BACCH-BACAPH
Improving Services Series

Designing pathways and networks

within integrated health systems

Systems, networks, pathways and journeys

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".*

When designing health systems it is essential to bring together all the perspectives of the various stakeholders involved (figure 1). This will include 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 that is fair, transparent and accountable), into a practical framework to improve outcomes to children and families.[1, 2]

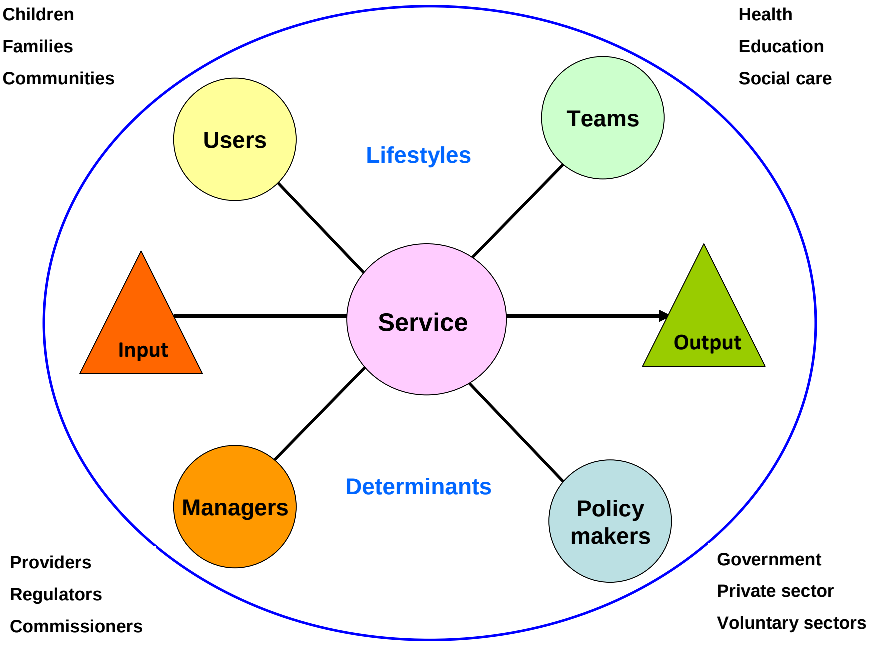

Figure 1: illustrating multiple stakeholder perspectives on service provision, based on a simple systems input-output mode, noting the external influences of lifestyles and determinants.

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[1] http://www.scotland.gov.uk/Resource/Doc/355013/0119868.pdf

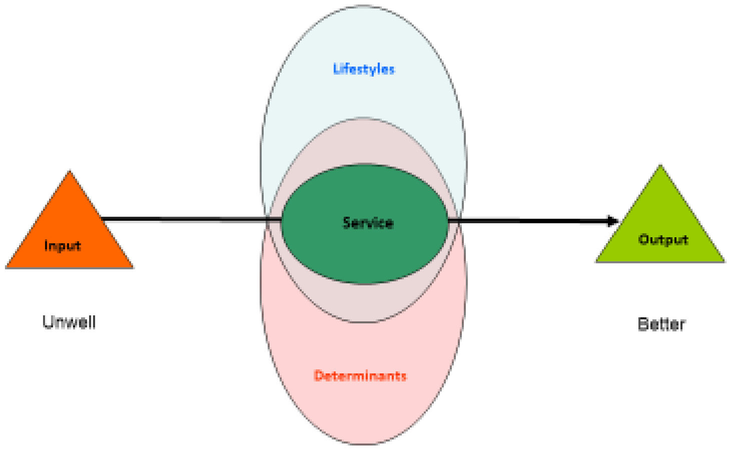
[2] http://users.actrix.com/bobwill/ssm.pdf

There is a constant dynamic tension/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 this may undermine the quality of care - amply illustrated in the Francis Report.[3]

Learning based on quality improvement and the generation of new knowledge is essential in order to respond to new information or changing circumstances. Health systems have a 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 improvement. 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 a “change agent”. The process of change is sometimes called a “transformation”. 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.



