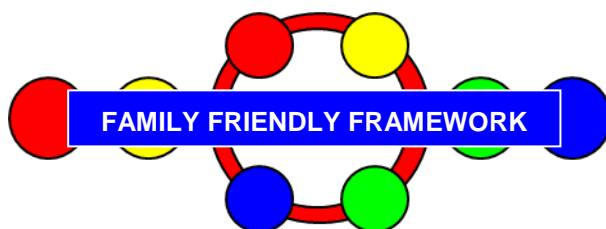




Introducing the "Family Friendly Framework"



**A whole systems approach to improve
the planning and commissioning of services
for children and families**

A discussion document for consultation

November 2012

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 working practices of all those working with children and their families;
- Encouraging greater 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

Please feel free to download and adapt for local use:

the Family Friendly Framework (for colour printers),

the Family Friendly Framework (for mono printers),

a PowerPoint presentation for the Family Friendly Framework,

frequently asked questions (FAQs) for the Family Friendly Framework,

consultation questionnaire (<https://www.surveymonkey.com/s/88G23SK>).

Please reference this document to BACCH when adapting it locally

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Executive summary – key points

This paper is for discussion and consultation with interested stakeholders. The intention is to try and improve the quality of planning and commissioning, delivery and regulation of services in order to achieve better outcomes for children and families through the adoption of a "family friendly framework".

In times of austerity and major systems reform, it is 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 social determinants to create a synergy to improve the health of this generation of children and young people, who in turn will take their health and well-being into adulthood to the future benefit of the next generation. This should help reduce future costs to public services.

The "family friendly framework" is based on the WHO systems approach, which combines values and evidence into a practical model, based on pathways, that guarantees that all the parts are in place and working well, in order to achieve better experience and outcomes for children and their families. It is not intended to be prescriptive, rather it is a framework which can be adopted and adapted depending on local circumstances.

The approach is applicable to all planners and commissioners, professional groups and agencies who work with children and families as the fundamental concepts are based on the values contained within the UN Convention on the Rights of the Child.

The family friendly framework proposes that:

- Overall the system must be clear about its purpose, be based on a framework of values, adopt evidence-based approaches to decision-making and have the capacity to continuously learn and improve.
- The overall purpose of services is to improve health, reduce inequities and to be sustainable.
- The values are based on the UN Convention on the Rights of the Child emphasising prevention through protection and promotion, participation and partnership at all levels and through the provision of high quality services based on pathways.
- Whole system improvement requires a system to detect and rectify problems, the ability to implement new knowledge as it becomes available and maintain system and individual competence through a process of continuous learning.
- To achieve good experience and outcomes for children, services should be designed around the needs of families.
- The simplest 'unit of service delivery' is the *journey* that an individual child and their family take through services. This may be a life course pathway, using universal services, or a condition-related service pathway when there are concerns or problems. The focus is on creating a partnership between practitioners and families and better communication between all involved.
- *Pathways* are 'units of service delivery' for similar concerns/conditions, for example, asthma, ASD or maltreatment. The generic parts of the pathway include prevention, recognition, assessment and interventions. The focus is on getting evidence into practice, bringing the component parts of the pathway together and strengthening the teams that deliver the care.
- *Networks* are 'units of service delivery' for a range of similar concerns/conditions, for example, cardiac conditions, safeguarding or disability. The focus is on integrating the organisations that host the teams, which deliver the component parts of the pathway, coupled with measurement that identifies the weakest links in the pathway across the network.

- At every level there has to be greater attention to the "prevention agenda" whether it be preventing problems, ameliorating their effects or reducing disability or disadvantage.
- The ethos at every level is to strive for improvement driven by innovation, evaluation and continuous learning.
- Long-term condition pathways generally have three phases - an initial phase (the development of the condition), a review phase (living with the condition) and a transition phase (either back to normality, on to adult services, or into end of life services).
- Each phase generally replicates the four component parts of prevention, recognition, assessment and also interventions, with a focus on health promotion and protection at every phase in order to reduce unnecessary future morbidity or mortality.
- Each component is based on best evidence, delivered by a competent team, with the right skill-mix and delivered as close to home as is safe and sustainable.
- These teams should be supported by administrative systems (or example information technology), clinical support systems (for example investigations) and quality improvement systems.
- Each component of the pathway is assigned to a provider who is best able to deliver that element with service level agreements that include standards, performance measures, resources available and the improvements expected.
- Groups of providers, teams and organisations should then work together within a managed network to ensure that resources are used effectively, families experience a seamless service and outcomes are equitable.
- The *whole system* requires collaboration between planners and commissioners, providers from all agencies and regulators - this requires an active partnership based on cooperation rather than competition between the various stakeholders.
- Consideration should be given to devolving more resource allocation decisions to managed networks that deliver programmes of care – so bringing decision-making closer to families and empowering practitioners.

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 future negative social or environmental impacts.

Purpose

The purpose of this paper is to:

- Promote a practical approach, called the "family friendly framework", to enable the delivery of high quality, safe services that improve both outcomes and equity for children and families.
- Propose the development of collaborative and integrated provider networks, which offer stability within the system in times of change and also bring decisions about the allocation of resources closer to and involving patients.
- Encourage a focus on quality and safety through continuous innovation and learning as an integral part of service delivery, through better measurement, feedback and resultant action.

Introduction

Recent changes across the UK, including recession, unemployment, austerity measures, changes to benefits,¹ could potentially contribute to making services for children and families more fragmented in the future². In England, the recent NHS reforms³ and changes in the public health landscape⁴ have brought considerable challenges to service delivery for children. However the simultaneous reconfiguration of planning and commissioning, provision and regulation in England may offer an opportunity to create a model of an integrated approach towards planning, delivery and improvement of services. Such a model is already implemented or under way in Scotland, Wales and Northern Ireland via targeted work in their respective Programmes for Government.

This paper uses the UK wide experience of changes in planning and commissioning children's services as an opportunity to review how the process is undertaken and makes proposals, for discussion with interested stakeholders, aimed at changing thinking and practice. The intention is to generate models that offers alignment and synergy between planners and commissioners, ultimately to achieve the common goal of improving the health and well-being for all infants, children, young people and their families in the UK.

