding to describe the component parts of pathways, then describing how networks are formed from teams providing the component parts and finally how they all come together within a whole system which then has the capacity to learn and evolve over time.

1. The basics. Fundamental to all forms of service delivery are:

- The use of best **evidence** - which may be quantitative, qualitative or econometric, throughout the whole system for commissioning, delivery and improvement.
- **Competence** - of practitioners in terms of knowledge, skills, attitudes, behaviours and capacity, all working within teams with the right skill-mix.
- Delivery in the right **setting** - both place and space, meaning an accessible geographical location, internal environment and access to support services.

- With attention to **timeliness** – which includes a proportionate response to initial concerns coupled with prompt provision of services and the achievement of timely outcomes.

2. Pathways. A patient journey is an individual's experience of services. Pathways represent the journeys of a group of people with a similar condition. There are four generic components to a pathway which should be considered when commissioning or providing services:

- **Prevention** - prevention includes primary, secondary, tertiary and quaternary elements nested within the four types of pathway included within a network.
- **Recognition** - through concern, screening or surveillance.
- **Assessment** - of the condition and the impact on the child, consequences for the family and contributing factors within the community.
- **Interventions** - medical, surgical, social, economic, psychological and many others.

3. Networks. A network is the structure for delivering pathways or programmes of care. Networks are central to the delivery of 'programmes of care' which are the 'units of service delivery' for a range of similar concerns/conditions, for example, cardiac conditions, safeguarding concerns or disabilities. Their focus is on creating integrated care from the perspective of families, delivering and developing pathways through a process of setting standards, developing relevant measures, audit and improvement.

The network management structure will also recommend priorities for investment and disinvestment, constantly striving for improvements in overall programme value. The network will also devise and implement a workforce strategy in collaboration with the commissioners, providers and the higher education institutions. The pathways included within the network include:

- **Life course pathway** - the life course pathway tackles both lifestyles and determinants of health through the twin processes of protection from hazards and promotion of assets and coupled with specific public health programmes.
- **Initial pathway** - the initial pathway covers the development and initial management of a condition.
- **Review pathway** - for an established long-term condition (disease or disability) the focus of the review pathway is to prevent and manage secondary complications of a primary condition.
- **Transition pathway** - covers the transition back to normality if a condition has resolved, transition to adult services for those conditions that persist and transition into palliative care where there are no further therapeutic options.

4. Whole system. The whole system must bring together four elements – a clarity of purpose, a framework of values to create an organisational culture which in turn impacts on the behaviour of individuals, accountable leadership and the capacity to continually learn through embedding evidence and creating new knowledge through innovation and evaluation.

- The overall **purpose** of services is to improve health, reduce inequities and unacceptable variations and to be sustainable in every sense of that word.

- The **values** are based on the UN Convention on the Rights of the Child emphasising both individual rights and then prevention through protection and promotion, participation and partnership at all levels and creating high quality services based on pathways.
- **Leadership** which endorses values and supports integrity, accountability, transparency of decision-making and engagement with all the relevant stakeholders.
- **Learning** from seeking out and applying new knowledge as it becomes available coupled with a system which detects and rectifies problems, in order to generate new knowledge which in turn enables escalating competence through continuous system, network, team and individual learning.

The potential benefits

The Family Friendly Framework potentially brings benefits to all the relevant stakeholders including families, professionals and providers, managers, planners and commissioners and policymakers.

- **Children and families.** Greater involvement through participation, better coordination and continuity of provision, linked to improved experience, safety and outcomes.
- **Professionals.** A focus on the implementation of evidence and development of best practice, learning from mistakes, leading to competent team working and continuous learning through innovation and evaluation.
- **Managers.** Greater collaboration between the teams within networks, breaking down silo working across organisations, a shift of focus from efficiency to effectiveness and equity, with greater clinical involvement/leadership and user participation throughout the whole system.
- **Planners and commissioners.** Adopting a long-term, life course approach to prevent conditions and health care costs. Coupled with less fragmentation, reduction in duplications or omissions, improvements in equity and therefore better overall value. Clear lines of accountability and a shared culture across different agencies to promote integration, partnership and collaborative working and so whole system value.

The implications

The implications and practical aspects of adopting the Family Friendly Framework are potentially profound as they require a culture of collaboration and co-production by all stakeholders along the pathway and within the whole system, rather than competition and fragmentation that have been encouraged by the introduction of a "free market" within public services.

Planners and commissioners

- Joint strategies across all planners and commissioners of services relevant to children and families, including health, education, social care and criminal justice systems to create an integrated whole system where all the parts are in place and working well together.
- Devolving more planning and decision-making regarding local allocation of resources to managed networks.
- Financing systems which enable resources to follow families through pathways and networks coupled with the introduction of programme budgeting, tariffs for long term conditions based on pathways, service line reporting and whole life costs.
- Integrating public health approaches to all forms of prevention across all pathways to prevent future morbidity.

Providers

- The development of managed networks with a relentless focus on quality improvement.
- All provider organisations sharing the same knowledge base and approach to implementation of evidence-based guidelines, service improvement and the development and maintenance of competence of practitioners and their teams.
- Shared quality improvement approaches across organisations based on continuous learning through knowledge acquisition, innovation and evaluation.
- Workforce planning based on the right skill mix to ensure competent teams working within networks and effective network management.

Regulators

- Including regulation based on pathways and networks, rather than organisations, to ensure overall value for money across the whole patient journey.
- Greater emphasis on both equity of access and equity of outcomes and reducing variations.
- Bringing together quality and economic regulators across different agencies, using a shared approach for measurement and improvement to achieve a greater value.
- A focus on embedding learning and sharing improvement rather than inspection alone.

Families

- Emphasis on co-production of health between families and the providers of services, based on better information, practical support and incentives.
- Greater participation in decision-making at all levels within the system, individual decisions, service improvement and policy development.
- More involvement of family support organisations in the development of pathways, standards, measures and improvement.
- Increased focus on strategies to enable greater resilience in children and their families, particularly for those living in disadvantaged circumstances.

Finally, services for children and families do not exist in isolation from the wider political, social and economic environments. Services must use resources wisely and uphold the principles of sustainable development in order to avoid any unintended consequences such as resource consumption and social or environmental impacts for future generations.

Introducing the “Family Friendly Framework”

A whole systems approach for the planning, delivery and improvement of services for children and families

Purpose

This paper was written to address the many concerns of BACCH members who were anxious that, with the twin drivers of austerity and reforms based on free market principles, services for children and families were becoming increasingly fragmented, thus impeding the drive for better experience through integration, efforts to reduce unacceptable variations and to improve outcomes.

BACCH and BACAPH do not believe that creating a market economy within healthcare is the best way of allocating resources and driving improvement, but recognises that professionals do have to work within the current system and must achieve the best they can for children and young people with the resources available.

The purpose of this paper is to:

- Introduce a practical whole systems approach, called the “Family Friendly Framework”, to enable improved delivery of high quality, safe services that achieve both better equity and outcomes for children and families.
- Embed the values contained within the UN Convention on the Rights of the Child throughout the system but particularly into the culture of delivering services for children, young people and their families.
- Propose the development of collaborative and integrated provider networks, which offer stability within the system during times of change and also bring decisions about the allocation of resources closer to and involving patients/families.
- Encourage a focus on quality and safety, through greater user participation, continuous innovation and learning as an integral part of service delivery, all based on meaningful measurement, feedback and resultant action.

Consultation with multiple stakeholders over four months has led to significant redrafting and improvement of the November 2012 consultation document and we would like to thank those who responded.

Introduction

Recent changes across the UK, including the recession, increasing youth unemployment,¹ austerity measures,² and changes to benefits,³ could all potentially contribute to increasing demand and make services for children and families more fragmented,⁴ resulting in greater variations in outcomes and inequalities. In England, the recent NHS reforms,⁵ Local Authority funding cuts of 30%⁶ and changes in the public health landscape⁷ have all brought considerable concerns and challenges for effective service delivery.

This paper uses the UK wide experience as an opportunity to review how planning and resource allocation is undertaken and makes proposals aimed at changing thinking and practice. The intention is to generate models which create alignment and synergy between all relevant stakeholders, ultimately to achieve the common goal of improving the health and well-being for all infants, children, young people and their families. Implementation of such models is already under way in Scotland, Wales and Northern Ireland.

The conceptual origins of the Family Friendly Framework arose from a Council of Europe strategy entitled "Child Friendly Health Care" which was endorsed in 2011 by the health ministers representing 47 nations of Europe, including the UK.⁸ It is based on WHO systems thinking,⁹ which combines purpose, values and evidence into a practical model, based on pathways, that guarantees all the parts are in place and working well together.

This paper therefore:

- considers the current context of services for children and families in the UK,
- proposes a 4x4 structure for the Family Friendly Framework,
- considers its application primarily within the planning and commissioning process in England,
- outlines the benefits of this approach and
- discusses the implications for key stakeholders including planners and commissioners, providers regulators and families.

BACCH and BACAPH are UK-wide organisations, so this paper does not address the detailed roles and responsibilities of individual organisations (for example, the new English structures following the Health and Social Care Act 2012), but it recognises that whatever national structures exist, there should be a shared approach in order to ensure integration between the various parts of the system. It is hoped that this paper will offer an approach to facilitate discussion between organisations to create more family friendly services, better use of resources and whole system value in the future.

The current context of services for children and families

Political

Europe has entered a period of profound economic austerity and while health services in the UK have initially been only partially protected in comparison to other public services, future governmental budgetary decisions along with demographic changes, new knowledge and service reforms all present major concerns.

¹ <http://www.ons.gov.uk/ons/rel/lms/labour-market-statistics/february-2012/statistical-bulletin.html>

² http://sticerd.lse.ac.uk/case/new/research/Social_Policy_in_a_Cold_Climate.asp

³ http://www.familyandparenting.org/Resources/FPI/Documents/FPI_IFS_Austerity_Jan_2012.pdf

⁴ <http://www.childrenengland.org.uk/upload/Perfect%20Storms%20-%20FINAL.pdf>

⁵ <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

⁶ <http://www.jrf.org.uk/sites/files/jrf/local-government-communities-full.pdf>

⁷ <http://www.dh.gov.uk/health/2011/12/public-health-factsheets/>

⁸ http://www.rcn.org.uk/_data/assets/pdf_file/0003/424677/CM2011113_E_CFH_guidelines_ExM.pdf

⁹ http://whqlibdoc.who.int/publications/2009/9789241563895_eng.pdf?ua=1

While the UK health system is ranked highly in comparison to other developed worldwide systems by the 2014 Commonwealth Fund Report¹⁰ concerns about the impact of recent reforms have been voiced, for example by the Peoples Inquiry in London who commented that “Where there was once, very recently, a world-leading service, there is now confusion and all too often chaos”.¹¹

Estimates vary, but a 20% reduction of budgets over a five-year period, is predicted in England¹² coupled with the aspiration to maintain and indeed achieve better quality of care during this challenging financial period. The Nuffield Report on the state of NHS finances¹³ concluded that while the NHS has risen to the challenge of living within its means, it is increasingly poorly placed to manage the impact of austerity.

Difficult decisions therefore need to be made centrally on where public resources are best invested, both within the NHS, and between the NHS and other Government Departments that contribute to health and well-being in different ways, such as the economy, education, the natural environment, the built environment and social benefits.

It is vital that the allocation and use of resources through the planning and commissioning process and services for children and families specifically, should be undertaken in ways that are explicit, collaborative and coherent, making best use of *all* the available resources to ‘add value’.¹⁴

England

The passage of the Health and Social Care Act (April 2012), in England, initiated the largest transformation within the NHS since its inception. Regardless of the legislation, successful implementation will depend on taking a very practical approach by all involved, especially during the turmoil of transition.

The central mantra of these reforms has been to put "clinicians and patients at the heart of the NHS" but concern has been expressed by both The Nuffield Trust¹⁵ and The Kings Fund¹⁶ about how this can be achieved in a system based on competition rather than collaboration.¹⁷ At the time of writing it appears that there will be a minimum of five commissioning bodies relating to children and families, in England, including NHS England, Regional and Area Teams of NHS England¹⁸, local Clinical Commissioning Groups, clusters of Clinical Commissioning Groups and Local Authorities. In addition there will be separate planning and commissioning arrangements relating to the Criminal Justice System, including Youth Offending Teams and some Academies of schools will be commissioning health services on behalf of pupils, coupled with parents in receipt of Direct Payments or Personal Budgets commissioning services for their personal use. However, the bulk of children's services will be commissioned between the NHS England and the area teams, Clinical Commissioning Groups and Local Authorities.

This set of complex changes is likely to cause instability within the system during transition and while ‘integration’ is a favoured term in relationship to providers; but less thought appears to have been given to ‘integration’ for either the planners and commissioners or the regulators of services. If integration is seen as a vital part of the culture that creates cohesion between different organisations, future success will depend upon sharing the same approach, values, thinking, behaviours, outcomes and models of service delivery as the essential prerequisite for effective joint working and partnerships.