In this diagram the input is represented by an orange triangle and the output by a green triangle. The transformation from unwell to better is achieved by the service in the centre of the diagram. The success of this transformation process is influenced by health determinants and lifestyles represented by the two ovals.

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

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[3] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/226703/Berwick_Report.pdf

	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, physical and economic environments, 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. The NHS contribution to tackling determinants is termed population health management in the NHS long-term plan which will be considered in more detail in a separate mini module. 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 of society.

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 timing;
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, clear values, leadership and the ability to learn.

These four stages with four parts create a 4x4 framework are illustrated in figure 3. 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.

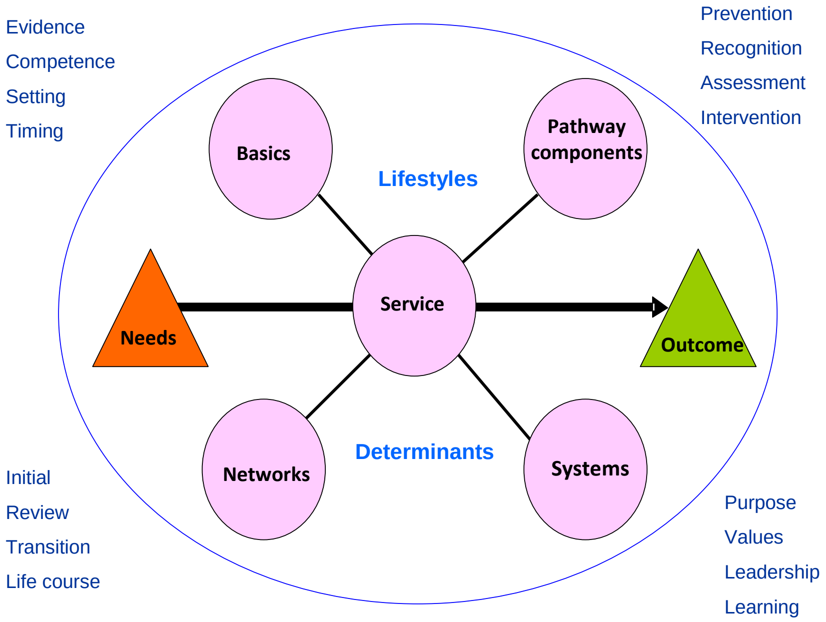

Figure 3: illustrating the essential elements that need to come together to create an excellent service.

For simplicity only two examples will be discussed - a short-term condition pathway and a long-term condition. Life course pathways will be considered in a separate mini module. 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.[4]

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 person (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 4.