The origins of the family friendly framework arise from a Council of Europe strategy entitled "child friendly health care" which has been endorsed by health ministers representing 47 nations of Europe in 2011, including the UK⁵. It is based on systems thinking, 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, in order to achieve better continuity and outcomes, through a process of learning through continuous innovation.

This paper therefore:

- Considers the current context of services for children and families in the UK
- Proposes a structure for the family friendly framework
- Considers its application primarily for the planning and commissioning process
- Outlines the benefits of this approach and
- Discusses the implications for planners and commissioners, providers and regulators of adopting this approach

¹ http://www.familyandparenting.org/Resources/FPI/Documents/FPI_IFS_Austerity_Jan_2012.pdf

² <http://www.childrenengland.org.uk/upload/Perfect%20Storms%20-%20FINAL.pdf>

³ <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

⁴ <http://www.dh.gov.uk/health/2011/12/public-health-factsheets/>

⁵ http://www.rcn.org.uk/_data/assets/pdf_file/0003/424677/CM2011113_E_CFH_guidelines_ExM.pdf

It is a starting point for discussion and consultation with professional organisations and other interested stakeholders. It is proposed to create further iterations in the future based on feedback and experience over time and reflecting the diversity of political, economic and social drivers of different parts of the UK. BACCH is a UK organisation so this paper does not address detailed roles and responsibilities of organisations (such as, the new English structures following the Health and Social Care Act 2012), but it recognises that whatever national structures exist they should have a shared approach to planning in order to ensure coordination between the various parts of the system. It is hoped that this paper will offer models to facilitate discussion between bodies to create more "family friendly" services and better outcomes in future.

The current context of services for children and families

Political

Europe has entered a period of economic austerity and while health services in the UK have initially been protected in comparison to other public services, future governmental budgetary decisions along with demographic changes, new knowledge and innovations present major challenges to the resources available. Estimates vary, but a 20% reduction of budgets over a five-year period, is predicted in England⁶. The aspiration to maintain and achieve better quality of care is challenging in this context.

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

It is clearly vital that the allocation of resources through the planning and commissioning process and those services for children and families specifically, should be undertaken in ways that are competent, collaborative and coherent making best use of *all* the available resources to "add value"⁷.

England

The passage of the Health and Social Care Act (April 2012), in England, signals the largest transformation within the NHS since its inception and while the primary legislation has been passed, much secondary legislation has still to be written. Regardless of the legislation, successful implementation will depend on taking a very practical approach by all involved, especially during the period 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 The Nuffield Trust⁸ and The Kings Fund⁹ about how this can be achieved in a system based on competition rather than collaboration¹⁰. At the time of writing (November 2012) it appears that there will be a minimum of six commissioning bodies relating to children and families, in England, including the National NHS Commissioning Board, Offices of the NHS Commissioning Board, Public Health England, 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 the pupils, coupled with parents in receipt of Direct Payments or Personal Budgets commissioning services for their own use. Having said this, the bulk of children's services

⁶ National Audit Office. Delivering efficiency savings in the NHS. Briefing for the House Commons Health Committee September 2011

⁷ <http://globalhealthdelivery.org/2012/05/value-based-health-care-delivery/>

⁸ <http://www.nuffieldtrust.org.uk/publications>

⁹ <http://www.kingsfund.org.uk/publications/>

¹⁰ http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/event_report_competition_integration_jan12.pdf

will be commissioned between the NHS Commissioning Board, Clinical Commissioning Groups, Local Authorities and Public Health.

This set of complex changes is likely to cause instability within the system and while "integration" is a favoured term in relationship to providers; 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 the "glue" that creates cohesion between different organisations, future success will depend upon sharing the same approach, values, thinking, outcomes and models of service delivery as an essential prerequisite for effective joint working.

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'¹¹ supported by the Early Years Collaborative¹² Reform is planned for adult Health and Social Care by a Bill within the next year but the implications for services for children and families are still awaited. However, there is also an anticipated Children's Bill which seeks to strengthen government action relating to the UN Convention on the Rights of the Child.

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 and social care services, and education are fully devolved to the Welsh Assembly Government. . Wales has enshrined the UNCRC in domestic legislation with the Rights of Children and Young people Measure 2011¹³, with a clear Welsh Government statement of '7 core aims for children' supported by 'Flying Start'¹⁴, 'Families First'¹⁵ and 'Communities First'¹⁶ programmes to address poverty, inequity and poor health outcomes via initiatives focused on children within families and communities.

Northern Ireland

Northern Ireland has its own legislative framework and therefore the Health and Social Care Act 2012 does not apply. While there is a single government department of Health, Social Care and Public Safety the planning and commissioning of services for children and families is fragmented across the five Health and Social Care Trusts, with no clear overriding strategy. This is being addressed through the 'Transforming Your Care' initiative¹⁷.

The outcome of the Children's Strategic Framework, that builds on the "Our Pledge"¹⁸, is awaited and it is hoped it will address the piecemeal approach that creates inequalities of service provision for children and families across the Province. Networks, where they exist, are the result of partnerships developed at practitioner level, rather than by commissioning or planning intentions.

¹¹ <http://www.scotland.gov.uk/Resource/Doc/238985/0065813.pdf>

¹² <http://www.scotland.gov.uk/Topics/People/Young-People/Early-Years-and-Family/early-years-collaborative>

¹³ <http://www.assemblywales.org/bus-home/bus-legislation/bus-leg-measures/business-legislation-measures-rightsofchildren.htm>

¹⁴ <http://wales.gov.uk/topics/childrenyoungpeople/parenting/help/flyingstart/?lang=en>

¹⁵ <http://wales.gov.uk/topics/childrenyoungpeople/publications/familiesfirst/?lang=en>

¹⁶ <http://wales.gov.uk/topics/housingandcommunity/regeneration/communitiesfirst/?lang=en>

¹⁷ <http://www.dhsspsni.gov.uk/index/tyc.htm>

¹⁸ http://www.delni.gov.uk/ten-year-strategy_1_.pdf

Given the relatively small childhood population, geographical isolation, it is essential to develop an integrated collaborative approach for delivery of pathways and networks across Northern Ireland. It is hoped that the proposals and approach in this FFF will be helpful to this process.

