PAEDIATRICS

A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND

CHAPTER 17: CLEFT LIP AND PALATE SURGERY

Feidhmeannacht na Seirbhíse Sláinte
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ROYAL COLLEGE OF PHYSICIANS OF IRELAND

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17.0 INTRODUCTION

Cleft lip and palate is a common birth defect affecting approximately 1:650 live births in Ireland. Children born with this congenital condition can present with interrelated complex issues, therefore are referred for management to the multidisciplinary cleft team in either Temple Street Children's University Hospital (Temple Street), Our Lady's the cleft teams at Temple Street, Crumlin, St. James's Hospital (SJH) and the Mater Misericordiae Hospital (MMH) unified their expertise and established the Dublin Cleft Centre (DCC) in 2000.

17.1 CURRENT SERVICE PROVISION

The management of cleft conditions requires a collaborative and multidisciplinary approach in order to achieve optimal results. The UK (United Kingdom) Clinical Standards Advisory Group (CSAG) report (1998) evaluated cleft care in the UK and recommended that children with cleft conditions receive treatment in centralised, high volume units with specially trained staff.

17.1.1 Dublin Cleft Centre

The DCC is a recognised national and international centre of excellence, delivering a high quality well coordinated multidisciplinary service for the management of cleft lip and palate and non-cleft related velopharyngeal dysfunction. The DCC multidisciplinary team comprises the following:

- Plastic surgeon with specialist training in cleft lip and palate surgery
- Cleft service manager / coordinator
- Speech and language therapists (SLT) specialising in cleft palate
- Cleft nurse specialists (CNS)
- Audiologist
- Orthodontist
- Paediatric Dentist
- Prosthodontist
- Oral and Maxillofacial surgeon
- Ear, Nose and Throat (ENT) surgeon / Airway;

with involvement of neonatologist, paediatrician, paediatric anaesthetist, respiratory, ophthalmology, dietetics, medical social work and clinical photography. Geneticists, psychologists and many others also have roles to play. The team manages the assessment and diagnosis of referrals received, and provides intervention from all team members as required, to remediate the child's difficulty and to maximise his/her potential development. Patients and parents are considered an integral part of the team. Referrals are received from medical and health and social care professionals. The service has evolved to incorporate referrals from foetal medicine units nationally. Expectant parents receive timely relevant information, counselling and support following an antenatal cleft diagnosis. The DCC is affiliated to the Craniofacial Society of Great Britain and Ireland (CFSGBI), and submits audit data collection annually. The multidisciplinary teams meet quarterly and have jointly developed protocols for the general management of children born with cleft lip and/or palate. The Cleft Lip and Palate Association of Ireland (CLAPAI) is an established family support group. Their website *www.cleft.ie* provides a contact point for parents and patients, and in conjunction with the DCC has developed a parent information pack which is available to families nationally through the maternity units or cleft coordinators.

The DCC has established a 'hub and spoke' model of care, with the hub in Dublin and spoke centres in Galway and Sligo. Close working relationships have been developed with regional and community services to reduce the burden of care where possible. For satellite clinics in Sligo, the cleft surgeon, cleft services manager and SLT travel to provide clinic services (twice yearly) in conjunction with the local consultant orthodontist and link SLTs. For Galway satellite clinics, the cleft surgeon and cleft coordinator travel to provide clinic services (6 clinics per year minimum) in conjunction with the local consultant orthodontist, SLT, ENT, audiology, nursing and community paediatric dental services. Palatal videofluoroscopy and nasendoscopy services are also provided locally where possible. There are service level agreements in place for both outreach clinics.

Dublin Cleft Centre Services

Medical	Consultants	SpRs	Registrars	SHOs
Paediatric Plastic Surgeons	2	1 (Crumlin)	2	2
Paediatric Maxillofacial Surgeons	1-2	0	0	0

Nursing	
General nurses	N/A
Specially trained nurses	2 cleft coordinators have completed a Cleft CNS course in the UK. The remit of the coordinator's post incorporates both clinical and administrative duties
Advanced Nurse Practitioners	None
Clinical Nurse Specialists	0.6WTE Temple Street
Allied Health and Social Care Professionals	
Speech & Language Therapists	Temple Street: 2WTE SJH: 1 WTE Crumlin: 1WTE UHG: 0.8 WTE
Dental	Temple Street: One theatre session and two clinic sessions per month (11 hours) Crumlin: Two dedicated clinics per month and ongoing access to dental services as required
Orthodontist	Consultant in SJH with one session per month in Temple Street and two sessions per month in Crumlin. Specialist orthodontist in SJH
Prosthodontist	SJH: 1 WTE
Maxillofacial	Two clinic sessions in SJH per month, and one all day theatre session and 2 afternoon sessions in Crumlin per month

