British Association for Community Child Health (BACCH) submission to Review of NHS Services for Children led by Sir Ian Kennedy

Outline

Addressing the cultural obstacles to improvement in outcomes for children, both within the NHS as well as between the NHS and other organisations that contribute to child health and well-being is long overdue and therefore this review is welcomed.

Our intention, for this submission, is to propose solutions which will address what we see as the key issues needed to create a culture (defined as "a set of shared attitudes, values, goals, and practices that characterizes an institution, organization or group") which will drive the continued and sustained improvement in children's services and their outcomes.

The structure of this submission will be in three parts that mirror the terms of reference of the Review, namely:

1. ***Cultural obstacles that can stand in the way of sustained improvement***
2. ***The scope as outlined within the terms of reference***
3. ***The wider agenda highlighted by David Nicholson***

The issues covered under each heading are summarised in Appendix 1.

As the intention is to be solution focused, this response will start with a short introduction, which briefly reviews recent policy initiatives, followed by a proposed model which has the potential to create a culture (a joint approach) which will align the collective aspirations of commissioners, providers and regulators across health, education, social care and other agencies.

Introduction

Both Bristol Paediatric Cardiology and Victoria Climbié Inquiry reports demonstrated poor quality, fragmented services, with a lack of leadership, little patient involvement, and poor communication between parts of the service. Worryingly there was no systematic system to identify and address problems when they were identified.

The National Service Framework (NSF) and Every Child Matters (ECM) produced standards and aspirations for improved quality of care, but did not fundamentally address the cultural issues identified in their parent reports. Although intended to implement the vision, the Change for Children Programme did not manage to bring the best of the NSF and ECM together. It was unsuccessful in uniting the cultures of different agencies and organisations, and failed to achieve the much needed transformation of service delivery at a local level.

As a result, there remains a multitude of commissioners, providers and regulators of services who perceive issues differently and assign varying priorities as a result. With each taking a different approach to their respective functions there is, as a consequence, no coherent alignment of principles or practice of working. This in turn undermines the objective of family friendly joined up services and ambition of better outcomes.

Many of the recent NHS reforms (targets and regulation, competition and contestability, voice and choice) have been orientated towards improving adult elective care, or straightforward medical emergencies (e.g. chest pain). They have not always suited children and families well, and some targets have actually undermined established coordinated, multi-agency working. The emergence of quality and quality improvement, as the driving forces for better experience and enhanced outcomes, are reforms that are welcomed and more likely to succeed in children's services.

When designing services, the whole pathway needs to be considered as a total entity; good outcomes for families require more than the sum of the individual parts. From experience, and from parental reports, we know that it is often the transition between components of a pathway that inhibits better experience. Good outcomes for children almost always require full engagement of families and, aligned with that (particularly for long-term conditions), the engagement of education and social services. Good design needs to be complemented by pathway-based assurance/improvement systems that actively seek out, and then correct, the weakest link of the pathway in a timely fashion.

Two outline examples of "whole system design based on pathways" are included in appendix 2 for paediatric cardiology and safeguarding services.

The immediate conclusion has to be that commissioning, provision and regulation of services across health, education social care and other providers, all need to be aligned to deliver evidence based pathways of care, with competent individuals, teams and organisations collaborating together to achieve continuous improvements within networks.

While this review concentrates on the NHS element of children's services, it is absolutely essential that any change in culture is adopted across all agencies contributing to services for children and families.

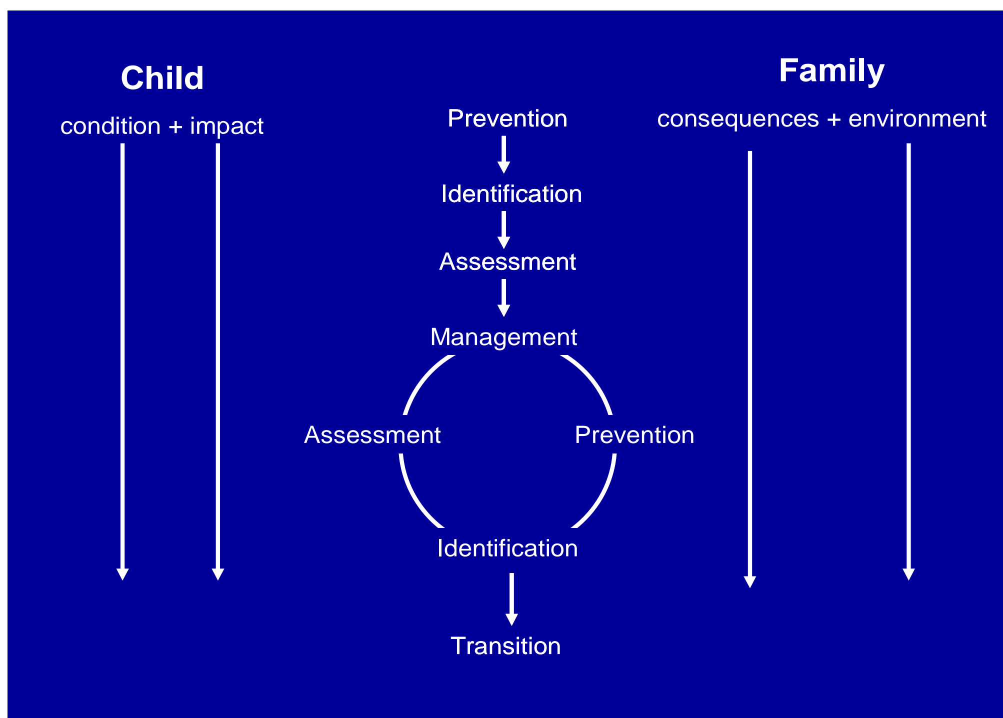
Reduced spending on public services secondary to the economic downturn is likely to result in all agencies taking the attitude of "not in my budget" and for agencies to become more "silo-like"; yet the real gains will only come from closer, better coordinated working between different agencies, supported by inter agency world-class commissioning and a regulatory process that seeks out and spreads best practice - in both the commissioning and delivery of services.

The proposed model

The proposed model has been expounded in three recent Royal College of Paediatrics & Child Health (RCPCH) publications that build on the 1994 BACCH paper "Services for Children - a Model for Purchasers and Paediatricians":

1. Understanding Pathways and Networks: which outlines the theory and potential for pathway network thinking.;
2. Modelling the Future I: a consultation paper on the future of children's health services (2007), which proposed models of service delivery based on pathways in networks for consultation with the wider audience;
3. Modelling the Future III: safe and sustainable integrated health services for infants, children and young people (2009), which outlines the changes that need to happen within UK children's health services to achieve better outcomes, with the recommendations at national, regional and local levels.