Epidemiological

Morbidity and mortality in childhood is changing. No longer are acute illness and injury, particularly in the under fives, the dominant morbidities. However, public expectations are changing and data from across the UK suggests that parents are taking their children to hospital more often than before creating pressure on acute services. Long term conditions, increasingly in adolescents, are now the predominant concern.

These long-term conditions are often related to changes in lifestyles, for example, eating/nutrition/exercise creating an epidemic of obesity, or changes in family structures and societal expectations creating a huge increase in mental health problems. Couple this change with increased survival through better specialist and intensive care of previously fatal conditions means a generation of young people are now surviving into adulthood with long-term conditions and disabilities.

This changing epidemiology of conditions has also been associated with increasing inequalities in society and a divergence in outcomes, with those who are most vulnerable in society being the most disadvantaged and achieving poorer outcomes^{19, 20, 21}.

Services

Sir Ian Kennedy's latest review²² for the Department of Health in England has starkly outlined that services in the UK have not yet fully evolved to meet these emerging challenges or "new morbidities"^{23, 24} and there is evidence that the UK is lagging behind its European counterparts.²⁵ More recently the NHS Atlas of variations have demonstrated significant variations in service outcomes for children and young people²⁶. There are no simple, single solutions for improving outcomes; it requires partnership between all those involved and a whole system approach.²⁷ Enhanced training of GPs has been singled out by some as an important first step including the RCGP in its Child Health Strategy (2010).²⁸

For a family living with a child with a long-term condition - the best management of the condition requires a multiagency approach that can manage the condition, address the impact of the condition on everyday living for the child and the consequences for other family members. This paper builds on the "think family" approach which recognises the impact on childhood of adult health problems and does not separate planning and commissioning of children's services from services for their parents^{29,30}

¹⁹ <http://www.marmotreview.org>

²⁰ <http://webarchive.nationalarchives.gov.uk/20110120090128/http://povertyreview.independent.gov.uk>

²¹ <http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review>

²² http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119445

²³ <http://pediatrics.aappublications.org/content/108/5/1227.full>

²⁴ <http://www.gosh.nhs.uk/news/press-releases/2011-press-release-archive/new-child-mortality-and-morbidity-review-programme/>

²⁵ <http://www.bmj.com/content/342/bmj.d1277>

²⁶ <http://www.rightcare.nhs.uk/index.php/atlas/children-and-young-adults/>

²⁷ <http://www.rcpch.ac.uk/system/files/protected/page/MTFIIIIDec09.pdf>

²⁸ [http://www.rcgp.org.uk/clinical-and-research/clinical-](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)

resources/~media/Files/CIRC/Child%20and%20Adolescent%20Health/CIRC_RCGP_Child_Health_Strategy_2010_2015_FINAL.ashx

²⁹

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

³⁰

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

In turn, this "family friendly" approach requires synergistic working between different professional groups, organisations and agencies to create integration or 'seamless care' meaning better coordination and continuity of services from the perspective of the family, with the delivery of services as close to home as is safe and sustainable.

Throughout all services there must be a greater focus on prevention - either 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 to prevent harm from the care or interventions provided. Without this focus on prevention in childhood long-term morbidities will overwhelm adult services. Examples would include the link between poor language development – educational failure – antisocial behaviour as well as mental health problems and obesity which often have their origins in childhood. This emphasis is sometimes called 'a life course epidemiological approach'.^{31 32}

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 needs to be recognised that the allocation of resources in terms of investment and disinvestment also happens at a provider level and there should be alignment between the priorities of planners and commissioners and providers.

Those responsible for the commissioning process must recognise that:

- services for children and families are a high complex system with many interdependencies;
- year on year changes/improvements will be needed as demography and knowledge changes;
- resources are not unlimited and therefore a process to make decisions based on explicit priorities will be needed;
- any proposals must be sustainable within the resources available and take a long-term/whole life approach to investment.

Truly effective planning and commissioning that delivers best value for money requires a strong partnership between all planners and commissioners across the children and families sector, providers and regulators, greater participation of users, with a relentless focus on quality and safety, with learning through 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 this then results in fragmented services. As Don Berwick, paediatrician and CEO Institute for Healthcare Improvement, has said – "if you pay for pieces, you get pieces".

Unlike "simple" elective surgical services, children's services are more 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 to parents with learning difficulties, mental health problems, substance abuse or those experiencing domestic violence. Often the child's problems are a "symptom of family dysfunction" and effective support for these parents by adult services will have a profound impact on the health and well-being of their children. It is therefore difficult to disentangle planning and commissioning services for children from either commissioning services for parents or public health commissioning. A good example of an evidence-based initiative which meets both these goals is the Family Nurse Partnership which intervenes with high risk mothers in the antenatal period through to their child's second birthday.

³¹ <http://www.ncbi.nlm.nih.gov/pubmed/15760279>

³² <http://www.bristol.ac.uk/populationhealth/methodology/lifecourse/>

Planners and commissioners and providers therefore 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. Additionally they must consider the impact of those conditions not only on the child but also the consequences for their families, particularly when a long-term condition exists.

The family friendly framework addresses these challenges by creating a model of service delivery that is easily understood, that could be adopted by planners and commissioners, providers and regulators and adapted through a process of learning from innovation and quality improvement.

The Family Friendly Framework (FFF)

At the heart of the family friendly framework is 'whole systems thinking'³³. A system has been 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"*.

In truly effective systems there is absolute clarity about the:

1. **purpose** of the system, the beneficiaries and the expected outcomes.
2. operational **values** that determine how the system works
3. **evidence** to aid decision-making whether these are for individuals or populations and systems or policy decisions.
4. ability to adapt and **learn** as conditions, circumstances or evidence change.

The purpose of the system is best represented by the expected outcomes.³⁴ High-level outcomes would be improvements in health (in the widest sense), reduction in inequalities and in outcomes that represent sustainability. Specific service related outcomes would then consider effectiveness, efficiency and equity with additional measures of "added value" across the whole system.

