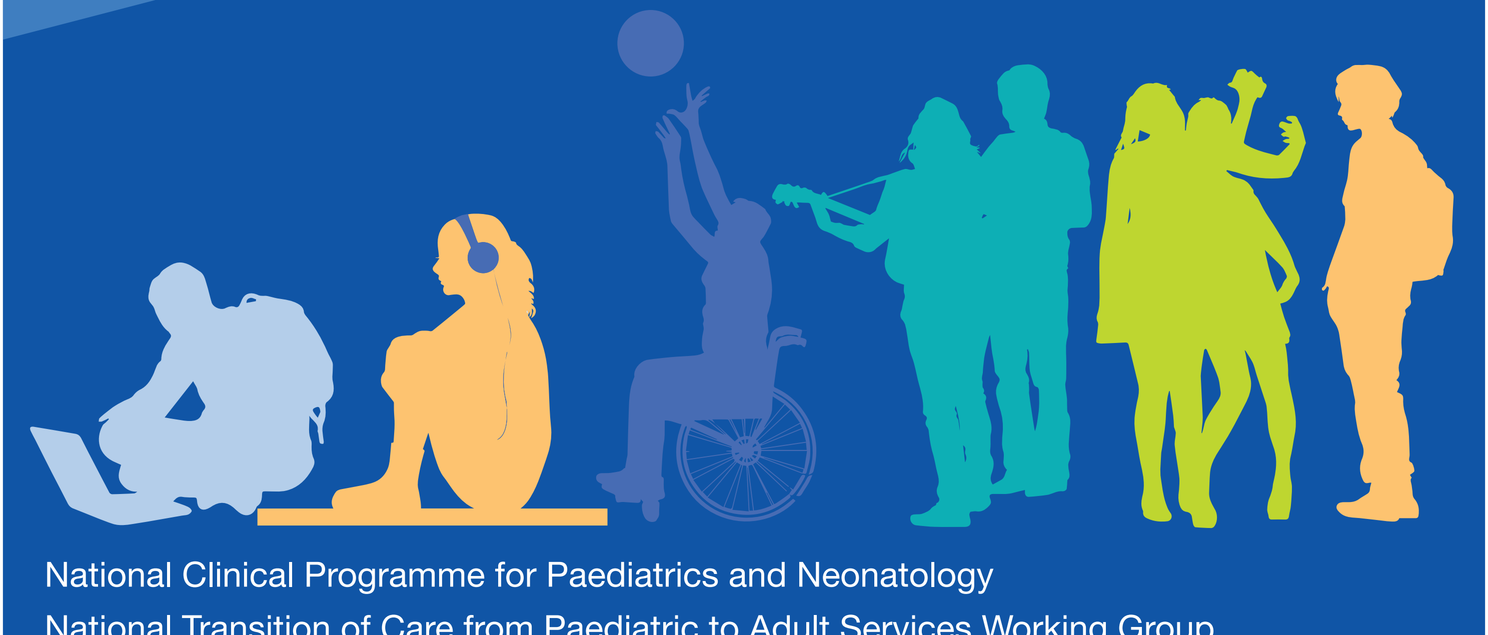
Transition of Care from Paediatric to Adult Services:

A National Framework



National Clinical Programme for Paediatrics and Neonatology
National Transition of Care from Paediatric to Adult Services Working Group

CDI Clinical Practice Guidance Document Cover Sheet

Document Type:	National Framework
Document Title:	Transition of Care from Paediatric to Adult Services: A National Framework
Document Author:	National Transition of Care from Paediatric to Adult Services Working Group
National Service/ Area:	All Health and Social Care Services providing care to children and adults.
Approved by:	Chief Clinical Officer Clinical Forum Group
Unique Identifier Number (UID):	CDI/0111/1.0/2025
Version Number:	1
Publication Date:	
Recommended Revision Date: *	February 2028
Electronic Location:	https://www.hse.ie/eng/about/who/cspd/transition-of-care/

* Refer to HSE National Framework for developing Policies, Procedures, Protocols and Guidelines (PPPGs)

Version	Revision Date	List Section Numbers Changed	Author

Contents

Foreword

Transition of Care from Paediatric to Adult Services

Dr Ciara Martin

National Clinical Advisor and Group Lead for Children and Young People

The work for this framework began in 2018 when a dedicated group of healthcare staff under the National Clinical Programme for Paediatrics and Neonatology came together to draft a set of standards for Transition of Care, based on international research and best practice. Following a hiatus this work was continued, supported by a multidisciplinary group from adult and children's services who came together as the National Transition of Care Working Group to bring in the voice of young people and the broader health and social care community and to complete this framework.

The themes and standards outlined in this document have been informed by the voices of the members of the Youth Advisory Council and through detailed survey feedback from children, young people and their parents/carers attending healthcare services in Ireland. From this engagement we heard how young people with a lifelong illness or disability who have been attending children's health and social care services for years have to move abruptly to a new service delivered by a completely new team of clinicians with new protocols, often in a different hospital or community setting, regardless of school or college or home location or of clinical relationships. We heard that for some young people, particularly those with complex intellectual and physical disability, the services that supported them as children are not available or do not exist in the adult health setting. In addition, we know that this transition of care occurs at a time of psychological, physical, and social change for the young person (Bonnie, Stroud, & Breiner, 2014).

Extensive feedback on transition of care was received from health and social care staff working in adult and children's services across the system on transition of care. It is clear that some clinical specialties and services in Ireland have excellent transition of care pathways but that some staff are frustrated with their inability to establish sustainable transition pathways for their patients.

The overall message is that good transition is not the norm and, until now, there has been no nationally agreed framework that would support the implementation of good transition of care. Transition from paediatric to adult healthcare is a complex, multi-dimensional process that must address the medical, psychosocial, educational, and vocational needs of young people with lifelong health conditions.

Effective transition of care services are crucial for promoting continuity of care, self-management, and positive health outcomes. We have clearly heard from of our young people and their families that they feel abandoned by the health service at this crucial time of their lives and we need to work together to change this reality. Using this framework will support the health service to building patient centred transitions of care into every clinical pathway and will support future planning for all health and social care services.

I would like to thank all of the children, young people, parents and health and social care staff who contributed to the development of this framework.

Executive Summary

Transition of care is an on-going gradual process where the focus is on preparing, educating and supporting young people and their families for adulthood and lifelong health as they move to adult health services.

Adolescence is the stage of life between 11 and 19 years of age. It is a unique stage of human development and an important time for laying the foundations of good health (WHO, 2024). It can be a time of great opportunity but also a vulnerable time, made even more challenging if a Young Person (YP) is living with a chronic health/ mental health condition or disability. Supporting the transition of care is an essential link between child and adult services and across primary, community and hospital settings.

The Transition of Care from Paediatric to Adult Services: A National Framework has been developed to guide all health professionals involved in providing care and support of YP with existing health conditions who are preparing to or as they move into adulthood and to adult services and to improve patient and family experience and outcomes. This document focusses on healthcare while recognising that transition of care can be impacted by the wider economy and society.

The purpose of this document is also to raise awareness about the opportunities and issues facing young people as they transition services within the healthcare setting and to provide guidance to those providing care and support for them on how to improve the delivery of transition care across a variety of settings. Throughout the document the abbreviation **YP** is used to represent **young people including adolescents and young adults**. The standards in this document are informed by the needs of YP and their parents/guardians/carers and informed by healthcare professionals providing services to them. These standards and guiding principles are generic in nature and are not targeted at any specific condition. It is, therefore, important to acknowledge that they are not prescriptive, and different services may vary in how they adapt and utilise the principles to suit their individual service requirements.

This document informs the health services on the standards required to meet the specific needs of YP as they transition to adult services in healthcare and to highlight the requirement to provide adequate funding and training to ensure a quality transition experience and optimise lifelong health for all YP in Ireland.

Overleaf are some of the voices which have informed this document.

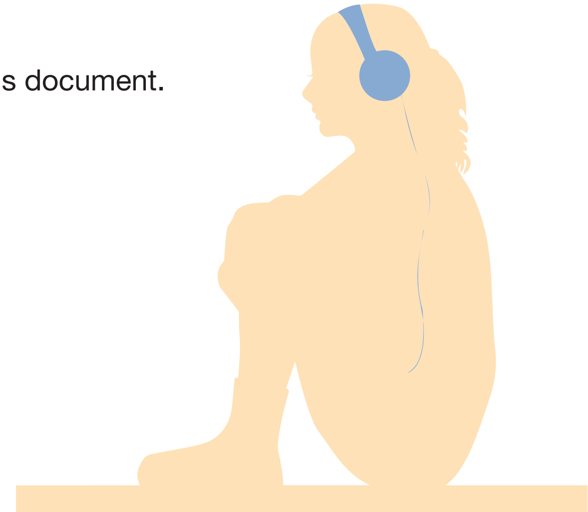


Figure 1. Young Person Experience of Transition of Care to Adult Services 2024

> “My [specialist] wanted me to transition to his adult clinic in the opposite side of the city but HSE wouldn’t authorise this. I now travel to a town in [another area] which takes 3 hours.”

> “I am always terrified to talk to the doctors. My mother comes with me. She doesn’t know what to ask either.”

> “I had been attending [childrens hospital] for quite some time…I had physiotherapy a few times around 16/17 [years] and they mentioned transition but then discharged me. No one else had mentioned transition. I was cut off from my service.”

> “Parents need more information. It is just as hard on my [mother] as it is on me. Even directions to the hospital.”

> “I don’t know if [adult hospital] has information on me. I am aware there are waiting lists for outpatients. If I needed care would I go to ED?”

1. Background

1.1 Adolescence and Young Adulthood: The opportunity for lifelong health

Adolescence and young adulthood are a time of great change and opportunity involving many milestones including: shaping one's own identity, achieving independence from parents/guardians, starting relationships outside the family unit, and planning a future vocation (Campbell et al., 2016). It a physically, socially and neurologically unique developmental period with the attainment of adult-like behaviours now often extending to 25 years and beyond (Bonnie et al., 2015).