In essence the model states that for acute illness or injury ("short term conditions") there need to be four components in place and working well together. The component parts are to *prevent, identify, assess and manage* acute conditions. When conditions are established ("long-term conditions") the same four elements need to be in place and working well together, but this time to prevent and manage the secondary complications of the primary condition.



Each component needs to simultaneously consider the condition, its impact on the child, the consequences for the family and any wider impacts. For each component part of the pathway there should be clear evidence of what needs to be done, translated into guidelines or protocols, a competent workforce, in sufficient numbers with the right education, to deliver the service in the right place and the right time. This approach then needs to be supported by the necessary administrative and clinical support services.

Different components of the pathway may be delivered by teams from different organisations, or with professionals from different agencies working effectively together in teams, where this is the best model. The individual teams then all work together within a wider managed network, all committed to delivering safe, effective services that are continually improving - so that year-on-year patient experience and outcomes improve. Many different professional groups need to come together and their parent agencies or organisations need to share the same approach, using the same thinking and language, to create a culture that can deliver a range of services to meet the health care needs of today's and tomorrow's children and young people and their families.

This approach therefore needs to be shared across different agencies (whether public sector, private sector or social enterprise), across primary, secondary and tertiary care, and needs to be reinforced and embedded by both the commissioners and regulators of services.

While the issues facing the health service may seem complex and daunting, the solutions are remarkably consistent and straightforward. However, any significant cultural change will require very consistent leadership over a prolonged period of time to reinforce the mantra. Stated simply, this is "doing the right things, to the right people, at the right time, with the right workforce, in the right place, in the right way, to achieve the right outcomes", all based on a model of pathways and networks backed by process of continuous quality improvement.

Responses to the Terms of Reference

1. Cultural obstacles that can stand in the way of sustained improvement

Perceptions of health services' role in child health and wellbeing and in safeguarding; the challenges to professional practice and how these can be met:

(a) Child Health and Wellbeing

The concerns about health service role in improving child health and well-being is probably best illustrated by injury prevention, but are equally true for obesity, substance abuse (including alcohol, nicotine and street drugs) or sexually transmitted disease.

Traditionally the NHS has provided excellent emergency services without any consistent attempt to reduce the burden of injury (the leading cause of both mortality and morbidity over the age of one year). The evidence suggests that one-off structural changes, sometimes backed by legislation (e.g. 20 mph residential speed limits, the fitment of smoke detectors, reducing domestic hot water temperature) are the most successful interventions to reduce injuries. Changing parental, child or young person behaviour is far more challenging to implement successfully (e.g. wearing cycle helmets, locking away medicines or cleaning products, driving more carefully).

Further reading

Accidental Injury Task Force reports:
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4064841
Better Safe than Sorry: Preventing Unintentional Injury to Children. Audit Commission (2007)
(www.audit-commission.gov.uk/health/nationalstudies/publichealth/Pages/bettersafethansorry_copy.aspx)
CAPT (2009)(www.capt.org.uk)
DCSF (2009) Accident prevention amongst children and young people: A priority review
http://www.dcsf.gov.uk/everychildmatters/resources-and-practice/RS00047/

(b) Safeguarding

The challenges around safeguarding are similar. The majority of serious child abuse occurs in a small proportion of the population. These families live in poverty compounded by substance abuse, domestic violence, mental health problems and learning difficulties. Parenting and childcare is just one additional element to juggle in the complex chaotic lives of these parents. Service response tends to be fragmented with multiple teams from mental health, substance abuse, adult social care, learning difficulties, housing and the police being involved, often focusing on the immediate needs of

adults and overlooking any formal assessment of parenting capacity. Most universal services such as a Healthy Child Programme, Sure Start, or Children's Centres marginalise these families still further, thereby creating even greater inequalities in health and health outcomes in their communities. It must be remembered that these are the tip of the iceberg and larger numbers (up to 20% of the population in some areas) who suffer often daily unremitting neglect with its profound long term consequences.

Further reading

Analysing child deaths and serious injury through abuse and neglect: what can we learn? A biennial analysis of serious case reviews 2003–2005 Marian Brandon, Pippa Belderson, Catherine Warren, David Howe, Ruth Gardner, Jane Dodsworth, Jane Black
Lancet series on Child Maltreatment (2008) (www.thelancet.com/series/child-maltreatment)

Cabinet Office (2007) Reaching out Think Families

(c) Challenges to Professional Practice

Injury prevention and safeguarding are two excellent examples of the challenges facing professionals. Successful programmes require a clear evidence base, translated into practical guidelines for practitioners. Currently the evidence base is relatively weak; it is not clear which agency or professional group should tackle this agenda, and often there is no active multi agency coordination of injury prevention programmes. The role of commissioners and regulators is unclear because again it is not obvious which organisations are responsible for what within injury prevention programmes.

Expanding safeguarding to include injury prevention, before ensuring child protection systems were fit for purpose (i.e. able to protect and support a larger proportion of children and young people), could be criticised as overloading the capacity of the child protection system.

Further reading

RCPCH/RCN submission to Lord Laming (www.rcpch.ac.uk/Media/News) (12 March 2009)

BACCH response to Laming

Injury Minimisation programme for schools (www.impsweb.co.uk/default.htm)

Solutions

The delivery of public health programmes for children and families need to be reviewed. The appointment of Directors of Public Health across local authorities and PCTs has great potential, but supporting public health capacity is limited. In many places paediatricians provide public health advice on screening and immunisation programmes, but increasingly these are not "joined up" with a wider health promotion programmes across PCTs and LAs.

There are some good examples of multi-agency groups working to reduce injuries and improve services for injured children.

Family Nurse Partnerships are evidence based interventions which have been proved to be effective for the most vulnerable families in society.

Adult services, working with parents whose behaviour patterns put children at risk, need to identify and assess whether those adults impose a risk to their children. Effective interventions must then be available to reduce the risk to tolerable levels.

The cultural shift is that prevention of illness, injury or neglect is an important and integral part of the whole pathway and as such needs to be commissioned, provided and regulated.

Challenges to leadership, especially given the disseminated responsibilities across the NHS on children's health and their healthcare and safeguarding and between departments of state/government departments

(a) Policymaking

The wider safeguarding agenda is a good example of the fragmented nature of leadership in this area. The Public Service Agreement (PSA) Programme Board has recognised the need to bring various government departments together to deliver these ambitious targets. Reducing deaths on the roads, death in the first few weeks of life, or at the hands of parents, all essentially require a similar approach. There needs to be an examination of the hazards children are exposed to, a determination of the frequency of exposure, and of the likelihood of harm as a result of this exposure. At each step, the evidence for prevention or reduction of harm needs to be examined, simultaneously reviewing how practical a programme would be in practice from the perspective of the beneficiaries, people delivering the programme, and those paying for it. Currently, there is often no consistency in deciding what needs to be done, who should do it, or how it is coordinated, e.g. how to protect children excluded from school who live with abusive or neglecting parents.