Values are important in any system because they guide how the system works and 'hold' the parts together.³⁵ Values relating to people may be called a philosophy and values relating to provision may be called principles. *Examples are included in appendix 1 and 2.* These values can be used to inform either a constitution³⁶ or a charter for services³⁷

Child Friendly Health Care^{38, 39} has distilled the United Nations Convention on the Rights of the Child⁴⁰ principles *that relate to services* down to following three principles:

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

³³ <http://www.who.int/alliance-hpsr/resources/9789241563895/en/index.html>

³⁴ <http://www.dh.gov.uk/health/files/2012/07/CYP-report.pdf>

³⁵ http://www.bacch.org.uk/policy/documents/IntegrationBACCHpositionssummary_final.pdf

³⁶ <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/nhs-constitution-interactive-version-march-2012.pdf>

³⁷ http://www.togetherforshortlives.org.uk/families/information_for_families/2456_together_for_short_lives_charter

³⁸ <https://wcd.coe.int/ViewDoc.jsp?id=1836421&Site=COE>

³⁹ http://www.rcn.org.uk/_data/assets/pdf_file/0003/424677/CM2011113_E_CFH_guidelines_ExM.pdf

⁴⁰ <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 in the system. This has often been overlooked in the past, but is now gaining increased credibility now there is a greater focus on improving the experience of services for families.⁴¹

Prevention is essential at every level⁴² to reduce future morbidity either through primary prevention (preventing the condition), secondary prevention (preventing the complications of the condition), tertiary prevention (preventing the condition and its complications creating disability or disadvantage) and quaternary prevention (preventing interventions causing harm). Public health approaches include protection from hazards (anything that has the potential to cause harm); promotion (increasing exposure to assets/positives that improve health) and this twin approach can be applied to both lifestyles and determinants of health. This approach is illustrated in figure 1.

Planning and commissioning in the future has to ensure alignment and synergy between interventions to change lifestyles, community interventions to tackle the determinants of health support and improve the effectiveness of services managing conditions in children and families.

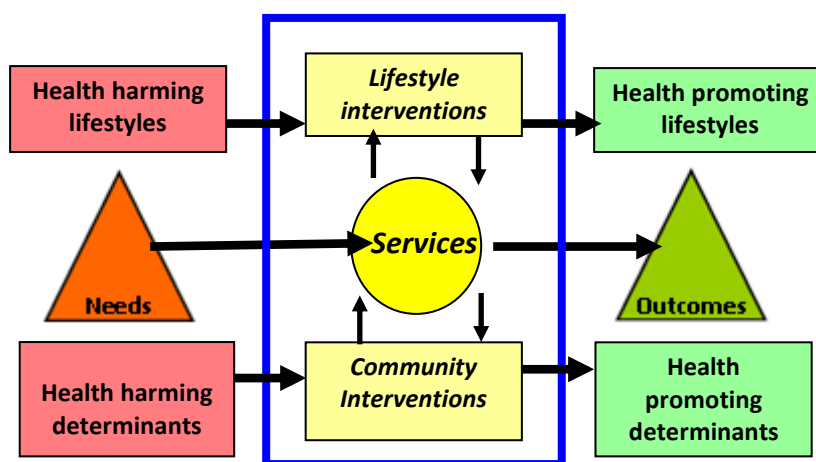


Figure 1: illustrating the alignment and synergy between interventions that change lifestyles and determinants with those services that meet the needs and improve outcomes.

The family friendly framework builds on both public health and children's social care concepts that recognise that children should not be seen in isolation from either their families or their social environment (communities). The needs of families are therefore represented by a triangle in figure 2, which illustrates this 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.

Provision based on pathways ensures that all the parts are in place to address the needs of the family and achieved the expected outcomes. Generally there are four component parts to a simple pathway which include prevention, recognition, assessment and access to a range of interventions. Each component part should be based on best evidence, delivered by a competent individuals working in teams, generally in convenient locations for families (presuming this is safe and sustainable)

⁴¹ <http://www.rcpch.ac.uk/participation>

⁴² http://www.nphp.gov.au/publications/language_of_prevention.pdf

These concepts can be represented diagrammatically in figure2:

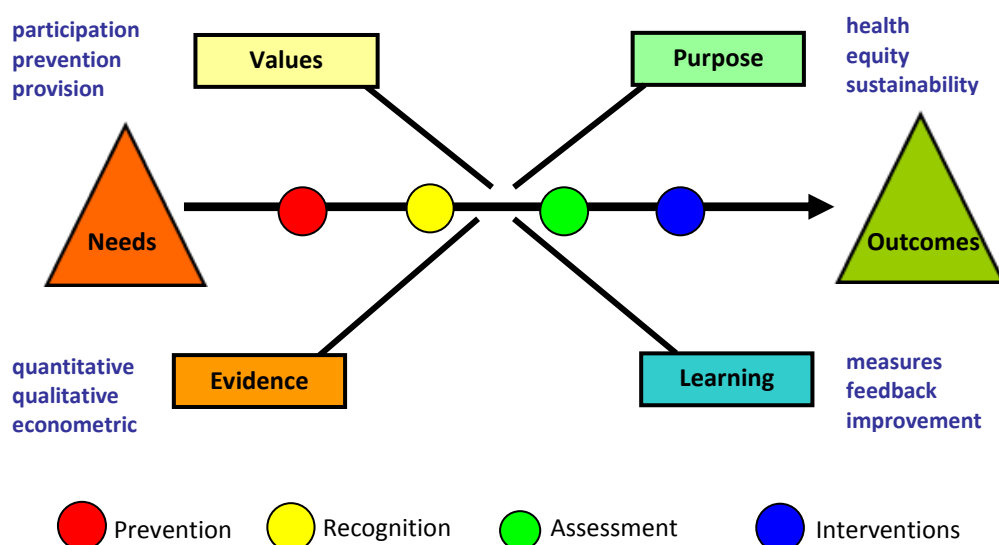


Figure 2: a representation of the family friendly framework integrating principles, purpose, evidence and learning with a pathway of care consisting of the components of prevention, recognition, assessment and intervention, addressing needs to create improved outcomes.