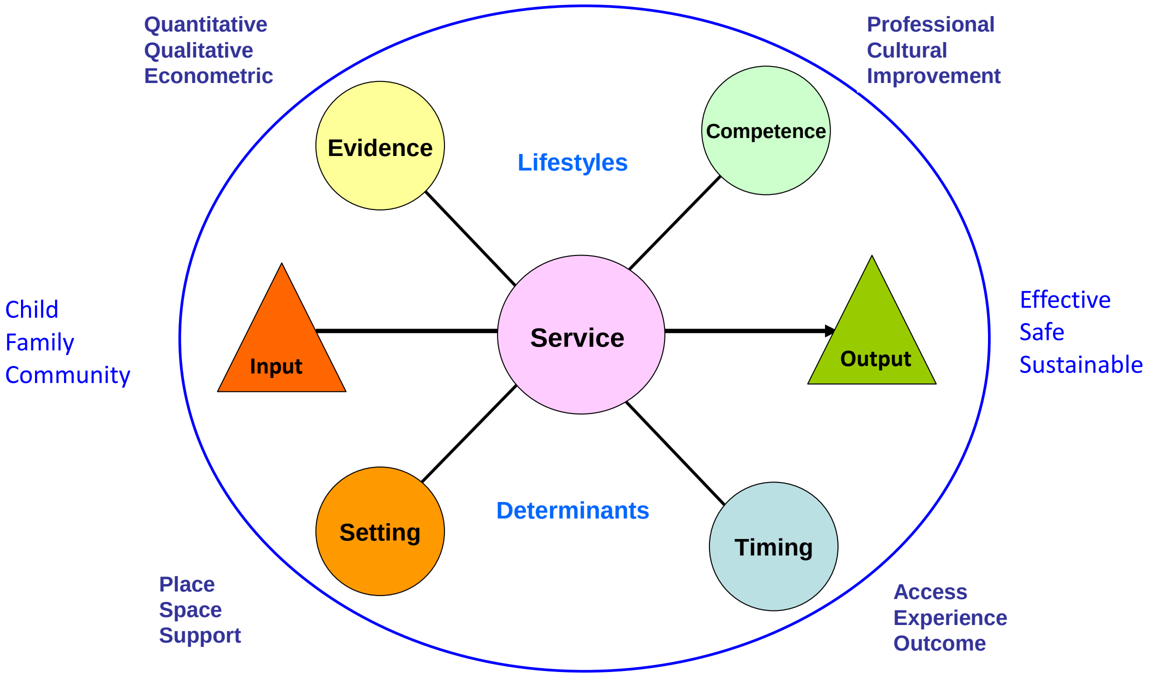

Figure 4: illustrating the four basic components that contribute to effective and safe service delivery namely evidence, competence, setting and timeliness.

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, being able to communicate well 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.[5]
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.

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[4] http://www.nejm.org/doi/full/10.1056/NEJMp1011024

[5] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/226703/Berwick_Report.pdf

Pathway components

Service pathways – a short-term condition

Short-term conditions cover predominantly self-limiting illnesses or injury and the assessment and management of concerns which do not require ongoing (long-term) 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 should be prevented and therefore planning and commissioning must link into primary prevention in order to tackle lifestyles and determinants within a 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 5).