¹⁰ <http://www.commonwealthfund.org/publications/fund-reports/2014/jun/mirror-mirror>

¹¹ <http://www.peoplesinquiry.org.uk/pdf/NHSattheCrossroadsfulldoc.pdf>

¹² http://www.nao.org.uk/wp-content/uploads/2011/12/NAO_briefing_Delivering_efficiency_savings_NHS.pdf

¹³ <http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/into-the-red-report.pdf>

¹⁴ <http://globalhealthdelivery.org/2012/05/value-based-health-care-delivery/>

¹⁵ <http://www.nuffieldtrust.org.uk/publications>

¹⁶ <http://www.kingsfund.org.uk/publications/>

¹⁷ http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/event_report_competition_integration_jan12.pdf

¹⁸ <http://www.england.nhs.uk/about/regional-area-teams/>

Scotland

Health and social care services are fully devolved to the Scottish Government and children's services are integrated through the programme 'Getting it Right for every Child' (GIRFEC)¹⁹ supported by the Early Years Collaborative.²⁰ The Children and Young People (Scotland) Bill²¹ was passed by the Scottish Parliament in early 2014 and this will be implemented over coming years. The Bill strengthens implementation of the UN Convention on the Rights of the Child in Scotland and enshrines key elements of the GIRFEC programme in Scots law, in particular, ensuring that every child has a named professional with overarching responsibility for monitoring and securing their wellbeing. The Public Bodies (Joint Working) (Scotland) Bill²² was also passed by the Scottish Parliament in early 2014. This bill will require NHS Boards and Local Authorities to operate joint budgets for health and social care and be held jointly responsible for integrated service delivery and outcomes.

Central policy is still the main driver for improvements in services, with regional planning groups sharing a key role in planning services across Health Board boundaries. However responsibility for service quality, safety and outcomes rests with Health Boards and this division can, at times, lead to tensions between regional and local priorities.

Wales

Health, social care services and education are fully devolved to the Welsh Government. Wales has enshrined the UNCRC in domestic legislation with the Rights of Children and Young People Measure 2011,²³ with a clear Welsh Government statement of '7 core aims for children', supported by 'Flying Start'²⁴, 'Families First'²⁵ and 'Communities First'²⁶ programmes to address poverty, inequity and poor health outcomes via initiatives focused on children within families and communities. The Welsh Government has recently (August 2013) published their first plan for Early Years and Childcare in Wales: 'Building a Brighter Future',²⁷ which sets out the direction of travel for the next 10 years with actions and timescales for delivery. The Plan brings coherence across different policies and programmes impacting on and influencing the early years. An Early Years Partnership Board was set up in January 2014 to advise on approaches to take the early years and childcare agenda forward, at pace, in order to deliver key elements of Building a Brighter Future.²⁸

Northern Ireland

Health, social services, and education are fully devolved to the Northern Ireland Legislative Assembly. Responsibility for policies affecting children is shared across a number of government departments. These include the Department of Health, Social Services and Public Safety (DHSSPSNI), the Department of Education for Northern Ireland (DENI) and the Office for the First and Deputy First Minister (OFMDFM).

The overarching policy on child health and wellbeing is the Ten Year Strategy for children and young people in Northern Ireland 2006-2016.²⁹ The strategy includes strategic goals in key areas affecting children and young people and takes into account the role of parents and families. It also examines the scope for achieving a more joined up approach within Government to children's issues. Responsibility for this strategy and for reporting to central UK government on the implementation of the UN convention on the rights of the child rests with OFMDFM.

¹⁹ <http://www.scotland.gov.uk/Resource/Doc/238985/0065813.pdf>

²⁰ <http://www.scotland.gov.uk/Topics/People/Young-People/Early-Years-and-Family/early-years-collaborative>

²¹ <http://www.scottish.parliament.uk/parliamentarybusiness/Bills/62233.aspx>

²² <http://www.scottish.parliament.uk/parliamentarybusiness/Bills/63845.aspx>

²³ <http://www.assemblywales.org/bus-home/bus-legislation/bus-leg-measures/business-legislation-measures-rightsofchildren.htm>

²⁴ <http://wales.gov.uk/topics/childrenyoungpeople/parenting/help/flyingstart/?lang=en>

²⁵ <http://wales.gov.uk/topics/childrenyoungpeople/publications/familiesfirst/?lang=en>

²⁶ <http://wales.gov.uk/topics/housingandcommunity/regeneration/communitiesfirst/?lang=en>

²⁷ <http://wales.gov.uk/topics/educationandskills/publications/guidance/building-a-brighter-future/?lang=en>

²⁸ <http://wales.gov.uk/topics/educationandskills/publications/guidance/building-a-brighter-future/?lang=en>

²⁹ <http://www.ofmdfmi.gov.uk/ten-year-strategy.pdf>

The DHSSPS sets policy for health and social care in Northern Ireland. This includes public health, child health and social services. In 2013 the DHSSPS consulted on new strategies for paediatrics and children's palliative care. Final strategies, setting out policies are expected in 2014. It is expected that the strategy will recommend the development of more formal networks for child health services.

The Health and Social Care Board working in partnership with the Public Health Agency for Northern Ireland has responsibility for the planning and commissioning of health services across NI. These services are delivered by five combined health and social care Trusts and Primary Care.

There are just under 400,000 children and young people aged 0-17 in Northern Ireland. The majority of children's health services are provided within Northern Ireland. However, some children and families have to travel outside NI to access very specialist services. The vast majority travel to centres in England for this care. Given the relatively small childhood population and geographical isolation, it is essential to develop an integrated collaborative approach for delivery of pathways and networks across Northern Ireland and with centres outside NI.

Epidemiological change

Morbidity³⁰ and mortality³¹ in childhood has changed dramatically over the last century and continues to evolve. No longer are acute illness and injury, particularly in the under fives, the dominant morbidities and suicide has overtaken road traffic injuries and is the leading cause of death in adolescence.^{32, 33} Long term conditions, increasingly in teenagers, are now the largest concern. These morbidities are often related to lifestyles, for example, eating/nutrition/exercise creating an epidemic of obesity, or changes in family structures coupled with societal expectations have created a huge increase in mental health problems. Add to this change increased survival through better specialist and intensive care services, means a generation of young people are now surviving into adulthood with long-term conditions and related disabilities. The case to shift towards better prevention has been amply illustrated in the recent Chief Medical Officer (England) report 'Our Children Deserve Better: prevention pays'.³⁴

This changing epidemiology, market forces and austerity measures have also been associated with increasing inequalities in society and to a divergence in outcomes, with those who are most vulnerable in society being the most disadvantaged and achieving poorer outcomes.^{35, 36, 37} The report of The Children and Young People's Health Outcome Forum recommends greater attention should be paid to reducing unacceptable variations and inequalities.³⁸

Services-balancing prevention and intervention

Sir Ian Kennedy's 2010 review³⁹ has starkly outlined that services in the UK have not yet fully evolved to meet these emerging challenges or "new morbidities"^{40, 41} and there is further evidence that the UK is

³⁰ <https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays/cmos-annual-report-2012-our-children-deserve-better-cmos-summary-as-a-web-page>

³¹ <http://www.rcpch.ac.uk/sites/default/files/page/Death%20in%20infants,%20children%20and%20young%20people%20in%20the%20UK.pdf>

³² http://www.ons.gov.uk/ons/dcp171776_355140.pdf

³³ http://www.ons.gov.uk/ons/dcp171776_355121.pdf?format=hi-vis

³⁴ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255237/2901304_CMO_complete_low_res_accessible.pdf

³⁵ <http://www.marmotreview.org>

³⁶ <http://webarchive.nationalarchives.gov.uk/20110120090128/http://povertyreview.independent.gov.uk>

³⁷ <http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review>

³⁸ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214928/9328-TSO-2900598-DH-SystemWideResponse.pdf

³⁹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119445

⁴⁰ <http://pediatrics.aappublications.org/content/108/5/1227.full>

⁴¹ <http://www.gosh.nhs.uk/news/press-releases/2011-press-release-archive/new-child-mortality-and-morbidity-review-programme/>

lagging behind its European counterparts.⁴² More recently the NHS Atlas of Variations has demonstrated significant variations in service outcomes for children and young people.⁴³ There are no simple, single solutions for improving outcomes; it requires partnership between all those involved and a whole system approach.⁴⁴ Enhanced training of GPs has been singled out by some as an important first step.^{45,46} Likewise the training of consultants has also recently been reviewed and the conclusions of Greenaway are that people need doctors who are capable of providing more general care, in broad specialties across a range of different settings.^{47,48}

The children and Young People's health outcomes Forum was set up in 2012 in response to concerns about the impact of the health and social care act on services for families. It initially reported in 2013⁴⁹ and having undertaken a comprehensive review of services, making 78 recommendations, reported on progress in 2014⁵⁰.

For a family living with a child who has a long-term condition, the best management of the condition requires a multi-agency approach that can not only manage the condition, but also addresses the impact of the condition on everyday living for the child and the consequences for other family members. The FFF builds on the "Think Family" approach which recognises the impact on childhood of adult health problems and does not separate the planning and commissioning of children's services from those services for their parents.^{51, 52, 53}

This aspiration has recently been endorsed within the report of the Independent Commission on Whole Person Care⁵⁴ which recommends "whole system change for whole person care" where "organisations behave as one system, people within them as one team". Although this report focuses on care for the elderly it does also recognise that "preventative interventions aimed at children should locate children within the broader context of the family, recognising the huge impact families and parenting has on child health, wellbeing and a raft of other life outcomes".

The greater focus on prevention to prevent conditions and the negative impacts of these conditions on health and well-being should be embedded throughout the whole system. This includes primary prevention to prevent the condition, secondary prevention to detect and intervene early, tertiary prevention to minimise the impact of the condition on everyday living and finally quaternary prevention (which overlaps with the safety agenda) to prevent harm created within the services or the interventions provided. Without this sustained focus on prevention in childhood, long-term morbidities will eventually overwhelm adult

⁴² <http://www.bmj.com/content/342/bmj.d1277>

⁴³ <http://www.rightcare.nhs.uk/index.php/atlas/children-and-young-adults/>

⁴⁴ <http://www.rcpch.ac.uk/system/files/protected/page/MTFIIIDec09.pdf>

⁴⁵ http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Child%20and%20Adolescent%20Health/CIRC_RCGP_Child_Health_Strategy_2010_2015_FINAL.ashx

⁴⁶ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214928/9328-TSO-2900598-DH-SystemWideResponse.pdf

⁴⁷ http://www.shapeoftraining.co.uk/static/documents/content/Shape_of_training_report_Final_Report.pdf_53900462.pdf

⁴⁸ http://www.ncb.org.uk/media/972611/130603_ncb_opening_the_door_to_better_healthcare_final.pdf

⁴⁹ <https://www.gov.uk/government/publications/independent-experts-set-out-recommendations-to-improve-children-and-young-people-s-health-results>

⁵⁰ <https://www.gov.uk/government/publications/improving-children-and-young-peoples-health>

⁵¹ http://webarchive.nationalarchives.gov.uk/20080107205404/http://cabinetoffice.gov.uk/upload/assets/www.cabinetoffice.gov.uk/social_exclusion_task_force/think_families/think_families.pdf

⁵² http://webarchive.nationalarchives.gov.uk/+http://www.cabinetoffice.gov.uk/media/cabinetoffice/social_exclusion_task_force/assets/think_families/think_family_life_chances_report.pdf

⁵³ <http://www.scie.org.uk/publications/atagance/atagance09.pdf>

⁵⁴ <http://www.hsj.co.uk/Journals/2014/03/03/u/e//One-Person-One-Team-One-System-final.pdf>

services. This emphasis, which is sometimes called ‘a life course epidemiological approach’^{55,56} is strongly endorsed by Dame Sally Davies in her 2013 CMO report.⁵⁷

Planning and commissioning

For the purposes of this paper commissioning is defined as “the process of allocating public resources to achieve the greatest gains in health and well-being within a defined population”. However, it also has to be recognised that the allocation of resources in terms of investment and disinvestment also happens at a provider level and there should therefore be an alignment between the priorities of planners and commissioners and those of providers.

Those responsible for the commissioning process must recognise that:

- services for children and families are highly complex with many interdependencies between children’s services and adult services for their parents;
- year on year changes/improvements will be required as demography, epidemiology and knowledge changes;
- resources will never be unlimited and therefore there must be a process to make transparent decisions based on best evidence and explicit priorities throughout the system;
- all proposals must be sustainable within the resources available and take a long-term/whole life approach to resource investment.

Truly effective planning and commissioning that delivers best value for money requires both clear leadership and strong partnerships between all planners and commissioners across the children and families sector, providers and regulators; a greater participation of users in the process, with a relentless focus on quality and safety, generating learning and new knowledge through the triple processes of innovation, evaluation and improvement.

One of the commonest concerns amongst practitioners, clinicians in particular, is that planners and commissioners do not understand the complexity of delivering services for children and their families and multiple competitive contracts results in fragmented services, as Don Berwick, paediatrician and CEO Institute for Healthcare Improvement, has observed – “if you pay for pieces, you get pieces”.