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 outcomes⁴³. This will require better cycles of measurement, feedback, reflection, change and evaluation if the system is to incrementally improve over time.

Adoption of the family friendly framework therefore creates integration which is family focused and pathway-based to ensure the right things are done, by the right people, in the right place, at the right time, all at the right cost. It recognises that outcomes are only as good as the weakest link in the pathway and that the identification and improvement of those weakest links are an integral part of service delivery.

The family friendly framework explicitly brings together purpose, values, evidence and learning into a practical framework, based on pathways, for the delivery of services. The concepts contained within the family friendly framework are equally applicable to planners and commissioners, providers (public, private or social enterprise), regulators of services and policymakers.

⁴³ <http://www.iom.edu/~media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf>

Application of the family friendly framework

Short-term conditions

Central to the family friendly framework is the description of a service pathway, from prevention through to interventions. Sometimes a single contact with the service provider (for example in primary care) after a concern has been recognised, covers both assessment and intervention, but more frequently, particularly for long-term conditions, a series of contacts with services are required to achieve the intended outcome. This is illustrated in figure3. These individual contacts may be within the health service, or may be with other agencies that contribute to the pathway.

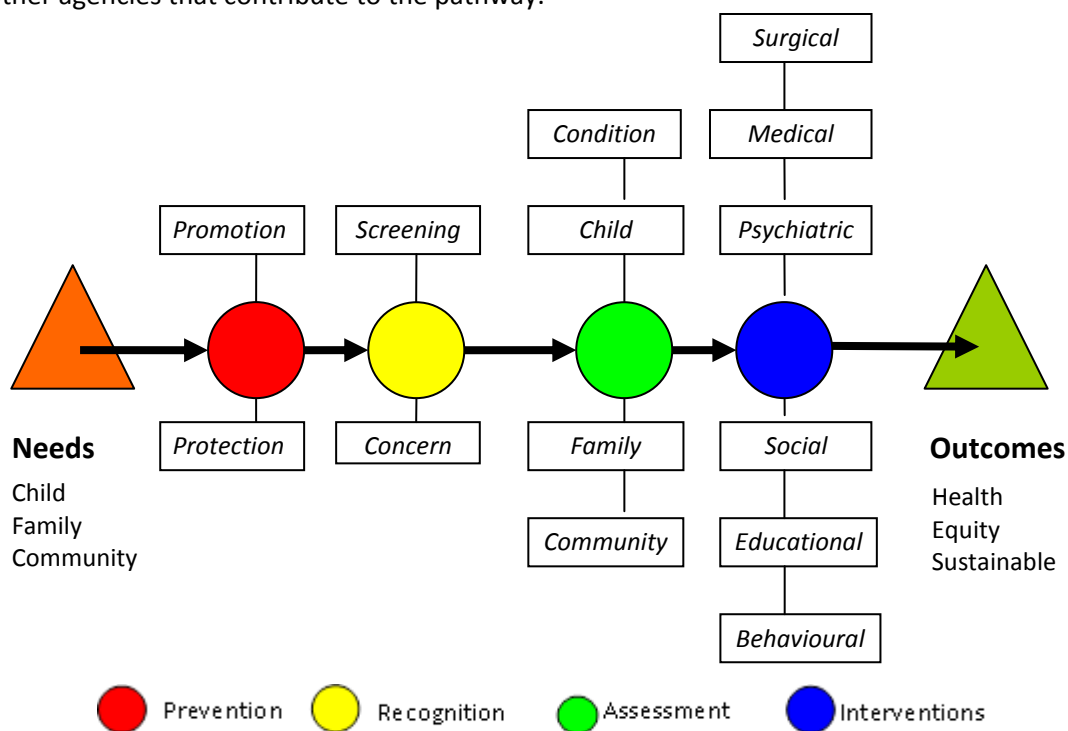


Figure 3: representing a short-term pathway, with needs on the left, outcomes on the right with the component parts of prevention, recognition, assessment and interventions in sequence in between.

Each component in the pathway should be evidence-based and delivered by competent people. However, as each component may be provided by a different service provider, it is essential that each provider is clear about their own boundaries, 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 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: 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 auditory ossicle movement causing conductive hearing impairment. Early-onset OME is associated with parental smoking and too short a period of breast feeding.

Primary prevention can be through either health promotion or health protection - specifically promoting breastfeeding and protecting children from cigarette smoke⁴⁴, the responsibility of Public Health England.

Recognition can be achieved through either an active process of case finding for example by screening 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.

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 competence 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. 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 alternative 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 matrix for planning and commissioning services, for example using the commissioners in England, as illustrated overleaf:

⁴⁴ <http://www.jpeds.com/article/S0022-3476%2805%2980843-1/abstract>

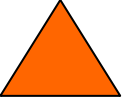
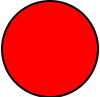




 Needs	 Prevention	 Recognition	 Assessment	 Interventions	 Outcomes
NHS CB	<i>Breast feeding promotion in primary care</i>	<i>Recognition of hearing impairment by GPs/10 care</i>			<i>Br feeding rates @6/52</i>
CCG			<i>Paediatric audiology assessment</i>	<i>Hearing aids SaLT Parent support</i>	<i>Access 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>Uptake Rates of smoking in pregnancy.</i>

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

Then this generic framework could be expanded to include more detail as and when necessary - for example to include the needs for condition/child, family and community with each having a separate matrix/table. This is intended to be used as an aide memoir to ensure the needs of the child, their family and the community are remembered and allocated to the appropriate planners and commissioners.

	Commissioners	Prevention	Recognition	Assessment	Interventions
Child	Specialist NHS services				
	General NHS services				
	Local Authority				
	Public Health				
	Third sector other				

	Commissioners	Prevention	Recognition	Assessment	Interventions
Family	Specialist NHS services				
	General NHS services				
	Local Authority				
	Public Health				
	Third sector other				

	Commissioners	Prevention	Recognition	Assessment	Interventions
Community	Specialist NHS services				
	General NHS services				
	Local Authority				
	Public Health				
	Third sector other				

Table : an illustration of how pathway components might be allocated to different commissioning bodies.