Audiology	Newborn infants are screened under the National Hearing Screening Programme (NHSP) and are listed for targeted follow-up with Community Audiology. Temple Street: Audiology appointments are available on the morning of monthly combined clinic. Audiology assessments are provided as part of multidisciplinary audit clinic at 5 years of age. Patients can also access audiology services via the four outpatient ENT clinics and may be directly referred to audiology services. Crumlin: Audiological services are accessed through the ENT Clinics SJH: Audiology assessments are routinely scheduled for patients attending for audit review age 5, 10, 15 and 18 years old.
ENT	Temple Street: No designated ENT session for cleft clinics Crumlin: 1 ENT session on the 3rd cleft clinic per month Airway patients are managed separately in Temple Street and Crumlin.
Medical Social Worker	Temple Street: Referral to MSW Department Crumlin: Referral to MSW Department
Management and Support Services	
DCC Management /Administration	Cleft Coordinator SJH/Crumlin: 1 WTE Cleft and Craniofacial Services Manager Temple Street: 1 WTE
Administrative Assistants	Temple Street: 0.4 WTE Cleft and Craniofacial Department 1WTE SLT Department 1WTE Consultant Secretary, Department of Plastic Surgery Crumlin: 1WTE Consultant Secretary, Department of Plastic Surgery 1WTE SLT Department SJH: 1WTE Orthodontics and Prosthodontics
Clinical Photography	Standard records are required pre- and post-operatively. Standardised Audit records are also taken at 5, 10, 15 and 18 years old.
Other Patient and Client Care	
Acute	Foetal medicine units, maternity hospitals and special care baby units, neonatology, paediatricians, airway management, respiratory, ophthalmology, genetics, dietetics, craniofacial services, radiology, general surgery, Percutaneous Endoscopic Gastrostomy (PEG) CNS, paediatric liaison team, cardiology, immunology, infectious diseases, physiotherapy, occupational therapy, phlebotomy, general ward management, high dependency and intensive care units (HDU/ICU).

Primary Care	General Practitioners (GPs), public health nurses, early intervention teams, community social work services, child protection services, family support services, community dental services, community SLT services, clinical psychology, educational psychology, community physiotherapy, community occupational therapy, community audiology, ENT services, orthodontics, schools.

Total Number of Beds

There are currently no protected beds. This service would benefit from protected bed spaces ensuring that scheduling of time specific surgery is within agreed DCC protocols, e.g. lip repair at 3 months, palate repair at 6-9 months, dentoalveolar surgery during childhood and early teenage years, alveolar cleft grafting at approximately 9 years, and orthognathic surgery in late teens.

Summary of Activity

There are approximately 182 surgical admissions to the DCC (Temple Street and Crumlin) each year (149-219 from 2008-12). Post-operative length of stay ranges from 1-2 nights for lip repair to 2-3 nights for palate repair or alveolar bone graft. Waiting times are less than 3 months for newly diagnosed cleft lip and palate referrals, with over 85% of referrals seen within 1 month. There are almost 1000 clinic attendances annually between Temple Street and Crumlin.

Referral Pathway

In all referrals, the first point of contact for the cleft team is usually through the cleft coordinator/manager.

1. *Antenatal Referrals*

   The DCC has developed guidelines and referral forms for units referring to the service. Referrals are received from foetal medicine units / maternity units for antenatal consultations with expectant mothers or couples following diagnosis of a cleft on scan. Contact is made by the cleft nurse coordinator/manager with the family within 24-48 hours of receipt of referral. Consultations with cleft team members are tailored to each individual family's circumstances.

2. *Newborn Diagnosis*

   The cleft coordinator/manager completes the standardised referral form and each newborn referral is triaged based on their clinical presentation as per the maternity unit. There is an established protocol on receipt of new referrals that contact is made by the coordinator/manager within 24-48 hours of receipt of referral. Contact is by telephone or visit to the maternity unit (in Dublin maternity hospitals only – this service should be expanded nationally). When a complex case is identified, the cleft coordinator promptly liaises with the consultant plastic surgeon and informs the neonatal team in the maternity unit of the management plan advised by the consultant plastic surgeon. Arrangements are put in place to transfer the baby to the paediatric hospital for multidisciplinary assessment and management, e.g. Pierre Robin sequence for airway and feeding issues. The cleft coordinator/manager liaises with the plastics registrar, neonatal team on call and bed manager to arrange transfer. Routinely, all referrals result in ongoing liaison with the referring team and community services, e.g. GP, public health nurse, early intervention team.