Unlike ‘simple’ elective surgical services, many children’s services are complex, due largely to a child’s dependence on their family and a wide range of determinants of health, over which they have little direct control. For example, in safeguarding services, the planners and commissioners of children’s services must also consider the services provided for parents with learning difficulties, mental health problems, substance abuse or those experiencing domestic violence. Often the child’s difficulties are a symptom of family dysfunction and effective support for their parents, by adult services, will have a profound indirect impact on the health and well-being of children. A good example of an evidence-based initiative which meets both these goals is the Family Nurse Partnership which intervenes with inexperienced or vulnerable families in the antenatal period through to their child’s second birthday.^{58,59}

Planners, policymakers and providers need to simultaneously consider interventions aimed at influencing the determinants of health/lifestyles to improve health and prevent problems and services which identify, assess and manage concerns or conditions as they arise. Additionally they must consider the impact of conditions not only on the child, but also the consequences for their parents and siblings, particularly when long-term conditions exist and prevent or mitigate any negative consequences for the child or other family members.

⁵⁵ <http://www.ncbi.nlm.nih.gov/pubmed/15760279>

⁵⁶ <http://www.bristol.ac.uk/populationhealth/methodology/lifecourse/>

⁵⁷ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255237/2901304_CMO_complete_low_res_accessible.pdf

⁵⁸ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212892/GFNP-PHASE-1-Evaluation-Summary-report-FINAL-for-PUBLICATION.pdf

⁵⁹ <http://www.scotland.gov.uk/Resource/Doc/355013/0119868.pdf>

The Family Friendly Framework addresses these challenges by creating a framework of service delivery that brings together a life course approach and service delivery approach based on pathways that is easily understood and that could be adopted by planners and commissioners, providers and regulators and then adapted through a process of learning through innovation and quality improvement.

The Family Friendly Framework

The myriad of services used by children and families could be likened to an ecosystem or a complex adaptive system which has been defined as “a set of interconnected elements, where what happens in one part of the system affects the rest, so that they act together as a whole”.⁶⁰

The key elements leading to the "success" of the human race includes a robust system for design based on 'simple rules' encapsulated within the four DNA base pairs, effective control systems, based on feedback loops for homeostasis (physiological and biochemical) and the capacity to adapt (to changing social and environmental conditions) through the ability to innovate, learn and communicate.

The **Family Friendly Framework** attempts to emulate and embed the properties of successful complex adaptive systems into the design, delivery and development of services for children and families. The Framework combines a child rights based approach,^{61,62} with best evidence and a 'whole systems approach',⁶³ coupled with a commitment to learning⁶⁴ through participation, innovation and quality improvement.

Values derived human rights must contribute to the culture of an organisation. They should guide the development of services and influence decision-making in conditions of uncertainty, for example where there is limited evidence. To differentiate values are relate to people have, the values that relate to services the terms "philosophy" and "principles" have been used respectively. Philosophical values contribute to professional 'cultural competence' whereas principles contribute to 'organisational culture'. Both are important, there is an overlap between philosophy and principles, so examples are provided in appendixes 1 and 2. These values, based on fundamental human rights, are universal and should create the backbone of any manifesto,⁶⁵ mandate,⁶⁶ constitution⁶⁷ or charter for services.⁶⁸

Good evidence is fundamental to the commissioning, safe delivery and improvement of services whether this is at a policy or a professional level. The highest level of evidence should be used, accepting that there are times when there is little evidence to inform decision-making, particularly health services research around optimal service configurations. In these circumstances engagement with relevant stakeholders, clear leadership, honest communication and explicit criteria for decision-making are essential.

A system is defined by the World Health Organisation as:

“all organisations, people and actions whose primary intent is to promote, restore or maintain health, whose purpose is to improve health and health equity in ways that are responsive, financially fair and make the best use of available resources”.

The Family Friendly Framework recognises the importance of bringing together the perspectives of various stakeholders (figure 1). A user perspective (a system that is easily understood and works for them), a clinician/practitioner/team perspective (a system that makes best use of their training and competencies), a management perspective (a system that makes best use of resources) and a political perspective (a system

⁶⁰ <http://www.directedcreativity.com/pages/PatternsOnePage.pdf>

⁶¹ <http://www.unicef.org/rightsite/sowc/pdfs/panels/The%20human%20rights-based%20approach%20for%20children.pdf>

⁶² http://www.who.int/hhr/news/hrba_to_health2.pdf

⁶³ <http://www.who.int/alliance-hpsr/resources/9789241563895/en/index.html>

⁶⁴ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/226703/Berwick_Report.pdf

⁶⁵ <http://www.ukyouthparliament.org.uk/wp-content/uploads/BYC-UKYP-manifesto-2013.pdf>

⁶⁶ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256497/13-15_mandate.pdf

⁶⁷ <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/nhs-constitution-interactive-version-march-2012.pdf>

⁶⁸ http://www.togetherforshortlives.org.uk/families/information_for_families/2456_together_for_short_lives_charter

that is fair, transparent and accountable), into a practical framework to improve outcomes to children and families.^{69, 70}

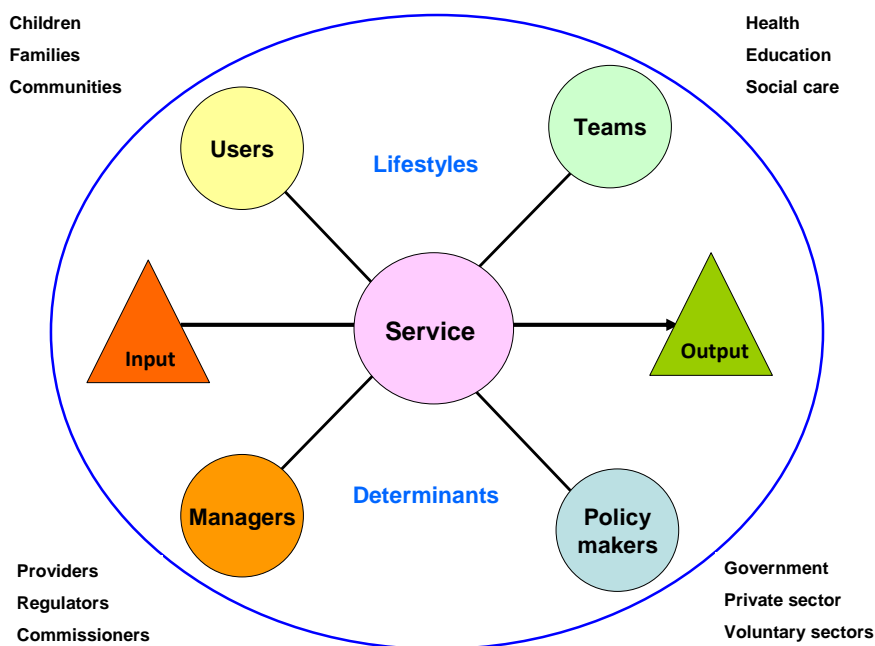


Figure 1: illustrating multiple stakeholder perspectives on service provision, based on a simple systems input-output mode, noting the external influences of lifestyles and determinants.

There is a constant balance between these different perspectives. If one dominates, others will become subordinate, resulting in potential inefficiency, inequity or harm, for example, if there is an excessive focus on targets and cost reduction (potentially a manager's perspective) this may undermine then quality of care (a user's perspective), amply illustrated in the recent Francis Report.⁷¹

Learning and the generation of new knowledge is essential in order to respond to changing circumstances. Health systems have a relatively strong track record of research in clinical sciences but a relatively weak investment in translational research and research related to health services delivery. The result is that health service structures have remained relatively immune to changing epidemiology, technological advances or service redesign. A culture of learning, based on innovation and evaluation, should therefore become an integral part of service delivery. This local learning then needs to be complemented with mechanisms to spread and adopt successful innovations rapidly throughout the whole system.

Introduction to systems thinking

At the simplest of levels an "output" is always a changed "input". Glucose is changed into energy, carbon dioxide and water in the Krebs cycle, the enzymes involved act as a catalyst or an "agent for change". The health service is also a change agent, in the very simplest of terms, the input being sick patients and the output hopefully well patients. In whole system's thinking the health system addresses "needs" (defined as the ability to benefit from interventions) to improve health and this improvement can be measured in a number of different ways by outcome measures. If improvements are sustained over time the term "impact" is used rather than outcome.

Added value in the system will be perceived differently by different stakeholders - some will value effectiveness over efficiency, some equity over effectiveness and vice versa. Considering the viewpoints of

⁶⁹ <http://www.scotland.gov.uk/Resource/Doc/355013/0119868.pdf>

⁷⁰ <http://users.actrix.com/bobwill/ssm.pdf>

⁷¹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/226703/Berwick_Report.pdf

different stakeholders therefore provides a framework for the evaluation of services. The views of each stakeholder are not mutually exclusive.

| | Primary | Secondary |
|---------------|---------------|-----------------|
| Users | Efficacy | Accessibility |
| Teams | Effectiveness | Acceptability |
| Managers | Efficiency | Affordability |
| Policy-makers | Equity | Appropriateness |

Systems thinking also recognises that individual care and services do not exist in a vacuum - they sit within a wider political, social and economic environment, which may either help or hinder the achievement better outcomes by influencing either lifestyles or determinants of health. It is therefore vital that, for example, economic, employment and benefit systems, which all contribute to the outcomes of life course pathways, work in synergy with public health, other agencies and the NHS to achieve a greater impact. In the Family Friendly Framework these external factors have been reduced to two terms – lifestyles that individuals have some control over and determinants that are less easily influenced by individuals and more in the control by society decisions.

The description of the Family Friendly Framework that follows is in four stages, each with four parts:

1. it starts with the **basics** that each team or individual providing a service component need to consider namely evidence, competence, setting and support services;
2. builds these **component parts**, namely prevention, recognition, assessment and interventions, into both life course and service pathways, then
3. combines the four pathways, initial, review, transition and life-course into **networks** and then,
4. examines the working of the **whole system**, which requires a clarity of purpose, values, leadership and the ability to learn.

These four stages with four parts create a 4x4 framework are illustrated in figure 2. The intention is for each step to build on the previous stage to build an increasingly complex system that integrates the parts to create a synergy that enables the best possible outcomes using the available resources wisely and sustainably.

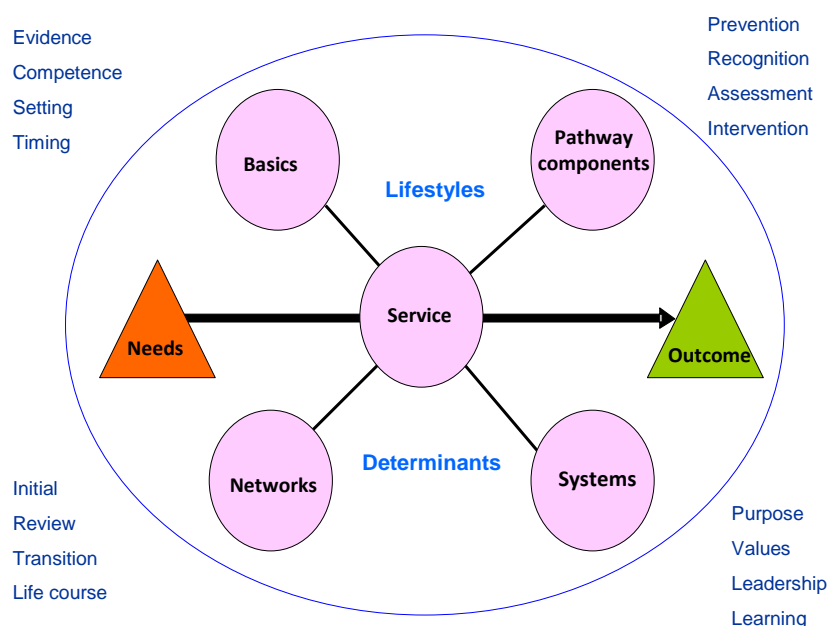


Figure 2: illustrating the essential elements that need to come together to create an excellent service.

For simplicity only three examples will be discussed - a short-term condition pathway, a long-term condition pathway and a life course pathway. Clearly there are potential overlaps between these three forms of

pathway/network and the critical skill of planners and commissioners is to ensure there is alignment and synergy between all parts of the system so there is best use of invested resources judged by the overall impact i.e. value in health care.⁷²

The basics

At the most basic level families want the system to ensure that services providers to do the right things (using best evidence), to the right families (needs), using the right people (competent teams), in the right setting (place/space), at the right time (timeliness) to achieve the right outcomes (output), as illustrated in figure 3.