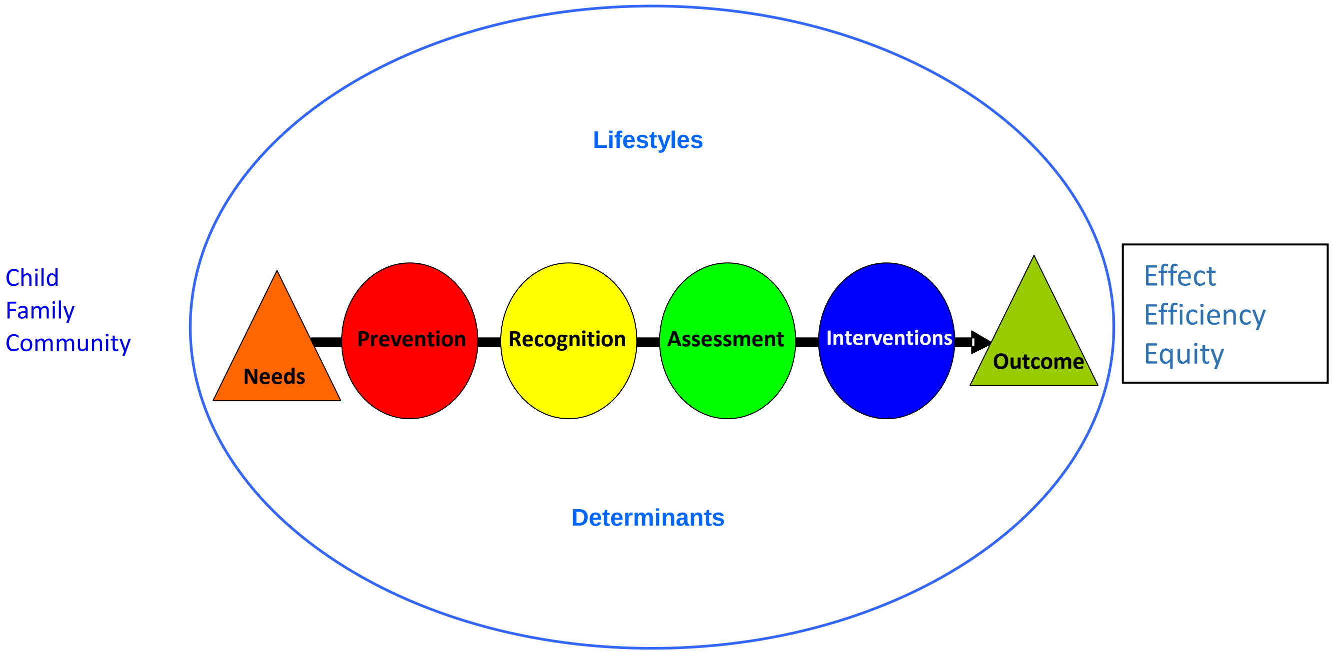

Figure 5: illustrating the component parts of a simple pathway, including the external influence of lifestyles and determinants

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 5, 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 covering lifestyles and wider health determinants.
2. Recognition may be through screening, surveillance or the recognition of symptoms.
3. Assessment includes symptoms, impact on the child and the capacity and consequences for the family. Occasionally it includes home and community assessment.
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. Tackling health determinants is covered in the Population Health Management mini-module.

Visually this four step process can be expanded (figure 6) to include more options available for each component, 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 within a wider integrated health system.

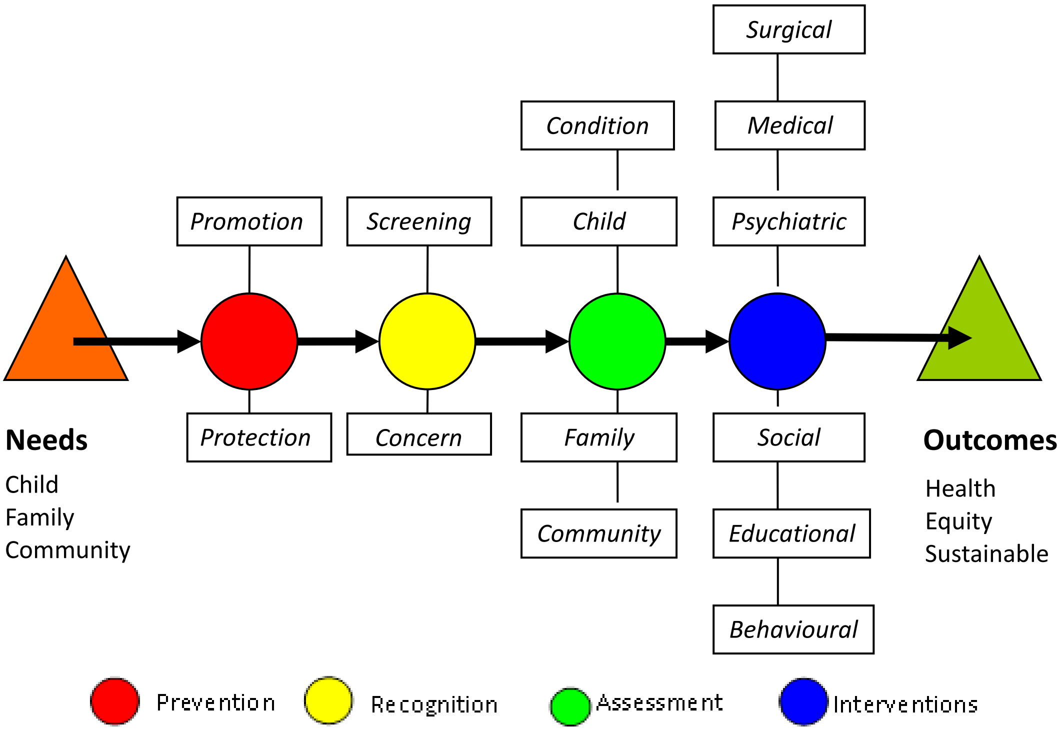

Figure 6: representing a short-term pathway, with needs on the left, outcomes on the right and the component parts namely prevention, recognition, assessment and interventions in sequence in between.