Addressing factors leading to intergenerational inequity are complex issues and require a joined up approach over a number of years to avoid the scenario where the children of vulnerable families perform poorly at school, are then excluded, experiment with illegal substances and through crime end up in the criminal justice system, all with a very large overall cost to society.

Further reading

Halfon, N. (2007a) A science-based framework for early childhood policy. Using evidence to improve outcomes in learning, behaviour and health of vulnerable children. Harvard University.

Marmot Review Consultation Report: Health inequalities post 2010

http://www.idea.gov.uk/idk/core/page.do?pageId=11057750

Munro, E (2005) A Systems Approach to Investigating Child Abuse Deaths. Br J Soc Work.2005; 35: 531-546

Reder, P, Duncan, S & Gray, M (1994) Beyond Blame: Child Abuse Tragedies Revisited (Routledge)

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(b) Commissioning

The commissioning of these services may be split across the Primary Care Trust, Practice Based Commissioners, the Local Authority, Specialist Commissioners, School Cluster Partnerships, Children's Trust Arrangements and increasingly individual budgets. It is rare for the commissioners to clearly delineate their boundaries or develop a shared culture for the commissioning of services. Secure accommodation, for example, whether it be mental health, education/social care, or within the criminal justice system is extremely expensive and it is often unclear how an individual young person ends up in one environment rather than another. The educational and mental health problems of those within the criminal justice system are well recognised, but often not addressed.

Further reading

World-class Commissioning

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndguidance/DH_080956

(c) Regulation

Just as provision and commissioning is fragmented, so is the process of regulation. Whilst there has been an increasing attempt to take a joined up approach to the regulation of safeguarding services, each regulatory agency tends to examine either an organisation or a professional group in their own way rather than looking at the whole system based on pathways, as the method of examining patient/client experience and the achievement of improved outcomes. The process tends to be driven by measures based on existing data rather than measures that matter. The process is modelled on the principles of quality assurance rather than quality improvement. For example, the Healthcare Commission inspection of children's hospital services has only had a limited impact on improving health services to children.

Further reading

National Audit Office report (www.nao.org.uk/default.aspx)

Healthcare Commission (2007a) Improvement Review, Improving services for children in hospital.

Healthcare Commission (2009) Improving services for children in hospital. Report of the follow up to the 2005/6 review.
NHS Institute for Innovation and Improvement (www.institute.nhs.uk)

Solutions

The basic model of designing services around families, with teams working together co-operatively within managed networks is not the culture or language currently being used across all agencies. The concept of continuous quality improvement does not seem to have percolated into local authority thinking, and both NHS and local authority children's services need to be implementing strategies to achieve "continuous quality improvement". This then needs to be supported by policymakers, commissioners and regulators.

The differences in culture between different government departments needs to be addressed. DCSF is a very large department that produces a lot of statutory guidance for implementation. DH (Children, Young People and Maternity Branch) is extremely small and gives very little statutory advice and depends on individual NHS Trusts to work with professional groups to implement best evidence. The Home Office tends to work independently from both DH and DCSF.

Commissioning arrangements for children's services also need to be reviewed. Guidance on how commissioners work together, the model for commissioning, the contract monitoring arrangements, an introduction of programme budgeting approaches across different agencies, and across primary, secondary and tertiary care all need to be addressed.

The regulation of children's services and the culture of the respective improvement agencies and the way they work together should also be reviewed. There needs to be a move away from regulating professional groups and organisations towards the inspection, regulation and improvement based on pathways and networks.

The balance between personal professional responsibilities and wider team responsibilities across the NHS and LA children’s services for safeguarding

The protection and safeguarding of children requires a team approach. No one professional group has all the prerequisite competencies that are needed to each undertake a comprehensive assessment of the whole family, deliver evidence based interventions to reduce potential future harm, as well as prosecuting perpetrators who have broken the law.

It is extraordinary difficult to create a "team" across the major agencies involved, namely social care, police and health. Often the reality is that a team of different professionals come together around

individual families as they present, rather than a coherent team working as one over a longer period of time. Each professional involved attempts to do their best but, by definition, a team works better together than the sum of the competencies of the individuals involved. All the theoretical models suggest:

i) That good team working requires a shared system of values, shared goals, great communication, clear evidence as well as shared infrastructure such as IT systems.

ii) The quality of decision-making at case conferences is often dependant on who is present, how comprehensive the assessment has been and thresholds for intervention are very dependent on the opinion within the room and the availability of local services.

iii) For families where there are multiple problems there may be many different agencies involved. The majority only work office hours, yet the children and young people require support during evenings, weekends and bank holidays.

Further reading

Mandy, P (1996). Interdisciplinary rather than multi-disciplinary or generic practice. British Journal of Therapy and Rehabilitation, vol. 3, no. 2, pp. 110-112

Johnson, P, Wistow, G, Schulz, R & Hardy, B (2003). Interagency and interprofessional collaboration in community care: the interdependence of structures and values. Journal of interprofessional care, vol. 17, no. 1, pp. 69-83.

Solutions

a) Shared training. All the evidence would suggest that teams need to train together as well as work together if real gains in quality and outcomes are to be achieved. Each agency needs to take a similar approach to hazard and exposure assessment, the same approach to evidence-based decision-making, and shared approaches to priority setting. Currently what is an acceptable risk to one agency may not be an acceptable risk to another.

b) Practical support for families. Currently social care, learning difficulties teams, substance abuse teams, mental health teams, health visitors and a range of other services may be involved with the most vulnerable families. Often the support is not 24/7, and the various teams do not work effectively together. While specialist service support is essential, a simpler process of practical everyday support needs to be developed to reduce unnecessary duplication.

c) The role of community children's nurses versus social workers versus community health workers in supporting families generally, and those with safeguarding concerns need to be resolved within the wider context of the children and families workforce.

Wider social/cultural factors, for example concerning professional training and development, and the status of children and families

a) Wider social/cultural factors

The impact of modern society on children's health and well-being should not be underestimated or ignored. The epidemiology of conditions presenting in childhood has changed dramatically over the last 20 years with reductions in infectious disease, but with significant increases in child mental health problems, children with disabilities and the consequences of excess calorie consumption.

This is an extremely complex issue that is difficult to clearly articulate. No one can dispute that there have been huge strides in "progress" in the last 100 years. But progress has come with a cost. Three of the greatest costs are human induced global climate change, the growth in inequalities both within and between nations, and the growth in the diseases and problems associated with affluence-mainly mental health and obesity.