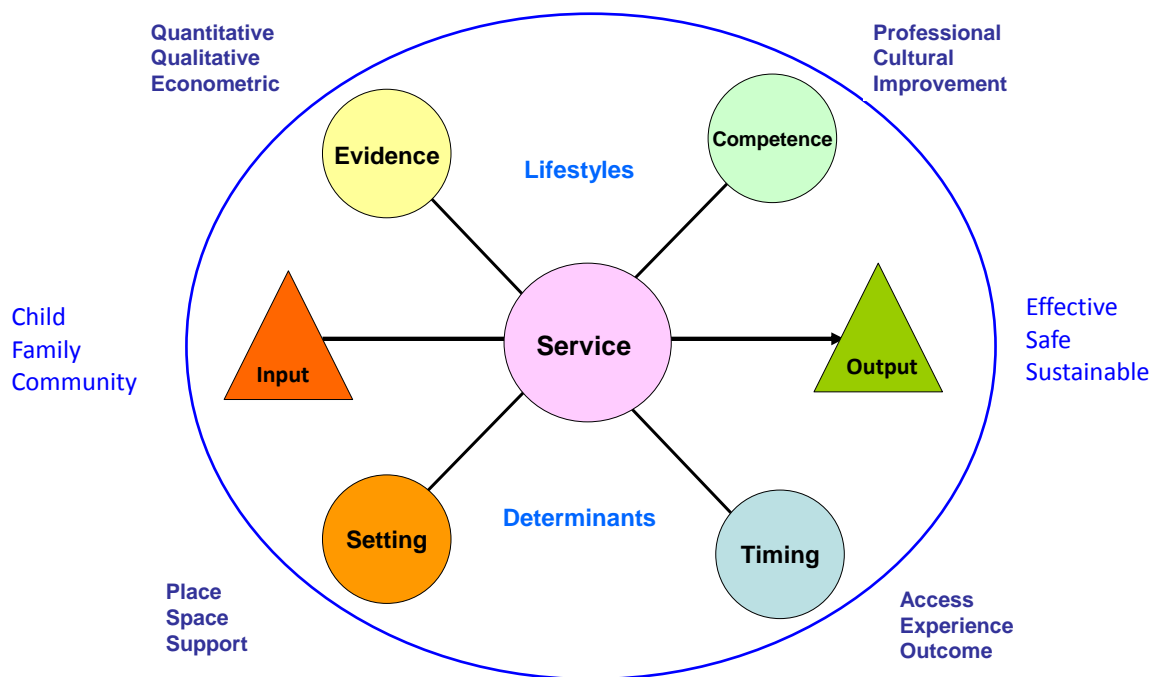


Figure 3: illustrating the four basic components that contribute to effective and safe service delivery namely evidence, competence, setting and timeliness.

1. Fundamental to an effective service/system is the use of **best evidence** - this may be quantitative, from systematic reviews or randomised controlled trials, qualitative, from user experience and market research, or econometric which examines price, value and cost benefit.
2. Next is the need for a **competent workforce** - competent not only in their professional sphere, but also culturally competent, for example, to communicate with children of all ages and their families. Additionally they must be competent in “quality improvement” and have the ability to perpetually learn throughout their professional lives.⁷³
3. Services then should be delivered in the **right setting (“place and space”)** - as close to home as is safe and sustainable, with the right environment for the work being undertaken with the necessary equipment and support systems, such as investigation, administration and information.
4. Finally, services should be delivered at the **right time** - providing a prompt response to the initial concern, with pathways organised to deliver their component parts in a timely fashion, to achieve good outcomes as soon as possible.

This basic approach has to be embedded within every component subsequently described in the sections on pathways and networks which follow.

⁷² <http://www.nejm.org/doi/full/10.1056/NEJMp1011024>

⁷³ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/226703/Berwick_Report.pdf

Pathway components

Two types of pathways will be considered. A service pathway - further divided into short-term and long-term condition pathways and then a life course pathway which should be considered as an integral part of service delivery as lifestyles and determinants also contribute to service outcomes at every stage.

Service pathways – a short-term condition

Short-term conditions cover self-limiting illness and the assessment and management of concerns which do not require ongoing care. Access to effective health care often starts with an awareness and recognition that something is wrong, which then initiates a consultation leading to further assessment and, if appropriate, access to interventions. In the ideal world many problems could be prevented and therefore planning and commissioning must link to the primary prevention agenda in order to tackle lifestyles and determinants within the life course pathway. Whilst some concerns may be completely managed in a single consultation, many require additional parts of the pathway of care to be brought together to create integrated care from a number of teams in different provider organisations (see figure 4).

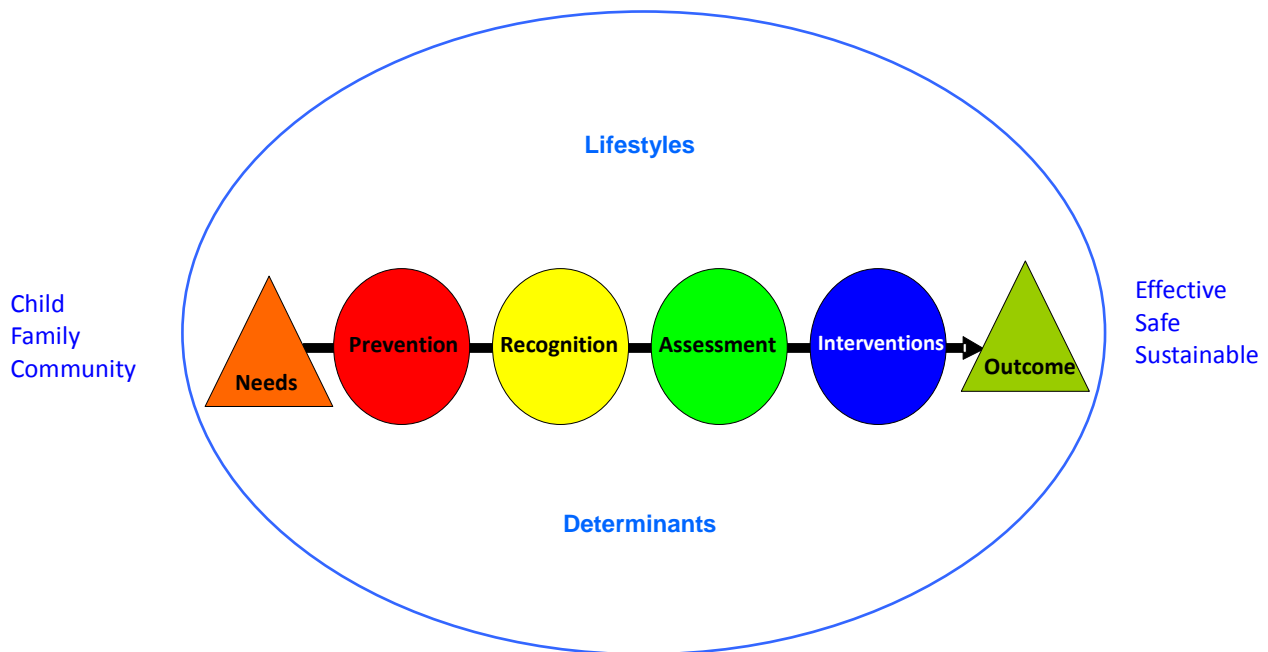


Figure 4: illustrating the component parts of a simple pathway, including the external influence of lifestyles and determinants

The concept of **provision based on pathways** ensures that all the parts are in place to address the needs of the family to achieve the expected outcomes.

The needs of families are therefore represented by a triangle in figure 4, which illustrates a holistic approach where a need is defined as the ability to benefit from an intervention or service. This concept of need can apply to an individual, a whole population of children or an identified vulnerable group, or problem within a community.

1. Prevention includes protection and promotion to tackle lifestyles and determinants.
2. Recognition may be through screening, surveillance or the recognition of symptoms.
3. Assessment includes symptoms, impact on the child and consequences for the family.
4. Interventions range from those provided by health, education, social care services and others.

The output is also represented by a triangle and can be measured using quantitative, qualitative or cost related measures.

Visually this four step process can be expanded (figure 5) to include the options available for each one, as an aide memoir. These individual components may be provided within the health service, or may be with other agencies or organisations that contribute to the pathway.

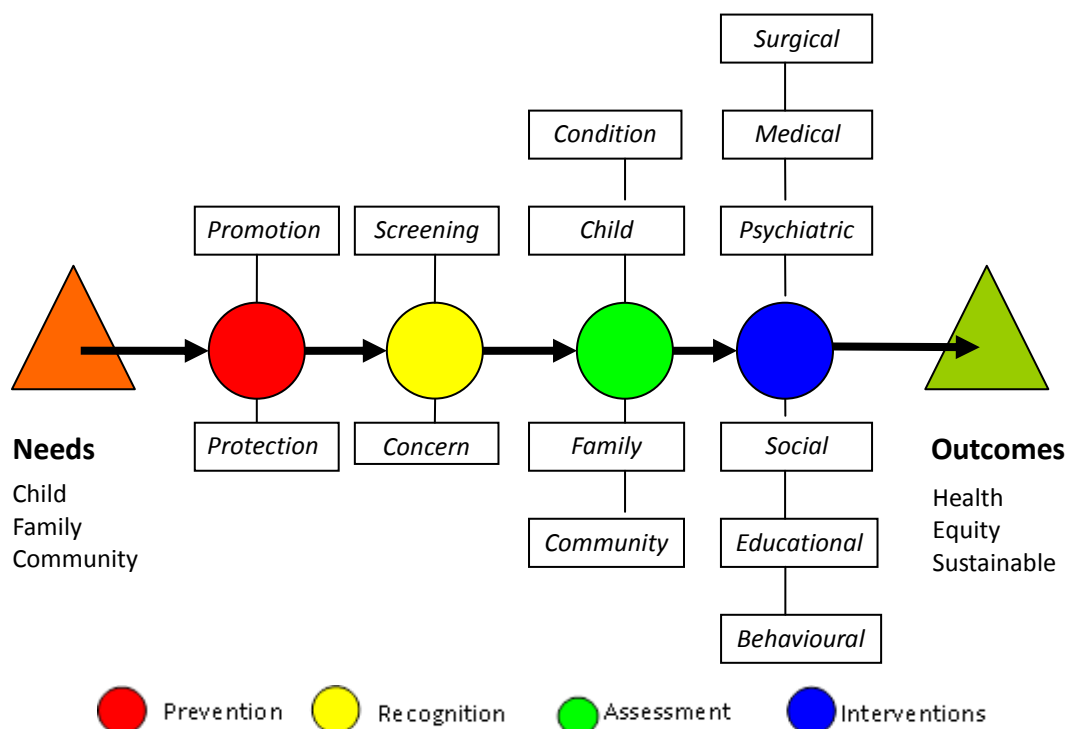


Figure 9: representing a short-term pathway, with needs on the left, outcomes on the right and the component parts namely prevention, recognition, assessment and interventions in sequence in between.

Each component in the pathway is evidence-based, delivered by competent people/teams, in the right place and at the right time. However, as each component may be delivered by a different provider, so it is essential that each provider is clear about their own boundaries and responsibilities, to prevent either omissions or duplications. The planners and commissioners of services likewise need to be clear about which parts of the pathway they are responsible for planning and commissioning. Similarly regulators should move from inspecting organisations, which provide a component of the pathway, to examining whole pathways or programmes of care focusing not only on quality of the components but on how they all work together to achieve better experience and outcomes.

Example 1: serous otitis media (glue ear)

Serous or secretory otitis media (SOM) is a collection of fluid that occurs within the middle ear. This can occur after a viral URTI or it can precede or follow acute bacterial otitis media. Middle ear fluid becomes thick and glue-like which then interferes with tympanic membrane movement causing conductive hearing impairment.⁷⁴

Primary prevention can be through either health promotion or health protection - specifically promoting breastfeeding and protecting children from cigarette smoke,⁷⁵ the responsibility of Public Health England.

Recognition can be achieved through either an active process of case finding for example by surveillance or through recognition by parents or health professionals. This should be covered by the Healthy Child Programme, the responsibility of Public Health as part of the Local Authority planning and commissioning responsibilities.

⁷⁴ <http://www.rcseng.ac.uk/healthcare-bodies/docs/published-guides/ome>

⁷⁵ <http://www.jpeds.com/article/S0022-3476%2805%2980843-1/abstract>

Assessment will involve defining the level of hearing impairment, assessing the impact of hearing impairment on the child's language and behaviour, ascertaining the family ability to manage the hearing impairment and determining the resources available in the local community. Planning and commissioning responsibility will be with Clinical Commissioning Groups.

Interventions may range from surgical - the use of grommets, medical interventions coupled with language or educational support or on-going monitoring. Health service interventions will be commissioned by Clinical Commissioning Groups, education support either by Local Authorities or academies of schools.

In this simple example the needs of families should not be forgotten - parents will need information and possibly training in augmented communication systems to overcome the hearing impairment. Where children attend preschool provision, the staff they will also need to be competent in communicating with hearing-impaired children.

This descriptive text could be translated into a tabular framework (table 1) for planning and commissioning services, for example using the commissioners in England, as illustrated below:

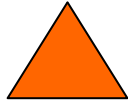
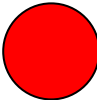
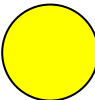
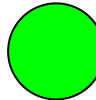
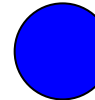

|  Commissioner |  Prevention |  Recognition |  Assessment |  Intervention |  Outcomes |
|--|---|--|---|---|--|
| NHS England | <i>Breast feeding promotion in primary care</i> | <i>Recognition of hearing impairment in primary care</i> | | | <i>Br feeding rates @6/52</i> |
| CCG | | | <i>Paediatric audiology assessment</i> | <i>Hearing aids SaLT Parent support</i> | <i>Access Timeliness</i> |
| LA | | | | <i>Teachers for the deaf Hearing loops</i> | <i>Language dev Educational achievement</i> |
| PH | <i>Smoking cessation</i> | <i>Healthy Child Programme</i> | | | <i>Rates of smoking in pregnancy. HCP uptake</i> |

Table 1: planning- illustrating how component parts for the management of a condition might be allocated to various commissioners in England. Key: CCG - Clinical Commissioning Group. LA - Local Authority. PH - Public Health.

