A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND

CHAPTER 6: DESIGNING QUALITY CHILDREN’S HEALTH CARE SERVICES
“Everyone in health care must recognise that they have two jobs when they come to work each day: doing the work and improving it”

Batalden and Davidoff (2007)

Designing a model of care that will meet the needs and preferences of children and their families is a substantial responsibility. It is also a remarkable and rare opportunity. This short reflection considers the key drivers of good care and service; reimagining our health system, our perceptions of quality and how it can be achieved through a new model of care for the years ahead.

Reimagine our System
Paediatrics has seen wonderful advances over recent decades. Developments such as vaccination, improved care of the newborn, surgical innovations and new medications have eliminated many of the historical perils and scourges of childhood that were familiar until recent times. Most children today can expect to live a long and healthy life. The benefits of new knowledge and technology however are born from complexity. Healthcare is no longer a simple interaction between individuals, it is now involves multiple relationships with professionals and technologies, in many places, possibly over several years or even a lifetime. The origins of health are even more complex extending across generations, society and the globe. We often refer to this complexity as “the system” and whilst it has brought a multitude of benefits it has also given rise to many of the challenges in modern healthcare; the risk of harm from care, the demand on treatments that are required by many, a sense of feeling lost or unheard and the difficulties in managing a lifetime of personal medical information are all examples.

As modern healthcare has evolved and become more complex it has not always been possible to ensure that the components of our system interact and align in the way we would want them to. In contemplating a model of care we have a chance to pause and consider what we really want. We can design a model of care, a system, which integrates and works together. We can design a model of care that respects the needs of the child as a whole, their physical, mental and spiritual needs, together. We can design a system that delivers the care needed each day but one that also has the capacity to continuously improve. We can design a model of care that delivers to our purpose, and that purpose must be quality.

There are two important facts to consider when viewing the model of care as a system. Firstly, modern systems rely on teams rather than individuals. This requires us to design for teamwork and communication so that teams have what they need to work together. Secondly, more important than pursuing excellence in any one part of the model of care is ensuring that all of its components, from home to hospital, fit together to achieve our goal:

Quality care and service for all children and families, in all parts of Ireland, all the time.

Reimagine Quality
Recent decades have seen an increased focus on the quality and reliability of health services. In 2001, the Institute of Medicine (IOM) in the US published a landmark document, Crossing the Quality Chasm, where it named six domains that represent quality in healthcare.
Quality care, they suggested, would be:

- Safe - Avoiding harm to patients from care that is intended to help them.
- Effective - Providing care based on scientific knowledge and which produces a clear benefit.
- Person centred - Providing care that is respectful and responsive to individuals’ needs and values.
- Timely - Reducing waits and sometimes harmful delays.
- Efficient - Avoiding waste of resources, times, ideas etc.
- Equitable - Providing care that does not vary in quality because of a person’s characteristics or ability to pay for care.
- Reliable – Providing services consistently and as intended at the appropriate time.

In Ireland today it is possible to identify many improvements throughout paediatrics and child health. Advances in effectiveness can be seen through the development of evidence-based practice, clinical guidelines and care pathways. Safety is more often seen as non-negotiable and failures to implement recognised safety interventions or to learn from adverse events is seen as unacceptable. However it is person centeredness that has shown the potential to be transformative in how we think about healthcare. Person centeredness challenges everyone to consider their purpose; how might we provide the right care to all children and their families in the ways that they want and need it?

In a paradigm shift that person centeredness makes possible Brilli et al. (2014) re-imagined the domains of quality from the point of view of the child and family, suggesting five:

- Don’t harm me
- Cure me
- Respect me
- Guide my care
- Keep us well

Whilst this perspective reflects the wants and needs of children it does so in a way that connects them to the wants and needs of the staff providing care; to have purpose, joy and meaning in their work. The concept of quality in healthcare will continue to change and as long as kindness and respect for the person (child, patient, client, family, carer or professional) are our core values it will continue to progress.

Reimagine Improvement

Traditionally healthcare has relied on research, innovation and education to drive improvement. These approaches remain important, as they have led to many of the advances in modern medicine; however the implementation of best practice is variable and often slow. In addition, the expansion of medical services, combined with an expanding and aging population, has pressed us to examine the value of new and existing interventions. A model of care that will reliably deliver quality and value requires not only good planning but also the ability to manage for day-to-day excellence and to improve.