The aetiology of these problems is attributed to "excessive individualism" and the adoption of "free-market principles" which have ignored resource consumption coupled with the social and environmental impacts of human activity in favour of individual will and organisational profit. Free-market principles (as they are currently interpreted) assume resources are unlimited and ignore the fact that humans live in a finite ecosystem.

b) Professional training and development

The changes in the epidemiology of childhood conditions needs to be mirrored by investment in research to reverse these trends and better management of these disorders. Unlike infectious diseases which are short-term conditions, much of this new morbidity requires a long-term approach often delivered across the home-community-school environment rather than in hospital settings. This requires a different set of competencies to those that traditional medical or nursing education provides. Ensuring that the children's workforce is fit for practice both now and the future has to be high on the government agenda and needs to be complemented with system redesign to enable more community-based provision.

It is probably unreasonable to expect that graduate or postgraduate training will give individuals all the skills that they will need throughout their professional working lives and systems for ongoing career-long education needs to ensure better systems to maintain competence in a changing world.

c) Status of children in society

This is a fundamental question asks "what value the UK places on the health and well-being of children in society today?". The findings from the 2007 United Nations Report on children's wellbeing placed Britain at the bottom of 24 developed nations. For example, why does the UK legal system allow corporal punishment of children, unlike 24 countries in the world who have banned the practice?

Further reading

Layard, R & Dunn, J (2009) The Children's Society: A Good Childhood: Searching for Values in a Competitive Age (Penguin)

Sustainable Development Commission (http://www.sd-commission.org.uk/)

New Economics Foundation (2007) *The European Un-happy Planet Index: An index of carbon efficiency and well-being in the EU. (http://www.neweconomics.org/)*
Child Public Health Mitch Blair, Sarah Stewart-Brown, Tony Waterston, Rachel Crowther.

Solutions

i) The quotation "today's decisions, for tomorrow's children" neatly summarises the approach that needs to be taken- i.e. to examine the future impact of today's decisions on the future health of generations to come, always taking a long-term view on investment rather than valuing short-term profit. The current chaotic financial systems and economic downturn should result in a major re-examination of the impact of free-market principles instead of valuing the combined impact of society in a measure such as the Gross Domestic Product (GDP). Alternatives such as social (Gross National Happiness) and environmental (the Happy Planet Index) measures need to be included as balancing measures.

ii) Shared education. The model of service delivery in the future will increasingly be of teams working with families rather than solely individuals. Team working requires different set of competencies to be developed. The potential for joint undergraduate, postgraduate and continuous professional development across all relevant professional groups needs to be explored and encouraged.

iii) Opportunities for involvement in society are limited for children and young people. The development of Children's Councils, greater participation in the running of schools and opportunities for involvement in community activities all need to be encouraged and available universally. Investment in the development of social capital within communities is of benefit to all members of the community and ultimately reduces the costs on public services through improving mental health and reducing crime.

2. The scope as outlined within the terms of reference

Dedicated children's services (including health visiting and other community services, paediatrics, CAMHS)

a) Child mental health/behaviour problems

Services for child mental health/behaviour problems may be delivered by primary care, CAMHS, community child health services, education based behaviour support teams, social services, and Youth Offending Teams. Few services work across the school-home boundary inevitably leading to inconsistent and possibly ineffective interventions. The numbers of young people recognised with attention deficit hyperactivity disorder (ADHD) and autistic spectrum disorders (ASD) have increased dramatically over recent years and this may be partly explained by policies within education/schools requiring greater academic achievement, that have unintended consequences for those young people with difficulties in concentration or behaviour now being labelled as having ADHD/ASD. Often there is a culture that access to special educational needs provision is limited by a diagnosis, and yet the spirit of the Special Educational Needs act was that educational support was related to children's needs not to a diagnosis. (Both ADHD and ASD can coexist with other comorbid conditions such as learning difficulties, specific learning difficulties, social communication disorders, language disorders, obsessive compulsive behaviours, and other personality disorders), therefore educational interventions purely based on diagnosis may be unhelpful. Even when there is support for academic tasks, provision of social skills support is inadequate leading to bullying due to their social communication difficulties. These children are therefore being failed with significant consequences – 'neglected' by the system which should be supporting them. There are considerable cultural differences between the various agencies affecting both diagnosis and management.

b) Community children's nursing

Health visitors, school nurses, community children's nurses, specialist children's nurses all have different roles and responsibilities which are not always appreciated by other agencies. Because of their different origins, they are often managed by different organisations for example health visitors in primary care, school nurses by PCTs, community children's nurses by acute trusts and specialist nurses by specialist hospital trusts. Depending on service level agreements with commissioning bodies, this causes cultural barriers as, some look at the whole families, others look after children whilst others focus on the condition or disease or specific interventions. The concept of a community children's nurse leading "a team around a family" is well established in palliative care, and a similar model needs to be adopted for all children with significant long-term conditions, including cerebral palsy, diabetes and mental health problems.

c) Community child health

Community child health largely refers to paediatricians who work in community settings who manage the healthcare needs of children with Long Term Conditions (LTCs) including disabled children, those with mental health problems, vulnerable children including safeguarding, together with public-health roles such as immunisation and health promotion programme implementation. Historically they were medical staff who transferred into the health service from Local Authorities after reorganisation in 1976. In some cases, rather than being integrated into paediatric departments they remained isolated in community units (later community trusts and later still primary care trusts). As a result, community paediatricians are often not employed by the same trust as the wider team of professionals with whom they work, which by the nature of their role may include a number of different teams including safeguarding teams, child mental health teams, disabled children's teams, palliative care teams as well as some participating in the acute hospital rota.

The recent policy initiative in "Transforming Community Services" to transfer the provider functions of PCTs into social enterprise organisations may affect the stability and continuity needed in services for vulnerable children and those with long term conditions due to the likely effect on recruitment/retention which in turn will impact on quality/governance, sustainability and outcomes of community services.

Further reading

Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions http://www.act.org.uk/

Transforming Community Services:

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093197

Solutions

The consensus is that wherever possible professionals working in the same team should share the same management structure in order to reduce the potential for fragmentation and silo working. Integration with child and adolescent or child and family therapy services remains contentious despite the obvious benefits of integrating the two teams.

Suggest you refer back to a time where this was the case in some areas and the benefits/impact for CYP and family.

Where integration into the same management team is not possible, programme budgeting based for networks should enable the transfer of resources to where they are most effective and should be supported.

Rather than have school nurses, health visitors, specialist nurses there should be a children's nurse education programme that enables children's nurses to work across a variety of settings and then develop career pathways that meet the needs of the population.