This generic framework can then be expanded to define and delineate the roles and responsibilities of individual providers in table 1, including more detail as and when necessary to include the needs for family and community with each having a separate framework/table. Table 2 for providers is intended to be used as an aide memoir to ensure the needs of the child, their family and the community are not forgotten and allocated to the appropriate planners and commissioners.

| | Providers | Prevention | Recognition | Assessment | Interventions |
|-----------|---------------------|------------|-------------|------------|---------------|
| Child | Specialist services | | | | |
| | General services | | | | |
| | Local Authority | | | | |
| | Public Health | | | | |
| | Third sector | | | | |
| | Private | | | | |
| Family | Specialist services | | | | |
| | General services | | | | |
| | Local Authority | | | | |
| | Public Health | | | | |
| | Third sector | | | | |
| | Private | | | | |
| Community | Specialist services | | | | |
| | General services | | | | |
| | Local Authority | | | | |
| | Public Health | | | | |
| | Third sector | | | | |
| | Private | | | | |

Table 2: provision - an illustration of how pathway components might be allocated to different providers.

Service pathways - a long-term condition pathway

Long-term conditions are those where an individual has to live with the disease or disability and the focus of care is on best management of that condition, prevention of complications and adjustments in lifestyle or adaption of the environment. The four component parts of the short-term condition pathway can be replicated into a whole programme of care for long-term conditions covering an initial phase, a cyclical review phase and a transition phase. This is illustrated in figure 6.

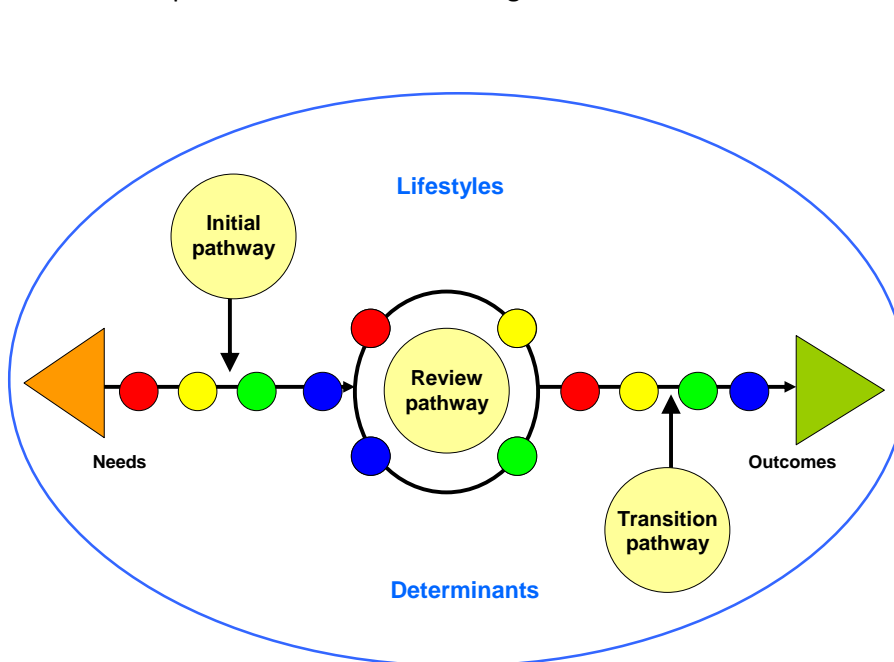


Figure 6: illustrating the long-term pathway with 3 phases – the initial, review and transition phases, each with four component parts.

1. The initial phase covers the development of the condition where the preventative element is to reduce the incidence of the condition.
2. The cyclical phase covers "living with the condition" and the preventative element is to reduce the complications of the primary condition and impact on daily living.
3. The transition phase is similar to the review phase but with a greater emphasis on the components required for successful transition. Occasionally where there is uncertainty about prognosis, there may be a need to plan for living through transition and end of life simultaneously.

Quaternary prevention is the prevention of unintentional harm throughout the pathway and links to the safety agenda.

Like the short-term pathway this diagrammatic representation of the initial, review and transition phases of long term condition management can be translated into a tabular framework, in table 3. Each cell would contain the basic information on what needs to be done (the evidence), the workforce requirements (competence) and the place of delivery.













| Component parts | Phases | | | | | | | | | | | |
|------------------|---|---|---|---|---|---|--|---|---|---|---|---|
| | Initial | | | | Review | | | | Transition | | | |
| |  |  |  |  |  |  |  |  |  |  |  |  |
| Child | | | | | | | | | | | | |
| Family | | | | | | | | | | | | |
| Community | | | | | | | | | | | | |

Table 3: illustrating the component parts of a long term condition pathway – bringing together the needs of a child, their family and the local community.

Detail can be inserted into each of the cells depending upon the evidence base available – family-based interventions, such as Family Nurse Partnerships, may be needed to address parenting issues and adult services to address any health problems of parents such as substance misuse or mental health disorders. Community based interventions would include those tackling the determinants of health and specific issues, such as, traffic speed, housing quality⁷⁶ or community safety. NHS safety initiatives to prevent unintentional harm or improve quality delivery should also be included.

It must be remembered that the planning and commissioning services is only one element of the commissioning portfolio which has be complemented by the commissioning of clinical and health services research,⁷⁷ workforce (recruitment, development and retention) and innovation and improvement - all to support sustainable service delivery.

⁷⁶ <http://www.scie.org.uk/publications/briefings/files/briefing19.pdf>

⁷⁷ <http://www.rcpch.ac.uk/system/files/protected/page/TT%20Exec%20Summary%20Final%20for%20web.pdf>

Example 2: an example of a long-term condition pathway: Down syndrome (DS)

Down syndrome (DS) is the commonest chromosomal disorder and the most common cause of learning difficulty and may be associated with medical complications in multiple organ systems. There are approximately 750 babies born with DS every year in the UK, with an incidence of 1:1000 live births. It is estimated that there are currently around 60,000 people with DS in the UK, but as life expectancy for children with DS has been steadily rising, the early identification and intervention in childhood for medical complications will have significant and far-reaching impact upon the overall burden of disease in adults with DS.

Purpose

1. To improve the health, well-being and overall quality of life of children with Down syndrome.
2. To reduce inequalities in outcomes.
3. To create a continuously improving, sustainable service within the resources available.

Aims

1. To identify medical conditions that could impair health and development as early as possible.
2. To support families who have a child with Down syndrome.
3. To improve community resources for children and young people with Down syndrome.

Evidence base

- Down syndrome Medical Interest Group UK and Ireland.⁷⁸
- American Academy of Pediatrics Clinical Report: Health Supervision for Children with Down Syndrome.⁷⁹
- European Down Syndrome Association Health Care Guidelines for People with Down Syndrome.⁸⁰

Table 4 illustrates how all the component parts relating to the child, family and community, for the four component parts of the initial review and transition pathways might be organised. Each cell of the table merely describes what needs to be done, the next steps would be to determine who and where the service should be delivered. These various elements would then be included within a within a network which focuses on long-term conditions and disabilities.

⁷⁸ www.dmsig.org.uk

⁷⁹ <http://pediatrics.aappublications.org/content/early/2011/07/21/peds.2011-1605>

⁸⁰ http://www.edsa.eu/files/essentials/edsa_essentials_2_healthcare.pdf

| Initial phase | | | | |
|-------------------------|---|---|---|--|
| Component parts | Prevention | Recognition | Assessment | Interventions |
| Foetus - newborn | <ul style="list-style-type: none"> • Education – risks of later pregnancy • family planning | <ul style="list-style-type: none"> • antenatal DS screening • newborn examination screening • ad hoc recognition | <ul style="list-style-type: none"> • a/n obstetric/ paediatric • cardiological • genetic | <ul style="list-style-type: none"> • termination • therapeutic interventions |
| Family | <p>Universal</p> <ul style="list-style-type: none"> • folate supplementation <p>High risk group</p> <ul style="list-style-type: none"> • reduce age of conception • pre-implantation genetic diagnosis | <ul style="list-style-type: none"> • parenting capacity | <ul style="list-style-type: none"> • parenting assessment | <ul style="list-style-type: none"> • parent support |
| Community | <ul style="list-style-type: none"> • Health promotion | <ul style="list-style-type: none"> • promotion of screening | | |

| Review phase | | | | |
|------------------|---|--|--|--|
| Component parts | Prevention | Recognition | Assessment | Interventions |
| Child | <ul style="list-style-type: none"> • health education • health protection | <p>Universal</p> <ul style="list-style-type: none"> • hearing screen • vision screen • thyroid screen • coeliac surveillance • cervical spine disorders surveillance • sleep related disordered breathing surveillance • growth surveillance • learning difficulties • language disorder • behaviour disorders • immunological disorders <p>High risk group</p> <ul style="list-style-type: none"> • cardiac • sleep disordered breathing | <ul style="list-style-type: none"> • paediatric • ophthalmology • ENT • biochemical/endocrinology • testing/gastroenterology • neurology/spinal orthopaedics • further investigation • cognitive assessment • communication assessment • motor development | <p>interventions as appropriate for the conditions detected additional immunisations flu, pneumovax</p> <ul style="list-style-type: none"> • • education in keeping with abilities • speech and language therapy • physiotherapy • occupational therapy |
| Family | <ul style="list-style-type: none"> • Benefits advice | | <ul style="list-style-type: none"> • parental information • sibling support needs | <ul style="list-style-type: none"> • expert parent programmes • family support |
| Community | <ul style="list-style-type: none"> • Leisure access for disabled | | | <ul style="list-style-type: none"> • in school support |

| Transition to adult services* | | | | |
|-------------------------------|--|--|--|--|
| Component parts | Prevention | Recognition | Assessment | Interventions |
| Young person | <ul style="list-style-type: none"> • health education programmes • preparation for adulthood • mentoring • financial support | <ul style="list-style-type: none"> • life skills • preparation for adult services • advocacy • continued annual screening/ surveillance as above | <ul style="list-style-type: none"> • participation skills • activities of everyday living • finances • social • educational • spiritual, cultural, religious • short breaks • housing, adaptations and equipment • parallel planning for end of life care – ACPs • sexual health needs | <ul style="list-style-type: none"> • Life skills programmes • Living arrangements • Support to manage adult benefits & funding • Adult education • Employment • Leisure • Health care – self care/ symptoms managed • Key worker & key worker designate in adult services • Stable and sustainable support in adult services • At centre of care |
| Family | <ul style="list-style-type: none"> • Advice on post 16 provisions • Psycho-social support • Information on options | Preparation for adult services – life without the YP at home | Short break needs Carer's assessment Financial Housing, adaptations – if YP to remain at home | Short breaks Employment Leisure Housing Psychosocial support |
| Community | <ul style="list-style-type: none"> • Post 16 provision available • Finance • Equipment (wheelchairs) | Identify services to move on to <ul style="list-style-type: none"> • Finance • Equipment (wheelchairs) • Transport | <ul style="list-style-type: none"> • Develop transition plan • Multiagency working • Key worker provision • Transport provision • Short break provision | <ul style="list-style-type: none"> • Social and leisure opportunities • Further/higher education opportunities • Employment opportunities • Appropriate housing/adaptation • transport • Training for staff |

Table 4: illustrating how all the component parts relating to the child, family and community, for the four component parts of the initial review and transition pathways might be organised.

*a small number of people with Down syndrome may have life-threatening conditions which will therefore need a transition pathway into palliative care services.

Life course pathways.

Recent reports by Marmot,⁸¹ Field,⁸² Allen,^{83,84} Rutter⁸⁵ and Davies⁸⁶ have all stressed the importance of either prevention or early intervention as the starting point to ameliorate the high cost of future morbidity - particularly special educational needs, contact with the criminal justice system, narrowing the attainment gap and reducing variations in quality of life.

Public health approaches include protection from hazards (anything that have the potential to cause harm - ranging from bullying to toxic air pollution) and the promotion of assets (increasing exposure to assets/positives that improve health, ranging from healthy family dynamics to high-quality education). This twin protection/promotion approach can be applied to both lifestyles (factors largely within the control of families) and the wider determinants of health (generally outside the immediate control of families). See appendix 3 for more complete explanation of pathogenesis and salutogenesis.

