WellChild
the national charity for sick children

8 Principles for Transition

Transition reference guide and tools to support health and care professionals to improve practice for all children and young people transitioning to adult services.

Contents

This resource has been created specifically to assist professionals planning the transition from children to adults services for young people with complex medical needs. The information in this document and the accompanying toolkit was produced and reviewed by health professionals including nurses. The guidance adheres to the NMC code of conduct and other relevant governing body guidelines. This resource also adheres to the Charity Commission's public benefit requirement via WellChild's charitable purposes.

Please note this reference guide and accompanying tools are designed to be working documents which will be updated, and new resources will also be created. Please make sure you are using the latest version by checking the version number and date updated at the bottom of the page.

Version	Issue Date	Reason for Issue/changes made	Updated by
1.0	May 2023	New Document	Working Group

Introduction

Background - What is Transition? Why is WellChild involved?

Preparing for adulthood is an important time in a young person's life when they should be planning for their future. In health services this is called transition and includes the preparation, transfer and settling into adult services. With rapid medical advancement and improvement in technology and equipment, more children and young people with complex medical needs are transitioning into adulthood. It is important that the appropriate support and services are in place to assist this complex, vulnerable and growing cohort to thrive as they transition from children's to adults' services and beyond.

As the national UK charity for children and young people with complex medical needs, WellChild's mission is to support these children and their families to thrive as they journey through life and support services. Specialist WellChild Nurse transition posts have been established, with further WellChild Nurse posts embedding transition as an element of the role. A dedicated working-group with a focus on transition was established to champion the transition agenda and what the charity can do to support this. Following on from the success of WellChild's 11 Principles for Better Training, and 10 Principles for Complex Discharge, it was identified by the working group that a similar resource would be beneficial for the area of Transition.

WellChild has already developed transition resources specifically for young people, parents and carers which can be found on the website via the following links:

- An easy read guide for young people transitioning to adult services, An easy read guide for young people transitioning to adult's services | WellChild
- Growing Up Using A Ventilator, a booklet to help young people and young adults who use a ventilator, Growing Up Using A Ventilator | WellChild
- Transition to Adult Services Q&A, Transition to adult services FAQs | WellChild

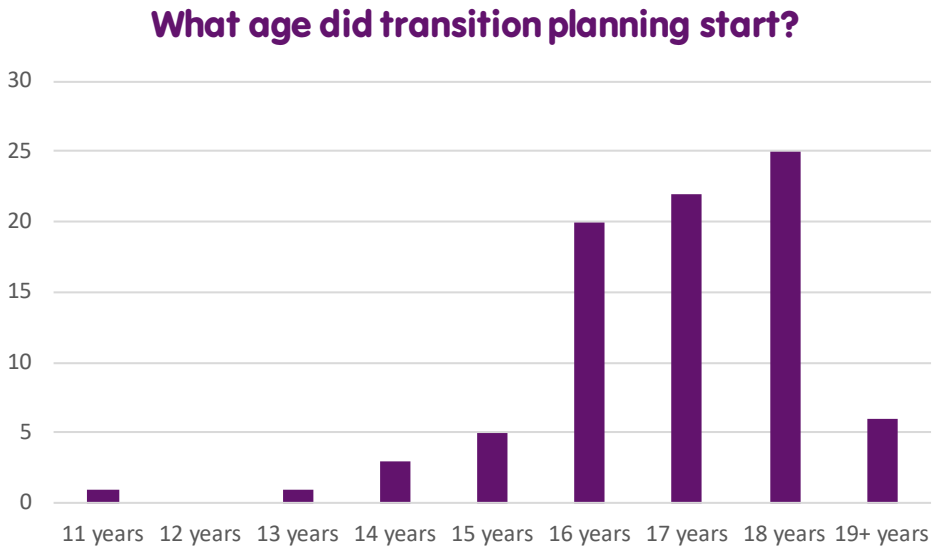
Learning from young people's experiences

"Nothing has happened. She has just gone over to adult services, and no one has contacted us since?" Parent, Nov 2022, WellChild Transition Survey

It is acknowledged that transition is approached differently depending on where you are in the UK, and who or what is available to support the process. As part of the scoping for this resource we wanted to hear directly from young people and their parents/carers to gather their experiences of transition. Questions focussed on the transition process itself, and what support the young person received. We also wanted to find out about experiences in general, including what worked well and what could be improved for others going through the process in future. The survey was designed to be completed on behalf of the young person with support from a parent or carer if needed, or by the young person themselves if appropriate. As such, the questions were asked from the young person's perspective but could be answered by the parent or carer where required.

