PAEDIATRICS

A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND

CHAPTER 8: INTEGRATED CARE

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Introduction

Integrated care is defined by the World Health Organisation as “a concept bringing together inputs, delivery, management and organisation of services related to diagnosis, treatment, care, rehabilitation and health promotion. Integration is a means to improve services in relation to access, quality, user satisfaction and efficiency.”

Distinction is made between:

- Horizontal integration (linking similar levels of care, e.g. multiprofessional teams)
- Vertical integration (linking different levels of care, e.g. primary, secondary and tertiary care)

Professional integration happens when different healthcare professionals or specialties work together to provide joined up services.

For the child and their family, integration means healthcare that is seamless, smooth and easy to navigate – a coordinated service which minimises both the number of steps in an appointment and the number of separate visits to a healthcare facility that are required. An integrated care pathway for children and young people that enables them to move from primary to secondary to tertiary care as required, and back again, in a seamless manner is the cornerstone of the national model of care for paediatrics.

International Trends in Paediatric Healthcare

In mapping out a future model of care for paediatric healthcare services in Ireland, consideration needs to be given to emerging international trends in paediatric healthcare, in particular those that have demonstrated improved clinical outcomes for children and young people. Currently, the focus is on:

- Delivering services as close to the child’s home as possible, including community and home-based care
- Treating children in ambulatory settings wherever possible, and admitting them for inpatient care only when necessary
- Concentrating expertise and experience in a single tertiary centre serving a critical mass population
- Using this centre to support integrated networks of tertiary, secondary and primary care
- Reducing the average length of stay in hospital
- Creating interprofessional practices and interdisciplinary teams
- Standardising care processes throughout the healthcare network
- Use of information and communications technology (ICT) to facilitate diagnosis and treatment to enable timely communication between clinical experts, secondary and primary care providers

8.1 CARE OF CHILDREN WITH CHRONIC CONDITIONS

The present healthcare delivery system evolved in response to the need to deliver acute episodic care for infectious diseases, and was not designed to provide ongoing care for complex chronic illness. Recent attempts to provide comprehensive coordinated care more effectively for individuals with complex diseases have introduced the ‘medical home’ concept, the chronic care model in primary care, and disease-specific, multidisciplinary specialty clinics. In 1992, the American Academy of Paediatrics adopted the recommendation that all children should have a ‘medical home’, which they defined as care that is “accessible, continuous, comprehensive, family-centred, coordinated and compassionate”.

Both the chronic care model and the medical home concept involve a multidisciplinary team that provide coordinated care based on planned visits with follow up telephone and electronic contact, and a focus on monitoring disease markers, delivering preventive services, and coaching patients and family members in disease self-management. Both also emphasise the need for accessible, ongoing comprehensive primary care, coordinated and co-managed with specialty care. This coordination of care is a central element, implying that the various aspects of comprehensive health care and related services integrate to promote unified delivery.

8.2 INTEGRATION BETWEEN PRIMARY CARE AND SECONDARY CARE

A major issue for general practitioners (GPs) is the difficulty and time it may take to obtain a consultant opinion about a child's condition. Many outpatient waiting lists are in excess of two months, and this can be a source of frustration for both parents and GPs. While most paediatricians will use 1-2 urgent slots per clinic for urgent GP referrals, these need to be protected and used appropriately.

Integration between primary care and secondary paediatric services can be improved by:

- Providing rapid access clinics for GPs, ensuring an appropriate environment for assessing urgent but non-emergency patients. These clinics would also allow for urgent follow up of paediatric patients from the emergency department who do not require admission but who need early consultant review. There should be easy access to facilities for investigations as well as the ability to provide short term treatment. Reducing paediatric outpatient waiting times is a key element in ensuring the success of these services.
- Improving ICT infrastructure to allow easier access by GPs to blood tests and radiology results. These results could then be discussed over the telephone with a paediatrician if required.
- Providing consultant paediatrician 'hotlines' providing GPs with access to telephone consultant paediatricians to discuss concerns.
- Introducing short stay units with a focus on early discharge home of children and avoiding overnight stays where possible. This will be more likely to happen if there is early consultant input and appropriate outpatient review facilities.
- Use of algorithms for the management of common conditions in child health.
- Ensuring strong links between GPs, public health nurses, paediatric health and social care professionals and public health doctors. Fully staffed paediatric services at primary care level, and children's disability network teams, should be accessible to GPs across the country and avoid overload of acute paediatric services.