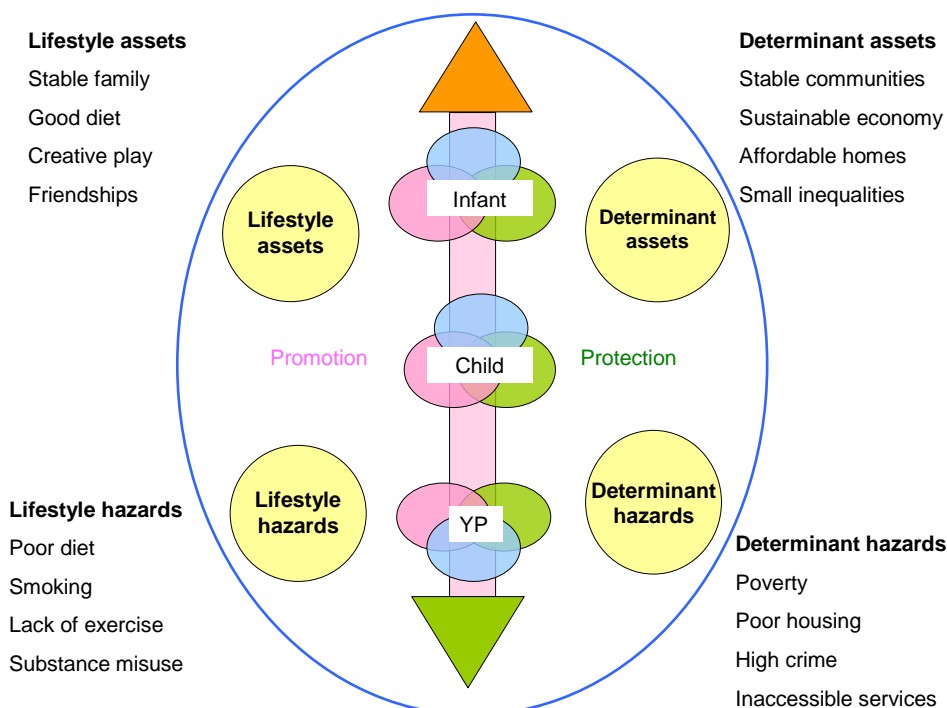


Figure 7: Illustrating a life course pathway (vertical) in the centre, with assets and hazards relating to determinants and lifestyles as the factors to be addressed at different times within the life course pathway.

This approach is illustrated in figure 7. The intention would be to align public health interventions with service interventions for example *protecting* individuals from excess calories, *promoting* exercise as well as managing diabetes and cardiovascular complications. Some of the key wider determinants for children include low income households, single parenthood, living in areas of deprivation, poor housing and low educational attainment of mothers.

This twin protection/promotion approach is then coupled with public health programmes targeted specifically on individual conditions are example and fluoride in water to prevent dental caries or folate in flour to prevent spina bifida.

⁸¹ <http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review>

⁸² <http://webarchive.nationalarchives.gov.uk/20110120090128/http://povertyreview.independent.gov.uk>

⁸³ <http://www.dwp.gov.uk/docs/early-intervention-next-steps.pdf>

⁸⁴ <https://www.gov.uk/government/publications/early-intervention-smart-investment-massive-savings>

⁸⁵ <http://www.acmedsci.ac.uk/p99puid115.html>

⁸⁶ <https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays/cmos-annual-report-2012-our-children-deserve-better-cmos-summary-as-a-web-page>

This promotion/protection strategy to primary prevention can be replicated for secondary (early detection), tertiary (preventing complications of the primary condition) and quaternary prevention (preventing harm from interventions i.e. the safety agenda)

The Family Friendly Framework builds on both public health and children's social care concepts that re-enforce that a child should not be seen in isolation from either their families or their physical and social environments (communities). The life course pathway approach recognises that health and ill-health, is created through a series of exposures to both positive and negative lifestyles and determinants throughout life from conception through to adulthood. The challenge for planners is to ensure the minimisation of hazards and the maximisation of assets to create the best possible health from the perspectives of either of an individual or a population/community in order to realise the benefits of prevention.⁸⁷ This requires alignment and synergy between policies spanning public health, health services and wider policies involving the environment, transport and macroeconomic policies to name just a few.

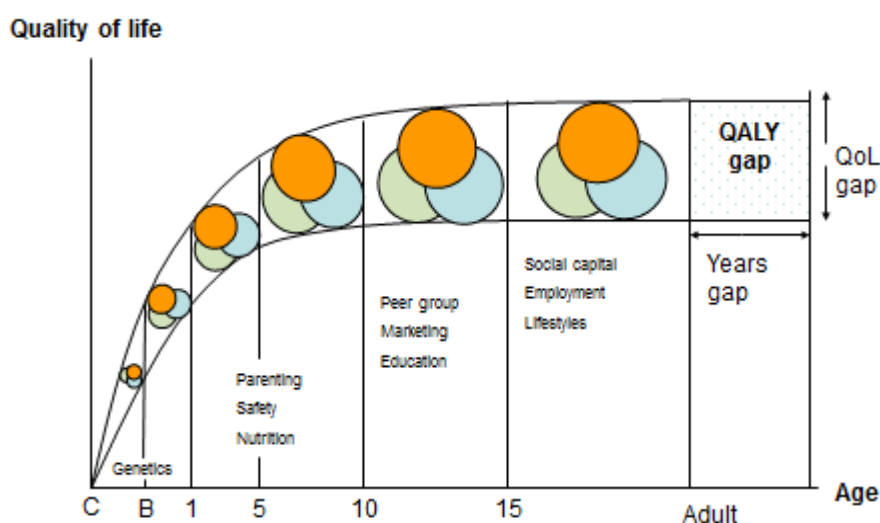


Figure 8: representing the differences in quality-of-life on different trajectories with age and the quality adjusted life year (QALY) gap between better and worse life course pathways.

Example 3: a life course pathway tobacco reduction

A similar approach can be taken, as illustrated in table 5 below, for the component parts that contribute to creating life course pathways. Once again the needs of the child, their family and their community should be considered in relationship to lifestyles, the social determinants of health and access to preventative services. Within each cell promotion and protection strategies should be considered.⁸⁸

⁸⁷ <https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays/cmos-annual-report-2012-our-children-deserve-better-cmos-summary-as-a-web-page>

⁸⁸ <http://www.nice.org.uk/guidance/PH14/chapter/introduction>

| | | Lifestyles | Determinants | Services |
|------------------|----------------------------|---|---|--------------------------------|
| Child | Preschool | | Parental smoking Smoking in media | Asthma services |
| | School | | | Health education in schools |
| | Young person | Health education Smoking enquiry in clinical consultations | Access to cigarettes near schools | Smoke stop services |
| Family | Parents | Tackling smoking in pregnancy | | Nicotine replacement |
| | Siblings | | Access to cigarettes | |
| | Extended family | Smoking cessation advertising | Tobacco taxation | Nicotine replacement |
| Community | Home | Smoke-free homes | Quality of housing | SUDI information |
| | Neighborhood | Smoke-free cars | No advertising Smoke free shops + leisure | |
| | Society | Smoke-free public places | Legislation increasing age of access Control of illegal imports | Health services |

Table 5: A worked example examining to reduce exposure to tobacco and manage the consequences.

Once again interventions should be evidence-based, delivered by competent professionals in the right place and at the right time. From a commissioning and planning perspective each contribution to the overall programme may be the responsibility of different government departments or commissioning bodies and adoration will be needed to ensure all the parts are in place and working well.

Life course pathways must not be seen in isolation from service pathways as they are relevant at every stage of the service pathway, for example reducing tobacco consumption is equally relevant to establish smokers as it is to smokers who have not established a regular habit.

Networks

Networks are central to the successful delivery of a family focused, whole systems approach to service delivery which connects service pathways and life-course pathways. Programmes of care create the practical connection between the initial, review, transition parts of service pathways with and life course pathways as illustrated in figure 9. The intention is that they are the structures that create collaborative integration between the various teams from different organisations that all contribute to improving outcomes. Network implementation started in Scotland in 1999⁸⁹ and was endorsed again in 2012 as part of an improving healthcare quality strategy.⁹⁰ There are many models for networks, depending on their purpose and function and further research and evaluation is a high priority to better understand the relationship between structure, process and outcomes. A definition relevant to multi-agency working, describes the function of managed networks as:

"a group of organisations, services and professionals working collaboratively to continually improve the services they provide through a process of learning from innovation and quality improvement".

The functions of a network have been described^{91, 92, 93} and are expanded in appendix 4. The essential elements include:

1. Contributing to Joint Strategic Needs Assessment (JSNA).
2. Delivering, developing and improving pathways through setting standards, developing relevant measures, audit and improvement.
3. Decision-making – particularly resource allocation – the network will recommend priorities for investment and disinvestment, constantly striving for improvements in overall programme value.
4. Workforce planning – devise and implement a workforce strategy in collaboration with the commissioners, providers and the higher education institutions.

Networks have received varying levels of political support over the past two decades, but if allocation of resources is to be moved closer to the patient then the roles of networks should be supported as they offer the potential to increase user and practitioner engagement and move decision-making closer to children and families.

A network delivered programme of care should include all the component parts required to achieve quality improvement, including intra-network resource allocation, workforce planning and service reconfiguration. The overall approach should encompass the total (pooled) budgets across participating agencies and the use of a programme budgeting and marginal analysis (PBMA)⁹⁴ approach, which is expanded in appendix 5 to aid decision-making about the distribution of resources should be explored further.

This PBMA approach has been successfully applied in a number of countries, particularly Canada,⁹⁵ has been implemented in the UK⁹⁶ but with limited application relating to services for children and families.⁹⁷ Two major benefits are the engagement and positive experience of clinicians and the transparency about costs and cost effectiveness that the process brings.

⁸⁹ http://www.sehd.scot.nhs.uk/mels/1999_10.htm

⁹⁰ http://www.sehd.scot.nhs.uk/mels/CEL2012_29.pdf

⁹¹ http://www.rcpch.ac.uk/sites/default/files/asset_library/Health%20Services/Managed%20Networks.pdf

⁹² [http://www.smn.scot.nhs.uk/documents/nhs%20scotland%20-%20mcns%20-%20a%20guide%20to%20implementation\[1\].pdf](http://www.smn.scot.nhs.uk/documents/nhs%20scotland%20-%20mcns%20-%20a%20guide%20to%20implementation[1].pdf)

⁹³ http://www.rcpch.ac.uk/system/files/protected/page/Bringing%20Networks%20to%20Life%20for%20web_0.pdf

⁹⁴ <http://www.medicine.ox.ac.uk/bandolier/painres/download/whatis/pbma.pdf>

⁹⁵ <http://www.nhlc-cnls.ca/assets/Mitton%20Presentation.pdf>

⁹⁶ www.yhpho.org.uk/resource/view.aspx?RID=10049

⁹⁷ <http://www.yhpho.org.uk/resource/item.aspx?RID=10048>

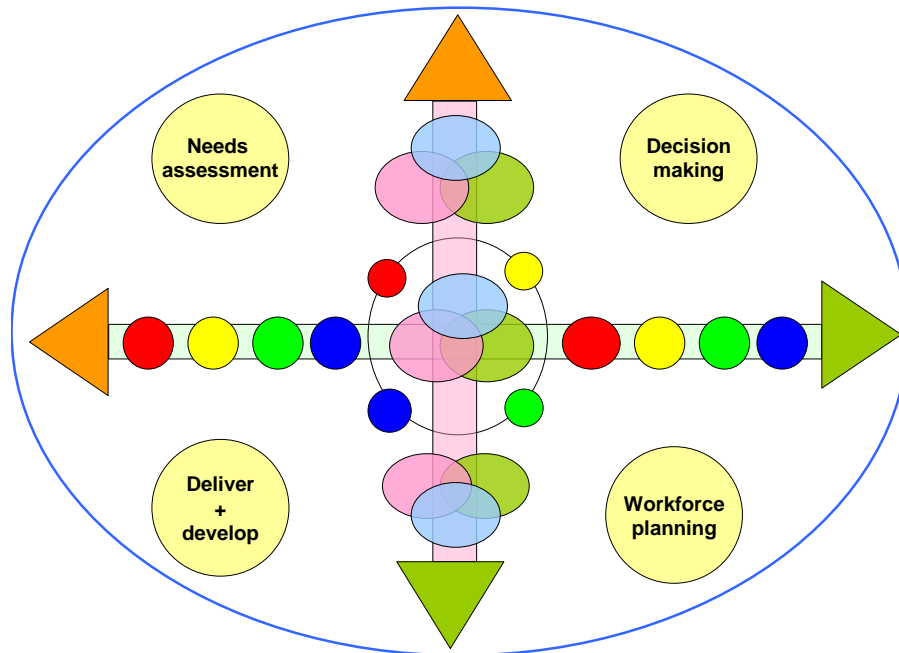


Figure 9: illustrating the overlap between service (horizontal) and life-course (vertical) pathways and the primary functions of networks.

There is virtually no discussion in the literature about the boundaries between the planning and commissioning process and network management process, but there would be benefits for planners and commissioners to concentrate on overall resource allocation and for network management to determine the more detailed allocation of resources within the network. This would enable a practical programme budgeting approach to be embedded within service delivery.

Whole systems

A whole health system would bring together several different networks and the life course pathway approach together into a comprehensive system which should meet the needs of the whole population (see figure 10). The broad programmes are summarised below and included in figure 10 and approximately map to modules of the English Maternity and Children's National Service Framework^{98, 99, 100, 101} and the Children and Young People's Health Outcome Forum Strategy.¹⁰²

- i. Promote the optimal development and determinants/lifestyles of all children - the **universal public health/life course programme**.
- ii. Reduce illness and injuries and their consequences - the **urgent, emergency and intensive care programme**.
- iii. Reduce long term conditions, disability and consequences of disability - the **long-term conditions programme**.
- iv. Reduce social ill health, inequalities and their consequences - **the vulnerable child and family programme**.
- v. Reduce emotional and behavioural disturbance and their consequences - the **child mental health programme**.
- vi. Improve maternity care and the outcome for new-born babies - the **pregnancy and new-born programme**.