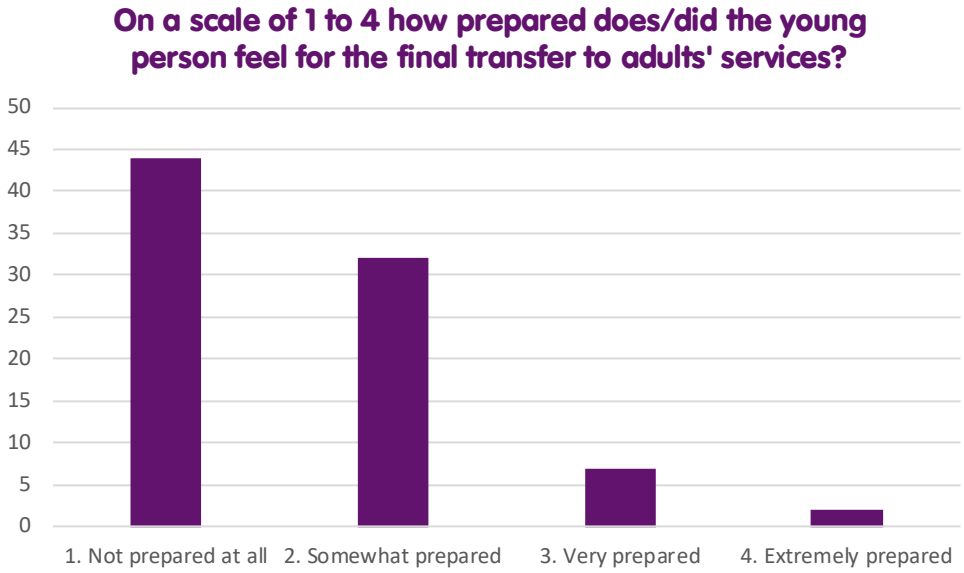
The full results of the survey can be found here survey results 2023 but some highlights have been included below.

According to the NICE Guidelines, transition planning should start at age 13 or 14 (Year 9) for young people with an Education Health Care Plan (EHCP) plan. It is beneficial to start transition planning earlier for young people with complex health needs to adequately prepare the young person and their family. For 88% of survey respondents transition planning started from the age of 16 onwards.

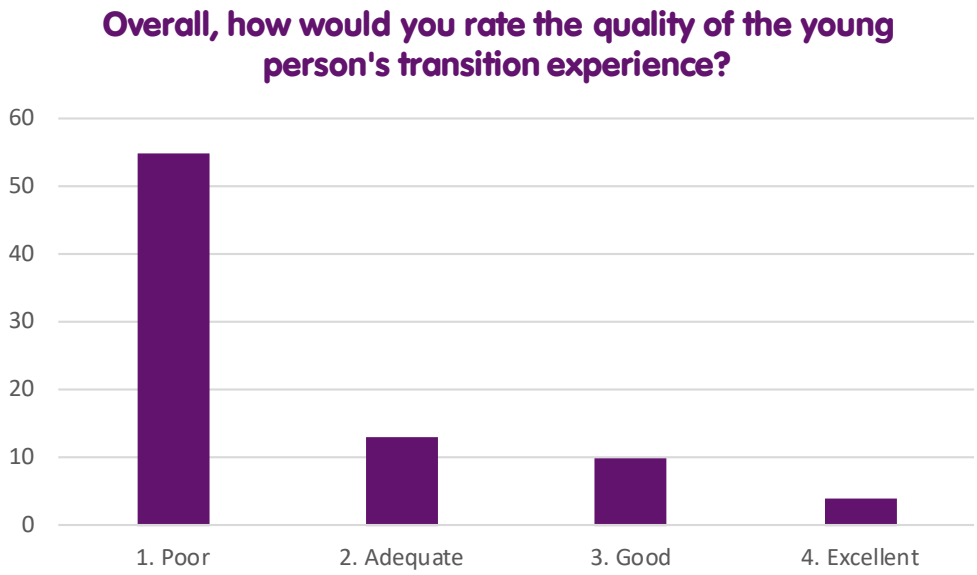


When asked if they felt transition planning started at the appropriate time for the young person, 58% said no. Further comments revealed many felt the process started too late, leaving both young people and parents unprepared for adult services. Others commented there was no formal, or structured, transition process.