It can also be a difficult time for YP and may place additional challenges on those who have emerging or existing physical, intellectual, sensory and/or mental health difficulties. Many serious diseases leading to premature death can stem from behaviours or experiences that have their roots in adolescence, such as, tobacco, alcohol and drug use, sexually transmitted infections, poor eating and exercise habits, violence, sexual abuse (WHO, 2024). The 2020 census of deaths shows that the mortality during this period of a young person's life is almost equal to the mortality experienced within the first year of life (Table 1).

Table 1. Deaths in Ireland 2020

Age range (year)	<1	1-4	5-14	15-24
Number of deaths	153	27	47	136

1.2 Mental Health in Adolescence

The WHO now identifies mental health disorders as the second largest cause of co-morbidity for children and adolescents. Adolescence and young adulthood can coincide with the emergence of mood disorders and YP with chronic health issues are at greater risk of difficulties with social functioning, anxiety disorders, depression and suicidal ideation and suicide attempts (Kennedy et al., 2007). Half of enduring mental illness emerges during adolescence but is under-recognised (WHO, 2024).

1.3 Chronic Disease and Disability in Adolescence

Circa 17% of young adults (15 to 19 years) in Ireland report experiencing a long-lasting condition or difficulty (CSO, 2022) in addition, advancements in medical treatment and technology have increased the life expectancy of children with complex needs who are transferring to adult care. There is an increased demand within adult services to treat childhood onset conditions despite minimal knowledge and training with respect to the needs of these patients (Peter et al., 2009). Living with any chronic disease during adolescence can represent a major psychosocial burden for young people and YP with chronic conditions are more likely than their healthy peers to engage in risky behaviours around sexual activity, smoking, alcohol and illicit drug use and to non-adherence to treatment (Suris et al., 2008, Fleming et al., 2002).

Adolescents with chronic conditions continue to fall through care gaps with negative clinical outcomes (Samarasinghe et al, 2020). This rise in morbidity and loss of follow up is evidenced in chronic diseases such as Renal failure, Diabetes and Mental Health disorders (Appleton, 2019, Corbett, 2019, Crawford, 2018).

1.4 Transition of Care to Adult Services in Ireland

In Ireland, over one third of the population is under the age of 25 years, and of this YP aged between 10 and 24 years represent approximately **18.3%** of the total population. Most healthcare services in Ireland are organised separately around children and adult populations. Many specialist services provide care for CYP up to the eve of their 16th birthday or for adults from the age of 18 years leading to difficulty accessing services for some 16 and 17 year olds. There are also circumstances where individual clinicians or paediatric services continue to provide care for individual CYP into adulthood to support continuity of care.

Some specialty services have developed models or pathways to address the needs of specific population groups including those attending cancer and mental health services and rare diseases. The majority of speciality services do not have specific transition of care pathways and in particular people living with a disability have challenges leaving paediatric services due to the paucity of specialist services for adults.

Coyne et al (2018, 2019) identified a lack of preparation and discussion around transition which is a key barrier to a smooth and successful transition, evidenced by research conducted with young people, parents and professionals. There is also a lack of preparation of parents related to their changing role and how they can encourage and support self-management behaviours in YP (Coyne et al, 2018, Thomsen et al., 2023).

Promoting and supporting a healthy approach to life for Young People (YP) can have beneficial effects for them personally and for the health of our future generations while also reducing the burden on our health system.

Preparing and supporting young people to optimise their health as they transition to adulthood will have significant lifelong impact and is particularly important for those living with disease/ disability.

This document informs the health services on the specific needs of YP as they transition to adult services in healthcare and to highlight the need to provide adequate funding and training to ensure a quality transition experience and optimise lifelong health for all YP in Ireland.

2. Voice of Young People and Parents/Carers

2.1 Voice of Young People and Parents/Carers

The voice of children, young people and their parents underpins this framework document as follows:

- Working group representatives met on three occasions with the members Young Advisory Council (YAC) established through Children's Health Ireland to hear the views of young people and to inform this framework document and on the design of a HSE information webpage for YP/ parents.
- A national survey of the Transition of Care experience of Young People (14 -26 years) and parents/ guardians/carers was opened for a nine-month period in late 2023 and 2024. YP and parents participated in the design of the survey (See Appendix x for more survey details).
- Consultation on the draft framework document included invitations for feedback from YP, parents and advocacy groups.

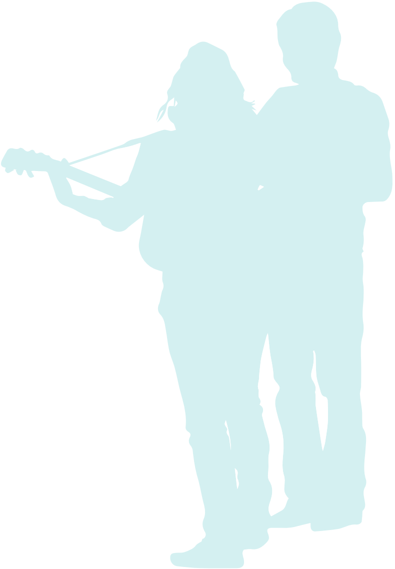
Sample direct quotes from YP and parents/ carers are included under the relevant standards for Transition of Care throughout this document. They reflect the experience/needs expressed by YP/ parents/carers and how they align to the key challenges this framework aims to address.

2.2 Aim of National Framework Document

This document aims to:

1. Provide best practice standards for transition of care based on the needs of YP, parents/ carers.
2. Provide initial guidance for all healthcare provider stakeholders across all specialities and settings in Ireland who provide care and support for YP, so they can initiate and improve upon existing transition support and services.
3. Support all YP with chronic health conditions to have a positive experience of transition to adult services, where they learn to self-manage their condition or disability, achieve their life goals and remain engaged within health and social care services.

These standards are not condition specific; rather they are standards that are applicable across all conditions.



3. Transition of Care

Transition is defined as 'the purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults ...as they grow up learning to live with their lifelong health condition,' (Dovey-Pierce & Christie, 2013).

Transition is often confused with "*transfer*" to adult services which is considered more as a point in time or single component of the wider transition process (Callahan et al., 2001). In previous years transition was considered more of an administrative step of simply transferring care from one service to another. In more recent years, transition services have evolved into an on-going gradual process which should start early **(from age 12 onwards)** and extend beyond transfer to the adult services.

The process of transition is complex and multifaceted, and it requires a change of thinking from the YP, parent/ guardian and from both paediatric and adult healthcare providers. Unfortunately, transition for YP with chronic health conditions, mental health issues, or disabilities is often poorly managed, unplanned, and under resourced from a financial and staffing perspective. This can lead to adverse consequences for YP's health and less successful outcomes overall.

Aims of transition:

- Support self-management
- Encourage independence
- Support future planning
- Improve clinical markers
- Educate YP about their condition
- Achieve a successful move from paediatric to adult services

(Care Quality Commission, 2014)

Poor transition is associated with:

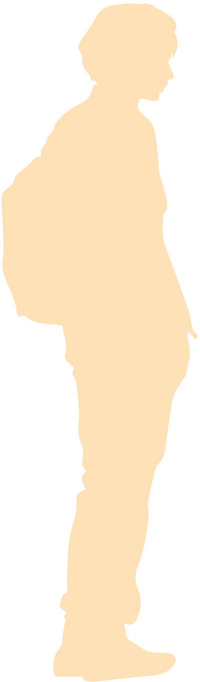
- Poor clinical outcomes
- Increase in non-adherence to treatment plan
- Increased risk of loss to appropriate follow up care
- Increased morbidity and mortality rates
- Lower patient and family satisfaction
- Increased healthcare costs associated with emergency department visits, hospitalisations, and intensive care admissions

(Crowley et al., 2011, Becker, 2020)

Benefits of successful transition:

- Improved clinical follow-up/attendance
- Improved patient & parent/guardian satisfaction
- Improved disease control & disease knowledge
- Improved documentation of adolescent issues
- Improved health related quality of life
- Vocational readiness

(Mc Donagh et al 2007, Harden et al., 2012, Colver et al. 2020)



4. Standards for Transition of Care

4.1 Standards for Transition of Care

Nine overarching standards have been identified as key elements to supporting transition of care, summarised below. These standards were developed for YP living with a variety of chronic conditions, mental health disorders, life limiting conditions, and disabilities. It is acknowledged that no one model fits all and that transition of care services and their effectiveness are strongly influenced by contextual factors related to the nature of the YP's condition. The variety of services for specific conditions will also have a considerable impact on the quality of transition of care delivery. Transition of care services for patients may differ, and therefore each service should adopt an individualised approach to their own transition service so that it meets the needs of the YP and families who avail of it. Resources for each of the standards are available at Health professionals webpage

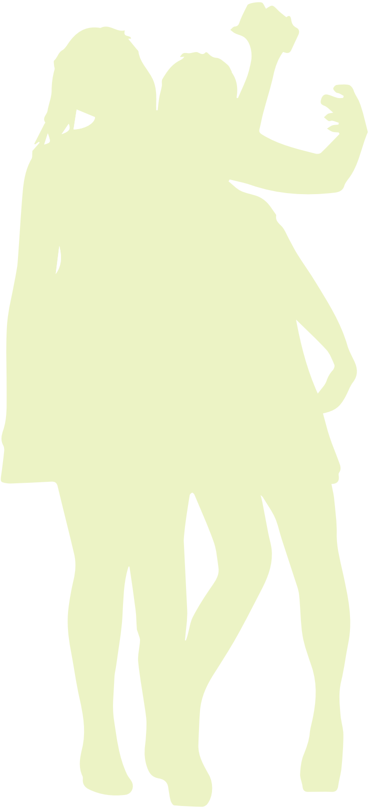


Figure 2. Summary Standards for Transition of Care

Standard 1

PLANNED SYSTEMATIC PROCESS

Transition is a planned systematic process taking place gradually over time, incorporating multiple systems and services while maintaining focus on the individual needs of the YP as its core.