Services dealing with children as part of their wider responsibilities, including primary care, A&E, ambulance and out of hours services; and some aspects of surgery

a) Primary care

Primary care is the bedrock of the UK health system and has a number of benefits over alternative systems where individuals see specialists rather than generalists as their first contact within the health service. However there are concerns that the quality of primary care for children and families may be lagging behind the development seen in primary care for older people or those with specific conditions such as coronary heart disease and diabetes or mental health problems, which have been driven by national targets. We need to change the current culture where children are under prioritised and provide GPs with enhanced training to coordinate the healthcare of children with long term conditions, and for the conditions that they see on an everyday basis. To support this, first contact provision should have ready access to specialist opinions when their competence is exceeded. In particular, GP training for child mental health problems is an area of great concern given the increased numbers of children presenting with these problems.

As a consequence of service reform, and the change in out of hours provision, it means that many families now present in emergency departments with primary care conditions. The recognition of the sick child will always remain challenging, but GPs are now expressing concerns about their abilities to confidently manage these children as they no longer see significant numbers of children who are acutely unwell, as there are reduced numbers of children with significant infectious disease

b) Acute paediatric services

Acute services are facing a unique crisis due to the reduction of middle grade doctors' hours from 100 plus per week down to 48, together with an imbalance of trainee numbers with consultant opportunities.

c) General paediatric surgery

Concerns about the quality of general paediatric surgery have been expressed repeatedly over the last decade. The crisis has been precipitated by general surgeons retiring and their replacements no longer being willing to undertake general paediatric surgery in DGH settings. The traditional approach

has been to refer these children to tertiary centres, but this then undermines the capacity for specialist paediatric surgery.

Further reading

Modelling the Future I, II and III (www.rcpch.ac.uk/Policy/ServiceReconfiguration/Modelling-the-Future)

Solutions

i) Urgent and emergency care. The integration of urgent care centres and emergency departments, sharing common resources such as investigations or short stay paediatric assessment units has not happened due to the cultural differences between primary and secondary care, and the lack of a whole systems approach to commissioning.

ii) Acute paediatric services. The only viable way forward is to reduce the number of inpatient units where these are close to the larger units that have the capacity to expand and expand consultant numbers to replace senior trainees. The advantage of this approach is improved patient care, better learning opportunities for trainees and better work life balance for consultants.

iii) Paediatric surgery. An alternative model needs to be found where children are not referred to tertiary centres, but to larger DGH centres that have the capacity to undertake general paediatric surgery safely. This may also be provided by an outreach team from the tertiary centre providing the specialist care, and the local team providing the supported care pre and post surgery.

Services working with adults whose condition may create pressures or risks for their families, including mental health, alcohol and substance misuse and domestic violence

a) There is widespread concern that adult services managing people with mental health, substance abuse, learning difficulties and domestic violence do not assess the parenting capacity of their clients (when they live with children) as part of their overall assessment. The recent National reviews of serious case reviews show that the majority of children who died do not have child protection plans, but that their parents are known to agencies. It is essential that this culture of considering problems in isolation, without the knowledge or capacity to consider the implications on the wider family (in particular, children), changes; and that other services are actively engaged and form part of the team that manages risk assessment.

b) The service response to families where there are multiple problems is not always coordinated and integrated in a way that delivers best value for money or best outcomes.

c) The needs of children of parents who are "locked up" for whatever reasons also need to be considered. Sentencing for women and men is very different; women are locked up for theft and fraud, men often for violence to others. Are custodial sentences for women the best way of altering their behaviour? What are the unintended consequences for children and young people?

Further reading

Barnados Policy and Practice briefing. When a parent goes to prison
Prison Reform Trust. Bromley briefings. Prison fact file 2008

Policy Exchange (2009). Less crime lower costs

Solutions

Finding ways for services for vulnerable adults to work more effectively with children and family services has to be one of the highest priorities for the next three years. The pathway approach proposed in this response which examines the condition, its impact on an individual, consequences for their family and wider community issues is equally appropriate for adult services. Indeed there are many good practices within children's services that would be appropriate for adult services to adopt.

3. The wider agenda highlighted by David Nicholson

The care of children outside specifically paediatric settings

a) Quality of accommodation

Despite the fact that there have been intercollegiate guidelines to drive the quality of standards in emergency departments, a recent survey demonstrates that these are often not being met. Many hospitals still do not meet the standards outlined in the National Service Framework, and children are also being seen in Independent Treatment Centres which do not meet the criteria for child friendly services, this needs to be recognised as culturally unacceptable.

b) Substance misuse services

Other anomalies include the fact that adult and substance misuse services start from age 18, and child and family therapy services do not cater for substance abuse so creating a hiatus for substance abuse if under the age of 18.

c) Access to health services in schools

The integration of many children with a wide range of disabilities into mainstream school is welcomed. However the unintended consequences for specialist staff such as Allied Health Professionals have not been fully realised with small numbers of AHPs trying to cover a large number of schools especially in services covering a wide geographical area. Often school accommodation is not suitable to the delivery of health services, and this limits both the provision and expansion of health service provision in extended schools.

Health visiting and community services

a) Skill mix within and organisation of community children's nursing teams

The management of nurses working with children and families is often split between primary care teams, PCTs and NHS hospital and mental health trusts. This reduces the potential flexibility of a nursing response to changing needs.

b) Poor equipment/ wheelchair /communication aids services

Difficulties with the provision of equipment, its repair, modification or replacement and some of the obstacles around which department funds equipment are some of the greatest perennial concerns for parents of disabled children. Equipment provision is an essential part of these children's therapy needs that allow them to integrate alongside their peers into their home and school communities.

Withholding communication or mobility devices due to budgetary constraints directly inhibits their social inclusion and in the 21st century is culturally indefensible.

c) Poor youth support services

YOTs are only involved after charges are brought rather than before crimes are committed. In many cases however the young person has been excluded from school, the home environment is poor, their finances limited, opportunities for leisure are nonexistent and they turn to crime. Greater investment in diversionary schemes is necessary to prevent further failure of this vulnerable group.

Pathways of care

BACCH fully supports the model of "pathways of care" for the planning delivery and improvement of services to children and families. The thinking needs to apply across our range of agencies including:

a) Primary secondary and tertiary care
b) Health, education and social care
c) Policy makers, commissioners and regulators

Pathways of care, delivered by competent teams working collaborative networks is at the heart of the model proposed in Modelling the Future.