Respondents were asked how prepared the young person is/was for the final transfer to adult services.



More than 50% of responses reflected the young person was not prepared at all, with 37% somewhat prepared, 8% very prepared and only 2% extremely prepared.



67% of people who completed the survey rated the quality of their transition experience as poor.

Although there are some areas of best practice demonstrated, the overarching picture the survey presented was that much work is needed to improve the experiences of this cohort.

Purpose- Why is this resource needed?

The aim of this resource is to ensure that health professionals are equipped to ensure young people with complex needs get the right care, in the right place and at the right time during transition to adult services.

The content of this framework is a consensus of nurses and other professionals actively leading and supporting young people throughout transition. The framework equips health professionals with key principles to achieve best practice for the transition process.

Intended benefits

The intended benefits of this framework are:

- To improve the transition experience of young people with complex medical needs before, during and after transfer to adult services.
- To raise awareness of and clarify the roles and responsibilities of all services and professionals involved in the transition process, so expectations can be managed. Transition is a collaboration between all those supporting young people. This includes both paediatric and adult professionals within health, education and social care.
- To provide a comprehensive resource for all professionals to access guidance and support when assisting a young person through transition. This is particularly relevant for those who may not be familiar with or have an awareness of the process, resources or documentation to support transition.
- To encourage a collaborative approach to transition planning ensuring the best outcomes for each young person.

- To define a level of quality for the delivery of planning and care when supporting a young person and their wider family through their transition journey.
- To provide a tool to guide service development and improvement.
- To improve equity and reduce variation, ensuring transition follows the same processes and pathways no matter where the young person lives.
- To support professionals to keep young people and their families informed of what lies ahead and record their achievements as they progress.

A collection of supporting resources are listed at the end of these principles under Useful existing reference resources.

Scope

Whilst there are some excellent transition resources currently available, the 8 Principles for Transition guide focuses specifically on young people with complex medical needs whose transition journey requires more coordination and collaboration than most to be successful and robust.

This framework is aimed at providing guidance for all professionals supporting young people as they transition from children's to adults' services. This may include professionals in a variety of environments within the health, education and social care sectors depending on the needs of the young person.

The framework is also a supportive tool for professionals who are unfamiliar with the transition process and aims to aid the understanding of the necessary steps to achieve a successful transfer of care.

Structure

The framework consists of 8 key principles, which subdivide into relevant guiding principles. The principles can be viewed together or in part as applicable to the transition process. There are some common themes which run through each of the principles. When collating the principles, the working party felt these themes are important enough to be repetitive. Where relevant, at the end of each principle, links to existing resources are provided to aid understanding and provide further information and tools. Key terminology and definitions have been highlighted and explained where beneficial.

The resource is freely available and accessible via the WellChild website here ».

The role of the working party

The health professionals listed below played key roles in the creation of these 8 Principles for Transition during development. This has included the following:

- Identifying the 8 principles needed when facilitating transition and drafting the recommendations for these.
- Providing clinical expertise in the development of the document.
- Reviewing and providing feedback on the layout, language and ease of use of draft documents.
- Collecting patient experience by circulating a survey to inform the development of the resource.
- Ensuring that the resource was up to date with local, regional and national guidance.

The working group will continue to be involved in the ongoing development of the resource and providing feedback on its use.

Members of the working party

WellChild Nurse Transition Forum:

Alison Shepard | WellChild Specialist Transition Nurse

Eden Carlisle | WellChild Community Childrens Nurse, Lead in Transition

Helen Martin | Helen Martin - WellChild Nurse, Community Paediatric Palliative Care

Janice Fauset-Jones | WellChild Transition Nurse for complex needs and long-term ventilation

Nina Heighington | WellChild Transition Nurse

Angie Fudge| WellChild Clinical Lead, Special School Nursing

Other Contributors:

Carolyn Lowe | Deputy Director of All Age Continuing Care

Stewart Birnie| Clinical Lead, Complex and Individualised Commissioning

From WellChild:

Alice Drury | Charitable Programmes Project Manager

Amy Mitchell | Director of Programmes

Callum Campbell | Family Information Officer

Glossary of terms

Transition: is defined as "a multi-faceted, active process that attends to the medical, psychological and educational/vocational needs of adolescents as they move from child to adult centred care" (Blum 1993). It is now advocated that this process starts in early adolescence (NICE, 2016)

Transfer: is the event of leaving children's and entering adult services.