⁹⁸ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4090552.pdf

⁹⁹ <https://www.gov.uk/government/publications/national-service-framework-children-young-people-and-maternity-services>

¹⁰⁰ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199952/National_Service_Framework_for_Children_Young_People_and_Maternity_Services_-_Core_Standards.pdf

¹⁰¹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216852/CYP-report.pdf

¹⁰² <http://www.dh.gov.uk/health/files/2012/07/CYP-report.pdf>

Where multiple networks come together to create a whole system of care for a community the “culture” within that system should be expressed consistently throughout each network. In truly effective systems there should be absolute clarity about:

1. the **purpose** of the system, the beneficiaries and the expected outcomes,
2. the operational **values** that determine the culture and how the system works,
3. **leadership** –based on integrity, accountability, transparency and inclusivity,
4. capacity to adapt and **learn** as conditions, circumstances or evidence changes.

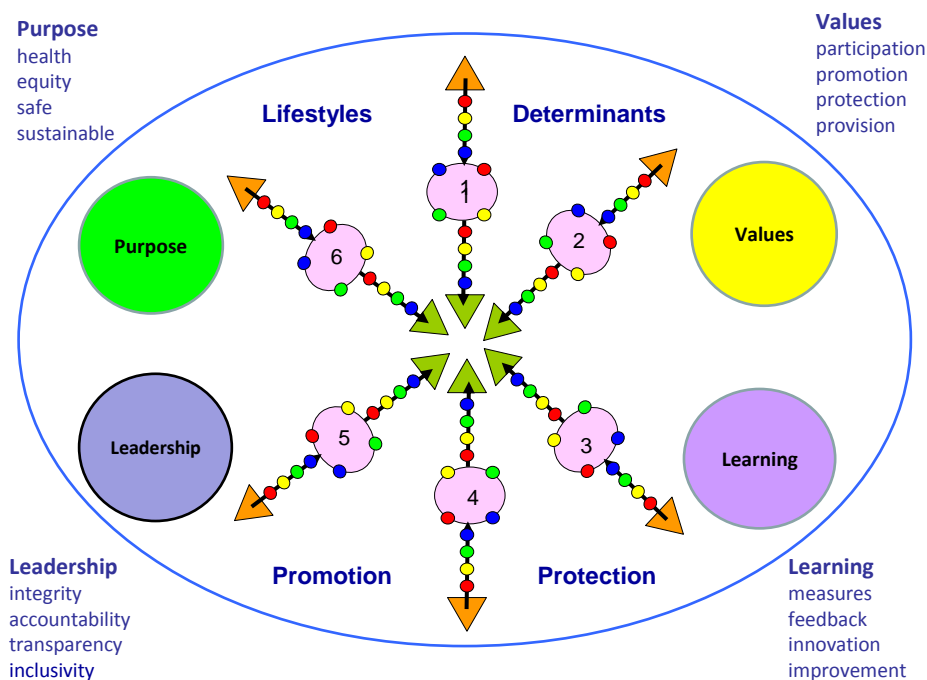


Figure 10: a representation of the Family Friendly Framework of the whole system including six networks and integrating values, purpose, leadership and learning.

The **purpose** of the system is best represented by the expected outcomes.¹⁰³ High-level outcomes would be improvements in health (in the widest sense), reduction in inequalities and in outcomes that represent sustainability (best long term use of resources). Specific service related outcomes would then consider effectiveness, efficiency and equity with additional measures of "added value" across the whole network.

Values are important in any system because they guide how the system works and ‘hold’ the parts together.¹⁰⁴ In systems dynamics they are the “simple rules” which guide how complex systems develop. Child Friendly Health Care,^{105,106} has distilled the United Nations Convention on the Rights of the Child.¹⁰⁷ values *that relate to services* down to following four principles that have practical application at throughout the system:

1. participation of users (in individual decision-making, in service improvement and in policy-setting);
2. protection from harm,
3. promotion of wellbeing
4. provision based on pathways (to ensure all parts are in place and working well together).

¹⁰³ <http://www.dh.gov.uk/health/files/2012/07/CYP-report.pdf>

¹⁰⁴ http://www.bacch.org.uk/policy/documents/IntegrationBACCHpositionssummary_final.pdf

¹⁰⁵ <https://wcd.coe.int/ViewDoc.jsp?id=1836421&Site=COE>

¹⁰⁶ http://www.rcn.org.uk/_data/assets/pdf_file/0003/424677/CM2011113_E_CFH_guidelines_ExM.pdf

¹⁰⁷ <http://www2.ohchr.org/english/law/crc.htm>

Participation at all levels is important because it gives the users of services a voice and influence within the system. This has often been overlooked in the past, but is now gaining increased credibility¹⁰⁸ particularly now there is a greater focus on improving the experience of services for families.¹⁰⁹ Participation should also be viewed as an integral part of service improvement and priority setting at a policy level.

Leadership. Leadership within any system is essential, it may be invested in an individual or team and should operate throughout the whole system, based on integrity, clear lines of accountability, transparency of decision-making with inclusivity - meaning active participation of both users and providers throughout the system.¹¹⁰

Learning. Finally, if a system is to be sustainable, it must be able to innovate, adapt and learn as knowledge, circumstances or evidence changes. The implication is that there should be a relentless drive for continuous quality improvement judged by concepts such as safety, experience and outcomes.¹¹¹ This process must be 'internal' and embraced throughout the system, rather than being the result of external inspection or regulation. Logically it would be the primary purpose of networked teams – seeking out and improving the weakest links in pathways. This will require much better cycles of measurement, feedback, reflection, innovation and evaluation if the system is to incrementally improve over time.¹¹²

Benefits of the Family Friendly Framework

There are many potential benefits of adopting a shared multi-stakeholder partnership approach to the planning, delivery and improvement of services for children and families. The immediate benefits are the reduction in duplication or omission of components in the pathway by various providers. In the medium term the approach should enable earlier adoption of new knowledge and improve the coordination and continuity of care. In the longer term the emphasis will be on sustainability and adding value through an incremental process of disinvestment in less effective and investment in more effective care coupled with continuous learning based on innovation and evaluation.

Families

- Improved experience and outcomes with
- more timely care, closer to home.
- A more integrated approach offering better coordination and continuity of services.
- Greater participation at every level.

Clinicians

- A method of getting consistent evidence into practice through the use of agreed guidelines, algorithms and protocols across the network.
- Investment in inter-professional training and better support by improved learning through improvement.
- Increased skill mix within multidisciplinary teams, coupled with staff rotations within the network.
- Greater involvement in decision-making and the allocation of resources across the network.

Managers

- Reduced costs through greater integration achieved by breaking down silo working.
- A shift from a short-term focus on efficiency, to a longer-term (whole-life) focus on effectiveness and equity (the added value agenda).

¹⁰⁸ <http://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf>

¹⁰⁹ <http://www.rcpch.ac.uk/participation>

¹¹⁰ <http://www.leadershipacademy.nhs.uk/discover/leadership-dimensions/>

¹¹¹ <http://www.iom.edu/~media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf>

¹¹² http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/pla_n_do_study_act.html

- A framework for continuous service improvement.
- Greater involvement of clinicians and families in decision-making, delivery and improvement.

Planners and commissioners

- Brings multiple planners and commissioners together with shared thinking/values/models and a culture of collaboration rather than competition.
- Less fragmentation, duplication or omission and therefore better value for money across the network.
- Clearer lines of responsibility and accountability.
- A framework for partnership working.

Informatics for improvement

Throughout the Family Friendly Framework there is a focus on learning within complex adaptive systems to improve safety, improve experience and achieve better outcomes. Knowing how well services are working is the first step on the road to improvement. This requires the development of measures that have meaning, matter to stakeholders, have the potential to first motivate and then monitor change, but this has to be a proportionate process, in the sense of the added value of measurement being greater than the burden of collection, analysis and presentation of data. BACCH intends to develop a framework based on the Family Friendly Framework for consultation in the near future based on the structure illustrated in figure 11 below.

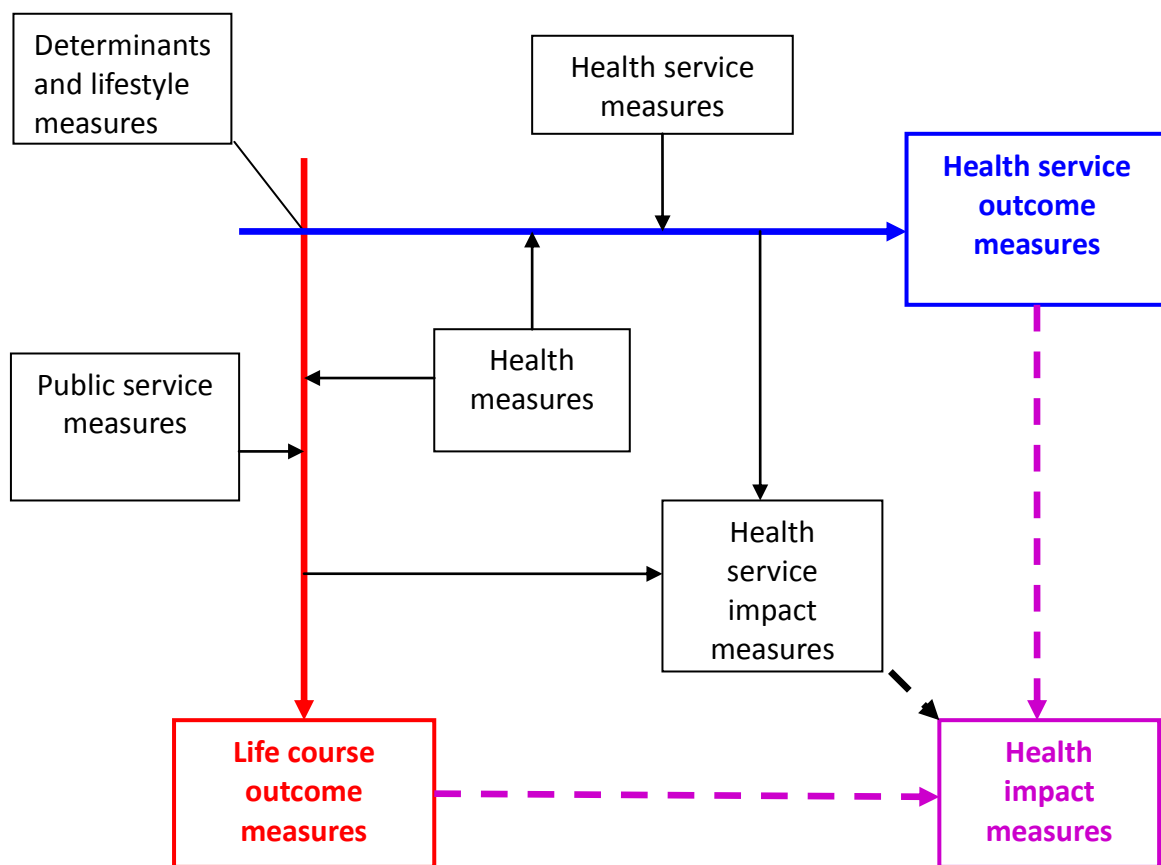


Figure 11: illustrating the framework for measures to support informatics for improvement

Implications of adopting the Family Friendly Framework

The implications of adopting the Family Friendly Framework by planners and commissioners, providers and regulators should not be underestimated, as it potentially has a profound impact on current structures and functions. Largely the approach is intended to create alignment and synergy between all of the parts, to enable resources to be used wisely, outcomes to be achieved and the best possible care for children and families.

At an operational level a network of related teams and organisations should be developed working together to create the best possible service, based on a pathway approach, linking measurement, improvement and learning to create whole system value, by using invested resources wisely.

The concept of networks has gained popularity within the NHS in England recently with the development of:

- clinical senates
- strategic clinical networks
- operational delivery networks
- local professional networks
- academic health science networks
- research networks and
- workforce planning networks.

More recently the Kings Fund has proposed 'family care networks' to improve the commissioning and provision of primary care.¹¹³ What is not yet clear is the accountability and crosscutting communication arrangements between these various networks and how the output of one network informs the work of other networks. For example, if the local professional network recognises the need for a piece of research, possibly on the skill mix required to deliver the service, how does the outcome of this research influence workforce planning?

The development and delivery of a networked team requires the relevant commissioners to jointly commission services with clarity relating to needs assessment, allocation of resources and expected outcomes. Capitated and Outcome-Based Incentivised Contract (COBIC) type approaches or service line management/reporting (SLR/SLM)¹¹⁴ should be evaluated where there is a clearly defined and cost-able pathway of care.¹¹⁵ Clearly there is potentially a large overlap between some planning and commissioning roles and responsibilities of a mature network. In order to create a greater professional leadership and user participation in the new system it would appear sensible to devolve some traditional planning and commissioning functions to the network and bring decision-making closer to the front line of service delivery. The concept of Accountable Care Organisations (ACOs) is relevant, where a group of providers come together to provide whole pathway, integrated care for a defined group of patients¹¹⁶ should be researched further.