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 unnecessary 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 reorientate from inspecting organisations, which provide a component parts 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 and also the experience of users.

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.[6]

***Primary prevention** can be through either health promotion or health protection - specifically promoting breastfeeding and protecting children from cigarette smoke,*[7] *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.*

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[6] http://www.rcseng.ac.uk/healthcare-bodies/docs/published-guides/ome

[7] 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 2) for planning and commissioning services, for example using the commissioners in England, as illustrated below:

▲ **Commissioner**	🔴 Prevention	🟡 Recognition	🟢 Assessment	🔵 Intervention	▲ **Outcomes**
NHS England	*Breast feeding promotion in primary care*	*Recognition of hearing impairment in primary care*			*Br feeding rates @6/52*
CCG			*Paediatric audiology assessment*	*Hearing aids* *SaLT* *Parent support*	*Access* *Timeliness*
LA/PH	*Smoking cessation*	*Healthy Child Programme*		*Teachers for the deaf* *Hearing loops*	*Language dev* *Educational achievement*

Table 2: 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 2, including more detail as and when necessary to include the needs for family and community with each having a separate framework/table. Table 3 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				

	Providers	Prevention	Recognition	Assessment	Interventions
Family	**Specialist services**				
	General services				
	Local Authority				
	Public Health				
	Third sector				
	Private				

	Providers	Prevention	Recognition	Assessment	Interventions
Community	**Specialist services**				
	General services				
	Local Authority				
	Public Health				
	Third sector				
	Private				

Table 3: provision – a tabular framework for 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 over a longer period of time and the focus of care is on best management of that condition, prevention of complications or comorbidities 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 7.

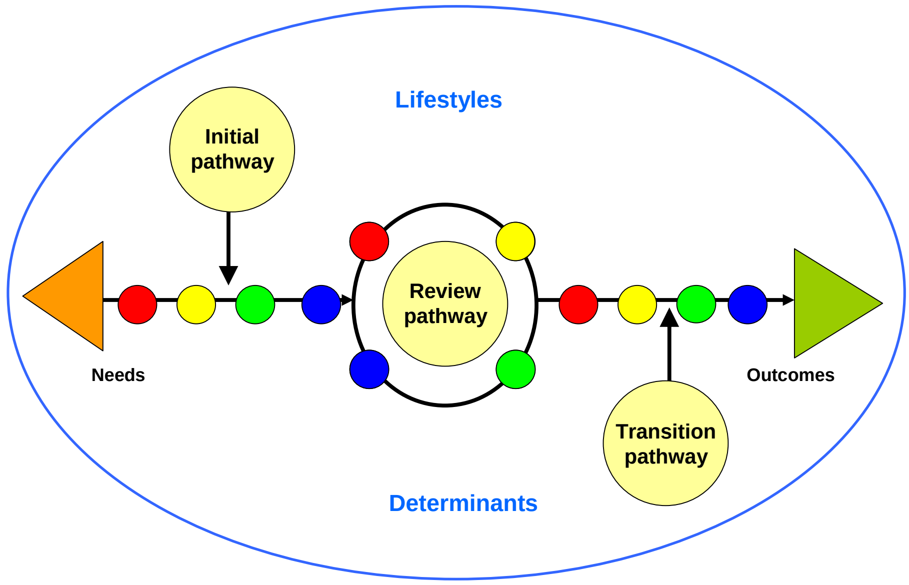

Figure 7: illustrating the long-term pathway with 3 phases – the initial, review and transition phases, each with four component parts.