PRINCIPLE 1 | Preparation for transition: Planning and managing expectations.

Everyone starts transition at a different age, but it is important to commence conversations as early as possible prior to transfer to adult services. This will help give young people and parents or carers time to prepare for the change. The expectations of all involved in co-ordinating transition should be proactively and formally managed prior to embarking on the transition journey. It is important to set realistic expectations and avoid making unrealistic promises about what transition will involve for each young person and their family. The professionals involved in the transition process should be aware of their responsibilities, and the lead professional for each young person should identify key milestones to meet to ensure a smooth transfer. The following principles must be considered when preparing to commence transition planning:

For young people and their families:

- Where possible, early discussions should take place when the young person reaches 11 years of age.
- The purpose of transition planning should be clarified at the start of the journey. Links could be made to existing resources for guidance on developmentally appropriate health care (see resources listed below).
- Details about how the law changes with regards to parental responsibility and the implications of the best interest decision/Liberty Protection Safeguards/Mental Capacity Act once a young person reaches 18 need to be explained clearly.

For the professionals involved in transition planning:

- A professional, called the "named worker" or "key worker", should be identified by the family, young person and the Multi-Disciplinary Team (MDT) prior to the commencement of transition.
- The purpose of transition planning should be clarified with all involved at the start of the journey.
- The process and structure of the transition journey should be explained with timelines, actions, and responsibilities, each delegated to the appropriate professionals and explained at each stage.
- An individual timeline should include details of planned training, meetings, shared consent, dates, reviews, and referrals for the onward journey after transfer.
- Any transition meetings should be an opportunity for the young person or their family/carer(s) to ask questions about the process and openly discuss any assumptions and concerns.
- During the transition journey, the lead professional should review expectations of the young person, family and the MDT periodically to ensure coordination and clarity.
- All of the above should be documented in the appropriate notes and shared with the young person, family, and MDT so expectations are managed and reassessed throughout the transition process. Please see Principle 4 on communication for guidance on what written information they should receive and alternative formats for anyone with learning disabilities or other languages.

Resources/reference guides:

- Appendix A - Transition Pathway
  See useful existing reference resources

PRINCIPLE 2 | Governance

Members of the MDT who support transition have an obligation to maintain confidence and capability in the skills they will need to enable transition, plus consistently evaluate the quality of their service delivery. To achieve this, consideration should be given to the following:

- Transition leads or the lead professional should maintain accurate records of transition for every young person, ideally using a database with audits and evaluations.
- The transition lead will need to be clear who holds parental responsibility for the child or young person.
- Consent will need to be obtained to match local guidelines and policies to ensure safe information sharing.
- Risk assessments will need to take place throughout the process. The designated person to complete risk assessments will need to understand local policies and be deemed competent.
- The MDT should engage in regular reviews of local processes related to transition and understand applicability.
- Professional teams need to be aware that it is acceptable to raise concerns when an unsafe transition is occurring. This should be done via local escalation procedures and in line with local safeguarding policies. Where applicable, an incident should be raised.
- Professionals supporting transition are suitably trained and accountable.
- There are accurate and regular audits of transition processes and monitoring of an individual's progress throughout transition.
- Provision of comprehensive patient focused literature and signposting for information and support services.

Resources/reference guides:
See useful existing reference resources

PRINCIPLE 3 | Identification

Any young person requiring transition planning should be identified at the earliest opportunity to enable planning to commence as soon as possible. The person who will lead on the young person's transition planning should be made clear. A continual assessment of need should be commenced at this time and reassessed throughout the transition process.