Standard 2

YOUNG PERSON AND FAMILY FOCUSSED

Transition is a process that places YP at the centre and recognises that their distinct needs evolve over time and which acknowledges the key supportive role of the family in this process.

Standard 3

KEY ROLES TO SUPPORT AND FACILITATE TRANSITION

A key worker/ coordinator should be available to the YP and family within the health care setting to advise, support and facilitate their transition process

A transition co-ordinator should support and monitor the design and implementation of the transition of care process across the service(s)

Standard 4

COMMUNICATION, COLLABORATION AND COORDINATION

Successful transition requires effective communication and collaboration between paediatric and adult services and is inclusive YP, their family and all key stakeholders, including; community services (particularly general practice), education, vocational, social and voluntary agencies.

Standard 5

SELF-MANAGEMENT

The transition process should empower the YP to develop the knowledge and skills required to manage their own condition. YP should be supported to take control of their own health and families should be encouraged to enable the process

Standard 6

READINESS ASSESSMENT

The transition process should recognise how challenging adolescence can be and the variation in readiness for transition from paediatrics to adult services. The transition process should include the need for on-going assessment of readiness on an individual basis.

Standard 7

TRAINING AND EDUCATION

Successful transition requires education and clinical experience for health and social care professionals (HSCPs) in the area of transition of care and adolescent health.

Standard 8

SUPPORTIVE RESOURCES

The transition of care process requires that YP have access to clear, developmentally appropriate, information and guidance resources to support them along the transition pathway and into adult services. In order to provide and develop these resources, IT, funding, administration, and staffing support is required.

Standard 9

FOLLOW-UP AND EVALUATION

Ongoing follow up, service evaluation, audit, service user feedback and research should be an integral element of the transition process.

STANDARD 1 – Planned Systematic Process

Transition is a planned systematic process taking place gradually over time across a number of services while maintaining the individual needs of the YP as its core.

Application into practice:

Paediatric and adult services should:

- Have a clear and aligned transition policy that is individualised, holistic and easily understood by staff, parents and YP and is accessible to all involved.
- Collaborate on pathway design and planning, service delivery and ongoing evaluation.
- Maintain a register of YP expected to transfer to adult services to inform planning.
- Track progress of YP until fully integrated into the adult service whether specialist or GP.
- Include a robust system to follow up and re-engage non-attenders.
- Operate a flexible non-attendance policy to facilitate YP and acknowledge that complex needs, intellectual difficulties and mental health can impact capacity and behaviour throughout the transition process.
- Have appropriate administrative support.

When planning a transition of care include:

- Engagement with the YP and their family
- Youth-focussed resources and environment
- Encouragement of YP and their family to take ownership of aspects of care
- Encompass all relevant professionals
- Incorporate a Readiness Assessment Tool / Checklist Health professionals webpage
- A planning meeting with YP and parents and the team at least annually

NOTE: Paediatric services should continue to be responsible for the care of the YP until the time that they have attended their first appointment in the receiving adult service and transfer has been completed.

Age of Transfer to Adult services:

- Should be based on needs of YP and not be an administrative process based on age milestones.
- **The TOC working group recommends that transition of care should occur after 18 years of age for those living with chronic illness or disability where possible** but recognise the current health system configuration makes this difficult to achieve.
- Evidence supports transition of care in later adolescence. Transitions at older ages are associated with improved patient satisfaction and outcomes (Yassaee et al, 2019).

Survey Finding:

Almost all (96%) had transitioned by 18 years old.Approximately half of YP/ parents/carers recommended that transition should happen at 19+ years.

The transition pathway should:

- Begin preparation early, ideally starting at age 12 years. Key phases across the transition timeline can be found here: Health professionals webpage
- Include an education component for YP and parents/guardians addressing relevant expected changes during adolescence, the challenges associated with specific medical conditions, medico-legal issues, and the differences between paediatric and adult services.
- Develop YP's self-management and self-advocacy skills.
- Support YP that may have multiple transitions and which may be at different times.
- Consider the range of capacity and ability of YP and include special supports and advocacy for those with specific requirements.
- Support YP who have an existing Emergency Care Plan which may need to be reviewed (noting Ambulance Care Plan applies up to 18 years only).
- Where appropriate, start conversations regarding Assisted Decision Making and provide information about the decision support service and advance health care directives in a phased approach. Develop an understanding and recording of a YP's will and preference.

> "Start questioning your child's paediatric consultant from the age of 13 at least about transition and have them start making referrals then in order to secure your own child's transition before discharge."
> [Parent/carer]

> "*I've had no preparation for moving to adult services, I am confused about what happens. I am nearly 16, autistic and have an intellectual disability I would like to know more about what happens when I'm an adult.*"
> [YP]

STANDARD 2 – Young Person and Family Focussed

Transition is a process that places the YP at the centre and recognises that their distinct needs evolve over time and which acknowledges the key supportive role of the family in this process

Application into practice:

Support YP through the Transition of Care Process

- Engage with YP and their families about transition early, ideally from the age of 12 years.
- From the beginning communicate directly with YP, e.g., introducing yourself to YP before the parent/guardian. Use assessment tools such as HEEADSS Health professionals webpage
- Use developmentally appropriate communication with YP, e.g., 'Me First Tool' and Developmentally Appropriate Healthcare Toolkit
- Provide **age banded clinics** in both paediatric (12-15 years) and adult (16-24 years) services.
- Provide YP with the opportunity to directly discuss the transition process and to participate in decisions regarding their care, services and supports. Provide information in advance of clinic visits, encourage them to write questions, include parent or other person support if they want and ask them what additional support they need. Moving from child to adult health services

- Support the YP to hold / develop a **personal health summary**.
- Incorporate **Peer Support** to share experiences and help each other problem solve, e.g., transition webinars or peer support groups. Involve YP in the design of transition services and policies, e.g., surveys or focus groups, to get their feedback on how the service can better meet their needs.

> *"Doctors should speak to parents and YP and give YP opportunity to ask questions.* ***Ask me first as I am the one with the symptoms.***
>
> *[YP]"*

> *Can you get people to be kind…and give me time to answer questions? I hate when people bamboozle me with … questions… My feelings often get hurt from silly people who treat me as if I'm stupid. I just need time.* [YP]

> *I have received no guidance preparation or help with this and don't know where to look for information. I have been asked to have my questions ready for my next appointment as it will be my last. I am anxious about this as I have no idea what I should be asking, yet feel that it is important that I ask the right questions.* [YP]

Provide Information that is YP / Parent Focused

- Use age-appropriate language and media accessible to different needs and abilities and deliverable in a number of modalities such as print, digital, multimedia, Easy Read.
- Use different methods of engagement aimed at YP e.g., videos, peer supports/groups, peer delivered information, art-based interventions (https://steppingup.ie/video-stories/).
- Develop a repository of relevant resource material and information, regularly updated.
- Consider using social media, including online transition groups, online fora, and designated transition websites, to provide information and peer support. Systems should be in place to monitor and moderate social media activities.
- Create a clinical environment appropriate for YP where they feel welcome and safe with:
  - ✓ Appropriate facilities such as correct seating, bathrooms etc.
  - ✓ Access to Wi-Fi
  - ✓ Age-appropriate reading material
  - ✓ If having age banded clinics remove younger children's toys.

Consent

- Include YP in the consent process aligned with HSE National Consent Policy.
- Provide YP with the option of time alone at clinic to facilitate privacy - consent from a parent/ legal guardian may be required depending on age and decision-making capacity.
- Ideally, having consistency in clinic staff fosters a trusting relationship with YP.
- **Note for HCPs:** Consent is not the legal basis for sharing necessary and appropriate data with other clinical services for the purposes of referrals. It is, however, good clinical practice to discuss with the person being referred. HSE Privacy Statement

Key Role of Parents/Guardians

- Identify and acknowledge the key role of parents/guardians.
- Facilitate additional accommodations and support from parents or others in the adult healthcare system, e.g., support with care during hospital admissions, advocacy, behavioural or emotional support, support to communicate and recall information.
- Encourage parents/guardians to be involved and support them with training and resources in their changing role and responsibilities over time. Where the YP's level of independence may be compromised due to their specific needs, parents/ guardians may need to be involved and engaged in all stages of transition.

> *I'm worried about dealing with a new team, a new hospital… and a million more things… major concerns about being cut out as we move to adult care… it will be a huge upheaval for us as a family and I'm already worried.*
> *[Parent/carer]*

> *I like to be included in the decisions with my mam with me. She always fights my corner and sometimes understands things better than me and can explain it my way. She is great for letting me talk and encouraging me.*
> *[YP]*

STANDARD 3 - Key Roles to Support and Facilitate Transition

A **key worker** should be available to the YP and family within the health care setting to advise, support and facilitate their transition process.

A **Transition co-ordinator** should support and monitor the design and implementation of the transition of care process across the service(s).

Application into practice:

Key Roles in Transition of Care

- Paediatric and adult services should have a designated Transition Co-ordinator within their teams to lead on planning, implementation and evaluation of transition across the service.
- Each service should identify specific team members to provide a team-based approach to transition.
- A Key Worker links directly with YP and family and is their key point of contact. Any member of the multidisciplinary team can take on the role, depending on the individual YP's needs. A nurse specialist or HSCP may be ideally placed to fulfil the role.
- The YP should be consulted on who is appointed as their Key Worker. It should ideally be someone with whom the YP has a meaningful relationship.
- The Key Worker and Transition Coordinator roles may be interchangeable but, ideally both are required.
- These roles require adequate training in adolescent health and transition and should have sufficient allocated time and administrative support to fulfil their roles.

Survey Finding:

Information about the healthcare team and points of contact was the most frequently requested information from YP & parents.

Responsibilities of Key Worker

- Oversee, coordinate, advocate for and support transition process for the YP.
- Ensure the YP receives relevant advice regarding self-advocacy, independent health behaviours, sexual health, education and vocation, psychosocial issues and health and lifestyle.
- Ensure the YP is well at time of transition.
- Direct the YP to appropriate sources of information, advice and peer support.
- Support the YP and family in completing transition readiness assessments and /or their individual health summary /passport (see Resource Section for examples).