8.3 IMPROVED FLOW THROUGH SCHEDULED SECONDARY AND TERTIARY CARE

Consistent with changes throughout our healthcare system, an increasing proportion of care is being delivered in ambulatory settings including outpatients, outreach clinics, telemedicine and in the home. The outpatients department is a crucial access point for the majority of children, where diagnostic tests are ordered and reviewed, and decisions regarding treatment are made. Many challenges exist when managing demand for specialist outpatient services, especially in children with complex needs, chronic disease or comorbidities, and these children should be managed on a shared care basis where possible.

Integrated outpatient services that are responsive to children's needs should include:

- Consultant paediatricians
- Clinical nurse specialists
- Dietitians
- Physiotherapists
- Speech and language therapists
- Occupational therapists
- Psychologists
- Social workers
- Community children's nurses working across both settings

In Australia, the Victorian Public Hospital Specialist Clinics Strategic Framework (2009) identified five high impact service improvements to be delivered, all of which are applicable to the Irish setting:

1. Increase capacity for new patients
2. Provide individualised appointments for all new patients
3. Set patient journey standards
4. Establish local specialist clinic telephone services
5. Better monitor outpatient services

Following visits by the national clinical programme leads to tertiary paediatric hospitals, it was apparent that while outpatient referrals are received from a variety of sources including GPs, area medical officers and the emergency department, almost all specialties experienced direct referral from primary to tertiary care, e.g. children with headaches were referred directly to a consultant neurologist, or those with innocent murmurs directly to cardiology. This results in extended wait times for new appointments and is not sustainable into the future.

A number of valuable suggestions put forward by multidisciplinary team members at these visits can help to improve patient flow through outpatients departments nationally, including:

- The appointment of general paediatricians with a special interest, e.g. in cardiology, in large regional centres
- Nurse-led clinics, and increased roles for advanced nurse practitioners
- National strategies / clinical guidelines for the management of conditions, e.g. innocent murmurs, endocrine conditions, asthma, epilepsy, via an electronic web portal
- Development of outreach clinics from the large tertiary centres to regional centres
- Rapid response first visit general paediatric clinics
- Introduction of managed care networks and better shared care services, e.g. for children with epilepsy
- Development of short stay observation units within emergency departments
- Business manager posts to manage outpatient clinics and streamline referrals from primary care

Reducing outpatient non-attendance can also contribute significantly to reducing waste in the system. In England, the NHS Improvement Forum developed a sustainability toolkit (2009) for improving cardiology outpatient pathways. This methodology is widely applicable, including suggestions to reduce or eliminate unnecessary follow up visits which contribute to high rates of non-attendance and increase waiting times.

In order to reduce waiting times and unnecessary appointments, and maximise clinical outcomes and the patient experience, there needs to be an understanding of demand, capacity and patient flow in the service:

- In measuring demand, the number of new referrals should be quantified each year, as well as the resources available to deliver outpatient services. Based on these data, any shortfalls in resources (e.g. staff, infrastructure) should be identified and managed appropriately.
- When scheduling appointments, standardised clinic templates should be developed that are appropriate to the specialty and local needs. Last minute clinic cancellations, e.g. due to study leave, should be avoided.

- Referrals from primary care should be made to general paediatrics in the first instance, where the child can be assessed and, if necessary, an onward referral can be made to the appropriate tertiary specialty.
- All referrals must contain the minimum required data for appropriate triage. Electronic referrals should be considered. A structured process for triage of new referrals that includes measurable performance metrics such as time to triage, categorisation of new referrals, and waiting times for new and routine appointments, should be implemented.
- Outpatient services should be delivered through consultant-led teams with care of the child shared between members of that team. This demonstrates to families that their child is being cared for by a team of healthcare professionals, not an individual.
- Care guidelines (initially locally, but later nationally) should be implemented.
- Communication structures between primary, secondary and tertiary paediatrics need to be optimised.
- Outpatient services should be continuously monitored and improved, e.g. number of new referrals, wait times, non-attendance rates, new to return ratios.
- Patients should be discharged appropriately from clinics.