At this stage it is recommended that the following should be considered:

- Identify a named key worker who coordinates transition and a lead consultant or GP who will support the process. The GP should be involved every step of the way.
- Inform the young person and parent or carer that they can request an annual health check from their GP if the young person has a learning disability and is aged 14 or over. The annual health check helps their GP get to know the young person better and become familiar with their needs, which will help once the young person reaches adulthood.
- Identify the MDT who is involved with the young person.
- Arrange a MDT transition meeting (to discuss transition and transfer arrangements e.g who the young person is being transferred to, how will they be offered appointments and who will provide equipment etc.) This should include professionals across health, community, General Practice, Social Care & Education.
- Identify and give clear guidance for the young person's access into urgent care during transition. This may be their local District General Hospital rather than the hospital where they have their specialty care. If this is the case, ensure local teams are aware of the young person's needs and who to contact for advice, by providing healthcare passports/advanced care plans.
- In the first instance a young person must be assumed to have capacity unless it is established that they lack capacity, in this instance the Mental Capacity Act must then be considered to assess the young person's mental capacity.
- Any training needs for those involved in caring for the young person should be identified and how that training is going to be delivered once the young person is 18 should be confirmed.
- Care plans should be in place prior to transition.
- The criteria for transition should be agreed, time scales established, and regular MDT meetings arranged. The timescales set should suit the individual young person's clinical situation, for example, it may be appropriate to delay transfer to adult services if the individual may be approaching the end of their life.
- Any necessary risk assessments should be completed, and actions identified from these should be allocated to the appropriate person.
- A list of equipment and supplies that will be required should be identified and compiled. Resourcing for these should be identified on transition to adult services.
- The relevant coordinating services in adult services must be contacted and provision arrangements agreed in advance for medication, surgery and equipment servicing.
- The young person's local area MDT should be involved as early as possible if the young person is in a tertiary centre.

Resources/reference guides:

See useful existing reference resources

PRINCIPLE 4 | Communication

Communication needs to be effective and meaningful between all parties to achieve a safe and timely transition to adult services. The following recommendations must be considered during the process of transition and transition planning:

- Clear expectations of roles and responsibilities should be set from the start including the roles of the young person and parent or carer.
- Any conversations must be open and honest, and should cover all possible outcomes, both positive and negative.
- All information being shared must be at a level that everyone can understand and reasonable adjustments should be put into place to enable this. Any barriers to communication i.e., learning disability, language and literacy should be considered and addressed.
- A variety of ways to share information should be offered. This may include audio recordings, easy read resources or translated information.
- The young person's preferred method of communication, for example: email, verbal, text, or written letter correspondence, should be discussed and identified in line with local Information Governance and data protection policies.
- Other resources that facilitate communication should be utilised, for example, advocacy, peer support, charities and third-party sectors.
- If the young person is on a Palliative Care Pathway, parallel planning using Advanced Care Plans (ACP's) or alternatives should be initiated.
- It is also recommended that patient Health Care Passports be used to share information on individual patient needs.
- Relevant professionals and parents should receive a copy of patient documents, for example Healthcare Passports and Advanced Care Plans. The professional whose responsibility it is to transfer documentation from child to adult paperwork must be identified.
- A comprehensive contact list of who needs to be involved in each area should be produced.
- Documentation should be in an accessible and appropriate place and shared as per local policy. The local ambulance service should be notified with Patient Specific Instructions as needed.
- Consent from family and the young person must be gained ahead of information sharing in line with local policy and safeguarding procedures.
- Be aware of barriers to patient information for other professionals and how to share confidential information securely e.g. email security, IT systems and/or phone calls.

Resources/reference guides:
See useful existing reference resources

PRINCIPLE 5 | Empowering the young person/parent/carer

The young person and their needs, aspirations and wishes should be central to all transition planning. Health and social care professionals should understand the individual young person and their family life, and work in partnership with them to provide support in the present as well as preparing for the future. To do this, the following must be considered:

- Empower the young person and include them in conversations as early as possible.
- The young person/parent/carer should be involved at all stages of transition planning.
- Assess the knowledge and capacity of the young person. Ensure they are empowered regardless of their cognitive abilities.
- The voice of a young person can be lost, when so much time is spent talking to parent/carers. Encourage parents and carers to empower the young person to make decisions where possible. Consider enlisting an advocate where there are concerns about hearing the voice of the young person.
- Ensure you have access to the right resources to support the young person. They may need alternative resources where relevant, like easy read or brail.
- Families should be aware who is leading the transition process. They must receive regular progress updates and have the opportunity to ask questions.
- The person(s) who hold parental responsibility need to be identified.
- Ensure the family are fully informed of how their role and parental responsibilities will change when their child becomes 18 and what they need to consider e.g., Lasting Power of Attorney / Court Appointed Deputy.
- Family dynamics and existing support networks should be explored and the impact on family life should be appreciated and taken into consideration throughout the transition process.
- Local support available across relevant sectors should be reviewed and relevant referrals made when appropriate including consideration of local third-party providers.
- Parental/family/carer's capacity to care for the young person's needs should be identified and risk assessed.
- A financial/benefits assessment should be arranged for the young person, and they should be signposted to appropriate funding where relevant.
- Families should be given notice of, and given every opportunity to attend MDT meetings. Minutes should be shared where appropriate.
- Families should have an opportunity to be introduced to ongoing care providers before transfer to adult services.
- Families should be provided with a contact list of key professionals and services prior to transfer to adult services.
- Young people and families should be empowered to ask questions and encouraged to participate in shared decision making where appropriate.
- Useful tools, including easy read resources, from organisations like Ready Steady Go, Ten Steps Transition, Mencap and WellChild cover topics such as mental capacity, information about adult services, and more.
- Involve the young person in the completion of Health Care Passports and ACPs wherever possible.

Resources/reference guides:

See useful existing reference resources

PRINCIPLE 6 | Assessment of needs

It is important to identify the young person's needs and how these will be met in adult services. Assessing need must be done across sectors including education and social care, in parfallel to consideration of health and medical needs.

The following must be considered:

- Identify who will provide equipment in adult services – including ongoing funding, provision, servicing, and who repairs and replaces broken equipment.
- Confirm new arrangements for the provision of medical and surgical supplies.
- Identify the patients route into urgent care. Place flags on ambulance service whilst still in transition if necessary. Find out if they will go to adult or paediatric A&E in the event of an emergency. Find out what admission to adult services will look like for the young person and family. Ensure there are clear plans of which services are looking after the young person during the transition period.
- As necessary refer on to adult safeguarding/learning disability nurses, to make sure reasonable adjustments are met in adult services.
- Find out what training needs there are for the young person, their parent(s), carers, and adult services staff. Ensure that there is a lead for training, delegation and renewal of competencies, and that there are competent training providers to meet any training needs.
- Review and evaluate any care plans early to ensure they are still valid when moving to adult services. For example, if they currently have oxygen, will they still have it in adults? Ensure adult services have copies of care plans and transition plans.
- A financial/benefits assessment should be arranged for the young person, and they should be signposted to appropriate funding where relevant.
- At 14 years of age services that will be involved with the young person at 18 should be identified. This includes consideration as to whether the young person has a primary health need. In this instance early notification should be made to NHS Continuing Healthcare (CHC) at age 14. This is then followed by a formal referral (completion of a decision support tool) to CHC at age 16. If the young person is in receipt of a Children and Young People's Continuing Care package of care, the guidance set out in the National frameworks for Children's and Young People's Continuing Care and NHS Continuing Healthcare on Transitioning young people should be followed.
- If the young person is regularly admitted to a paediatric critical care service, a transition process for critical care should occur in parallel to other speciality transition needs, including professionals from adult critical care.

Resources/reference guides:

- Appendix B - Early Notification Form
  See useful existing reference resources

PRINCIPLE 7 | Partnership working

Successful transition planning requires the engagement of the young person, parent/carer, family and various members of the MDT within the hospital, community, and local authority to enable the young person to have a safe transfer to adult services. Partnership working is key to preparing the young person for this transition.

To ensure successful partnership working, the following principles must be considered:

- The specific needs of the young person as this will influence the team that need to support the young person and family.
- The young person's short, medium, and long term needs should be identified and reassessed regularly. Consider reflecting on the aspirations within the young person's EHCP.
- Clarification of the services that are required such as local, regional, statutory, and others that are supportive including charitable and hospice organisations which are instrumental in improving a young person's quality of life.
- The young person's entitlement for service provision should be considered.
- Ideally there should be an identified key worker to facilitate partnership working.
- Clear timescales and expectations for transfer should be established at the start of the process.
- Roles and responsibilities of all those involved should be identified and documented to mitigate risk.
- Work collaboratively with anyone involved in the young person's care, including social care, education, hospices and third sector organisations.