- Provide case management and plan appointments.
- Liaise between paediatric, adult, GP, community and education services, if involved.
- Accompany the YP to adult services and handover to adult service key worker.
- In the absence of an adult service, co-ordinate and attend a meeting with the YP and GP.
- Coordinate the transfer of information to adult services.
- Follow up with YP for a minimum six months, but ideally longer, after transfer to evaluate transition and prevent drop out of services.

> *There just seems to be a few gaps in knowledge between my old clinic and the new one, things that were in my file that I didn't know or questions I couldn't answer etc. Perhaps a meeting with the relevant doctors/nurses and the patient at the start of the transition would help get everyone on the same page.*
>
> [YP]

> *.. referrals/checkups (cardio, renal, ENT) were no longer scheduled by anyone and it is then up to the carer to figure out what needs monitoring and when. Inappropriate as a carer is not a medical professional.*
>
> *[Parent/carer]*

Responsibilities of Transition Co-ordinator

Often with a nursing background (Betz et al, 2020), the responsibilities of the **Transition Co-ordinator** will work with both paediatric and adult service to:

- Develop and agree transition process set out in relevant SOPs/ supporting documentation.
- Support both services to identify adolescent/transition process team members and key workers.
- Support training and education of all healthcare teams on needs of adolescents and transition of care.
- Organise, support and advocate for key workers in their specific role (see above).
- Work with both services on yearly forward planning to support seamless transition experience for YP and families.
- Track transition of care process implementation within both services including post transfer to assess integration of YP into adult services.

STANDARD 4 - Effective Communication and Collaboration

Successful transition requires effective communication and collaboration between Paediatric, Adult Services, GPs, the YP and their families, and is inclusive of relevant key stakeholders including other services, education, vocational, social, and voluntary agencies.

Application into practice:

Paediatric and Adult services should work together to:

- Develop an effective co-operative working relationship between all services irrespective of the setting.
- Identify number of YP that will require transition to adult services and plan and design operational and clinical processes to optimise the patient experience.
- Agree and implement an acceptable timeframe for referral. Ideally **transition should occur within 12 months** of receiving referral.
- A pre-transition medication review may be indicated for complex cases to ensure continuity of care, e.g., those YP on unlicensed medication, polypharmacy or using high-risk medications and those susceptible to significant financial burden on transition to adult services.
- Identify and communicate any concerns regarding YP at higher risk of non-attendance and to work with the YP and parent/ guardian to plan how to optimise attendance.
- Paediatric services should develop referral documentation in consultation with YP that provides comprehensive information including medical history, mental health history, physical and social history relevant to the YP.
- Develop a **transfer checklist** to identify information to be shared and use templates such as **patient passports** or **health summaries** to facilitate this. Health professionals webpage.

  Relevant data should be sought from all disciplines involved in YP care including community-based services.
- Include operations and administration in the transition team.
- Establish **clear and regular methods of communicating** with each other (e.g., via email, meeting, designated contact persons) to effectively plan, deliver and review their shared transition service ideally supported by information and communications systems and health records.
- Collaborate to plan for YP with complex needs where it may be necessary to identify multiple adult specialists/consultants, in multiple locations, who will work with paediatric services and the GP.
- Collectively plan for YP with specific needs (e.g., mental health concerns, physical and/or intellectual disabilities) who may have additional requirements or a more flexible approach to their transition of care, e.g., an extended period of parallel care or shared meetings with key worker support from both services.

- If there is no existing dedicated adult service in place, both paediatric services and adult physicians should liaise to identify options to create or adapt existing services to include those YP who require transition to adult services.

Responsibility of Care

- The responsibility of care of the YP lies with the paediatric team until the YP has transferred (attended 1st clinic appointment) to adult services.
- If the YP is not being transferred to an adult service, the responsibility of care of the YP lies with the paediatric team until the GP has accepted coordination of YP's care.

Between specialist services and GP/ community services

- All YP should have a GP as part of the transition process.
- Involve GP/community services early and keep informed to support the YP.
- GP/community services can be particularly helpful in monitoring non-attenders.
- GP/community services should have knowledge of adult services to ensure appropriate referral pathways.
- Nominated community pharmacist should be copied in communications relating to medications, to enable appropriate vigilance for errors at transition and to support adherence at this 'at-risk' time.
- Ensure that close working arrangements are maintained with community mental health teams, community social work and other agencies in the event of emergency presentation.

> "*The thing with being in paeds is when you were admitted to hospital you always knew a familiar face. Now going to adults you could end up in any ward…. telling your whole story over and over again.*
> *[YP]*"

> "*This is a very stressful time for the YP and it's not made any easier when no one listens or talks to each other in the different departments to get a clear understanding and history of the patient.*
> *[Parent/carer]*"

Between services and YP and families

- Both paediatric and adult services should consult with the YP on their transition plan, based on their individual needs, e.g., geographical preferences, if YP attending college, nearest specialist centre etc.
- Services should work together to facilitate YP and their families to become familiar with their future adult health services such as shared clinics, handover clinics or pre-clinic visit to adult services.
- YP and family should be informed of the plans to transfer care **at least one year** in advance of the transfer allowing them time to prepare for the move.
- Maintain open communication with YP around the time of transfer. Ensure that the timing of transfer is right for each individual YP. YP should be supported to ask questions, particularly of the adult service, in advance of transfer.
- Avoid transferring during periods of unstable health and increased stress such as exams or personal issues.
- Paediatric teams should be encouraging and adopt a positive attitude regarding moving to adult services to instil confidence in YP and their families and help relieve their anxieties.
- Paediatric teams should be transparent about what adult services are available for YP and support them to prepare for differences in their healthcare.

Survey Finding:

YP say the communication they received from the healthcare team as unclear, difficult to understand and too brief.

STANDARD 5 - Self Management

The transition process should empower the YP to develop the knowledge and skills required to manage their own condition. YP should be supported to take control of their own health and families should be encouraged to enable the process.

Application into practice:

Self-management

- Self-management encompasses all actions taken by YP to recognise, treat and manage their own health either independently or in partnership with the healthcare system.
- The process of teaching YP to self-manage should be carefully planned, youth friendly and developmentally appropriate.
- YP require a planned process of gradual shift of roles, skills and knowledge from family to the YP as they become more independent.
- Start early **(from approximately age 12 onwards) i**ntroducing support for self -management and gradually shifting skills and responsibilities from family to YP, building on their knowledge over time. Take into consideration complex care and/ or mental health needs from the start and tailor process to each YP's ability to achieve independence as an adult.
- Assess YP education needs and gaps in knowledge using tools such as **Transition Readiness Checklist** Health professionals webpage and repeat at least annually.
- Self-management programmes can be generic to all YP with chronic health conditions/ living with disability requiring transition, or they can be disease/ disability specific.
- A specific self-management education programme tailored to the individual YP should be developed to empower them with the knowledge and skills essential to care for themselves and supporting a successful transition to adulthood: Health professionals webpage

Parents/families/carers

- Recognise the role of family and the shift in roles from primary carers to a more a supportive role in self-care. Provide support to families during this process of 'letting go'.
- Education, which may be a structured programme, should be available to families/ carers.

- Adapt content to family/ carers needs and the role they will take in the YP's adult health and social care.
- Information regarding differences in adult services, guardianship, advocacy, capacity and consent issues may be required.

> *I'm very nervous when my mam [won't be able to] ring like she does now to get my care and get me seen when I run into a problem.*
>
> *[YP]*

> *…if I have to query an appointment or contact adult hospital on my son's behalf they won't speak with me (GDPR) even though my son has Autism and a learning difficulty and struggles with reading and writing.*
>
> *[Parent/carer]*

Healthcare professionals should

- Develop appropriate knowledge, communication and interpersonal skills to engage with and inform YP and family.
- Access resources to help them address issues important to young people, e.g., fertility, sexuality, relationships (HEEADSSS assessment, THREADs) Health professionals webpage
- Encourage time alone in clinic independent of parents/guardians to provide YP opportunity to practice 1:1 interactions with healthcare team. Begin with a few minutes alone initially and gradually build up time alone approaching transfer. Consent from parent/guardian may be required. It may be necessary to dedicate additional time to appointments to facilitate this.
- Develop age banded clinics (12-15 years and 16 -24 years) where feasible in paediatric and adult services to create an age-appropriate environment where self-management skills can be practised and facilitated.
- Adult services should continue to **assess and provide education and support around self-management to YP after they transfer.** Maintain flexibility around expectations of self-management, adjusting for specific learning, mental health, physical, dietary, and other complex needs.
- Link with community resources, voluntary organisations and relevant patient groups who can provide additional information and support to the YP and their family.

STANDARD 6 - Readiness Assessment

The transition of care process should recognise how challenging adolescence can be and that there is a broad variation amongst YP in readiness for transition from paediatric to adult services. The transition process should incorporate on-going assessment of readiness on an individual basis.

Application into practice:

- Readiness in transition of care pertains to the identification of knowledge and awareness of YP's condition and the need to establish achievable goals at different stages in the journey of transition of care.
- Healthcare teams should agree on a Readiness Assessment Tool/Checklist that suits their specific service.
- Following on from this evaluation, teams should develop a care plan to help prepare YP and parent/guardian for adult approach to self-care, including legal changes in decision-making, privacy, consent, self-advocacy and access to information.
- Healthcare teams should provide YP with links to resources, self-care management information, suitable advocacy services, and culturally and developmentally appropriate community supports.

> *I was 18 when I transferred and was a very difficult time, felt very alone and clueless at adult service.*
> *[YP]*

Readiness Assessment Tools should

- Identify each YP's specific needs and goals and that of their parents/guardians, with priority being given to knowledge, awareness of risk-taking behaviours, self-care and future development.
    - Encompass the following important elements:
    - Knowledge of condition
    - Knowledge of medication
    - YP's ability to communicate with health services and to attend appointments alone (if applicable)
    - Identify point of contact to make appointments/ seek help.
- Be adaptable to consider individual needs of YP and role of parents/guardians.
- Support identification of optimal time of transfer
- Be used regularly at least annually to identify and address gaps in skills and knowledge requiring intervention during the transition planning process.