Further reading

A guide to promote a shared understanding of the benefits of managed local networks
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4114364.
Scottish Executive (1999) The introduction of managed clinical networks within the NHS in Scotland.
Scottish Executive (2002) Promoting the development of managed clinical networks in NHS Scotland

RCPCH (2007c) Services for Children in Emergency Departments.
HBN 23: Hospital accommodation for children and young people

Arrangements to develop the NHS' contribution to safeguarding children

a) Combined health, social care police assessment services

The issue of forming a competent team around a family where there are child protection concerns has already been discussed. One specific issue not previously addressed is the roles and relationships between paediatricians and forensic medical examiners. Forensic medical examiners often do not have paediatric training and since the interpretation of physical signs are different between children and adults, this is unacceptable.

b) Managed networks with sufficient expertise and capacity

Managed networks for child protection do not exist within the health service. If a child presents with renal failure there are specialist services available to support the paediatricians involved. If a child

presents with multiple fractures finding a specialist in osteogenesis imperfecta, or an expert in fabricated illness is often extremely difficult especially at short notice.

c) Arrangements to implement the findings of serious case reviews and child death overview panels

Repeatedly reports reviewing serious Case reviews show the same underlying problems year-on-year and there is concern that any recommendations from child death overview panels will be similarly ineffective in achieving a reduction in future deaths, injuries or abuse.

Management of the transition to adult care

a) Long term conditions

Children with previously fatal conditions are living longer, many into adulthood. Adult services have not yet responded to this need and the model of service delivery is often not in line with the children's model of care that young people and families have previously encountered. For young people who are dependent on others for activities of daily living, their parents are often their carers. Whilst independence for young people is important, the majority remain dependent on their parents and issues arise when, for example, parents are unable to stay with them during hospital admissions. Commonly, adult medical specialists and nursing staff do not have the pre-requisite skills to look after this group of dependent young people. Sadly, sometimes parents are inappropriately excluded from outpatient consultations too. Services need to be developed to support these young people and provide a standard of care appropriate to a first world country.

b) Young people with Attention Deficit Hyperactivity Disorder

Adult psychiatrists have no training or competence in the management of this disorder. The result is that young people find it difficult to access a service as both GPs and adult psychiatrists refuse to be involved.

c) Palliative care services

Generally, children’s palliative care services operate up to the age of 18 or 19. The majority of adult palliative care services are unable to manage young people and their families, as services have traditionally been orientated towards adults with cancer. As young people with life threatening conditions live longer the need for adaptation to provide appropriate care settings and social interaction for this very different group is paramount and requires our adult colleagues and commissioners to recognise this need for a cultural shift.

Solutions

Adult rheumatology and renal services are beginning to appoint new/young adult workers to act as their advocates during health service contact to make the transition between children and adult services. There are also a range of young adult services including specific inpatient provision emerging so as to better meet their specific needs.

The development of specialist children and young persons' nurses can enable better preparation for the transition to adult services.

How the NHS works with its partners to support children

a) Health maintenance and promotion should become a compulsory national curriculum subject of equal standing to numeracy, science and literacy.

b) Children missing school or excluded from school all need a comprehensive health assessment, too many times they have unrecognized health problems that prevent the young person engaging with their education.

c) Looked after children, particularly those who have experienced multiple placements, require extended support post 18, especially if they have children of their own.

How the NHS responds to the needs of families as well as individuals

The NHS should respond to three and possibly four elements, which need to be simultaneously assessed during NHS consultations.

- the child's condition
- the impact on the child
- the impact on the family
- the impact on the community

The reverse also holds true, and interventions may be needed to reduce the negative impact of the community on the family or the child (for example bullying, poverty, crime reduction) sometimes the child is a symptom of the family and therefore parental interventions rather than child orientated interventions are needed (for example behaviour problems, child abuse). The psychological or emotional state of the child will also have an impact on the child's condition or disease progress/prognosis.

The health service needs to have the capacity to either directly address these issues or indirectly tackle these issues through partnership with other professional groups or agencies.

4. Other relevant issues not included in terms of reference

Public service management

a) ***Planning blight with organisational reorganisation***

The different cultures of management between the Department of Health and Department of children's schools and families has already received mention. At local level good teamwork and personal relationships are essential in the provision of children's services. Reorganisation of any part of the service can have a substantial impact on the outcomes within the network as teams and individuals need to relearn their relationships.

b) ***Need to work towards integrated children's units***

Integrated organisations are likely to be able to provide better support for integrated teams, and shift resources to where they are best utilised. Integrated organisations based on networks, with pooled budgets, and a program budgeting type approach are likely to provide the best platform for the continuous improvement in the quality of children's services.

c) ***Vertical integration versus horizontal integration***

Vertical integration is important, for acute care pathways, where children need to move seamlessly from primary care through secondary care to tertiary care. Horizontal integration is important where the child has a long-term condition, and requires input from a range of local services for its optimal management.

Financial systems

Children's health services are particularly vulnerable to activity-based tariff systems of financing because of the complex care offered to whole families, rather than just conditions. Financial systems need to recognise the interventions for three elements - treatment of the condition, the management of the impact of the condition on the child and support for the consequences for the family. Further work is needed to determine whether HRG approaches, based on pathways or year-of-care, offer better opportunities for continuous improvement.

Information

Health reforms have predominantly relied on competition and contestability, on patient choice, plurality of provision and payment by results. Data to inform patient choice, investment to create plurality and payment by condition intervention is simply either unavailable or too difficult to collect.

Targets that do not create unintended consequences are extremely difficult to generate, particularly for complex care. There are examples of unintended consequences of recent changes in one sector on another, for example changes in out of hours provision has resulted in increased numbers of children attending emergency departments; 4 hour targets in emergency rooms force admission to hospital rather than observation; PbR discouraging long term follow up and continuity of care of children with long term conditions and encouraging increased referrals to tertiary centres. Children's services are often not financially viable and therefore not a priority for Foundation Trusts. Measures need to be introduced to encourage and drive joined up thinking between agencies such as looked after children and those with special educational needs

Conclusions

This review is welcomed as it concentrates on the cultural changes that are needed for improvement of children's services that have not been addressed by previous policy initiatives such as the National Service Framework or Every Child Matters. Some of these cultural issues are alluded to in chapter 7 of Healthy Lives, Brighter Futures, otherwise known as the Child Health Strategy, but to date this has had little impact on everyday thinking and practice.

Critical to the future success are three elements:

1. Designing a system that delivers the best experience and outcomes for families.
2. Creating a system that identifies the weakest points in Pathways as the focus for immediate continuous quality improvement.
3. Greater investment and emphasis on prevention whether at a primary or secondary level.

This approach needs to be adopted by policymakers, commissioners and regulators of services who will all need to support a combined approach across health, education and social care to deliver a new model based on teams working in partnership with families, collaborating together within managed network.

For this approach to be successful there needs to be a substantial change in the cultures of every organisation that provide services to children and families. Evidence based decision-making needs to be adopted across all agencies, compliance needs to be replaced with responsibility, innovation and some of the potential risks need to be accepted as part of service delivery, so that continuous quality improvement becomes an integral part of everyday work that in turn becomes more rewarding and motivating. The organisational culture then moves from a didactic top-down culture towards a bottom-up empowering learning culture.