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 or comorbidities 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 quality and 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 4. 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 4: 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, domestic violence or mental health disorders. Community based interventions would include those tackling the determinants of health and specific issues, such as, traffic speed, housing quality[8] or community safety. Again there is a link here to Population Health Management to improve outcomes of service pathways. 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, workforce (recruitment, development and retention) and innovation and improvement - all required to support sustainable service delivery.

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[8] http://www.scie.org.uk/publications/briefings/files/briefing19.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 single cause of learning difficulty; it may be associated with medical comorbidities 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 of medical comorbidity will have significant and far-reaching impact upon the overall quality-of-life and 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 inequities 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.[9]
- American Academy of Pediatrics Clinical Report: Health Supervision for Children with Down Syndrome.[10]
- European Down Syndrome Association Health Care Guidelines for People with Down Syndrome.[11]

Table 5 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.

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[9] www.dmsig.org.uk

[10] http://pediatrics.aappublications.org/content/early/2011/07/21/peds.2011-1605

[11] http://www.edsa.eu/files/essentials/edsa_essentials_2_healthcare.pdf

Initial phase				
Component parts	**Prevention**	**Recognition**	**Assessment**	**Interventions**
Foetus - newborn	• education – risks of • later pregnancy • family planning	• antenatal DS screening • newborn examination screening • ad hoc recognition	• a/n obstetric/ paediatric • cardiology • genetic	• termination • therapeutic interventions
Family	**Universal** • folate supplementation **High risk group** • reduce age of conception • pre-implantation genetic diagnosis	• parenting capacity	• parenting assessment	• parent support
Community	• health promotion	• promotion of screening		

Review phase				
Component parts	**Prevention**	**Recognition**	**Assessment**	**Interventions**
Child	• health education • health protection	**Universal** • 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** • cardiac • sleep disordered breathing	• paediatric • ophthalmology • ENT • biochemical/endocrinology • testing/gastroenterology • neurology/spinal orthopaedics • further investigation • cognitive assessment • communication assessment • motor development	interventions as appropriate for the conditions detected additional immunisations flu, pneumovax • • education in keeping with abilities • speech and language therapy • physiotherapy • occupational therapy
Family	• benefits advice		•parental information •sibling support needs	• expert parent programmes • family support
Community	• leisure access for disabled			• in school support

Table 5:

Transition to adult services*				
Component parts	**Prevention**	**Recognition**	**Assessment**	**Interventions**
Young person	• health education programmes • preparation for adulthood • mentoring • financial support	• life skills • preparation for adult services • advocacy • continued annual screening/ surveillance as above	• 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	• 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	• 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	• post 16 provision available • Finance • Equipment (wheelchairs)	Identify services to move on to • Finance • Equipment (wheelchairs) • Transport	• Develop transition plan • Multiagency working • Key worker provision • Transport provision • Short break provision	• Social and leisure opportunities • Further/higher education opportunities • Employment opportunities • Appropriate housing/adaptation • transport • Training for staff

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.

Summary

Pathway design with network delivery within integrated systems will form the backbone of new models of care and NHS planning, delivery and improvement envisaged by the NHS Long-Term Plan future. Pathway thinking enables the component parts of the pathway to be clearly described and a network of providers can then decide who does what and then allocate resources appropriately.

This new way of working will require leadership to bring multiple stakeholders together and explain pathway development to those outside the NHS not familiar with the concept within Integrated Health Systems.

This in turn will is dependent upon a clarity of purpose, translated to outputs and outcomes, supported by data at key points along the pathway. The evaluation of pathways should be an integral part of service provision, based on meaningful measures that represent quality and experience, in order to detect and then rectify the weakest links to continuously improve value. Evaluation based on pathways will be the topic of a separate BACCH-BACAPH Improving Services Series of mini module.

The intention is to create networks that deliver high quality care which will perpetually learn both through new research and through delivering quality improvement and so improve the lives of children and families.