Long-term conditions

The short term pathway based on four components 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 (back to health, onto adult services or towards end of life care). This is illustrated in figure 5.

The initial phase covers the development of the condition - the preventative element is to reduce the incidence of the condition. The cyclical phase manages long-term conditions and the preventative element is to reduce the incidence of the complications of the primary condition. 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.

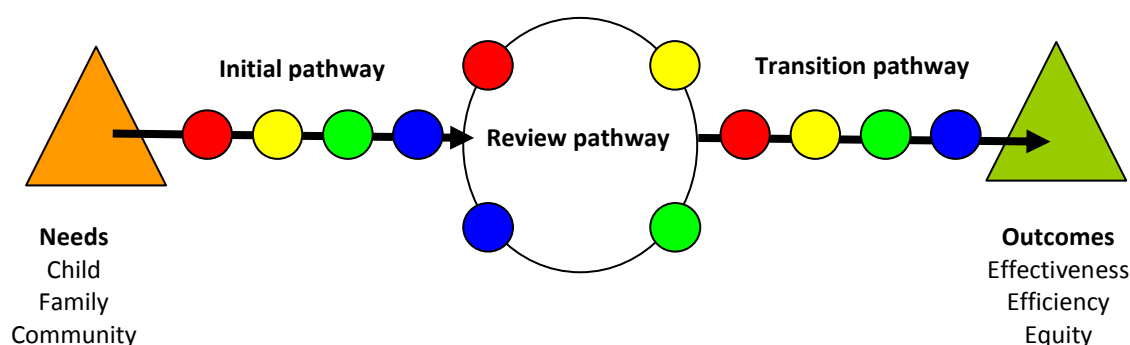


Figure 5: illustrating the long-term pathway with 3 phases – the initial, review and transition phases, each with four component parts.

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 matrix.

	Initial				Review				Transition			
Component parts												
Child												
Family												
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 the health problems of parents. Community based interventions would include those tackling the determinants of health and specific issues such as traffic speed, housing quality or community safety. NHS safety initiatives to prevent unintentional harm through service delivery may also be included.

An illustration for Downs's syndrome is included in appendix 3.

It must be remembered that planning and commissioning services is only one element of the commissioning portfolio and should be complemented by the commissioning of research, workforce (recruitment, development and retention) and potentially innovation all to support service delivery.

A practical approach to planning and commissioning

Any planning and commissioning framework should be understandable to all stakeholders particularly clinicians and users who should now be at the heart of day-to-day decision-making. It should combine children's rights, systems thinking and evidence into a practical outcome orientated framework, which is driven by the needs of both children and their families and have the capacity to continually improve through a process of learning.

As the commissioning landscape in England expands to include academies of schools, personal budgets, community sector and health-insurance, so it will be important to ensure that all planners and commissioners of health, education and social care, who may be using existing and newer models, share a common approach.

A commonly adopted cycle of commissioning ⁴⁵ had three steps –

- needs assessment,
- service definition and procurement
- performance monitoring.

Subsequent refinements ⁴⁶ identified the steps in a whole system approach to urgent and emergency care ⁴⁷ to –

- analyse and plan,
- design pathways,
- specify and procure
- deliver and improve.

The NHS Institute for Innovation and Improvement model starts with "build partnerships" ⁴⁸ at the beginning of the commissioning process (see figure 6) and BACCH endorses this five step process and this paper concentrates on the prerequisites for building partnerships and the practicalities of designing pathways and discusses how the development of networks can aid the delivery of integrated care.

⁴⁵ 2009 DH/DfES guide for planning and commissioning

<https://www.education.gov.uk/publications/eOrderingDownload/285374b.pdf>

⁴⁶ Royal College of General Practitioners

<http://www.rcgp.org.uk/revalidation-and-cpd/centre-for-planning-and-commissioning.aspx>

⁴⁷ http://www.rcgp.org.uk/revalidation-and-cpd/~media/Files/CIRC/Urgent_emergency_care_whole_system_approach.ashx

⁴⁸ NHS Institute for Innovation and Improvement

http://www.institute.nhs.uk/planning_and_commissioning/general/planning_and_commissioning_home.html

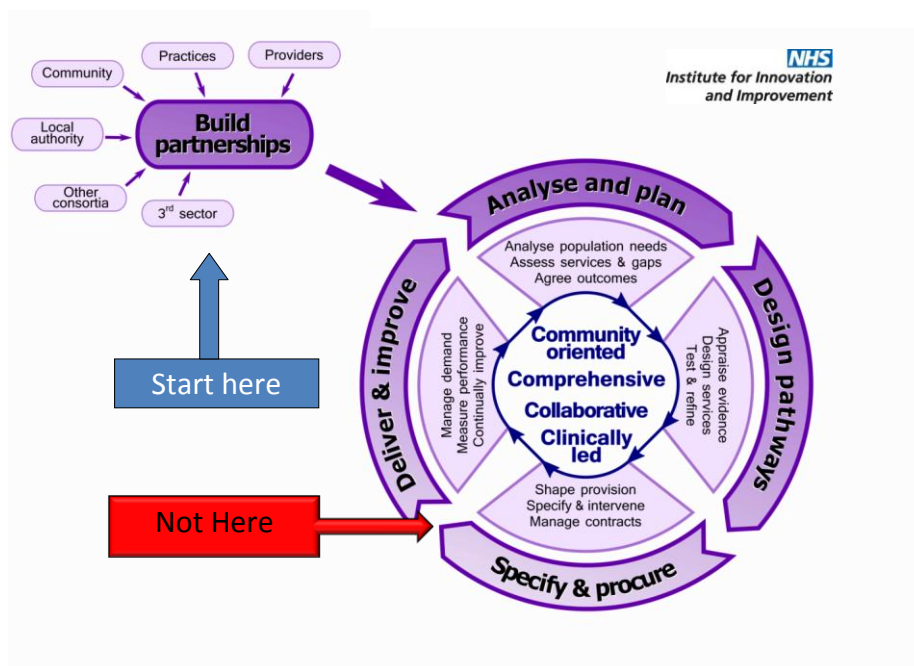


Figure 6: The NHS Institute for Innovation and Improvement approach to commissioning starting with building partnerships with stakeholders. (with thanks to Charlie Keeney)

In practice a five step model based on this diagram may include the following steps:

1. Build partnerships

- Agree purpose and outcomes
- Agree shared values
- Agree model of service delivery - the family friendly framework.