3. *Late Presentation of Cleft Palate*

Occasionally a baby may not be diagnosed with cleft palate prior to discharge from the maternity unit. The baby may present with feeding issues and a diagnosis of cleft palate can be made by the GP or public health nurse who then refer to the DCC. Children can present with occult or submucous cleft palate during early childhood, with referrals received from ENT, SLT or GPs. Clinical consultation is prioritised for these children, and where appropriate a speech assessment is arranged prior to first consultation with the plastic surgeon.

4. *Non-cleft Velopharyngeal Insufficiency / Dysfunction (VPI/VPD)*

Patients with VPI/VPD are referred by ENT or community services such as SLT, GP or public health nurses for palatal assessment if the child has speech issues. Although they may not have a cleft condition they require access to the specialised services of the consultant plastic surgeon and SLTs attached to the cleft team. Assessments may involve:

- Initial SLT assessment and clinical examination to rule out a cleft condition
- Objective assessment of palatal function with videofluoroscopy and/or nasendoscopy
- Possible referral to genetics team based on clinical assessment, with further referrals based on outcome of genetic consultation
- Return to cleft clinic for team decision on management based on the results of investigations
- Management may involve palatal or pharyngeal surgery and ongoing speech and language therapy

This is a tertiary centre accepting referrals from the 26 counties covered by the Health Service Executive (HSE). There is an established, standardised integrated cleft care pathway for management from birth to adulthood for all children referred to the DCC. Neonatologists and paediatricians refer children to the cleft team based on their established working links with either Temple Street or Crumlin. When accepting a referral, the cleft coordinator will consider which paediatric unit is most appropriate, based on any relevant medical issues such as cardiac or metabolic conditions associated with the cleft conditions, ICU/HDU bed availability, geographical location, parental preference to attend a particular centre and accessibility to outreach clinics.

Referrals by Location (2002-12)

Ballinasloe	31	Limerick	46
Castlebar	8	Mayo	14
Cavan	23	Mercy University Hospital, Cork	0
Clonmel	16	Mount Carmel, Dublin	13
Coombe, Dublin	126	Mullingar	41
Cork	19	National Maternity Hospital, Dublin	111
Drogheda	59	Northern Ireland	5
Ennis	5	Portlaoise	18
Galway	49	Rotunda, Dublin	122
Kerry	19	Sligo	34
Kilkenny	29	Wexford	37
Letterkenny	33	Waterford	30
Total Number of Referrals: 888			

There are approximately 70-100 new patient registrations to the DCC each year. As this is a tertiary referral service, patients referred to the DCC are linked in with other hospitals for shared care locally as appropriate.

17.1.2 Cork University Hospital

The multidisciplinary team at CUH provide services for cleft children in Cork and some of the wider Munster area. The service is well integrated with Cork University Maternity Hospital, and has close links with community colleagues in Dentistry, Orthodontics and Speech and Language Therapy. There is an academic partnership with University College Cork.

Core team members comprise:

- Consultant Plastic Surgeon (Cleft Specialist)
- Specialist Registrar and SHO
- Senior Speech and Language Therapist
- Paediatric Dentist
- Otorhinolaryngologist
- Audiologist
- Orthodontist
- Consultant Oral and Maxillofacial Surgeon

There are also a number of additional support services provided:

- Administrative support
- Clinical photography (1 session/month at combined clinic; audit photographs taken at 5, 10, 15 and 18 years)
- Paediatric Anaesthesia
- Departments of Neonatology and Paediatrics
- Genetics
- Cleft Lip and Palate parent support group (founded by parents whose children attended CUH)
- Clinical nutrition and dietetics
- Medical social work
- Bru Columbanus adjacent to CUH campus provides 'home from home' accommodation on a donation basis for those who need to be near to the hospital

Summary of Activity and Clinics Held

Cleft multidisciplinary team combined clinic	10 clinics per year
Resonance clinic (combined plastic surgeon and SLT review)	Approximately 30 patients per year
Plastic surgery clinic (pre-and post-surgical review)	40 clinics per year
Dentist / Orthodontist	1-2 clinical sessions per month

Speech and Language Therapy

As well as the combined cleft lip and palate and resonance clinics, the SLT provides specialist assessment and intervention, e.g. 18 month baseline assessment, 3 year assessment for cleft type characteristics, second opinion review in conjunction with community-based SLTs, and electropalatography.