The success of networks will be determined by how well they reduce duplications or omissions in provision, rectify the perverse incentives that exist in current systems and enable local decision-making to increase the overall value of integrated provision. The Buurtzorg (meaning neighbourhood care) experience in the Netherlands demonstrates how the fragmentation between different providers can be reduced and overall value improved.¹¹⁷

To support this approach, regulators will need to inspect whole pathways and networks instead of individual organisations involved with delivery. Regulation of the commissioning process and assessment of network capacity to innovate and learn must also be included within the inspection and improvement of a network.

¹¹³ http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/commissioning-and-funding-general-practice-kingsfund-feb13.pdf

¹¹⁴ <http://www.kingsfund.org.uk/sites/files/kf/service-line-management-quality-efficiency-kings-fund-january2011.pdf>

¹¹⁵ www.changemodel.nhs.uk/dl/cv_content/65254

¹¹⁶ http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/accountable-care-organisations-united-states-england-shortell-mar14.pdf

¹¹⁷ <http://www.ncbi.nlm.nih.gov/pubmed/24400466>

The implications for families will be greater participation both in decisions that affect their own health, in effect increasing co-production of health, and, greater participation in the service improvement and resource allocation decisions at a local level. The challenge will be to engage and enable families who are least well off in society to contribute to reducing inequities in health outcomes.

Planners and commissioners

- Combined approaches across all planners and commissioners of services relevant to children and families including health, education, social care and criminal justice systems to create an integrated whole system.
- Devolving some current planning and commissioning functions regarding allocation of resources to mature managed networks.
- Financing systems that enable resources to follow patients through pathways and networks and the introduction of programme budgeting based on pathway tariffs.
- Integrating public health approaches to prevention across all pathways.

Providers

- The development of standards, measures and audit within managed networks with a relentless focus on quality improvement.
- All provider organisations sharing the same knowledge base and approach to implementation of evidence-based guidelines and training of practitioners.
- Shared quality improvement approach across organisations based on pathways and networks.
- Workforce planning based on the right skill mix to ensure competent teams working within networks.

Regulators

- Basing regulation on pathways and networks to ensure overall value for money based on effectiveness, efficiency and equity.
- Greater emphasis on both equity of access and equity of outcomes.
- Bringing together quality and economic regulators across different agencies, using a shared approach for measurement and improvement to achieve a greater impact.
- A greater focus on embedding system learning and sharing successful improvement.

Families

- Co-production of health between families and providers of services.
- Greater participation in decision-making at all levels within the system.
- Greater involvement of family support organisations in the development of pathways, standards, measures and improvement.
- More participation enabling greater resilience children and their families particularly for those living in disadvantaged circumstances.

Summing up

This paper is written at a time of turmoil within public services, forced by market forces, increasing privatisation and austerity measures. The core thinking is based both on the values contained within United Nations Convention on the Rights of the Child coupled with the best available evidence. It has combined a “whole system approach”, because the health and well-being of children cannot be seen in isolation from the health of families and the wider community. Improvement based on learning within these systems must be embedded within the professional and organisational cultures at all levels. The intention is to embed best practice into present and future organisational structures rather than suggest structures which will depend on local circumstances and the stage of development of services.

The Family Friendly Framework approach is therefore intended to be adopted and adapted locally in order to improve the quality of services to children and families across all agencies, not just within the health service, as the underlying principles are universal. Suggestions are included in appendix 7.

In times of austerity it is increasingly important that planners and commissioners, providers and regulators; public, private and community sectors; families, practitioners and community members, all work together to align services, lifestyles and determinants so that this generation of children and young people take their health benefits into their future.

The evolution of the current planning and commissioning process has been briefly described and the application of the Family Friendly Framework and its relevance in the planning process, particularly in creating partnerships, designing pathways and developing networks, has been illustrated using examples. The intention is to develop further examples for reference purposes which will be hosted on the BACCH website.

BACCH, BACAPH and the affiliated groups intend to develop further papers - the next being “informatics for improvement” to support on-going learning within the system and so the development of better services for children, young people and their families and showcase examples of good practice.

It is hoped that through consistent application of the principles within the Family Friendly Framework can overcome the relentless application of free market principles which are driving the short term focus on efficiency rather than the long term focus on value and sustainability.

We would welcome criticism, suggestions and examples based on your discussion and practical experience of using the Family Friendly Framework.

www.BACCH.org.uk
www.BACAPH.org.uk

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Appendix 1: values developed by the Children and Young People’s Inter-Agency Group (CIAG)

Members of the Children and Young People’s Inter-Agency Group (CIAG)¹¹⁸ endorsed the UN Convention on the Rights of the Child and share the following values in relation to working with children and young people.

Respect We respect the equality, dignity and personal integrity of every child and young person in society.

Responsibility While children and young people learn about and grow in personal responsibility, adults must take overall responsibility, both collectively and individually, for the safety and well-being of all children and young people in our society.

Voice The perspectives and views of children and young people should be sought and listened to, and given increasing weight in policies and decisions about them as they grow older.

Collaboration All organisations should work collaboratively across boundaries to achieve the best outcomes for each child, young person and family they serve.

Whole-system approaches Children and young people have the right to services that work together to prevent problems occurring, that intervene early to prevent problems from escalating and that achieve the best long-term outcomes.

Continuous improvement Services should learn together to implement best practice based on evidence, and create systems of improvement concentrated on changing the weakest points in the system.

Appendix 2: values developed by European Union to protect the rights of children

The European Union (EU) Treaty of Lisbon,¹¹⁹ supported by the Council of Europe, introduces the protection of children’s rights among the EU’s objectives for internal and external policies, supporting the idea that EU laws and policies are child proofed and contributing to promoting children’s rights and interests so that children and young people should:

- have parents who love, protect and care for them,
- enjoy the best possible health,
- be heard, treated with respect and have their views taken into account,
- be able to access to play, leisure, sporting and cultural activities,
- have a comprehensive range of education and learning opportunities,
- be free from abuse, victimisation and exploitation,
- have their race and cultural identity recognised,
- live in safe homes and in safe communities which support their physical and emotional wellbeing,
- not be disadvantaged by poverty.

¹¹⁸ http://www.ncvys.org.uk/UserFiles/Policy/CIAG_ServingChildrenAndYoungPeopleBetter_Oct09.pdf

¹¹⁹ http://europa.eu/lisbon_treaty/full_text/index_en.htm

Appendix 3: understanding protection/promotion and pathogenesis/salutogenesis.

Pathogenesis. When studying the aetiology and pathogenesis of a disease or condition the generic public health approach is to consider the factors that contribute to the development of a condition may relate to the individual, for example a pre-existing problem, age or other vulnerability. The agent is the factor that causes the condition, it may be an infective, toxic, or a form of energy. The development of the condition may then be aggravated by the environment for example poverty, access to services, or social issues such as racism.

This public health approach examines both of the *frequency of exposure* to the hazard and estimates then *likelihood of harm* as a result of exposure. In health we combine both *frequency and likelihood* of harm into the generic term "risk". Having understood the hazard, exposure and likelihood of harm, control measures are then put in place to prevent future harm. The stages are set out below.

- a) first identify the hazard (hazard = potential to cause harm)
- b) then assess the frequency of exposure (frequency = probability of encountering the hazard)
- c) then estimate the likelihood of harm (likelihood = probability of harm as a result of contact with the hazard)
- d) then plan control measures - (based on evidence of effectiveness) and
- e) finally evaluate/monitor and feedback the impact of control

This approach is the foundation of health protection programmes.

Salutogenesis is the opposite of pathogenesis it studies the assets in a persons life estimates the probability of exposure and likelihood of benefit. This approach is the foundation of health promotion programmes.

Appendix 4: the functions of a managed network

- Contributing to needs assessment, using the Joint Strategic Needs Assessment (JSNA) as a starting point.
- Understanding spending – the network will create an accurate budget for the different elements within the programme.
- Creating value for money – the different elements of spend will be subject to analysis to determine relative value for money, using key indicators such as productivity and cost-benefit analysis.
- Measurement for improvement – the network will develop measures to monitor equity, safety, experience and outcomes.
- Prioritisation – service developments will be prioritised in line with the local ethical framework and prioritisation criteria. The network will recommend internal priorities for investment and disinvestment.
- Service planning – will be undertaken in line with the commissioning specification for services for Children and Young People and their Families (CYP&F).
- Clarifying the interfaces between agencies and between services to children and services that adults.
- Care pathways – the network will oversee a process of agreeing, adopting and improving condition specific pathways.
- Clinical standards – the network will agree relevant standards which will be updated depending on new knowledge and the priorities within the network.
- Learning and quality improvement – the network will undertake quality improvement which will be based on an analysis of variation in performance at all levels.
- Workforce planning – the network will devise and implement a workforce strategy in collaboration with the providers and the higher education providers.
- User and public participation is paramount and should be secured at every possible level.

Appendix 5: Programme Budgeting and Marginal Analysis

The starting point is an appraisal of the current distribution of resources between different services or different parts of the care pathway for specific conditions with a view to improving future resource allocation in those same programmes. Marginal analysis is the analysis of the added benefits and added costs of a proposed investment (or the lost benefits and lower costs of a proposed disinvestment) within the programme. Marginal analysis then looks at the effect of incremental changes to the way in which resources could be allocated in order to gain the most health benefit (the impact). Marginal analysis is based on three basic economic principles:

1. resources are scarce relative to need, which means that choices have to be made.
2. decisions on where to allocate resources (priorities) should be made on the basis of explicit criteria. One criterion is efficiency, which is about maximising the benefit from available resources.
3. allocating resources to one service means that this resource is not available for other services. The benefit that the resources might have produced in another service is an opportunity cost.

These economic principles underpin the health economic framework for priority-setting. Practically the use of this framework revolves around five questions about the use of resources:

- i. What resources are available?
- i. How are these resources currently allocated?
- ii. Who are the main candidates for more resources and what is their cost-effectiveness?
- iii. Are there any areas of care which could be provided more efficiently, so releasing resources for investment elsewhere? (Technical efficiency)
- iv. Are there any areas of care which, despite being effective, should receive fewer resources because a proposal from (iii) is more cost-effective? (Allocative efficiency)

Appendix 6: a specification framework.

| | |
|--------------------------|--|
| Network | |
| Services included | |
| Lead Commissioner | |
| Lead Provider | |
| Period | |
| Date for Review | |

| | |
|---|---|
| Concerns/conditions/disease groups covered by the network. | |
| Population Needs | <ul style="list-style-type: none"> • Incidence and prevalence of each major condition/disease group (from JSNA) • Population covered |
| Current service provision | <ul style="list-style-type: none"> • Description • Positives • Negatives • Expenditure |
| National/local context | <ul style="list-style-type: none"> • Political • Practical |
| Evidence base | <ul style="list-style-type: none"> • Quantitative • Qualitative • Econometric |
| Statutory responsibilities | |
| Scope | <ul style="list-style-type: none"> • Aims and objectives of service • Service description • Pathways included • Referral thresholds/routes/exclusions • Any acceptance and exclusion criteria • Interdependencies with other services/networks • Recognition of problematic areas/areas of high risk |
| Pathway description | <ul style="list-style-type: none"> • Life course components • Initial pathway • Review pathway • Transition pathway • Child-condition and impact • Family-consequences and lifestyles • Community-interventions and determinants |
| Applicable Service Standards | <ul style="list-style-type: none"> • Applicable national standards e.g.: NICE, Royal College • Applicable local standards |
| Outcomes | <ul style="list-style-type: none"> • Measures |
| Key service measures | <ul style="list-style-type: none"> • QI measures derived from the standards - both the process and outcome with an emphasis on "indicators for improvement" |
| Providers involved | |

| |
|--|
| <ul style="list-style-type: none"> • Health services - primary, secondary, tertiary • Local Authority • Social enterprise/community interest • Private sector |
| Responsibilities of provider organisations |
| Network development priorities |
| Priorities for service improvement <ul style="list-style-type: none"> • Safety • Experience • Outcomes • Value for money |
| Workforce development plan <ul style="list-style-type: none"> • Recruitment • Retraining and development • Retention |
| Research priorities <ul style="list-style-type: none"> • Health services research • Research currently undertaken that is likely to influence practice in the next 10 years • Skill-mix and training |
| Future proofing <ul style="list-style-type: none"> • Horizon scanning for likely future developments |
| Sustainable development-impact of service delivery <ul style="list-style-type: none"> • Use of natural resources • Social impact • Environmental impact |

Appendix 7: Suggestions for using the Family Friendly Framework

1. A framework for local contract negotiations between commissioners and providers.
2. Improving pathway organisation between providers.
3. To aid network development and performance.
4. Engagement with patient groups/representatives.
5. A starting point for improvement initiatives, for example, children and young people's participation.
6. A framework for reducing demand/need through a focus on prevention throughout the pathway.
7. A framework for engaging stakeholders in investment/disinvestment strategies, ideally linked to PBMA.