The adoption and translation of the United Nations Convention on the Rights of the Child, together with other relevant conventions and charters, needs to be considered as a possible strategy to embed a shared culture of values across the providers of services to children and families (see appendix 3).

Appendix 1: Summary of Issues Covered

Cultural obstacles that can stand in the way of sustained improvement:

- Perceptions of health services' role in child health and wellbeing and in safeguarding; the challenges to professional practice and how these can be met;
- Challenges to leadership, especially given the disseminated responsibilities across the NHS on children's health and their healthcare and safeguarding and between departments of state/government departments;
- The balance between personal professional responsibilities and wider team responsibilities across the NHS and LA children's services for safeguarding;
- Wider social/cultural factors, for example concerning professional training and development, and the status of children and families.

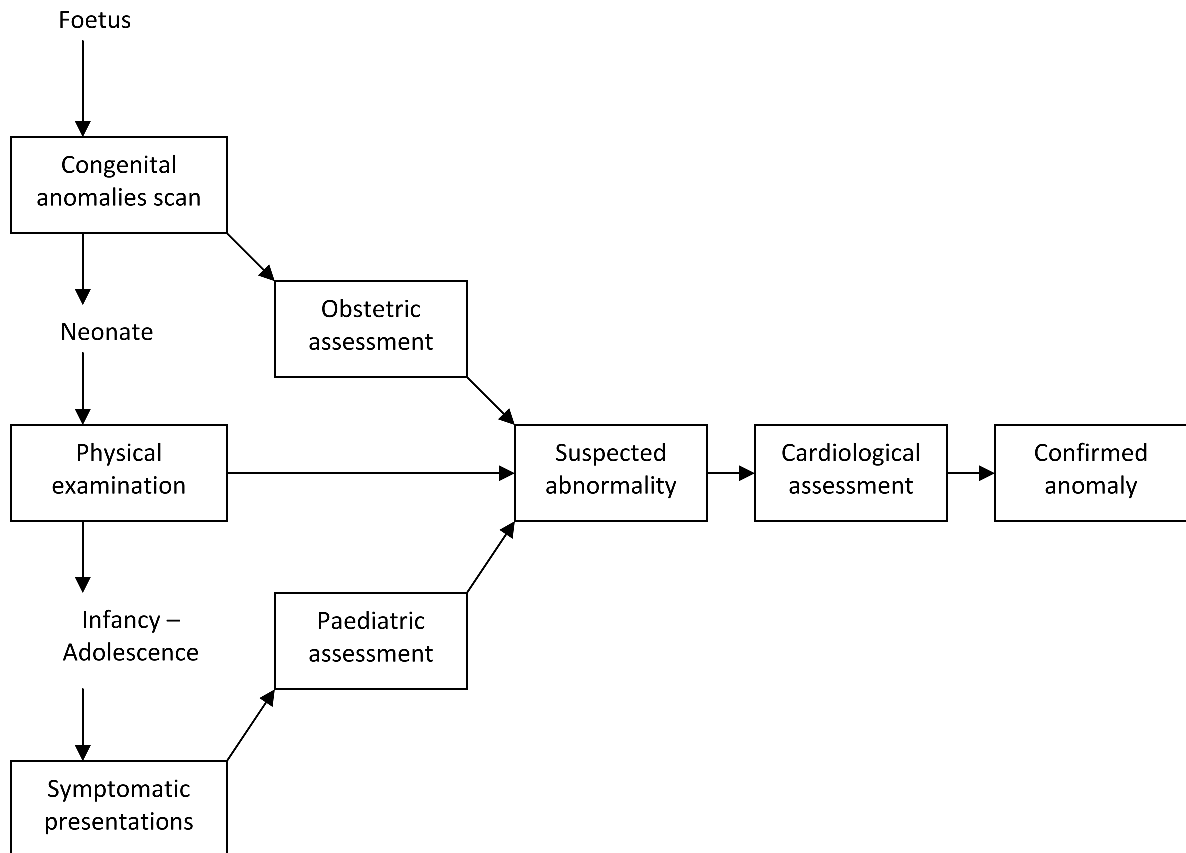
The scope as outlined within the terms of reference:

- Dedicated children's services (including health visiting and other community services, paediatrics, CAMHS);
- Services dealing with children as part of their wider responsibilities, including primary care, A&E, ambulance and out of hours services; and some aspects of surgery;
- Services working with adults whose condition may create pressures or risks for their families, including mental health, alcohol and substance misuse and domestic violence.

The wider agenda highlighted by David Nicholson:

- The care of children outside specifically paediatric settings;
- Health visiting and community services;
- Pathways of care;
- Arrangements to develop the NHS' contribution to safeguarding children;
- Management of the transition to adult care;
- How the NHS works with its partners to support children;
- How the NHS responds to the needs of families as well as individuals.

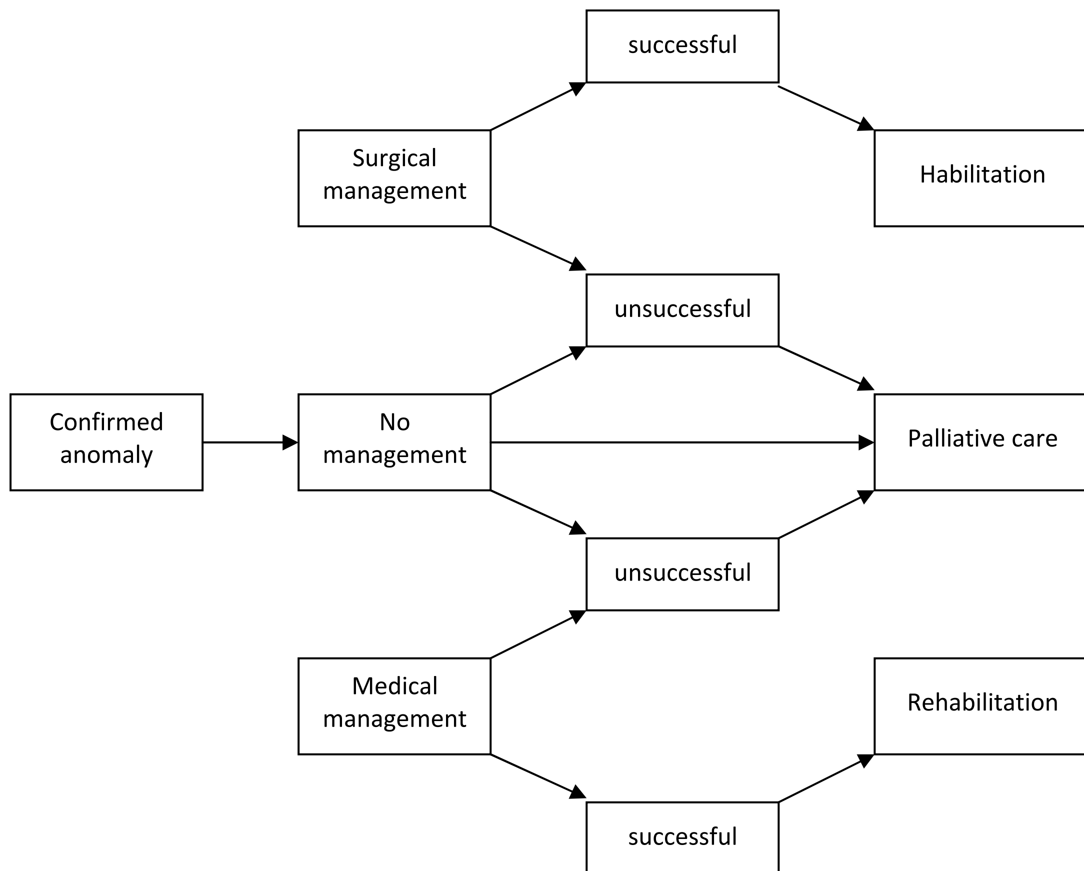
Appendix 2: Care pathway table – from identification to confirmation