Orthodontics

The service has links to orthodontic clinics in Limerick, Tralee, Waterford, and Clonmel. Close links have been established with HSE dental services and their referrals. There are also links with Maxillofacial Surgery (Prof. Duncan Sleeman) and Restorative Dentistry (Prof. Finbar Allen) in Cork University Dental School with joint clinics at St Finbarr's Hospital. There is a good working relationship with Mr. Eamonn McKiernan in the DCC.

The majority of referrals are directly from the cleft lip and palate combined clinic. All patients undergo a full orthodontic assessment, clinical records acquired and given oral health promotion. Part of the service involves orthodontic expansion to prepare for alveolar bone grafting. Subsequent treatment involves prioritised, comprehensive fixed orthodontic appliances in the teen years, and retainer aftercare. Later treatment may involve preparation for orthognathic surgery if necessary and there are close links with the maxillofacial service during this period. There is an annual audit of facial growth and dental health outcomes.

Dentistry

A community-based paediatric dentist is part of the core cleft lip and palate combined team. Treatment is provided directly or liaises closely with their local dental clinics/ practitioners. Access to dental treatment under general anaesthesia is provided when necessary in CUH via the University Dental School and Hospital Cork.

Referral Pathway

All referrals are coordinated through the Department of Speech and Language Therapy. Complex airway cases or other surgical requirements are referred to the DCC.

1. *Antenatal*

   There are close links with antenatal services and referrals are received following anomaly scans. On receipt of referral, telephone contact is made with the expectant mother to arrange an appointment with the consultant plastic surgeon and SLT to begin to offer support and information. Contact is maintained until birth of baby.

2. *Newborn Diagnosis*

   Referrals received from Cork University Maternity Hospital are reviewed within 24 hours by Plastics and Speech and Language Therapy. Early feeding assessment, advice and support is provided. The infant and mother will continue to be reviewed during their inpatient admission. Joint appointments with the consultant plastic surgeon and SLT are usually within one week of referral.

3. *Late Presentation/Late Diagnosis/Submucous Cleft Palate*

   Referrals are received from GPs, ENT consultants and SLTs, or parents may make direct contact to discuss concern and a referral is then advised via their GP.

17.2 PROPOSED MODEL OF CARE

The agreed vision for cleft services is a centralised national service with integrated cleft care across the patient lifespan, focused on providing an equitable high quality service with no geographical variation. Additional required staffing resources are detailed below to bring Irish cleft services in line with recognised multidisciplinary involvement at clinics. A full consultant-led dental service is needed in Temple Street, along with specialist consultant paediatric dental services in the community. An all island cleft registry should be established which would facilitate an all-island cleft audit encompassing Cork and Belfast. A national cleft unit should have protected beds and theatre time. National feeding guidelines should be rolled out.

17.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

17.3.1 Staffing

Cleft Nurse Specialist

The cleft CNS plays an integral role in supporting and educating families and allied health services managing a baby born with cleft lip and/or palate. This is a complex condition and may present with specific feeding and/or airway issues, warranting expert nursing knowledge to give appropriate advice, support and intervention from initial diagnosis to young adulthood. The internationally recognised UK CSAG report recommended, and later saw, the implementation of the standard 30 new births per whole time equivalent cleft CNS. This facilitates a CNS visiting the family within 24 hours of referral to the cleft team. There were 106 newborn referrals to the DCC in 2013 and only 0.6WTE cleft CNS in Temple Street, which falls far below the recommended standards for this service. The appointment of a further 2.5 cleft CNS posts across Temple Street and Crumlin would bring the DCC closer to the recognised international standards for nursing support. The cleft CNS would work with the cleft coordinators/managers to identify service needs and provide an equitable national service 365 days a year.

With a team of cleft CNSs in place, consideration should then be made to appointing a lead clinical nurse specialist. This role would incorporate managerial and clinical roles within the team. The lead cleft CNS would have a strategic role attending professional meetings and quarterly meetings with other lead nurses in the UK to ensure continued development and best practice. Audit, research and teaching would also be an essential part of this role.

Dentistry

The development of a shared care dental protocol for services across Temple Street and Crumlin, and community dental services, has already been proposed to the HSE: Dental Services for the Management of Dental Care of Children with Cleft Lip/Palate in Ireland. Implementation of this protocol will depend on both acceptance by HSE Dental Services and the establishment of a full dental service at CUH. An increase in designated consultant sessions is required to provide a more equitable service for children attending Temple Street.