Suggested Performance Metrics for Outpatient Services

1. All referrals should contain the minimum dataset set out by HIQA and where this is not supplied the referral should be sent back to primary care
2. Clinical prioritisation occurs only if the healthcare professional accepts the referral
3. Telephone and internet consultations are counted as activity – virtual consultations are likely to increase
4. Web-based referrals are the way forward
5. Patients who have been seen in the emergency department, where a diagnosis has been determined and agreed by the relevant outpatient service consultant and treatment started, are regarded as review appointments in outpatient clinics. Those seen in short stay observation or assessment units who require additional follow up may require a new appointment slot.
6. Establishment of rapid access clinics whereby patients are seen in an expedited manner within 14 days
7. Provision for nurse-led and HSCP-led clinics – both groups should receive their own referrals, make clinical decisions and discharge patients from their care
8. New to return ratio is calculated by dividing the number of follow up attendances by the number of outpatient new attendances. It should be 1:2.
9. No child waiting longer than 20 weeks to be seen
10. 'Did not attend' (DNA) rate is calculated by dividing the number of DNA's by the number of appointments made. DNA rates should be reduced to < 10%.

8.4 TRANSITION TO ADULT SERVICES

Many children and young people now survive into adult life with complex conditions that previously would not have survived infancy. These conditions can affect many body systems and aspects of a young person's life. Poorly planned transition from paediatric to adult health services can be associated with an increased risk of non-adherence to treatment and loss to follow up, resulting in serious consequences – both in terms of morbidity and mortality, as well as increasing anxiety or psychological distress and impacting on social and educational outcomes. Successful transition planning and programmes depend on careful collaboration between child and adult services.

Transition is a process that should be planned and managed, not a single event. Staff working with young people must balance the need of the young person for privacy and confidentiality, and their wish to take more responsibility for their own health care, with the need for their parents to have sufficient information to provide the ongoing support often required. There are several models for good transition with no clear evidence that any one is superior. Different approaches may be needed for different types of conditions according to their prevalence and how their specialist health care is organised. Healthcare professionals may need to consider further development of their knowledge and skills in working with young people, including:

- the biology and psychology of adolescence
- communication and consultation strategies
- multidisciplinary and multiagency teamwork
- understanding the relevant individual conditions, their evolution, and potential consequences in adult life

As they get older, children need to become more involved in decisions relating to their care or treatment so that by the time they are young adults they have learned to take responsibility for their own health. The task is more complicated for those with long term health problems, with many children and young people now surviving with previously fatal conditions that can present new or unfamiliar challenges. Most young people will look forward to becoming adults and moving from school to higher education or work, regardless of medical conditions or disabilities, and it is important that healthcare professionals reinforce these positive attitudes rather than focus on medical issues or problems. They may also need help with self-care and in developing their communication and decision making skills, to manage social, educational and employment opportunities and challenges as part of independent living. Their parents may also benefit from support and information on advocacy.

Planning Transition to Adult Services

An investment is required in terms of time, resources and commitment – but this is small in comparison to that invested in each child throughout their childhood. Implementing improved care transition involves:

- Recognition of the importance of the process
- Adequate consultation with professionals and users
- Flexibility in the timing of transition
- A period of preparation for the young person and their family
- Effective information transfer
- Monitoring of attendance until the young person is established in the appropriate adult service

It is important to recognise the differing perspectives of paediatricians, adult physicians and GPs. It can be difficult for paediatric staff handing over a patient to another service when they have become attached over many years. As many of these long term conditions can be rare, and until recently relatively unknown in adult practice, they may also worry about a lack of expertise among their adult colleagues. On the other hand, adult specialists can share this worry, but also can find it difficult to focus on the needs of these young patients when they are overwhelmed with large numbers of older adults, many with multiple pathologies.