2. Analyse and plan

- Population needs assessment
- Service needs assessment
- Priority setting for investment and disinvestment.

3. Design evidence based pathways

- Define the component parts of the pathway (both NHS and non NHS)
- Write standards based on best evidence
- Determine resources required.

4. Specify* and procure

- Agree outcomes and areas for improvement
- Identify the key measures along the pathway
- Allocate resources and manage contracts.

5. Deliver and improve

- Measure and create feedback for quality improvement
- Innovate and evaluate, in order to learn
- Spread learning.

* A sample outline specification is included in appendix 4.

Pathways, programmes and networks

Due to the complexity of services for children and families it seems pragmatic to group similar services together to form managed networks in order to deliver a programme of care. Inevitably there will be boundaries to manage between the networks because individual families may require input from more than one network. Likewise professionals may be part of more than one team or one network, particularly those working in more universal services, which assess families at the start of many different pathways.

The broad programmes are summarised below and approximately map to modules of the English Maternity and Children's National Service Framework⁴⁹ and the Children and Young People's Health Outcome Forum Strategy⁵⁰.

- i. Promote the optimal development and determinants/lifestyles of all children - the universal **public health programme**
- ii. Reduce illness and injuries and their consequences - the **urgent and emergency care programme**
- iii. Reduce 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**

Managed networks

Managed networks are a concept for delivering high quality care to a population across a geographical area with Implementation started in Scotland in 1999⁵¹ and was endorsed again in 2012 as part of an improving healthcare quality strategy.⁵² There are a wide range of models for networks, depending on their purpose and function. A definition relevant to multiagency 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^{53, 54, 55} and are included at appendix 5.

Networks have had varying levels of political support over the past two decades. If allocation of resources is to be moved closer to the patient then the roles of networks should be revisited as they offer the potential to engage practitioners more and move decision-making towards the child and family.

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 in service delivery.

⁴⁹ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4090552.pdf

⁵⁰ <http://www.dh.gov.uk/health/files/2012/07/CYP-report.pdf>

⁵¹ http://www.sehd.scot.nhs.uk/mels/1999_10.htm

⁵² http://www.sehd.scot.nhs.uk/mels/CEL2012_29.pdf

⁵³ http://www.rcpch.ac.uk/sites/default/files/asset_library/Health%20Services/Managed%20Networks.pdf

⁵⁴ [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)

⁵⁵ http://www.rcpch.ac.uk/system/files/protected/page/Bringing%20Networks%20to%20Life%20for%20web_0.pdf

Clearly there is potentially a large overlap between some planning and commissioning roles and responsibilities and those of a mature network. In order to create greater professional leadership and user participation in the new system it would appear sensible to develop network capacity and competence in order to devolve some traditional planning and commissioning functions to the network and bring decision-making closer to the front line of service delivery.

Programme budgeting

A network delivered programme of care should include all the component parts and steps to drive quality improvement, including intra-network resource allocation, workforce planning and service reconfiguration. The overall approach should encompass a total (pooled) budget across participating agencies and the use a programme budgeting and marginal analysis (PBMA)⁵⁶ approach to aid decision-making about the distribution of resources.

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. Practically the use of this framework revolves around five questions about the use of resources:

- i. What resources are available?
- ii. How are these resources currently allocated?
- iii. Who are the main candidates for more resources and what is their cost-effectiveness?
- iv. Are there any areas of care which could be provided more efficiently, so releasing resources for investment elsewhere? (Technical efficiency)
- v. 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)

This PBMA approach has been successfully applied in a number of countries, particularly Canada⁵⁷, has been implemented in the UK⁵⁸ but with limited application relating to services for children and families⁵⁹ two major benefits are the engagement and positive experience of clinicians and the transparency about costs and cost-effectiveness which the process brings.

⁵⁶ <http://www.medicine.ox.ac.uk/bandolier/painres/download/whatis/pbma.pdf>

⁵⁷ <http://www.nhlc-cnls.ca/assets/Mitton%20Presentation.pdf>

⁵⁸ www.yhpho.org.uk/resource/view.aspx?RID=10049

⁵⁹ <http://www.yhpho.org.uk/resource/item.aspx?RID=10048>

Informatics for improvement

Knowing how well services are working is the first step on the road to improvement. It requires the development of measures that should have meaning and yet be a proportionate process, in the sense of the added value of measurement being greater than the burden of collection and analysis of data. A brief description of a framework for measurement is included here which BACCH intends to develop further in the near future. It should be acknowledged that the language and semantics around metrics is inconsistent in the literature and the framework proposed attempts to map onto the family friendly framework.

Figure 2 acknowledged the importance of aligning lifestyles and determinants of health with the aspirations of service delivery. These lifestyles and determinants, coupled with other public health programmes combined together create life course outcomes.

The framework is based on bringing together the separate outcomes of life course pathways and service delivery pathways into a combined measure reflecting sustainable outcomes – a measure of impact, illustrated in figure 7.

At the end of the life course and service pathways are outcome measures which will indicate whether the intended outcomes have been achieved, but these alone will not demonstrate where in the pathway any problem lies. Therefore each pathway will require some measurements of health status (based on the health of individuals or a population) and measures of service delivery (including the experience of services), relevant to population-based interventions or individual-based interventions.