Resources/reference guides:

See useful existing reference resources

PRINCIPLE 8 | Preparation for final transfer and the onward journey

Everything should be in place before the young person's final transfer to adult services and all those involved in care should know their role. The young person and their parent/carer should be fully aware of the logistics involved in transfer to adult services and the following must be considered in advance:

- Offer for the young person and parents/carers to visit adult wards to meet the adult team prior to transfer. This could be a visit to an adult unit/clinic/day centre/college or via use of a social story. This should also include facilitating a visit to adult critical care to allow introduction to the critical care team and the environment – to lessen anxiety associated with this.
- Closure with the children's teams can be important for the young person and their family. Make sure there is time to say goodbye before they move on.
- Consider potential for adult services engagement from 17 and children services remaining involved on the periphery after 18.
- Ensure there is a referral letter to adult services with a transfer document and discharge letter from children's services at transfer.
- Ensure the young person and their family have the contact details of the new professionals, and that they are given as much information about the new adult units as possible.
- Ensure that the final paperwork is complete and up to date before date of transfer. Paperwork might include health passports, a care plan, the route into urgent care, etc.
- Ensure that all equipment has been provided and medical and surgical supplies are ordered.
- Ensure that emotional support needs for the young person and their parent/carer have been addressed and communicated during transfer.
- Ensure the young person is offered and attends appointments in adult services. A safety net should be in place so that if the young person does not attend or is not brought to appointments by their parent or carer there is a robust and timely follow up. This should be followed up by adult services and flagged back to their children's referring team, or GP if needed.

Resources/reference guides:
See useful existing reference resources

Summary

The 8 Principles for Transition resource provides an overview of the steps needed to help facilitate a safe and comprehensive transition from children's services to adult services for young people with complex health needs. These individuals require a bespoke, coordinated and collaborative transition plan to ensure transfer to adult services is a success. This means that healthcare professionals play a pivotal role in delivering a positive transition experience, and these principles summarise how to do this well. The accompanying transition pack provides the tools for health and care professionals to deliver these principles and help guide service development and improvement. The documents are freely available and have been designed so that they can be adapted to meet local needs. All documents currently in the toolkit are available for download via the WellChild website here ».

Useful existing reference resources

These documents are up to date at the time of publishing.

- 10 Steps Transition to Adult Services: 10stepstransition.org.uk
- Annual Health Check, Easy Read, Mencap: Annual Health Checks | Mencap
- Annual Health Check, NHS Coventry and Warwickshire CCG: Annual Health Check - YouTube
- Child and Young Person's Advance Care Plan, ReSPECT: Advance Care Plan (with ReSPECT) – CYPACP
- Developmentally Appropriate Healthcare Toolkit, Northumbria Healthcare: Developmentally Appropriate Healthcare Toolkit : Northumbria Healthcare NHS Foundation Trust
- Easy read guide for young people transitioning to adult's services, WellChild: An easy read guide for young people transitioning to adult's services | WellChild
- Guidance for: Paediatric to Adult Critical Care Transition, PCCS and ICS: Guidance for Paediatric to Adult C C Transition.pdf (pccsociety.uk)
- HEADSS training app, RCPCH: app.appinstitute.com/heeadsss
- Health Passport, example: MyHealthcarePassport (england.nhs.uk)
- Hospital care for young people with a learning disability, Moving from children's services to adult services, Mencap: Hospital care for young people with a learning disability | Mencap
- Lasting Power of Attorney and Deputyship, Together for Short Lives: Lasting Powers of Attorney and Deputyship - Together for Short Lives
- Ready Steady Go Transition Programme, TIER: TIER Network - TIER Homepage (readysteadygo.net)
- Social stories and comic strip conversations, National Autistic Society: Social stories and comic strip conversations (autism.org.uk)
- The Mental Capacity Act, Together for Short Lives: The Mental Capacity Act - Together for Short Lives
- Transition and handover from children's to adult health services, Welsh Government: Transition and handover from children's to adult health services
- Transition to adult services, RCPCH: Transition to adult services | RCPCH
- Transition to Adult Services Pathway, Together for Short Lives: Transition to Adult Services Pathway from Together for Short Lives

References:

- Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Slap GB. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolescent Health. 1993 Nov; 14 (7): 570-6 Transition from children's to adults' services for young people using health or social care services, February 2016
- Transition from children's to adults' services, Quality standard, December 2016

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Patron: The Duke of Sussex

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For more information about WellChild:

t 01242 530007
w www.wellchild.org.uk
e info@wellchild.org.uk

WellChild, Office 23, Sunningend Business Centre
22 Lansdown Industrial Estate, Cheltenham, Gloucestershire, GL51 8PL