Psychology

Psychology is recognised in the CSAG report as an integral part of the multidisciplinary team providing care to patients with cleft conditions. To date, there have been no designated psychology sessions for the DCC, representing a significant deficit. Regular access to Psychology for cleft lip and palate patients is also required in CUH.

Speech and Language Therapy

SLT assistants are required, either at each site or shared between sites.

17.3.2 Information Technology (IT)

The appointment of a data manager to the DCC is required, with appropriate technological and administrative support. Data management support will likely be needed in Cork. Funding is also required for the following:

- Increased number of licences for the cleft database
- Upgrade of cleft database to cloud system that can be accessed across sites for the development of an electronic patient management system
- Access to broadband in Crumlin to facilitate access to database
- Improved website containing information for parents, service users and professionals

A shared national database would facilitate audit and cross-unit management of patients between Dublin and Cork.

17.3.3 Specialised Equipment

A cone beam 3D Computer-aided Tomography (CT) scanner is required for the Cleft Orthodontic Unit in SJH. Children and young people attend SJH for orthodontic services from 5 years onwards.

SLTs require up to date assessment and therapy equipment including:

- Nasometer for Crumlin/Galway
- Electropalatography and portable electropalatography for SJH
- Improved radiological equipment in Crumlin and Temple Street for the recording of videofluoroscopy examinations
- Flexible Nasendoscopes
- Electropalatography hardware, software and plates
- Tablets and appropriate apps

A loan system should be put in place for patients for tablets and portable electropalatography.

Dedicated office space is needed for the cleft coordinator in Crumlin, equipped with telephone, fax, photocopier, scanner, computer, email and administrative support.

17.3.4 Education and Training

Clinical professionals need to ensure they have the skills, competence and training to deliver a high quality service through continuous professional development and attendance at relevant training courses and national/ international conferences.

The DCC and Cork team also provide education and training to many groups including maternity units, public health nurses, speech and language therapists, medical students and nursing programmes. They have an excellent relationship with the CLAPAI and willingly engage with service users.

17.4 PROGRAMME METRICS AND EVALUATION

The DCC have an established database with cross site ethical approval and patient consent, which facilitates data collection. This enables comparison of treatment outcomes on an international level and ensures patients receive the best possible care, and also allows the multidisciplinary team to develop and coordinate services according to patient need. The cleft service in Cork must contribute to this database.

Parameters monitored include:

- Antenatal diagnosis of cleft lip
- Standardised audit records at 5, 10, 15 and 18 years of age
- Multidisciplinary audit records
- All Ireland inter-centre outcome analysis
- Lead time: initial contact and clinical attendance
- Monitoring of waiting lists (clinics, nasendoscopy, videofluoroscopy)
- Monitoring adherence to timing of surgery protocol

The DCC liaises with the HSE Anomalies Registry team for annual cross referencing of patients presenting with cleft conditions. The team also had major involvement in the recruitment of families for the orofacial genetics study, and should continue to participate in international research programmes. A national research agenda covering all sites should be developed, informed by the service users.

17.5 KEY RECOMMENDATIONS

- Increase cleft clinical nurse specialist posts by 2.5WTE across Temple Street and Crumlin, with development of the role of lead clinical nurse specialist
- Increase consultant paediatric dentist sessions
- Ensure access to psychology services for cleft lip and palate patients
- Provide data management support to the DCC and CUH, with appropriate IT systems in place to facilitate data collection and analysis
- Ensure appropriate equipment available for all multidisciplinary team members

17.6 ABBREVIATIONS AND ACRONYMS

CNS	Clinical Nurse Specialist
CSAG	Clinical Standards Advisory Group
CFSGBI	Craniofacial Society of Great Britain and Ireland
CT	Computer-aided Tomography
CUH	Cork University Hospital
DCC	Dublin Cleft Centre
ENT	Ear, Nose and Throat
GP	General Practitioner
HDU	High Dependency Unit
HSE	Health Service Executive
ICU	Intensive Care Unit
MMH	Mater Misericordiae Hospital
PEG	Percutaneous Endoscopic Gastrostomy
SHO	Senior House Officer
SJH	St. James's Hospital
SLT	Speech and Language Therapist
SpR	Specialist Registrar
UK	United Kingdom
VPI/VPD	Velopharyngeal Insufficiency / Velopharyngeal Dysfunction
WTE	Whole Time Equivalent

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