GPs may be consulted by young people during transition and asked to take on a wider role. Up to that point, the paediatrician may have looked after all minor ailments in their patients with complex problems, with the result that the GP is then poorly equipped to take over more of the young person's care when they leave paediatrics. Information sharing with GPs and others in the community and primary care may also be inadequate. Other health promotion and preventive staff in the community may have little or no interaction with these young people resulting in missed opportunities for advice or interventions.

Timing of Transition to Adult Services

Each service should have a policy on the timing of transfer. While there is no one right time or age for transition, the suggestion is between the ages of 16-18 years. Rigid age limits defining children's and adult services are not desirable, as the timing must depend on the developmental readiness and health status of the individual adolescent as well as the capabilities of the adult providers. Time since completion of treatment might be relevant in some cases, and transition should, where possible, be during remission rather than relapse or active disease. Chronic illness and its treatments can result in both physical and psychological delay in maturation.

Preparation for transition should begin by mid-adolescence, at the latest, when discussions with the individual young person should encourage independence and reassess their understanding of their condition, its treatment and possible side effects, and how to access help from professionals. A schedule of likely timings and events should be discussed both individually with the patient, and if appropriate with their parents or guardians who will likely support and guide them through the process. Young people need to be given information on their rights, including confidentiality and consent, as well as how to deal with specific medical situations.

If transfer is to a distant clinic, the adolescent should receive detailed information and visit the adult clinic well in advance, preferably with a trusted carer, to introduce them to the adult environment and staff. The coordination of this process can be undertaken by a member of the multidisciplinary team caring for the young person, such as clinical nurse specialists or therapists, who can address patient concerns prior to formal transfer.

8.5 KEY RECOMMENDATIONS

- An integrated care pathway for children and young people that enables them to move from primary to secondary and tertiary care as required, and back again, in a seamless manner is the cornerstone of the national model of care for paediatrics.
- Integration between primary care and secondary paediatric services can be improved by providing rapid access clinics for GPs , improving ICT infrastructure to allow easier access by GPs to blood tests and radiology results, providing consultant paediatrician 'hotlines' to support GPs, use of algorithms for the management of common conditions in child health and ensuring strong links between GPs, public health nurses, paediatric
  health and social care professionals and public health doctors
- Both the chronic care model and the 'medical home' concept involve a multidisciplinary team that provide coordinated care based on planned visits with follow up telephone and electronic contact, and a focus on monitoring disease markers, delivering preventive services, and coaching patients and family members in disease self-management.
- In measuring demand, the number of new referrals should be quantified each year, as well as the resources available to deliver outpatient services. Based on these data, any shortfalls in resources (e.g. staff, infrastructure) should be identified and managed appropriately.
- When scheduling appointments, standardised clinic templates should be developed that are appropriate to the specialty and local needs. Last minute clinic cancellations should be avoided.
- Referrals from primary care should be made to general paediatrics in the first instance, where the child can be assessed and, if necessary, an onward referral can be made to the appropriate tertiary subspecialty.

- All referrals must contain the minimum required data for appropriate triage. Electronic referrals should be considered. A structured process for triage of new referrals that includes measurable performance metrics such as time to triage, categorisation of new referrals, and waiting times for new and routine appointments, should be implemented.
- Outpatient services should be delivered through consultant-led teams with care of the child shared between members of that team.
- National clinical guidelines should be developed and implemented.
- Communication structures between primary, secondary and tertiary paediatrics need to be optimised.
- Outpatient services should be continuously monitored and improved, e.g. number of new referrals, wait times, non-attendance rates, new to return ratios.
- Patients should be discharged appropriately from clinics.
- Successful transition planning and programmes depend on careful collaboration between child and adult services.
- Transition is a process that should be planned and managed, not a single event.
- Preparation for transition should begin by mid-adolescence, at the latest, when discussions with the individual young person should encourage independence and reassess their understanding of their condition, its treatment and possible side effects, and how to access help from professionals.

8.6 ABBREVIATIONS

CDU	Clinical Decision Unit
DNA	Did Not Attend
GP	General Practitioner
HIQA	Health Information and Quality Authority
HSCP	Health and Social Care Professional
ICT	Information and communications technology
NHS	National Health Service
OPD	Outpatients Department
PAU	Paediatric Assessment Unit

8.7 REFERENCES

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