Notes on table

Symptomatic presentation may occur before physical examination

Care pathway table – from confirmation to outcome



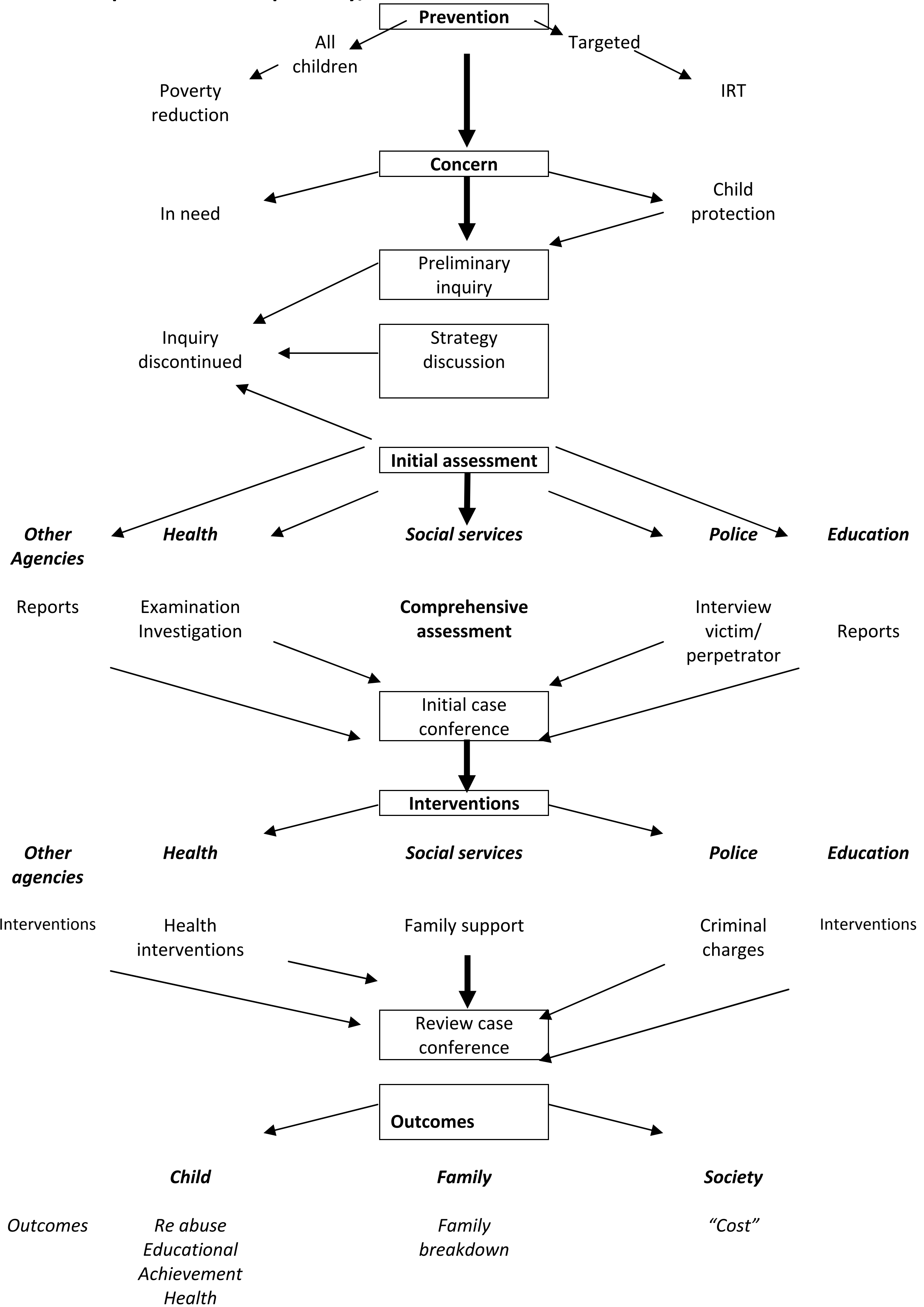
Notes on table

Habilitation and rehabilitation are interchangeable.

Outcomes are dichotomous for ease of presentation.

Combined options of medical and surgical intervention should also be included.

Child protection - the pathway/network



Appendix 3: Health service aspects of the United Nations Declaration on the Rights of the Child

The 42 Rights, included in the UNCRC, can be divided into

- those applicable to the health service, subdivided into:
  - those applying to relationships between children and adults
  - those applying to services for children and families.
  - those with application at a community level

Those applying to people may be called a ***philosophy,*** whereas those applying to services may be called ***principles.***

Philosophical values, applying to relationships, include

- children have the right to have their opinions take into account (article 12)
- children have the right to receive and share information (article 13)
- children have the right to think and believe what they want (article 14)
- children have a right to privacy (article 16)
- children have the right to reliable information (article 17)

Principles applying to services, include

- all organisations concerned with children should work towards what is best for each child (article 3)
- all children have the right of life (article 6)
- children should not be separated from their parents unless it is for their own good (article 9)
- governments should ensure that children are properly cared for (article 19)
- children who have any kind of disability should have special care and support so that they can lead independent lives (article 23)
- children have the right to good quality healthcare (article 24)
- children have a right to relax and play and join in a wide range of activities (article 31)
- children should be protected (article 13, 34, 35, 36)
- children have the right to clean water, nutritious food and a clean environment (article 24)
- children have a right to a standard of living that is good enough to meet their physical and mental needs (article 27)
- children who have been neglected or abused should receive special help to restore their self-respect (article 39)