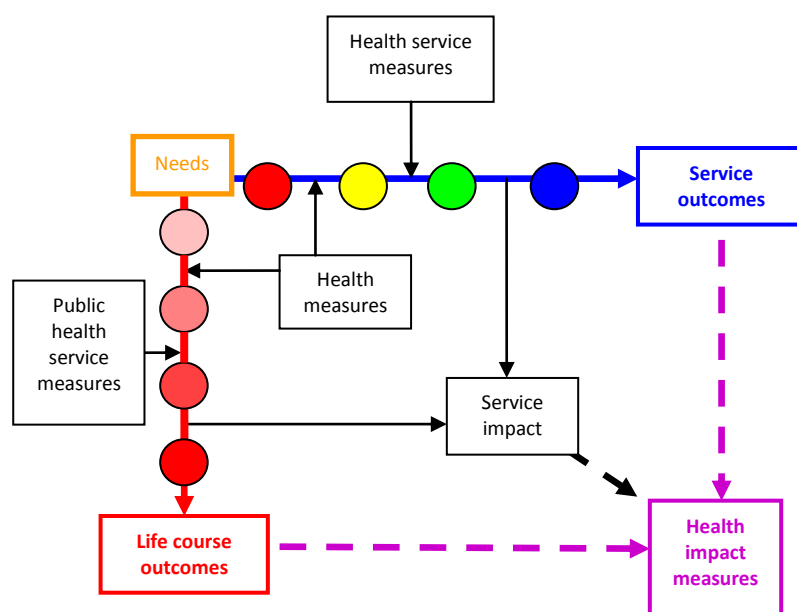


Figure 7: illustrating the combination of life course outcomes and service outcomes to create health impact measures representing sustainable outcomes over time.

This high-level conceptual framework can be developed into groups of measures that represent needs, service delivery outcomes, life course outcomes and health impact measures.

The **needs** that should be considered relate to the child (the condition and its impact), family (lifestyle and consequences of living with a child with a long-term condition) and community (wider determinants of health and impact of the child's condition on others).

Measures of **service delivery** include the output from the component parts of the pathway (for example the yield of a screening test or the outcome of assessment) and measures of the component parts which include structure and process (for example our guidelines/protocols in place and the competence of staff)

Outcome measures include any change in health status as a result of contact with services. The added value can be judged by measures of effectiveness, efficiency and equity. Increasingly measures of experience including acceptability, affordability and accessibility are included as 'outcome measures' from a user's perspective.

Health **impact measures** are a reflection of the sustainability of outcomes (outcomes maintained over a period of time) and the impact of having a condition on the achievement of life course outcomes such as attendance and achievement at school.

The choice of measures will depend on the stage of development of services, any particular local concerns and resources available. The important point being that measures should be fit-for-purpose namely the measures chosen should be meaningful, matter to stakeholders, motivate reflection, learning and improvement and should be able to be used to monitor change over time.

Benefits of the family friendly framework for planning and commissioning

There are many potential benefits to adopting a shared multi-agency approach to the planning, delivery and regulation of services to 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 a process of continuous learning based on innovation and evaluation.

Patients

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

Clinicians

- A method of getting evidence into practice through the use of agreed guidelines, algorithms and protocols across the network.
- Potential for 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

- Greater integration achieved through breaking down silo working.
- A shift from a short-term focus on efficiency, to a longer-term focus on effectiveness and equity (the added value agenda).
- Greater involvement of clinicians in decision-making delivery and improvement.

Planners and commissioners

- Brings multiple planners and commissioners together – a shared thinking/value/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 accountability.

Implications of 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 the planning, delivery and improvement of services. Largely the approach is to create alignment and synergy between all of the parts, to enable resources to be used wisely, intended outcomes to be achieved and care to be a good experience for children and families.

Planners and commissioners

- Combined 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.
- Devolving some planning and commissioning functions regarding allocation of resources to managed networks.
- Financing systems that enable resources to follow patients through pathways and networks and the introduction of programme budgeting.
- Integrating public health approaches to prevention across all pathways.

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.
- Shared quality improvement systems 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 outcomes.
- Bringing together quality and economic regulators across different agencies, using a shared approach for measurement and improvement to achieve a greater impact.

Families

- Coproduction 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.
- This participation enabling greater resilience children and their families particularly for those living in disadvantaged circumstances.

Summing up

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 and designing pathways, has been illustrated using two examples. The intention is to develop further examples for reference purposes which will be hosted on the BACCH website.

The family friendly framework has been derived from many sources and the approach is intended to improve the quality of services to children and families across all agencies, not just within the health service, as the underlying principles are derived from the UN Convention on the rights of the Child.

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 and well-being benefits into the future.

This paper has been deliberately written as a consultation paper in order to create discussion, feedback and improvement for future iterations. It is available as a PDF and a Word document so you can cut and paste for local use if you so wish. A PowerPoint presentation is also available to download and adapt from the BACCH website along with this paper.

To facilitate consultation a questionnaire is available to complete on-line.

<https://www.surveymonkey.com/s/88G23SK>

We would welcome your input and encourage you to discuss the family friendly framework with colleagues and complete the consultation questionnaire and your suggestions for improvement to be included in future editions.

www.BACCH.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)⁶⁰ endorse 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 Lisbon⁶¹, 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.

⁶⁰ http://www.ncvys.org.uk/UserFiles/Policy/CIAG_ServingChildrenAndYoungPeopleBetter_Oct09.pdf

⁶¹ http://europa.eu/lisbon_treaty/full_text/index_en.htm

Appendix 3: 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 is 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, 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

To identify medical conditions that could impair health and development as early as possible.

To support families who have a child with Down syndrome

To improve community resources for children and young people with Down syndrome

Evidence base

- Down syndrome Medical Interest Group UK and Ireland (www.dmsig.org.uk)
- American Academy of Pediatrics Clinical Report: Health Supervision for Children with Down Syndrome (<http://pediatrics.aappublications.org/content/early/2011/07/21/peds.2011-1605>)
- European Down Syndrome Association Health Care Guidelines for People with Down Syndrome (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 • 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	Universal <ul style="list-style-type: none"> • folate supplementation High risk group <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 	Universal <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 High risk group <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</p> <p>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 – letting go	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 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

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

Appendix 4: a sample outline specification.

Network	
Services included	
Commissioner Lead	
Provider Lead	
Period	
Date of 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"> Positives Negatives Expenditure
National/local context <ul style="list-style-type: none"> Political Practical
Evidence base
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"> 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

<ul style="list-style-type: none"> • 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 5: 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.
- Measuring 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.