- Examples of readiness assessment tools are available here:
[Health professionals webpage]

Transition of care should be delayed if the YP is not ready or their condition is in a state of crisis. Planning can and should continue during periods of crisis or instability.

Consent

- The Assisted Decision-Making (Capacity)Act 2015 applies to those aged 18 years +. Where appropriate, start conversations regarding the supports available under the Act and provide information about the decision support service and advance health care directives in a phased approach. Develop an understanding and recording of a YP's will and preference.

- Under the Assisted Decision Making (Capacity) Act (S.I. No205/2023) a person over the age of 18 years is presumed to have capacity. Where a person's decision-making capacity is called into question, the first step must be to support that person as much as possible to make their own decision.

  For further information on when an assessment of capacity might be appropriate and what it involves please see:
  Codes of Practice for Healthcare Professionals published by the Decision Support Service.
  HSE National Consent Policy

STANDARD 7 - Training and Education

Successful transition requires education and clinical experience for medical, nursing and health and social care professionals (HSCPs) in transition of care and adolescent health

Application into practice:

- There is a requirement for greater emphasis on adolescent health in health care professional curricula and greater investment into staff training and development nationally to enable staff working in children and adult services to provide a high-quality transition service across all specialities.
- Recognition of the need for appropriate resources and supports to enable adult services to accept YP and provide care in an age-appropriate environment with staff trained in the needs of YP.
- The topics included in a comprehensive adolescent health training programme can be found here: Health professionals webpage

> *I feel let down and forgotten about by the system, and alone in my [illness] management.*
>
> *[YP]*

Examples of training programmes for healthcare staff

- Local transition team education days.
- Adolescent health and transition of care training days for all staff including primary care.
- National or international study days on adolescent health and transition of care.
- Access to online training resources for adolescent health **(see examples in the resource section).**
- Develop online training resource in Ireland via current training institutions and HSE.
- Development of multidisciplinary/ interdisciplinary training programme across both paediatric and adult services on adolescent health and transition of care.
- Healthcare posts that enable working in both the paediatric and adult healthcare system to promote continuity of care during transition.

STANDARD 8 - Supportive Resources

The transition of care process requires that YP have access to clear, developmentally appropriate, information and guidance resources to support them along the transition pathway and into adult services.

Information for YP and families

- Transition of care information packs should be developed by paediatric services to be given to each YP and their family when they start transition preparation.
- Adult services should also develop an information or "welcome pack" to provide to YP transferring into their services.
- Paediatric and adult teams should collaborate on the development of agreed templates for medical summaries, transfer letters, patient passports and information on clinics to ensure standardisation across the services Health professionals webpage ideally supported by Transition Co-ordinators (see Standard 3).
- Paediatric and adult transition teams should collaborate with other teams to share resources and information which could be used or adapted.
- The development of a peer-to-peer transition of care support 'network' should be explored, with consideration given to governance, management, structure and operational functions of the 'network'.
- A mobile application for YP which provides education about self-management should be developed. This should be tailored so that it is accessible to all YP regardless of physical, sensory and intellectual impairment (see Standard 5).
- Resources should be developed for parents/guardians to help them to manage the change in their role when the YP transitions to adult services and how to support their YP to develop self-management and self-advocacy skills. Moving from child to adult health services
- YP and parents should be provided with information on where to access emergency services during and after transition of care and where their health records may be accessed.
- Healthcare teams should link with voluntary organisations to develop and access community-based resources, peer support, etc.

Information sources for YP

- Links to other sites that provide information and materials for transition for YP, parents and healthcare providers available at:

  Health professionals webpage

  Moving from child to adult health services

- www.steppingup.ie is an excellent free resource targeted at young people. This website offers YP a video where a young adult talks about this stage of the transition, and peer support by introducing them to transition stories from their peers.
- www.cphealthcaretransition.eu provides free resources targeted at young people with cerebral palsy and other child-onset disabilities. It provides information for YP and parents about transition, preparing for the adult healthcare system, and managing their health.

STANDARD 9 - Supporting YP Integration into Adult Services

Follow up, service evaluation, audit, service user feedback and research should be vital components of the transition process.

Application into practice:

Supporting YP Integration into Adult Services:

- Documentation and communication of the first adult service consultation should be provided to all relevant services. In some cases, one paediatric/GP visit post adult clinic visit may be scheduled as part of follow up.
- After their transfer to the adult service, the YP should be encouraged to identify their own healthcare needs including making requests for follow up, if required.
- Poor outcomes can be avoided if YP receives regular follow up and education. Follow-up with YP via phone or face to face should take place post transfer for an extended period (at least up to 18 months) to ensure YP is established in adult service/ identify additional support required. The timelines and responsibility for follow up should be agreed by both paediatric and adult teams.

When YP has difficulty integrating into Adult Service

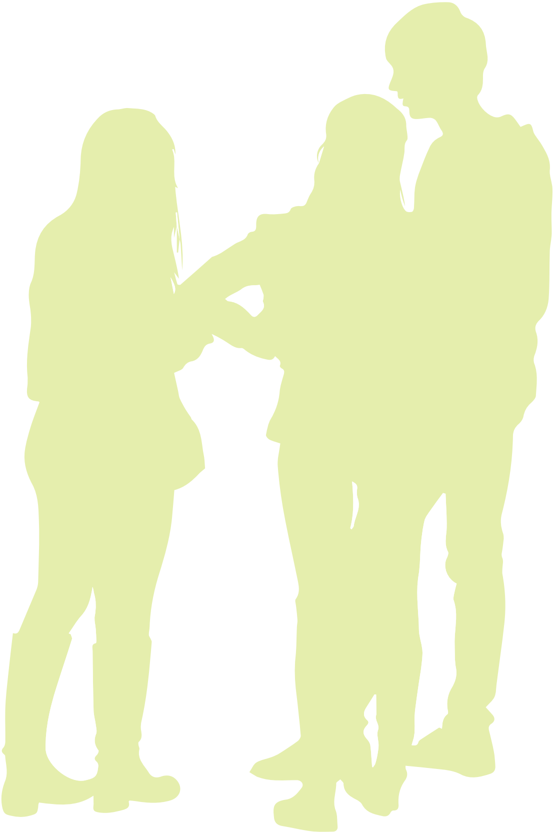
- The transition process within services should be regularly monitored, with a policy in place for those who do not successfully complete the transition process.
- The transition pathway should include a system to track attendance at appointments/ scheduled follow up calls including a plan with a named individual assigned to follow up if YP fail to access adult service at time of transfer or post transfer.
- Flexibility should be built into the pathway to accommodate re-entry for those who do not attend appointments or dis-engage with adult services.
- Feedback should be sought from those YP and families who have not successfully transitioned to adult services to identify improvement opportunities.

Service Evaluation

- Adult and paediatric teams should review the transition of care aspects of their service on a regular basis including policy and pathway review, research and audit of effectiveness including measurement of:
  - Attendance rates
  - Waiting list times
  - Health outcomes e.g., HbA1c levels in diabetes or faecal calprotectin in IBD
  - Feedback from YP, families, adult and paediatric teams, GPs and community agencies
  - Benchmarking against other services

- YP should be involved in the design of service evaluation.
- Transition teams should share success and innovations in practice with other teams/services.
- Examples of transition of care benchmark documents and service evaluation tools can be found via the links in the Health professionals webpage

> *Simply being there for your patient and showing nothing but kindness and warmth is ultimately the most important thing I needed more than any certain facility or plan.*
>
> [YP]



References

Agency for Clinical Innovation and The Sydney Children's Hospitals Network (2014) Key Principles for Transition of Young People from Paediatric to Adult Health Care. https://aci.health.nsw.gov.au/__data/assets/pdf_file/0011/251696/Key_Principles_for_Transition.pdf

Appleton R., Connell C., Fairclough E., Tuomainen H., Singh SP. (2019) Outcomes of young people who reach the transition boundary of child and adolescent mental health services: a systematic review. European Child & Adolescent Psychiatry (2019) 28:1431–1446 https://doi.org/10.1007/s00787-019-01307-7

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*(5), 469–480. https://doi.org/10.1037/0003-066X.55.5.469

Assisted decision-making (Capacity) Act 2015 (S.I. No 205. Section 10(4)) Regulations 2023 https://www.irishstatutebook.ie/eli/2023/si/205/made/en/print

Becker, J., Ravens, E., Pape, L., & Ernst, G. (2020). Somatic outcomes of young people with chronic diseases participating in transition programs: a systematic review. Journal of Transition Medicine, 2(1).

Betz C., L and Coyne I., (2020) *Transition from Pediatric to Adult Healthcare Services for Adolescents and Young Adults with Long-term Conditions: An International Perspective on Nurses' Roles and Interventions*. Springer Nature Switzerland AG: Springer International Publishing. 336.

Broad, K. L., Sandhu, V. K., Sunderji, N., & Charach, A. (2017). Youth experiences of transition from child mental health services to adult mental health services: a qualitative thematic synthesis. *BMC psychiatry*, *17*(1), 380. https://doi.org/10.1186/s12888-017-1538-1

Brenner, M.,Kidston, C., Hilliard, C.,Coyne, I., Eustace-Cook,J., Doyle,C., Begley, T., Barrett, M.J.(2018) Children's complex care needs: a systematic concept analysis of multidisciplinary language. European Journal of Paediatrics 177:1641–1652 https://doi.org/10.1007/s00431-018-3216-9

Callahan, S.T., Winitzer, R.F., Keenan, P. (2001) Transition from paediatric to adult-oriented health care: a challenge for patients with chronic disease. Curr Opin Pediatr. 13(4):310-6. doi: 10.1097/00008480-200108000-00004. PMID: 11717554.