There are many elements that will support the model of care but five are essential:

- Patient Partnership
- Clinical Leadership
- Integrated governance
- Improvement knowledge
- Data
1. **Patient Partnership**
   
   The purpose of all health services is to provide for patient needs in a manner that serves patient preference. This requires a new relationship between patients and providers that recognises this and balances it with other demands such as cost, staff availability, location and the wishes of other patients. Focusing on the outcomes that matter to patients and their experience within the health system are important and can only be developed in partnership. Getting real patient input requires the development of training and supports for patients and families who wish to become involved.

2. **Clinical Leadership**
   
   The role of leaders is to promote, articulate and share a vision of quality for the real world. Leaders shape a culture and create the conditions that enable staff to deliver quality care. Clinical (nursing, allied health, medical) leaders are particularly important because of their credibility and their understanding of the complexity of the healthcare system. Clinical leaders need to be seen to act to the values of their organisations as well as speak to them. Leadership must be sought, nurtured, coached and developed if we are to get the leaders we want and need for the model of care.

3. **Integrated Governance**
   
   Governance provides the structures, agreed rules and standards that allow complex healthcare systems to achieve quality. It also provides accountability that is open, transparent and appropriately responsive. Governance must oversee learning systems that ensure that all organisational experience is used to improve. Integrating governance structures across traditional lines (clinical, operational, finance) accepts the interdependency of all parts of the system and improves how they work together. Good governance serves as a link between the senior levels of organisations and those working directly with children and their families.

4. **Improvement Knowledge**
   
   Improvement science has emerged from the theories of W. Edwards Deming and experience from the fields of psychology, social science, engineering, statistics and business know how. Deming described four essential areas that needed to be understood and addressed for improvement to occur; 1) the psychology of change 2) Systems 3) Measurement variation and 4) The method of building improvement knowledge. Most improvement methodologies have their origins in the application of Deming’s theories, including Lean-Six-Sigma, Total Quality Management and the Model for Improvement. Regardless of which method is applied to the process of improvement the value of using proven methods is well accepted. Many methods focus on simple principles such as the importance of standardisation or ensuring that all activity must benefit the patient. All methods highlight the need to access the unique knowledge that frontline staff possess and the importance of involving them in any change process. Everybody working in healthcare requires a basic understanding of quality improvement methods recognising that it is everybody’s responsibility. Some require advanced training to support implementation and quality improvement efforts.

5. **Data**
   
   Central to all theories of quality is the need for measurement and data. Without data it is impossible to show evidence of improvement. For many clinicians this requires new knowledge about the application of data that differs from that used in medical research. Understanding the value of using small amounts of data over time and the importance of how that data is presented in order to influence behaviour is critical. Better use of information technology to assist with data collection and analysis will support implementation of the model of care.
In addition to using data to aid improvement activity, it may also be used to identify improvement opportunities. Measuring variation within and between healthcare systems is a useful means of identifying possible areas of concern but also examples of positive deviance, where solutions to system wide problems may have already been implemented. Examining variation on important childhood outcomes such as mortality, globally or across other high income countries allows us to identify health systems and models of care that have addressed important problems. Openness and transparency of key data is essential if we are to learn from each other. There will always be a degree of variation and recognising when this normal is important so as not to react unless necessary.

In reimagining improvement we place it as an equal goal to completing our everyday work. Improvement becomes continuous and the principles of improvement are applied to all that we do. Medical research and education remain central to the progress of child health and must continue to be supported but they must integrate with implementation and quality improvement strategies. Equally quality improvement should seek to benefit from the rigor of academic scrutiny and evaluation to ensure it too is always evidence based.

**Imagine**

“In dreams begins responsibilities”

*WB Yeats (1914)*

Shortly after Yeats wrote these words the people of Ireland began to shape the country they had long imagined. A century later we are have a new opportunity to improve the lives of children and their families. A new opportunity to improve the health of our population, to improve the quality of healthcare and to improve the use of limited resources.

Irish health professionals have been planners, leaders and frontline staff in some of the best children’s hospitals and healthcare systems in the world. As health professionals we must continue to advocate for the resources needed while at the same time playing our part in leading, collaborating and delivering a world-class model of care for children and families for today. As health professionals we must be ambitious and challenge ourselves to push the boundaries of science through research but also through service.

This model of care will contribute to the future health, wellbeing and fortune of our country. It will also speak to our values as a country. One that cares for those unable to represent themselves. One that cares for those exhausted from caring and unable to ask. Or one that cares for those who simply need hope, kindness and support.

**Together we can.**

**References**