Campbell F., Biggs K., Aldiss SK., O'Neill PM., Clowes M., McDonagh J., While A., Gibson F. (2016) Transition of care for adolescents from paediatric services to adult health services. Cochrane Database of Systematic Reviews 2016, Issue 4. Art. No.: CD009794. DOI: 10.1002/14651858.CD009794.pub2. https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009794.pub2/pdf/full

Canadian Association of Pediatric Health Centres (CAPHC), National Transitions Community of Practice (2016). A Guideline for Transition from Paediatric to Adult Health Care for Youth with Special Health Care Needs: A National Approach. https://ken.childrenshealthcarecanada.ca/xwiki/bin/view/Transitioning+from+Paediatric+to+Adult+Care/A+Guideline+for+Transition+from+Paediatric+to+Adult+Care

Care Quality Commission (2014). From the Pond into the Sea -Children's transition to adult health services). https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf

Central Statistics Office (2016) Census (2016) Summary Results - Part 1. https://www.cso.ie/en/csolatestnews/presspages/2017/census2016summaryresults-part1/

Colver A, Rapley T, Parr JR, McConachie H, Dovey-Pearce G, Le Couteur A, McDonagh JE, Bennett C, Maniatopoulos G, Pearce MS, Reape D, Chater N, Gleeson H and Vale L. (2020) Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services – implications of a 5-year research programme. Clin Med https://doi.org/10.7861/clinmed.2019-0077

Corbett, T., & Smith, J. (2022). Supporting adolescents with type 1 diabetes during the transition from child to adult services: a literature review. Primary Health Care, 32(5).

Coyne, I., (2018) Transition for Adolescents and Young Adults with Cancer, in Nursing Adolescents and Young Adults with Cancer: Developing Knowledge, Competence and Best Practice, P.R. Olsen and S. Smith, Editors. Springer International Publishing: Cham. p. 173-198.

Coyne, I., Sheehan A., Heery E., While A., (2019) Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences. J Clin Nurs,. **28**(21-22): p. 4062-4076.

Coyne I., Malone H., Chubb E., While A., (2018) Transition from paediatric to adult healthcare for young people with cystic fibrosis: Parents' information needs. Journal of Child Health Care. **22**(4): p. 646-657.

Crawford, K., Wilson, C., Low, J. K., Manias, E., Williams, A. (2020). Transitioning adolescents to adult nephrology care: a systematic review of the experiences of adolescents, parents, and health professionals. Pediatric Nephrology, 35, 555-567.

Crowley R., Wolfe I., Lock, K., McKee, M. (2011) Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of Disease in Childhood* 2011; **96:548**-553. https://adc.bmj.com/content/archdischild/96/6/548.full.pdf

Department of Health, Western Australia. Paediatric Chronic Diseases Transition Framework. Perth: Health Networks Branch, Department of Health, Western Australia; 2009. **Obsolete-for reference only.** https://ww2.health.wa.gov.au/~/media/Files/Corporate/general-documents/Health-Networks/Child-and-Youth/Paediatric-Chronic-Diseases-Transition-Framework.pdf

Dovey-Pearce G., Christie D. (2013) Transition in diabetes: Young people move on - we should too. Paediatrics and Child Health 23(4):174–179. https://doi.org/10.1016/j.paed.2012.12.009

Fleming E., Carter B., Gillibrand W. (2002) The transition of adolescents with diabetes from the children's health care service into the adult health care service: a review of the literature. Journal of Clinical Nursing 11, (5) 560-567. doi: https://doi.org/10.1046/j.1365-2702.2002.00639.x

Fortune, J., Ryan, J.M., Walsh, A., Walsh, M., Kerr, C., Kroll, T., Lavelle, G., Owens, M., Hensey, O., Norris, M. (2023) Transition from child to adult services for young people with cerebral palsy in Ireland: Influencing factors at multiple ecological levels. Developmental Medicine and Child Neurology. Doi:10.1111/dmcn.15778

Gleeson, H., Turner G. (2012) Best practice: Adolescent focus. Transition to adult services. Archives of Disease in Childhood - Education and Practice. 97:86-92. https://ep.bmj.com/content/edpract/97/3/86.full.pdf

Great Ormond Street. Transition to adult services. https://www.gosh.nhs.uk/your-hospital-visit/transition-adult-services/

Great Ormond Street (2018/2019) Great Ormond Street's Transition Workbook. https://media.gosh.nhs.uk/documents/SH-255-GOSH-booklet-FINAL.pdf

Harden PN., Walsh G., Bandler N., Bradley S., Lonsdale D., Taylor J., Marks SD. (2012) Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure. British Medical Journal Clinical Research 344 (jun01 1): e3718. http://dx.doi.org/10.1136/bmj.e3718

Hart, L. C., Mouw, M. S., Teal, R., & Jonas, D. E. (2019). What Care Models Have Generalists Implemented to Address Transition from Pediatric to Adult Care?: a Qualitative Study. Journal of General Internal Medicine, 34(10), 2083–2090. https://doi.org/10.1007/s11606-019-05226-wHughes RG, (2008). Patient safety and quality: an evidence-based handbook for nurses. (Prepared with support from the Robert Wood Johnson Foundation). Rockville, MD: Agency for Healthcare Research and Quality (US). 08-0043. www.ahrq.gov/professionals/clinicians-providers/resources/nursing/resources/nurseshdbk/nurseshdbk.pdf

Jarvis, S., Richardson, G., Flemming, K., Fraser, L. (2021) Estimation of age of transition from paediatric to adult healthcare for young people with long term conditions using linked routinely collected healthcare data. International Journal of Population Data Science. 6:1:20. https://doi.org/10.23889/ijpds.v6i1.1685

Johns Hopkins All Children's Hospital. Transition to Adult Care. https://www.hopkinsallchildrens.org/Services/Pediatric-and-Adolescent-Medicine/Adolescent-and-Young-Adult-Specialty-Clinic/Transition-to-Adult-Care

Kennedy A., Sloman F, Douglass J.A, Sawyer S.M. (2007) Young people with chronic illness: The approach to transition. Internal Medicine Journal. 37 (8) 555-560. https://doi.org/10.1111/j.1445-5994.2007.01440.x

Kerr, H., Widger, K., Cullen-Dean, G., Price, J., O'Halloran, P. (2020) "Transition from children's to adult services for adolescents/young adults with life-limiting conditions: developing realist programme theory through an international comparison". BMC Palliative Care 19 **(**115) https://doi.org/10.1186/s12904-020-00620-2

Leavey G., McGrellis S., Forbes T., Thampi A., Davidson G., Rosato M., Bunting B., Divin N., Hughes L., Toal A., Paul M., Singh S.P. (2019) Improving mental health pathways and care for adolescents in transition to adult services (IMPACT): a retrospective case note review of social and clinical determinants of transition. Social Psychiatry and Psychiatric Epidemiology 54:955–963 https://doi.org/10.1007/s00127-019-01684-z

McDonagh JE., Shaw KL., Southwood TR. (2006) Growing up and moving on in rheumatology: development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. Journal of Child Health Care 10(1) 22-42. https://doi.org/10.1177/1367493506060203

McDonagh JE., Southwood TR., Shaw KL. (2004). Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. Rheumatology (Oxford) 2004; 43 (6):737–43. https://doi.org/10.1093/rheumatology/keh163

McNamara N., McNicholas F., Ford T., Paul M., Gavin B., Coyne I.., Cullen, W, O'Connor K., Ramperti N., Dooley B., Barry S., Singh, S.P. (2014) Transition from child and adolescent to adult mental health services in the Republic of Ireland: An investigation of process and operational practice. Early Intervention in Psychiatry, 8 (3): 291 –7. https://doi.org/10.1111/eip.12073

Narla, N. P., Ratner, L., Bastos, F. V., Owusu, S. A., Osei-Bonsu, A., & Russ, C. M. (2021). Paediatric to adult healthcare transition in resource-limited settings: a narrative review. BMJ Paediatrics Open, 5(1) e001059. https://doi.org/10.1136/bmjpo-2021-001059

National Clinical Programme for Rare Diseases (2019) Guide for planning the transition of young people with a rare disease from paediatric to adult healthcare services. https://www.hse.ie/eng/about/who/cspd/ncps/rare-diseases/resources/transition-guide-for-rare-diseases-v1-0.pdf

National Institute for Clinical Excellence (NICE) Guidance*.* (2016) Transition from children's to adults' services for young people using health or social care services. https://www.nice.org.uk/guidance/ng43

Noyes J., Rees S., Hastings R., Mason H., Hain R., Lidstone V., (2014) Bridging the Gap: Transition from Children's to Adult Palliative Care.

Pape, L., Ernst, G. (2022) Health care transition from pediatric to adult care: an evidence-based guideline. *Eur J Pediatr* **181**, 1951–1958. https://doi.org/10.1007/s00431-022-04385-z

Peter NG., Forke CM., Ginsburg KR., Schwarz DF. (2009) Transition from pediatric to adult Care: internists' Perspectives. Pediatrics. 123 (2), 417-23. https://doi.org/10.1542/peds.2008-0740

Ravens E, Becker J, Pape L, Ernst G (2020) Psychosocial benefit and adherence of adolescents with chronic diseases participating in transition programs: a systematic review. J Trans Med. https:// doi. org/ 10. 1515/ jtm- 2020- 0009

Royal Australasian College of Physicians. (2014) Transition of Young People with Complex and Chronic Disability Needs from Paediatric to Adult Health Services. https://www.racp.edu.au/docs/default-source/advocacy-library/transition-of-young-people-with-complex-and-chronic-disability-needs.pdf

Royal College of Nursing. (2013) Adolescent Transition Care-RCN guidance for nursing staff. https://www.swswchd.co.uk/image/Clinical%20information/Transition/Adolescent%20Transition%20Care-%20a%20guide%20for%20nurses%202013.pdf

Royal College of Nursing Library (2022) Children and Young People: Transition to Adult Services. https://www.rcn.org.uk/library/subject-guides/children-and-young-people-transition-to-adult-services

Royal College of Physicians, Future Hospital Programme. (2015) On the margins of medical care - Why young adults and adolescents need better healthcare. https://www.rcplondon.ac.uk/file/2366/download

Ryan, J.M., Walsh, M., Owens, M., Byrne, M., Kroll, T., Hensey, O., Kerr, C., Norris, M., Walsh, A., Lavelle, G., Fortune, J. (2022) Transition to adult services experienced by young people with cerebral palsy: A cross-sectional study. Developmental Medicine and Child Neurology, 65(2), p 285-293.

Samarasinghe, S.C., Medlow, S., Ho, J., Steinbeck, K. (2020) Chronic illness and transition from paediatric to adult care: a systematic review of illness specific clinical guidelines for transition in chronic illnesses that require specialist to specialist transfer. *Journal of Transition Medicine*, vol. 2, no. 1, 2020, pp. 20200001. https://doi.org/10.1515/jtm-2020-0001.

Sheehan A., While A., Coyne I., (2015) *The experiences and impact of transition from child to adult healthcare services for young people with Type 1 diabetes: a systematic review.* Diabetic Medicine, **32**(4): p. 440-458.

Singh S.P, Anderson B, Liabo K, Ganeshamoorthy, T. (2016) Supporting young people in their transition to adults' services: summary of NICE Guidance. British Medical Journal BMJ 2016; 353 https://doi.org/10.1136/bmj.i2225https://www.irishstatutebook.ie/eli/2023/si/205/made/en/print

Suh E., Stratton K., Leisenpring W., Nathan P., Ford J., Freyer D., McNeer J., Stock W., Stovall M., Krull K., Sklar C., Neglia J., Armstrong G., Oeffinger K., Robison L., O Henderson T. (2020) Late mortality and chronic health conditions in long term survivors of early adolescent and young adult childhood cancers: a retrospective cohortive analysis from the Cancer Childhood Survivor Study, The Lancet (Oncology). 21(3): p421-435

Suris J-C, Michaud P.A, Akre C, Sawyer S (2008) Health risk behaviors in adolescents with chronic conditions. American Academy of Paediatrics. 122 (5): e1113-e1118. https://doi.org/10.1542/peds.2008-1479Thomsen E., Hanghoj S., Esbensen B., Hansson H., Boisen K., (2023) Parents' views on and need for an intervention during their chronically ill child's transfer to adult care. J Child Health Care. **27**(4): p. 680-692.

Trivedi, A., Sharma, S., Girgis, D. (2021) Transition of care for young people moving to adult healthcare services. The Pharmaceutical Journal. Vol 306 No. 7950; 306(7950) https://pharmaceutical-journal.com/article/ld/big-shoes-little-feet-transition-of-care-for-young-people-moving-to-adult-healthcare-services

Viner R. (1999) Transition from paediatric to adult care. Bridging the gaps or passing the buck? Archives of Disease in Childhood 81(3) 271–75. https://doi.org/10.1136/adc.81.3.271

World Health Organisation (2014) Health for the World's Adolescents. A second chance in the second decade www.who.int/adolescent/second-decade

World Health Organisation. (2016) Transitions of Care: Technical Series on Safer Primary Care. https://apps.who.int/iris/bitstream/handle/10665/252272/9789241511599-eng.pdf

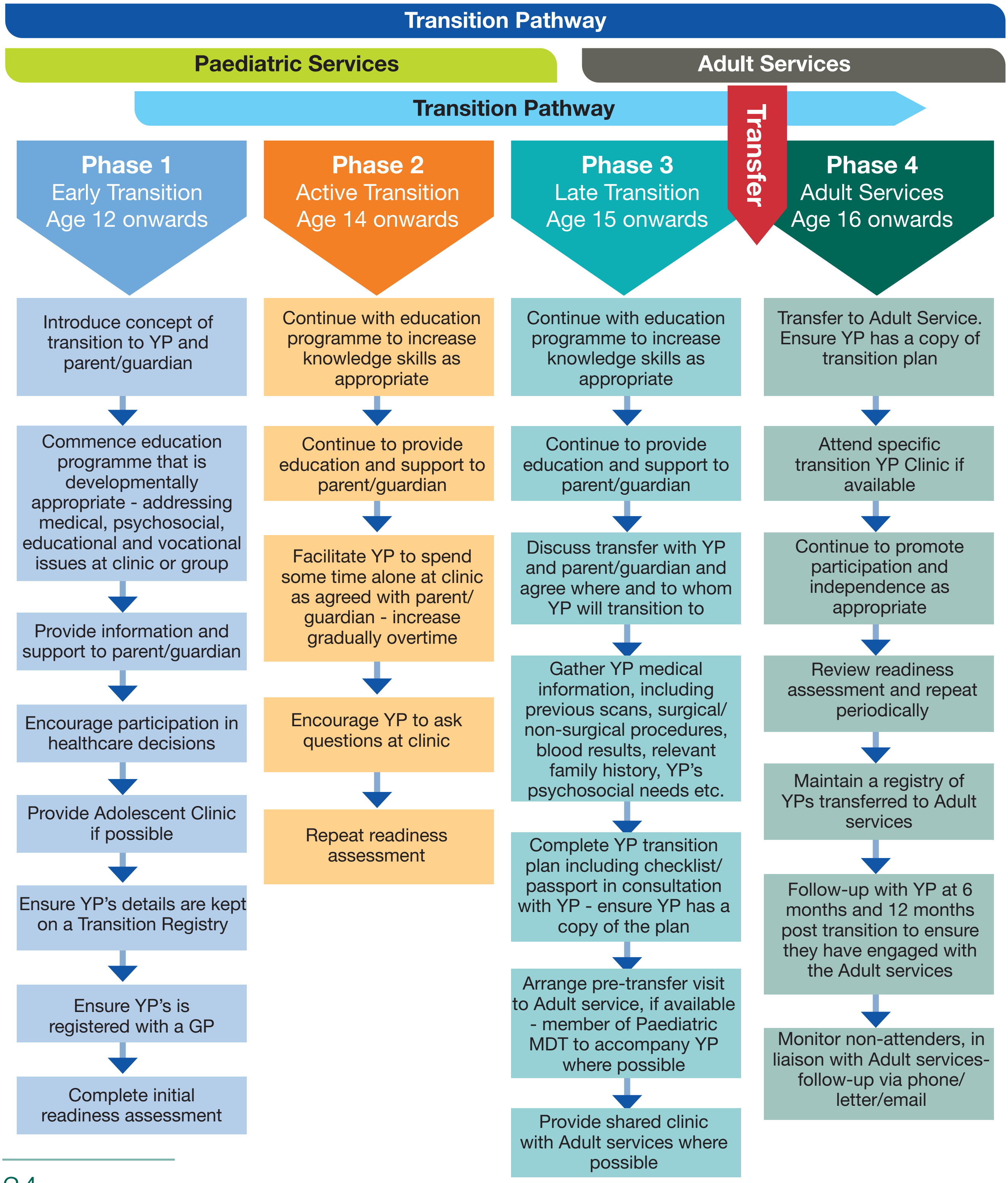
Yassaee A., Hale D., Armitage A., Viner R. (2019) The Impact of Age of Transfer on Outcomes in the Transition From Pediatric to Adult Health Systems: A Systematic Review of Reviews. Journal of Adolescent Health 64(6) 709-720. https://www.jahonline.org/article/S1054-139X(18)30808-5/fulltext

Appendices

Appendix 1

Transition of Care Pathway

The transition pathway is a tool to facilitate the implementation of transition programmes into routine clinical practice. The key components of transition of care identified in the standards set out earlier in this document are embodied in the transition pathway.



Transition Pathway

Paediatric Services | **Adult Services**

Transition Pathway

Transfer

Phase 1
Early Transition
Age 12 onwards

- Introduce concept of transition to YP and parent/guardian
- Commence education programme that is developmentally appropriate - addressing medical, psychosocial, educational and vocational issues at clinic or group
- Provide information and support to parent/guardian
- Encourage participation in healthcare decisions
- Provide Adolescent Clinic if possible
- Ensure YP's details are kept on a Transition Registry
- Ensure YP's is registered with a GP
- Complete initial readiness assessment

Phase 2
Active Transition
Age 14 onwards

- Continue with education programme to increase knowledge skills as appropriate
- Continue to provide education and support to parent/guardian
- Facilitate YP to spend some time alone at clinic as agreed with parent/guardian - increase gradually overtime
- Encourage YP to ask questions at clinic
- Repeat readiness assessment

Phase 3
Late Transition
Age 15 onwards

- Continue with education programme to increase knowledge skills as appropriate
- Continue to provide education and support to parent/guardian
- Discuss transfer with YP and parent/guardian and agree where and to whom YP will transition to
- Gather YP medical information, including previous scans, surgical/non-surgical procedures, blood results, relevant family history, YP's psychosocial needs etc.
- Complete YP transition plan including checklist/passport in consultation with YP - ensure YP has a copy of the plan
- Arrange pre-transfer visit to Adult service, if available - member of Paediatric MDT to accompany YP where possible
- Provide shared clinic with Adult services where possible

Phase 4
Adult Services
Age 16 onwards

- Transfer to Adult Service. Ensure YP has a copy of transition plan
- Attend specific transition YP Clinic if available
- Continue to promote participation and independence as appropriate
- Review readiness assessment and repeat periodically
- Maintain a registry of YPs transferred to Adult services
- Follow-up with YP at 6 months and 12 months post transition to ensure they have engaged with the Adult services
- Monitor non-attenders, in liaison with Adult services- follow-up via phone/letter/email

Appendix 2

Literature Sources

To date there are few policies or guideline documents available in Ireland specifically dedicated to the transition of YP with long term conditions or living with a disabilty from paediatric services to adult services. A number of specialities including rare diseases and epilepsy have addressed transition in their model of care documents with their respective National Clinical Programmes.

These standards are based on a review of international literature, transition guidelines and evidence based best practice on transition. The following documents were used to inform these standards:

Department of Health, Ireland. Sharing the Vision. A Mental Health Policy for Everyone (2022)

Pape, L., Ernst, G. Health care transition from pediatric to adult care: an evidence-based guideline. Eur J Pediatr ***181****, 1951–1958 (2022). https://doi.org/10.1007/s00431-022-04385-z*

National Institute for Clinical Excellence (NICE) guideline. Transition from children's to adults' services overview (2021)

Clinical and Translational Allergy. Current transition management of adolescents and young adults with allergy and asthma: a European survey (2020)

Health Service Executive (HSE), National Clinical Programme for Rare Diseases. Model of Care for Transition from Paediatric to Adult Services (2018)

Paediatric Rheumatology. Successful implementation of a clinical transition pathway for adolescents with juvenile-onset rheumatic and musculoskeletal diseases (2018)

European Academy of Paediatric consensus statement of successful transition from paediatric to adult care for adolescents with chronic conditions (2017)

National Institute for Clinical Excellence (NICE) guideline. Transition from children's to adults' services for young people using health or social care services (2016)

Canadian Association of Paediatric Health Centres (CAPHC). A Guideline for Transition from Paediatric to Adult Health Care for Youth with Special Health Care Needs: A National Approach (2016).

Royal College of Physicians, Future Hospital Programme. On the margins of medical care - Why young adults and adolescents need better healthcare (2015)

Royal Australasian College of Physicians. Transition of Young People with Complex and Chronic Disability Needs from Paediatric to Adult Health Services (2014)

Agency for Clinical Innovation (ACI) and The Sydney Children's Hospitals Network. Key Principles for Transition of Young People from Paediatric to Adult Health Care (2014)

Care Quality Commission. From the pond into the sea: Children's transition to adult health services (2014)

Royal College of Nursing (RCN) Adolescent Transition Care – guidance for nursing staff (2013)

Department of Health, Western Australia. Paediatric Chronic Diseases Transition Framework. Perth: Health Networks Branch, Department of Health, Western Australia; (2009)

The Royal College of Physicians of Edinburgh Transition Steering Group. Think transition: Developing the essential link between paediatric and adult care (2008)

Appendix 3

On-Line Survey of Healthcare Professionals

An online survey of medical healthcare professionals was conducted and distributed via RCPI in 2018 to identify:

- ✓ Awareness of transition amongst professionals
- ✓ Barriers to transition
- ✓ Needs/requirements to support successful transition

Findings:

- A total of 128 responses were received.
- Responses to the survey were submitted from both Paediatric and Adult services with the majority of respondents directly involved in transitioning from Paediatric to Adult services.
- Approximately 60% of respondents had no structured transition processes in place within their services with up to 90% of those YP transitioning having additional complex needs.
- The survey looked at the age that was most appropriate to initiate the transition process-responses varied between the ages of 12 and 18 years of age, with majority weighting given to 18 years of age for transferring into adult services. When questioned on resources, guidelines and policies available to facilitate transition the majority of respondents felt that there was a shortage in resources available.

Appendix 4

National Survey on Transition of Care Experience YP/Parent/Carers 2023/2024

A National Survey of the Transition of Care Experience of YP, parents and carers was opened for a period of nine months between 2023 and 2024. Survey respondents could access the survey online or on paper.

Facilitated by Your Voice Matters the survey aims were to:

1. Capture the lived experiences of young people (YP) and their families during the transition from paediatric to adult healthcare services.
2. Identify opportunities to make transition services more person-centred.

Developed collaboratively with key stakeholders and including feedback on its design from the members of the Youth Advisory Council (CHI), the survey combined both qualitative and quantitative questions on the experiences of transition of care. Data collection and analysis were conducted using Sensemaker® software.

The survey included YP or parents and carers attending a range of healthcare services for care related to chronic health conditions and disabilities across the Republic of Ireland.

The survey had 118 respondents, including:

- 76 family members, carers, or friends of YP who had transitioned
- 40 YP (aged 14–26) 24 of whom had transitioned and spanned 14 counties and engaged with 21 different healthcare specialties. This diverse representation offers a broad view of the challenges and complexities YP and families/carers face in the transition to adult services across Ireland.

The full survey report can be found here: Health professionals webpage

In person meetings with members of the Youth Advisory Council, CHI and the survey responses have informed this framework.

The National Transition of Care from Paediatric to Adult Services Working Group captured the lived experiences of 40 young people and 76 parents transitioning from paediatric to adult health and social care services in a survey from September 2023 to July 2024.

WHAT YOU SAID

“I have received **no guidance, preparation or help with this and don’t know where to look for information.** I have been asked to have my questions ready for my next appointment as it will be my last. **I am anxious** about this as **I have no idea what I should be asking...**” *[Young person]*

“I’ve had **no preparation** for moving to adult services, I am **confused** about what happens. I am nearly 16, autistic and have an intellectual disability. **I would like to know more** about what happens when I’m an adult.” *[Young person]*

“**I’m very nervous when my mam can’t ring like she does now** to get my care and get me seen when I run into a problem.” *[Young person]*

“Overall my transition of care was very smooth from the nurse’s standpoint both paediatrics and adults and who continue to show **amazing support and care** unlike any other.” *[Young person]*

“**I’m worried** about dealing with a new team, a new hospital… and a million more things… major **concerns about being cut out** as we move to adult care… it will be a **huge upheaval for us as a family** and I’m already worried.” *[Parent]*

HOW WE CAN IMPROVE

- Listen to your concerns about the transition
- Provide age appropriate information and resources
- Begin transition planning at age 12
- Support young people to manage their own health

MORE INFORMATION

https://www2.hse.ie/services/moving-from-child-to-adult-health-services/

Clinical Design & Innovation
Person-centred, co-ordinated care

Your experiences helped to inform the development of a Transition of Care Framework and online resources created by the National Transition of Care Working Group.

Appendix 5

Working Group Members and Contributors 2018 – 2020

Dr Orla Killeen (Chair)	Consultant Paediatric Rheumatologist, OLCHC
Dr Elizabeth Barrett	Associate Clinical Professor, UCD & Consultant in Child and Adolescent, Liaison Psychiatry, CHI
Ms Emma Butler	Senior OT, OT4Children, RCSI
Ms Alison Cashell	Clinical Nurse Co-Ordinator for Children with Life Limiting Conditions (CNM2), CHI @ Temple Street
Prof Imelda Coyne	Prof of Children's Nursing, Trinity College, Dublin
Dr Ellen Crushell / Prof Alf Nicholson	Clinical Lead (Paediatrics), National Clinical Programme for Paediatrics and Neonatology
Dr Pairic Curran	Consultant Paediatrician, Portiuncula University Hospital
Ms Jacqueline de Lacy	Programme Manager, National Clinical Programme for Paediatrics and Neonatology
Ms Áine Derwin	Community Support Specialist, Disability Support Services
Ms Lisa Edwards	Renal Department Co-Ordinator, CHI @ Temple Street
Ms Siobhán Horkan	Programme Manager, National Clinical Programme for Paediatrics and Neonatology (2017-2019)
Ms Ann Mills	Senior Physiotherapist, Laura Lynn
Ms Patricia Minnock	RANP Adult Rheumatology, Harold Cross Hospice, Dublin
Ms Naomi Oldenburg	Project Co-Ordinator, National Clinical Programme for Paediatrics and Neonatology (2017-2019)
Ms Margaret O'Meara	Coordinator of Nursing Services for Children with Complex Nursing Needs, Galway
Ms Yvonne Owen	Epilepsy Transition Coordinator, NCHG + Epilepsy Ireland
Dr Helena Rushe	Psychology Department Manager, CHI @Temple Street
Dr Yvonne Smith	National Co-Lead, Acute Medicine, Consultant Cardiologist
Ms Marienne Tierney	Coordinator of Nursing Services for Children with Complex Nursing Needs, Laois/Offaly
Dr Órla Walsh	Adolescent Medicine Specialist and General Paediatrician

Working Group Members and Contributors 2023

Dr Ciara Martin (Chair)	Consultant Paediatrician (Emergency Medicine), National Clinical Advisor and Group Lead, Children and Young People, HSE
Ms Amanda Breen	Social Worker, Central Remedial Clinic, Health and Social Care Representative
Ms Fionna Brennan	Director of Nursing, CHI
Dr Aideen Byrne	Consultant in Immunology (Allergy), CHI
Dr Patricia Byrne	Consultant Child and Adolescent Psychiatrist
Prof Imelda Coyne	Prof of Children's Nursing, Trinity College, Dublin
Ms Jacqueline de Lacy	Programme Manager, National Clinical Programme for Paediatrics and Neonatology
Ms Denise Dockery	Health and Social Care Representative
Dr Omar El-Sheriff	Consultant Gastroenterologist, St Vincents University Hospital
Ms Dervela Gray	General Manager, National Clinical Advisor Children and Young People, Manager, National Clinical Programmes, RCPI
Ms Mary Hamzawi	Clinical Nurse Specialist Inflammatory Bowel Disease, St Vincents University Hospital
Dr John Hayden	Senior Lecturer, School of Pharmacy and Biomolecular Sciences, RCSI, Pharmacy Representative
Dr Orla Killeen	Consultant Paediatric Rheumatologist, CHI
Dr Hannah Linane	Fellow in Adolescent and Young Adult Palliative Medicine
Dr Susan McAnallen	RCPI Fellow in Transitional Nephrology
Dr Fiona McElligott	Consultant in Paediatric Palliative Medicine
Dr Nuala Murphy	Consultant Paediatrician, National Clinical Lead for Paediatric Diabetes
Dr Beatrice Nolan	Consultant in Paediatric Haematology, CHI
Prof James O'Byrne	Consultant Metabolic Physician and Consultant Clinical Geneticist, Mater Hospital
Ms Niamh O'Sullivan	Nurse, Adolescent and Young Adult Cancer, St James Hospital
Ms Noelle Power	Registered Advance Nurse Practitioner Respiratory/Cystic Fibrosis, UL Hospital
Ms Kerry Russell	Director of Quality, Safety and Risk, CHI
Dr Órla Walsh	Adolescent Medicine Specialist and General Paediatrician, CHI
Mr Michael Walsh	Programme Manager, National Clinical Programme for People living with Disability